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Critical epidemiology in action: Research for and by indigenous peoples

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A B S T R A C T

Global social justice movements, including transnational activism for indigenous rights, are working to promote health equity by transforming public health research and policy. Yet little social scientific research has examined how professional epidemiologists are figuring within such efforts. Discussions are unfolding, however, in critical sectors of epidemiology about how to improve the profession's input into advocacy. Findings from a multi-sited ethnographic study of epidemiological research for and by indigenous peoples in three settings (Aotearoa/New Zealand, the continental U.S., and Hawai'i) demonstrate how researchers/practitioners connect epidemiology and advocacy by: (1) linking the better-known legitimacy of quantitative methods to a lesser-known causal framework that positions colonialism as a sociopolitical determinant of health, (2) producing technical critiques that aim to improve the accuracy and accessibility of indigenous population health statistics, and (3) adopting a pragmatic flexibility in response to the shifting political conditions that shape when, whether and how epidemiological findings support advocacy for indigenous health equity. Attending closely to the credibility tactics at hand in this work, and to the skills and sensibilities of its practitioners, charts new directions for future research about epidemiology's contributions to advocacy for health equity.

Introduction

Recent decades of transnational advocacy to promote social justice in health have featured epidemiological data and methods (e.g., Breilh, 2008; Colvin, 2014; Ichihō et al., 2013; Inhorn & Whittle, 2001; James, 1993; Potts, 2004; Walter & Andersen, 2013). Yet little social scientific research has examined how professional epidemiologists figure within these efforts to advance health equity. Some social scientific works caution instead that relying on epidemiological and other quantitative data can render "evidence" too narrowly, and in ways that primarily serve the interests of globally powerful institutions and actors (e.g., Storeng & Béhague, 2017). Others offer potent reminders that neither accurate epidemiological data (e.g., Briggs & Mantini-Briggs, 2016), nor policy changes achieved through social justice advocacy (e.g., Epstein, 2007), are necessarily sufficient to destabilize entrenched political and cultural barriers to health equity. While recognizing such constraints and complexities is vital, it is also clear that social justice advocacy is influencing the collection and interpretation of health data—including the population health statistics central to epidemiology. To date, social scientific studies of these processes have primarily focused on lay activists, as in Epstein's (1996, 2007) influential analyses of U.S. activists' strategic use of the credibility of epidemiological and other scientific knowledge in advocacy to promote racial/ethnic, sexual, and gender equity in health research and policy. Professional researcher/practitioners who adopt critical approaches to epidemiology also leverage the credibility of science, however, as they aim both to understand and ultimately to transform sociopolitical determinants of health.

Within epidemiology itself, discussions are unfolding about how to

best apply the profession's findings in such transformative work (e.g., Muntaner et al., 2012; Putnam & Galea, 2008). Pega, Kawachi, Rasanathan, and Lundberg (2013), for instance, constructively suggest that specific study designs might best help to translate epidemiological findings about political determinants of health into policy impacts. Yet major questions remain about how, exactly, the production of epidemiological data connects with its capacities to support advocacy. For example: What other dimensions of specific studies, the knowledge that they produce, and the sensibilities and skills of those conducting them, may also shape the production of epidemiological knowledge that is useful in advocacy to shift health research practices, resource flows and/or policies?

In this paper, I chart preliminary answers to these questions by focusing on key "credibility tactics" (Epstein, 1995, p. 417) that professional epidemiologists use when working to promote health equity. I draw examples from a transnational ethnographic study of epidemiology conducted for and by indigenous peoples in three settings: Aotearoa/New Zealand, Hawai'i, and the continental United States. Researcher/practitioners conducting this work explicitly discuss and employ strategies for leveraging the better-known cultural and political authority of epidemiology, in order to address lesser-known indigenous health inequities and their sociopolitical determinants.

"For and by" marks research that departs from long histories of research "about" indigenous peoples, little of which engaged communities or substantively incorporated their perspectives (Smith, 1999; Solomon & Randall, 2014). Such work therefore prioritizes both collaborating with communities in producing knowledge, and mobilizing the resulting findings to advance indigenous health equity. Work in this

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field often explicitly counters the ways in which conventional health statistics have misrepresented or overlooked indigenous health, and aim to better document colonialism and its legacies as sociopolitical determinants of health inequities. Researcher/practitioners combine detailed technical knowledge of epidemiology with insights into the politics of health advocacy. They sometimes engage in such advocacy directly themselves, and other times collaborate with government administrators, elected officials and organizations who do so.

This multifaceted, critical and reflexive work is grounded in an overarching recognition of how knowledge and power connect. While in part reflecting the specificities of indigenous experiences, examining the strategies and sensibilities of researcher/practitioners conducting this work poses broader questions about how epidemiology can help to better understand, and to ultimately transform, sociopolitical determinants of inequitable health.

Indigenous epidemiologies and scientific credibility

Epidemiology for and by indigenous peoples uses epidemiological methods to monitor inequities in indigenous health compared to majority groups in national populations (Gracey & King, 2009; Smylie, Crengle, Freemantle, & Taulii, 2010), and to assess colonialism and its legacies as sociopolitical determinants of these patterns (Anderson et al., 2006; Jones, 2006; Paradies, 2016). Such work is most visible in contexts that feature ongoing advocacy for indigenous rights alongside well-documented population health disparities (Stephens, Porter, Nettleton, & Willis, 2006). These include major settler colonies (Wolfe, 2013) like the so-called “CANZUS” nations of Canada, Australia, New Zealand and the United States. Across all, health professionals, policy-makers, and broader public audiences commonly view claims about sociopolitical determinants of indigenous health as moral and political, with unknown or unclear scientific validity. A strong cultural connection between quantitative data and credibility is also evident across all, reflecting in part the continual privileging of numerical data in prominent “evidence-based” global health trends. Using quantitative statistics therefore lends credibility to calls to recognize indigenous health inequities and their sociopolitical determinants. Epstein characterizes such methodological-moral linkage in health advocacy as “yoking together methodological (or epistemological) arguments and moral (or political) arguments so as to monopolize different forms of credibility in different domains” (1995, 420; emphasis in original).

The ways in which researcher/practitioners ‘yoke together’ epidemiological methods with calls for indigenous health equity reflect recent decades of transnational activism for indigenous rights. Recognizing the close ties between knowledge and power, this activism has featured numerous initiatives for greater indigenous control of research (e.g., Krupat, 2002; Pihama, Cram, & Walker, 2002; Trask, 2013). One outcome has been the rise of epidemiology for and by indigenous peoples. Major initial studies and publications in this field were underway by the 1980s in Aotearoa/New Zealand (Keefe et al., 2002; Pomare, 1980; Pomare & De Boer, 1988; Reid, Robson, & Jones, 2000), in the 1980s and 1990s in the Hawaiian Islands (Aluli, 1991; Braun, Look, Yang, Onaka, & Horiuchi, 1996; Grandinetti et al., 2002; Look, 1982), and by the 1990s in the continental U.S. (Beals, Manson, Mitchell, Spicer, & Team, 2003; Grossman, Krieger, Sugarman, & Forquera, 1994; Iyasu et al., 2002; Lee et al., 1990; Slattery et al., 2007).

Reflecting this broader context, some studies present epidemiological data while explicitly referencing major transnational activist goals of promoting indigenous rights to cultural distinctiveness (e.g., King, Smith, & Gracey, 2009; Walters, Beltran, Huh, & Evans-Campbell, 2011) and sovereignty (Anderson et al., 2016; Schultz & Rainie, 2014). Others document how conventional population health statistics reflect limited indigenous input, resulting in erasure and misrepresentation. Burhansstipanov and Satter (2000), for instance, describe the problematic practice of continental U.S. public health agencies collecting, but

then not reporting, data about indigenous health. Freemantle and colleagues (2015) describe how pervasive misclassification of race and ethnicity in vital statistics across numerous nations leads to chronic underreporting of indigenous mortality. From Aotearoa/New Zealand and Australia, Kukutai and Walter (2015) discuss how official health data often serves state agendas rather than representing indigenous experiences. Additional works from multiple settings (Reid & Robson, 2007; Walter, 2016; Walter & Andersen, 2013) highlight how inaccuracies and omissions in conventional health statistics can fuel racialized assumptions that biological difference causes indigenous health disparities, and/or that indigenous peoples are a “sick, troubled population that is dependent on external help” (Cameron, Andersson, McDowell, & Ledogar, 2010, p.101).

In order to counter such omission and misrepresentation, researcher/practitioners conducting studies for and by indigenous peoples repurpose epidemiological methods to provide fuller portraits of indigenous health inequities and their sociopolitical determinants. While many within indigenous health research are advocating for expanded definitions of “evidence” that recognize diverse forms of knowledge (e.g., Walker & Bigelow, 2011), epidemiology for and by indigenous peoples reflects a complementary tactic: Strategically leveraging the more well-recognized credibility of quantitative evidence in general, and of epidemiological methodologies in particular, in order to help procure the recognition and resources needed to protect and promote indigenous health.

Here I use data from both interviews with researcher/practitioners who work in this field, and a review of publications that they identified as key illustrations of it, in order to document the sensibilities, skills and practices at hand in their work. Epidemiology for and by indigenous peoples features a diverse combination of indigenous researchers and non-indigenous allies who share a focus on promoting indigenous health equity, supporting indigenous capacity-building for research, and emphasizing collaborative research methodologies. All work within a variety of academic and community-based research settings, and compete for both public and private national, regional and occasional international funding—little of which is specifically allocated to indigenous health. Researcher/practitioner accounts of the goals, practices, and impacts of their work emphasize how ongoing political challenges to indigenous health equity position epidemiology as a significant tool in indigenous health advocacy.

Methods

Aotearoa/New Zealand, the continental U.S., and Hawai‘i were selected as settings for studying the transnational rise of epidemiology for and by indigenous peoples due to their broadly shared colonial legacies for indigenous health, and visibility in existing transnational professional networks among indigenous epidemiological researchers. They have also been less represented in publications describing quantitative population research for and by indigenous peoples in “CANZUS” nations, compared to Australia and Canada (e.g., O’Neil, Reading, & Leader, 1998; Walter & Andersen, 2013).

Data was gathered from 2013–16 across all settings and from three interrelated sources: (1) interviews with epidemiological researchers and practitioners, (2) review of relevant published research, and (3) participant observation in select workplaces and at professional conferences. This paper focuses on selected themes from the first two. Semi-structured interviews with (n=47) epidemiological researcher/practitioners included questions about key studies, findings and participants that they identify as being part of epidemiology for and by indigenous peoples; how they became involved in this work; how they view its goals, and conduct research and engage in other professional activities to achieve these (with individually-tailored questions about their experiences with specific projects or studies); what they enjoy most and find most challenging about their work; and what they view as key examples to date of resource/policy and other concrete impacts

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