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; Ichijo 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 & Behague, 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
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, & Taualii, 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, policymakers, 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, & Horiuichi, 1996; Grandinetti et al., 2002; Look, 1982), and by the 1990s in the continental U.S. (Beals, Manson, Mitchell, Spencer, & Team, 2003; Grossman, Krieger, Sugarman, & Forquer, 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. Burkhanstapanov 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.
of this field. I also noted examples of these impacts in publications, conference presentations and workplace conversations, and triangulated these sources of information in subsequent interviews and/or by locating reports from relevant regional and national health agencies (some accessible online, others in regional libraries in each setting).

Interviews ranged from 50 to 354 min in length (the longest was conducted across two separate meetings), with a median of 85 min. The majority were conducted in person at the interviewee’s workplace, but 13 (28%) took place via phone or videoconference. All interviews were recorded and transcribed. I recruited interviewees in each setting by consulting with researchers known to me or my contacts in indigenous public health for initial suggestions, by contacting authors of relevant publications, and by referrals from existing interviewees as the study progressed. The number of researchers interviewed versus contacted in each setting was 18/21 (86%) in Aotearoa/NZ, 22/26 (85%) in the continental U.S., and 7/8 (88%) in Hawai‘i. Those contacted and not interviewed either expressed interest in the study but were unable to schedule a meeting time, or did not respond to two or three attempts to contact them.

Among researchers interviewed, 85% self-identified as indigenous and 15% as members of either settler majority populations or other ethnic groups. All had educational and employment experience in epidemiology, public health or closely allied fields. The majority (59%) held doctorate or medical doctor degrees, with 28% holding master’s degrees and 13% bachelor’s degrees. A substantial majority (72%) had been working in indigenous health for between ten and twenty years. University-based research centers and government agencies are prominent employers for epidemiologists across all settings, but other institutional forms are also common. Independent consultancies, for example, are present in all and especially significant in Aotearoa/New Zealand. Community-based organizations are also significant, and especially visible in the continental U.S. as twelve Tribal Epidemiology Centers (TECs) (e.g., Tribal Epidemiology Centers, 2013). Overall, researchers’ primary workplaces at the time of interview were: 57% academic, 30% community-based, and 13% government. Many were working across more than one of these employment sectors when I spoke with them, however, or had previously worked in a different sector than at present. Although some consider themselves to be “practitioners” more than “researchers” per se, I will use the latter term alone as shorthand for both for the remainder of this article.

Since conventional keyword and subject searches cannot identify studies that prioritize indigenous health equity in framing their questions, measures or analyses, I identified relevant publications through an iterative process of literature searches in PubMed and Google Scholar, coupled with input from researchers interviewed. Initial search terms coupled regional population identifiers (e.g., Māori, American Indian & Alaska Native, Native Hawaiian) with prominent epidemiological outcomes across settings (e.g., general health status, mortality, cardiovascular disease, cancer, diabetes, mental health conditions, and major infectious diseases such as influenza and pneumonia), as well as outcomes specifically emphasized in indigenous population health research (e.g., tuberculosis, sudden infant death syndrome). Reviewing these, I then focused on specific studies and investigators concerned with promoting indigenous health equity, countering erasure and misrepresentation, and/or documenting sociopolitical determinants of indigenous health. Through both interviews and subsequent review of study reports and draft publications, researchers confirmed key studies and investigators that constitute their field, and I received similar feedback when presenting preliminary study findings at indigenous health and social scientific conferences from 2014–2016.

Researchers identified studies and investigators from the 1970s–1990s onward as seminal works in this field. With help from three graduate research assistants, I compiled recent and current works from these origins through 2016 for each setting. While recognizing that a “grey literature” of reports and other materials wield substantial influence in indigenous health research and advocacy, I focus on peer-reviewed research here given both its accessibility and significance in cultivating scientific credibility for advocacy—and especially, on the specific publications that researchers highlighted during interviews.

Using MAXQDA qualitative data analysis software (VERBI, 1989–2016), I coded content themes across interview transcripts and publications. Initial codes reflected the major topics covered in interviews (see above). I then developed more specific sub-codes based on the content of transcripts and these selected publications. Findings presented here primarily reflect coding of references to: determinants of indigenous health; data, evidence and related terms/concepts; and advocacy, activism and related terms/concepts. Overlap between the latter two especially identified illustrations of applying epidemiological data in advocacy.

Ethics review for this study was provided by the Institutional Review Board at [AUTHOR INSTITUTION]. All participating researchers provided individual informed consent, and all have received multiple opportunities to review this paper before its publication. A number have provided feedback to affirm findings, correct factual errors and/or suggest areas to clarify or elaborate, and these changes were incorporated during revision. Any errors that remain are my own. Not all researchers with publications cited here were interviewed as part of this study, or vice versa.

Findings

Scientific credibility and indigenous health advocacy

Researchers across settings underscored how advocacy for indigenous health equity faces numerous political and cultural barriers, such that epidemiological data improves the odds of success but never guarantees it. Most also emphasized how data to document inequities provides an essential starting point. “No data, no problem” one continental U.S.-based researcher quipped, quoting a former colleague and mentor; while another summarized: “I’ve always seen data as being a tool for getting resources to solve problems.” Others across settings elaborated that epidemiological data holds special persuasive potential in advocacy, given how it uses scientific methods to identify causal connections in quantitative terms. As two Māori researchers noted, for example:

So if you can put in front of them [policymakers] data that they are safe with, that they understand, that speaks to them, that they get an odds ratio, they understand the confidence interval— “Oh my goodness! The risk IS twice higher. Wow!” And, “because the numbers have told me that,” then you can possibly have more traction.

I think quantitative data is important, because for many, particularly for clinicians, particularly for other researchers and for policy people, it’s what they can get their head around—and it gives them the sort of, the jolt [that a problem needs solving]?

In these ways, researchers positioned epidemiology as a tool that can be persuasive to audiences who take numbers seriously. All study settings feature prevalent cultural understandings that statistics are straightforward reflections of the realities of population health, along with some more nuanced views that recognize how the constraints of statistical procedures, measurement limitations, and cultural assumptions shape epidemiological data—and some more critical views, that consider how all health knowledge reflects the assumptions of those who collect and interpret health data. Researchers frequently articulated this critical view, often elaborating that their approach to research values diverse ways of knowing as well as multiple methods. As one Native Hawaiian researcher commented, for example, conducting research involves making design and methodology decisions that depend “…on what you want to do, the questions you want to ask and how you want to answer them—and what you want to use it for.” By this logic,
epidemiological methods may not always be the best fit for particular health research projects. For the purposes of supporting advocacy to redress indigenous health inequities, however, many described that not only documenting inequities, but also filling gaps in understandings of sociopolitical determinants of indigenous health, provides knowledge that is helpful.

Researchers provided numerous examples of how cultivating a body of epidemiological knowledge about these topics facilitates advocacy. Many noted that being able to persuasively frame indigenous health inequity as a colonial legacy in general, as well as being able to reference specific studies or lines of published work, can help them to hold ground during presentations to policymakers or other stakeholders—especially when audience members respond skeptically or critically to their concepts and/or methods. Many added that publishing work in esteemed professional venues can especially enhances its credibility in such interactions. As one Māori researcher explained, for example, debates about funding indigenous health projects within national review committees can shift when knowledgeable members point out that previous work on a proposed topic “has been published in the Lancet” or other high-profile journal.

Researchers highlighted a number of specific published studies as especially central to their field. These studies specifically challenge misrepresentation and stereotype by connecting the better-known legitimacy of quantitative methods to lesser-known discussions of colonialism as a sociopolitical determinant of health, and by engaging in critical technical discussions that aim to improve the accuracy and accessibility of indigenous population health statistics.

**Quantification and sociopolitical determinants: Colonialism and its legacies**

Publications across all three settings document indigenous health inequities and work to connect them with colonialism and its legacies. In so doing, they frequently also call for improvements in future research by challenging common stereotypes—footnoting, for example, needs to better understand the diversity and complexity of indigenous health problems and patterns.

This body of epidemiology also reflects Paradies’s (2016) insight that indigenous health research tends to focus primarily on either colonial histories or present-day colonial legacies. In the former vein, for example, Blakely and colleagues (2011) connect ethnic disparities in cancer rates in Aotearoa/New Zealand to tobacco use, and historically contextualize these relationships by noting how tobacco’s introduction fueled British colonial dispossession of Māori lands—a process which predominantly took place between 1840–1940. In Hawai‘i, some studies connect regional colonial disruptions since the 1700s to current health outcomes like higher rates of psychiatric disorders among Native Hawaiian youth (Andrade et al., 2006; Pokhrel & Herzog, 2014); while others directly connect the United States’ illegal overthrow of the Hawaiian monarchy in 1893 in current high rates of both mental health (Yuen, 2000) and cardiometabolic diseases (Mau, Sinclair, Saito, Baumhofer, & Kaholokula, 2009) among Native Hawaiians. While these works encourage readers to recognize these connections by providing historical references alongside epidemiological data, efforts to directly quantify the links between colonial histories and contemporary indigenous health are also underway. These have arguably developed most visibly in the continental U.S., through the framework of historical/colonial trauma (Brave Heart, Chase, Elkins, & Altschul, 2011; Evans-Campbell, 2008).

Epidemiological studies of historical/colonial trauma (e.g., Balsam, Huang, Fieland, Simoni, & Walters, 2004; Duran et al., 2004) aim to document how collective past experiences of disruption, violence and loss continue to impact indigenous communities through multiple generations via a number of potential social, cultural and biological mechanisms. Resulting data has supported intervention studies that include experiential learning about colonial impacts on health, such as the Yappalli project of collectively re-walking the Choctaw Trail of Tears (Schultz, Walters, Beltran, Stroud, & Johnson-Jennings, 2016). While most North American indigenous health researchers support such commemorative and cultural revitalization activities, some note the challenges of quantifying the impacts of historical events, and/or debate whether historical/colonial trauma may be too universalizing or broadly defined to serve as an effective advocacy tool (Kirmayer, Gone, & Moses, 2014). Researchers in other settings attributed its relatively high profile in the U.S. to cultural preferences for psychologically-focused theories of wellbeing here; and the political challenges facing AIAN, as a highly minoritized group with major internal cultural and historical diversity (compared to the larger population profiles and more historically/geo graphically concentrated colonial histories in Aotearoa/New Zealand and Hawai‘i), may also account in part for this regionalized interest in developing a broader conceptual framework.

Alongside these direct historical references, additional studies across all settings also focus on how present-day colonial legacies, such as socioeconomic deprivation and racial discrimination, impact indigenous health. In Aotearoa/New Zealand, a key prospective study by Keefe and colleagues (2002) documents the health impacts of neoliberal restructuring in the 1990s by connecting involuntary unemployment to higher mental health and mortality outcomes among factory workers—with greater socioeconomic precarity promoting Māori vulnerability to these impacts. Baxter and colleagues (2006) use national cross-sectional survey data to additionally correlate higher rates of mental health conditions with ongoing Māori experiences of greater social adversity and political marginalization. Moreover, Crengle, Robinson, Ameratunga, Clark, and Raphael (2012) link racial discrimination to depression, tobacco use, and reduced school achievement among Māori youth, while Harris, Cormack and colleagues examine its connections to multiple health inequities (Cormack, Harris, & Stanley, 2013; Harris et al., 2012a; Harris et al., 2006)—documenting, for example, links between self-reported racial discrimination by a health professional and lower cancer screening rates for Māori (Harris et al., 2012b).

Epidemiological studies in Hawai‘i and the continental U.S. also address racism as a determinants of indigenous health, though focus somewhat less on socioeconomic adversity than the above (likely due to cultural and political pressures in U.S. public health, as critics have long noted—e.g., Krieger, 1992). The 1990s Hawai‘i’s Native Hawaiian Health Research Project examined type 2 diabetes and heart disease prevalence rates (e.g., Grandinetti et al., 2007), considering how identity and social experience shape Native Hawaiian health (Grandinetti et al., 2002). Subsequent cross-sectional surveys relate obesity to perceived overt and covert discrimination among Native Hawaiians (McCubbin & Antonio, 2012), and examine how acculturation and perceived racism connect with self-reported hypertension (Kaholokula, Iwane, & Nacapoy, 2010). In the continental U.S., Johnson-Jennings, Belcourt, Town, Walls and Walters (2014) provide cross-sectional data suggesting that a causal connection between racial discrimination and tobacco use in a multi-urban Two-Spirit population sample is mediated by experiences of pain, which may reflect an embodied reaction to discrimination.

These epidemiological investigations of discrimination also commonly note needs to better address the complexities at hand in indigenous experiences of health. Kaholokula and colleagues, for example, underscore how acculturation and Native Hawaiian identity connect in multiple and not necessarily inverse ways. In the continental U.S., Simonds and colleagues’ (2014) similarly note diverse and complex relationships between cultural identification and levels of trust in health care institutions among older AI patients in Oklahoma. In these ways, epidemiological studies not only emphasize that colonial legacies of discrimination shape indigenous identities, perceptions and experiences, but highlight gaps in current public health understandings of the diversity and complexity in how they do so.

Additional studies from the continental U.S. further document diversity and complexity in indigenous health, and call for fuller portraits...
of indigenous experiences in future epidemiological research. Key works note, for example, the numerous culturally distinctive understandings/experiences of wellness (e.g., Hodge & Nandy, 2011), and the marked sociodemographic diversity in AIAN health patterns (e.g., Dillard, Smith, Ferucci, & Lanier, 2012; Henderson et al., 2008). Publications from a major multi-sited epidemiological study of both psychiatric and physical health outcomes (e.g., Beals et al., 2013; Spicer et al., 2003; Whitesell, Beals, Mitchell, Manson, & Turner, 2009) especially highlight needs to better account for how variations in cultural meanings shape experiences and impacts of trauma across different AIAN communities (Jervis et al., 2006).

These brief examples introduce some of the major ways in which researchers conducting epidemiology for and by indigenous peoples use publications to promote recognition of colonialism and its legacies for indigenous health. The works described not only articulate this broader causal framework, but also feature ongoing, constructively critical calls for richer conceptualizations of how historical, cultural, sociodemographic factors combine to produce current patterns in indigenous population health. As the following section elaborates, additional publications couple these calls for change in conceptualizing indigenous health with detailed technical discussions of how to improve indigenous population health statistics, as another key credibility tactic.

Methodological critique and epidemiological credibility

Credibility in epidemiology accrues in part through the profession’s visible (and often vigorous) discussions of statistical methodologies, much of which concern how to reduce bias and misclassification, control for confounding, and rectify other potential sources of error (Morabia, 2015). Work for and by indigenous peoples engages directly in these discussions. Both transnational collaborations (e.g., Freemantle and colleagues, noted previously) and numerous regionally-specific studies, for example, highlight how racial/ethnic misclassification errors undermine accurate portraits of indigenous health. In Aotearoa/New Zealand, where a national health care system collects ethnicity data across different sectors through multiple strategies, leading works by Cormack and colleagues (e.g., 2013) as well as Rosbon and Harris (2007) emphasize how inaccuracies in ethnicity classification often undermine recognition of indigenous health inequities. Others add that misclassification can potentially obscure how health promotion efforts may benefit Māori (e.g., Sandiford, Salvetto, Bramley, Wong, & Johnson, 2013). To more accurately assess how ethnicity and health relate, Curtis, Wright, and Wall (2005) tested four common practices while studying breast cancer rates, concluding that record linkages with either census data, hospital admission or death records best correct misclassification.

In the continental U.S. (Rhoades, 2005), Castor and colleagues (2006) note that misclassification errors are especially common in urban AIAN morbidity and mortality statistics. Disease-specific studies further document such errors, and how they obscure indigenous health concerns (e.g., as in epidemiological studies of AIAN and cancer, like Becker et al., 2008; Bliss et al., 2008; Wiggins et al., 2008). Record linkage also figures as a key corrective here. A 2014 special issue of the American Journal of Public Health illustrates how linkages to Indian Health Service (IHS) databases can markedly improve data accuracy for a variety of health outcomes (Cheek, Holman, Redd, Haberling, & Hennessy, 2014; Espey et al., 2014; Jim et al., 2014; Wong et al., 2014). Yet in both publications and interviews, researchers highlight IHS database limitations: In addition to focusing only on those seeking health care (rather than general community populations), they are estimated to include only half of all persons who identify as AIAN in the U.S. (Cheek et al., 2014), frequently exclude urban AIAN (Freemantle et al., 2015), and may include non-indigenous people (Hiozous, Strickland, Palacios, & Solomon, 2014). As one alternative, Dankovchik, Hoopes, Warren-Mears, & Knaster (2015) describe the Northwest Tribal Epidemiology Center’s work with multiple tribes and urban AIAN health organizations to develop a regional AIAN registry. Data linkage to this resource has helped to correct misclassification and improve the accuracy of AIAN statistics in a wide range of state health data systems.

While highlighting needs to correct racial/ethnic misclassification errors, some researchers also note how broad categories for indigenous identities such as “AIAN” (Satter et al., 2014), and “Māori” (Cormack & Harris, 2009; Kukutai, 2004) are themselves aggregations that meet statistical sampling needs, but can obscure localized, community-level experiences unless thoughtfully constructed (see also Van Dyke et al., 2016). To date, concern about the loss of indigenous data through statistical aggregation has been most elaborated in response to regionally-specific concerns in Hawai‘i.

Researchers in the Hawaiian Islands emphasize how ethnic-specific health data had been gathered since prior to statehood in 1959 here, yet was never publicly reported. Later 20th century practices of aggregating “Asian & Pacific Islander” in U.S. health statistics further obscured the health profiles of Native Hawaiians and other Pacific Islanders (NHOPI), through numerical domination by much larger Asian American groups (Mau et al., 2009; Taualii, Quenga, Samoa, Samanani, & Dover, 2011). Taualii (2007) emphasizes that despite a 1997 federal directive to separate Asian American and NHOPI categories, many state and federal agencies failed to comply through the 2000s. While aggregation can be necessary for statistical power, researchers question why doing so across ethnic groups (rather than across years or through other techniques) became conventionalized, given its high cost of erasing data about NHOPI health. In response, Taualii and colleagues (2011) provide methodologies for disaggregating NHOPI data from national databases, and are working with researchers in the continental U.S. to develop community-based strategies for improving sample sizes in health research involving small populations (Korngiebel, Taualii, Forquera, Harris, & Buchwald, 2015).

Like aggregation, age standardization is another common and routinized statistical procedure in epidemiology. Māori researchers identify one of their key publications as a call for rethinking it. Robson et al., (2007) describe how conventional standardization methods underestimate differences in Māori and non-Māori mortality. They illustrate how using common World Health Organization standard populations often reduces the magnitude of mortality rates and width of confidence intervals, and the rank-ordering of causes of death, relative to standardizing to the (generally younger) age structure of the Māori population itself. To better fulfill needs for accurate epidemiological data to effectively guide health policy, they propose an international indigenous population standard as one potential solution.

In these both transnational and regionally-specific ways, researchers use their technical expertise in epidemiological methods to call for greater scientific validity in indigenous population health data, further connecting epidemiological credibility with the goal of redressing indigenous health inequities. Researchers’ accounts of their work to use such credibility to garner resources or shift policy to promote indigenous health equity then highlighted the political sensibilities that many integrate with this technical expertise, in order to best translate epidemiological data into effective advocacy.

Credibility in action: Policy impacts in regional contexts

Researchers emphasized how effective advocacy requires flexibly incorporating epidemiological data into multiple stories, in order to most strategically respond to the competing agendas, shifting players, and uncertain loyalties at hand in political decision-making. One Māori researcher, for example, described the growth of “a rights-based discourse around Māori health” in Aotearoa/New Zealand through the preceding decade as a welcome trend, yet added that within policy debates it serves as “just—again, it’s another story, another way to argue? That works sometimes, with some people.” Another expressed a similar sense of pragmatic flexibility, noting: “I think that actually, it’s helpful to have a range of cards in your hand that you can play when
you need to….and that you can play the card that is most suited to the situation or context.”

Advocacy to promote greater attention to racism and Māori health through shifting recent political trends illustrates these strategic sensibilities. Researchers in the 1990s successfully advocated for key national health surveys in Aotearoa/New Zealand to include items about racial discrimination (enabling the work by Crengle, Harris, Cormack and others, described above). By 2002, racial discrimination was explicitly referenced in the national Ministry of Health policy for Māori health, He Korowai Oranga. Yet in the 2000s national political tides in New Zealand shifted markedly against so-called “race-based” approaches to policy. The Ministry of Health’s Māori health chartbooks (Tatau Kahakura) in 2006 and 2010 did not explicitly mention racial discrimination, nor did the 2014 “refresh” of He Korowai Oranga.

Māori researchers described how the associated movement to replace “race-based” with “performance-based” health outcomes enabled them to continue leveraging their credibility in quantitative methods however: As scientific consultants, they now asked why targets for Māori health differed from those for the majority population, if as one noted “we are supposed to be delivering a system that gives the same health outcomes...for all population groups?” In response, national targets for childhood immunization rates were revised for the first time to be equal across all population sectors (New Zealand Ministry of Health, 2016), rather than remaining lower for Māori. Māori epidemiological researchers also continued analyze data about racial discrimination, and anti-racist coalitions continued to develop in the health sector (Came, McCreanor, & Simpson, 2016)—keeping this topic in view, despite the political chill. Sociopolitical currents are now shifting again to support more explicit discussion of how racial discrimination (e.g., New Zealand Ministry of Health, 2015) and especially institutional racism (e.g., New Zealand College of Public Health Medicine, 2015) impact Māori health.

Other settings also feature successful examples of epidemiologically-informed advocacy. In Hawai‘i, successful advocacy for the 1988 Native Hawaiian Health Care Improvement Act highlighted not only the power of data for indigenous advocacy, but also continuing needs for it. Subsequent advocacy at the federal level recently culminated in the first-ever release of National Health Survey data specific to Native Hawaiians & Pacific Islanders (Centers for Disease Control and Prevention, 2017b). Epidemiological data is also figuring prominently in advocacy at the state level, including within a major recent call for socioeconomic and environmental reforms to improve indigenous health there (Hawaii Public Health Institute Department of Native Hawaiian Health University of Hawaii, 2016).

Epidemiological data has also contributed to successful advocacy for AIAN health in the continental U.S. One Tribal Epidemiology Center staff member described how, on a regional level:

The big purpose of [our work] is to give tribes their own data. So that they can then use it for their decision-making, for their programming, for their own community-based type interventions…. And giving them baseline data, oftentimes, so that they can track to see if they’re making progress or not…. And so it’s self-advocacy, but it’s also giving them the tools to then speak for themselves at other forums and other places that they may need to.

Other researchers/practitioners provided local and regional examples ranging from greater tribal control of health care, to fuller inclusion of urban AIAN populations and clinics in federal and state funding, to federal reimbursement of culturally-specific healing ceremonies. At the national level, advocates for the Special Diabetes Program for Indians (SDPI) successfully procured initial federal funding in 1997, which has been continually (outside of some uncertain months in late 2017) reauthorized by Congress through 2019, for community-based programs to improve primary and secondary prevention. Such sustained federal support contrasts strikingly with the chronic underfunding of indigenous health care here (e.g., Warne & Bane Frizzell, 2014). Throughout this time period, advocates have prominently employed epidemiological statistics correlating SDPI activities with measurable reductions in diabetes-related morbidity and mortality among AIAN (Centers for Disease Control and Prevention, 2017a; Wilson et al., 2005).

These brief examples illustrate how researchers across all three settings not only reflexively and strategically cultivate epidemiological data about indigenous health, but also leverage its credibility to help promote less well-recognized concerns about sociopolitical determinants of indigenous health inequities. In so doing, they actively recognize the challenges of advocating for indigenous health equity, yet have successfully applied such data in advocacy to shift policies and procure resources for indigenous health.

Conclusion

Attending closely to researcher/practitioners who integrate insights from broader social justice movements with technical expertise in epidemiology foregrounds the credibility tactics at hand, in translating epidemiological knowledge into advocacy for health equity. The findings presented here specifically describe how researchers’ critical and reflexive approaches to producing and circulating epidemiological knowledge shape how they strategically translating epidemiological data into a body of research that informs effective advocacy. These examples therefore pose broader questions for further study, about exactly how epidemiology and epidemiologists do and should contribute to efforts to advance health equity. For example: How do not only features of study topics, designs, and methods, but also the experiences and sensibilities of researchers, shape the ways in which epidemiological findings are useful in advocacy? How do broader social justice movements influence all of these factors, and promote constructively critical understanding of the strategic value of epidemiological methods and data for supporting health equity? How do such critical sensibilities specifically include understandings knowledge and power, in ways that facilitate the use of epidemiological methods as tools for representing diverse and often under-recognized dimensions of population health?

Exploring these questions further in a variety of settings would help to disseminate additional ‘lessons learned’ about how to best conduct epidemiology in ways that promote health equity. Such work takes seriously the proposition that sectors of the profession that are influenced by social justice movements, and/or that are centered on the concerns of minoritized and marginalized population sectors that generate such movements, often reflect “as much intellectual power...and more political relevance” (Connell, 2007, p. xii) than mainstream approaches. More explicitly addressing credibility strategies and tactics as components of professional expertise also has implications for improving recruitment, teaching and training in critical approaches to epidemiology. How might such efforts benefit, for example, from more systematic critical questioning and discussion of knowledge, power and advocacy? Such engaged and supportive inclusion of more diverse perspectives and concerns also stands to improve opportunities for productive collaboration between epidemiologists and communities that experience health inequities.

My focus here on selected participants, works and advocacy examples from three settings does not provide a comprehensive overview of epidemiology for and by indigenous peoples, and only briefly addresses how both transnational themes and regional specificities characterize the field. This analysis also does not address emerging issues like how current shifts toward multiple race/ethnicity categories in population statistics are posing new challenges to addressing misclassification, or the broader questions that indigenous-centered research raises about how collective rights, sovereignty and self-determination relate to the production and control of health data (Rukutai & Taylor, 2016).

This analysis does, however, introduce the strategic and nuanced
leverage of quantitative and epidemiological credibility that research/practitioners in this field employ, and profiles some of its successful contributions to advocacy to promote indigenous health equity. It therefore underscores how conducting epidemiology that is oriented around health equity does not introduce politics into science, but counters the often tacit political assumptions which are already there—or as one Māori researcher aptly noted, how “Data doesn’t speak for itself; we speak for it.”

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