First Nations Community Well-Being Research and Large Data Sets: A Respectful Caution

Abstract

Health researchers are increasingly encouraged to use large, community-level data sets to examine factors that promote or diminish health, including social determinants. First Nations people in Canada experience disparity in a range of social determinants of health that result in relatively low community well-being scores, when compared to non-First Nations people. However, First Nations people also possess unique protective factors that enhance well-being, such as traditional language usage. Large data sets offer First Nations a new avenue for advocating for supports and services to decrease health inequity while developing culture-based evidence. However, care must be taken to ensure that these data are interpreted appropriately. In this paper, we respectfully offer a cautionary note on the importance of understanding culture and context when conducting First Nations health research with large data sets. We have framed this caution through a narrative presentation of a simple and concrete example. We then outline some approaches to research that can ensure appropriate development of research questions and interpretation of research findings.

Keywords
Language, large data sets, social determinants of health, well-being, First Nations

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Introduction

An understanding of population health is essential in effectively implementing interventions aimed at improving well-being, and it begins with accurate and complete health information (Smylie, 2010). Large data sets that include a variety of community-wide measures of biological health status and access to health services are typically utilized in developing this

understanding. Access to accurate data and appropriate analyses are crucial as recommendations stemming from these data and analyses have the potential to be implemented within communities. Unfortunately, high-quality data and appropriate analyses regarding the health and well-being of First Nations people in Canada are scarce (National Collaborating Centre for Aboriginal Health, 2013; Smylie, 2010). This may result in decision makers and governments making changes to existing policy or implementing new policy regarding the health of Canadians with less than optimal information.

Given the growing discussion around using large data sets for research in Indigenous communities, we provide a cautionary demonstration that aims to analyze publicly available data regarding social determinants of community well-being for First Nations in Canada without the appropriate apparatus of best practice approaches to Indigenous health research. Our purpose is to respectfully show that researchers must use caution when interpreting relationships in these data. Specifically, given that traditional language has been conceptualized as being related to increased well-being, we chose the relationship between traditional language use and community well-being as a demonstration. Although we illustrate this caution with a specific example, the purpose of this paper is to encourage academic and non-academic researchers to consider context when utilizing large data sets for research with First Nations Peoples. This necessity of context has been noted in relation to both individual- and community-level data. King (2015) emphasized the requirement of focus groups or discussion circles to provide frame of reference for the findings from a study by Ryan, Cooke, Leatherdale, Kirkpatrick, and Wilk (2015) that traditional language use is related to smoking. Walls, Whitbeck, and Armenta (2016) actually carried out the recommendation touted by King (2015) and this paper and demonstrated that the relationships between Aboriginal spirituality and poorer psychological outcomes were reduced once perceived discrimination and historical losses were accounted for statistically. Unfortunately, this small sample of papers represents the minority, and many researchers are still presenting potentially harmful findings regarding Indigenous Peoples by overlooking the importance of context in large data set analysis.

Large Data Sets

First Nations Profiles (AANDC, 2006b). The federal government department Indigenous and Northern Affairs Canada (INAC; formerly Aboriginal Affairs and Northern Development Canada [AANDC] and before that, Indian Affairs and Northern Development) offers a potentially useful data source for First Nations communities on social determinants of health. INAC creates community profiles based upon community-level data from various subdivisions within INAC, and includes information regarding governance structures, federal funding utilization, geography, population statistics, income and employment, language, education, and mobility for the majority of First Nations communities within Canada (AANDC, 2006b). While some sectors of these First Nations Profiles are updated on a more regular basis, Statistics Canada collects data every 5 years. However, the variables collected by Statistics

Canada represent what might be described as independent variables,[1] which are of less utility unless dependent variables[2] can be identified.

The Community Well-Being Index (AANDC, 2006a). To better understand the discrepancy in well-being between Canadian urban communities and rural First Nations communities, INAC has developed the Community Well-Being (CWB) Index. The creators of the index also aimed to expand high-quality, cost-effective research on the social determinants of health for First Nations communities (McHardy & O'Sullivan, 2004). However, there has been relatively little use of the CWB Index as a research tool. This index is a quantitative measure of First Nations communities' social and economic well-being, and provides a tool to determine whether well-being is improving, declining, or remaining stable. Using Statistics Canada's census data regarding population, the CWB Index uses four main community indicators to calculate a score: income,[3] education,[4] housing,[5] and labour force.[6] These scores range from 0 to 1, with higher scores representing more positive community well-being. Both the census data and CWB Index are revised every 5 years. Categorizing these social determinants helps to clarify which community indicators are problematic among First Nations communities, where improvements are necessary, and in which domain communities experience the most difficulty. The CWB Index represents a potential *dependent variable* for some large data set analyses.

Language

Many First Nations people identify the ability to speak their language as an important social determinant of health. Language is often the vehicle by which knowledge is translated, including cultural traditions and values (National Collaborating Centre for Aboriginal Health, 2013). In addition, languages are necessary to ensure knowledge is exchanged through generations, particularly for cultures that value oral traditions (Battiste, 1998). Shared language is also essential for a shared worldview—affecting overall belief systems and identity development (Battiste, 1998; Hallett, Chandler, & Lalonde, 2007).

One tragic result of colonialism and, specifically, the residential school era in Canada is the disruption of entire generations of traditional-language speakers. For instance, over 60% of adults having attended residential school report the loss of their traditional language as a direct consequence (First Nations Information Governance Centre [FNIGC], 2012; Milloy, 1999). This disruption has left many communities with fewer traditional language speakers, especially in

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[1] An *independent variable* is a variable that represents the cause of an outcome, which is independent of that outcome.

[2] A *dependent variable* is a variable that represents the outcome of a specific cause.

[3] The CWB *income* factor is income per capita, transformed via a logarithmic function to account for dependent individuals and those with no income (McHardy & O'Sullivan, 2004).

[4] The CWB *education* factor includes the proportion of the population with at least a Grade 9 education and the proportion that has obtained a high-school diploma or higher level of education (McHardy & O'Sullivan, 2004).

[5] The CWB *housing* factor refers to both the quantity and the quality of houses available (McHardy & O'Sullivan, 2004).

[6] The CWB *labour force* factor considers both the participation in the labour force and also the percentage of those aged 15 or above who are employed (McHardy & O'Sullivan, 2004).

smaller communities. For example, according to the most recent First Nations Regional Health Survey (RHS), 36.2% of First Nations people reported that they use a First Nations language most often in their day-to-day life. However, in communities of less than 300 individuals, only 15.5% use their traditional language most often (FNIGC, 2012). Another consequence of fewer traditional-language speakers in the communities is the effect on younger generations. For instance, 83.8% of adults aged 60+ who reside in a First Nations community report understanding or speaking a First Nations language; only 59.4% of those aged 18–29 understand or speak their language (FNIGC, 2012).

Not only is language essential for maintaining traditions and oral history, but it is also an important factor that contributes to the well-being of First Nations people. Hallett et al. (2007) showed that traditional language use among community members was related to lower incidence of youth suicide. Specifically, they found that First Nations communities in British Columbia with greater than 50% of their population speaking a traditional language had lower youth suicide rates when compared to the provincial average for First Nations youth. In communities in which fewer than half of the population spoke their traditional language, youth suicide rates were much higher (Hallett et al., 2007). Results from RHS also indicated that traditional language may have a protective effect against suicidality. For instance, First Nations adults with an intermediate understanding or fluency of their traditional language reported lower rates of suicidal thoughts (18.1%) and suicide attempts (11.5%) compared to those with only a basic understanding of their traditional language (25.8% for suicidal thoughts and 16.0% for suicide attempts; FNIGC, 2012). The importance of traditional language within Aboriginal communities is also echoed in the recently released Truth and Reconciliation Commission of Canada's (2015) Calls to Action, which include recommendations for revitalizing and maintaining traditional languages through relevant programming.

Methods

Data

Once again, this example is being utilized to illustrate the widespread issue of lack of context and potential misinterpretation of analyses from large data sets. Using information publicly available on the Statistics Canada and INAC websites, we created a database that included information on population size, median age, and proportion of traditional language speakers, as well as the respective CWB indices in each community. To ensure accuracy, all data were entered by one researcher and then reviewed by another. We randomly selected 10% of the resulting data to inspect further for errors and found that the error rate was negligible.

In total, 370 of the 617 First Nations communities in Canada were included in our analyses, as only these communities received CWB scores and reported all other variables of interest. The average population in these communities was 764.97 (SD = 900.57), with an average age of 26.68 (SD = 7.71) and CWB score of 57 (SD = 9.92). CWB scores from 2006

were chosen in an attempt to match the year of Statistics Canada and INAC data so that all data were representative of the same point in time.

Results

Analyses

Hierarchical regressions were computed between Aboriginal language knowledge (represented by the percentage of the population speaking a traditional language) and 2006 CWB score (AANDC, 2006a). Total population of the community and median age were controlled for in steps 1 and 2 of the hierarchical regression. Results indicated that knowledge of traditional language predicted a reduced CWB score, $\Delta F(3, 379) = 124.046$, $p = .00$. That is, in these data, communities with a greater proportion of language speakers had overall a *lower* CWB score. However, this is not the complete story and terminating analyses here would be extremely problematic. This initial result contradicts other quantitative evidence and culture-based evidence that speaking a traditional language enhances well-being for First Nations individuals (e.g., Hallett et al., 2007). As Indigenous mental health is the primary area of research of our team, we understand the positive influence that speaking a traditional language has on community and individual well-being and realized that the relationship was likely influenced by other variables.

To consider other factors that could be contributing to this incongruent finding, we returned to the data and began examining it for variables related to important social determinants of health. The INAC First Nations community profiles included a variable called "Geographic Zone," which provides a score of 1 to 4. This score represents how removed each community is from the nearest service centre (i.e., major city). Zone 1 includes communities no farther than 50 km from the nearest city, while Zone 4 indicates that a community does not have year-round road access to the nearest city. We carried out a bivariate correlation and found that an increase in Aboriginal language speakers in a community was related to remoteness ($r = -.537$, $p \leq .000$). Subsequently, we conducted our hierarchical regression analysis again, this time controlling for remoteness in addition to total population and median age. The relationship between traditional language speakers and CWB Index was non-significant, $\Delta F(1, 365) = .305$, $p = .581$, showing that remoteness was accounting for the majority of the variance explaining the relationship between knowledge of traditional language and CWB Index. We do acknowledge that this example is a simplified analysis of complex data for the purposes of highlighting important conceptual issues in culturally and contextually appropriate research with large data sets.

Discussion

This study highlighted an important issue in the interpretation of large data sets, which may be particularly relevant when the researcher is removed from communities and unfamiliar with the context in which the data were gathered. We showed that without thoughtful interpretation, traditional language—a variable that is an indicator of a successful, thriving community—emerged as a predictor of decreased community well-being in our initial analyses.

However, we also knew that this relationship was likely confounded by other factors, specifically by communities' remoteness. Generally, communities that were more remote (i.e., farther from the nearest major city) had a greater number of traditional language speakers, yet remoteness and associated isolation bring additional challenges (e.g., limited access to services, affordable food, adequate housing, and employment opportunities) that can negatively influence community well-being.

In addition to these challenges, there are issues with the nomenclature used by the CWB Index. In this index, well-being is composed of four elements: income, education, housing, and employment, which roughly constitute socioeconomic status. However, the construct of well-being, particularly for Indigenous Peoples, is often much more holistic and incorporates connection with culture, nature, and the spiritual world (Canadian Institute for Health Information, 2009). Therefore, a community with a low score on the CWB Index is likely impoverished, but community members may still report high levels of well-being due to cultural connection.

Results of this study provide a concrete example and cautionary note for researchers interested in exploring large-scale community-level data. Had we simply stopped our exploration at the initial finding and pursued publication of these data in a peer-reviewed journal, the results could have been disastrous. Decision makers are moving toward more frequent utilization of findings from academic research to justify funding decisions and as a rationale for supporting the implementation or termination of projects and initiatives. The initial finding from this study may have been used to support the elimination of funding for cultural programming or culture-based approaches to healing, further disrupting the ability of communities to support their traditional languages, practices, and culture-based approaches to well-being. Problematic interpretation could have implications for funding or program planning, for example; however, we have not identified an example of this in the peer-reviewed literature.

Recommendations for Research Approaches

Researchers using large-scale data sets must adopt additional safeguards to ensure that their conclusions are accurate and valid and, above all, cause no harm. A history of colonization and assimilation has resulted in a unique context that cannot be understood solely with Western, and primarily quantitative, research approaches. Although many Aboriginal communities experience similar social determinants of health, context dictates what influence these determinants have in individual communities (Reading & Wien, 2009). Fortunately, there are a number of helpful approaches researchers can use in partnership and collaboration with communities to ensure that they are conducting research in an appropriate manner. Mixed quantitative-qualitative designs are beneficial in allowing communities to provide the context for the researcher to situate their findings (Wendt & Gone, 2012) and offer an option for research questions that require both the standardization of a quantitative approach, but also the additional interpretative benefits of a qualitative design (Bartholomew & Brown, 2012). A researcher can collect numerical information and analyze this information according to Western methods, but then utilize qualitative data in interpretation to ensure that the quantitative data are

contextualized. This approach can lead to both credible, generalizable findings and accurate measurement of phenomena, all viewed from the appropriate cultural and contextual lenses (Tashakkori & Creswell, 2007).

Two-Eyed Seeing is another research method that can assist researchers working with large-scale data sets. With this approach, researchers aim to "see from one eye with the strengths of Indigenous ways of knowing, and to see from the other eye with the strengths of Western ways of knowing, and to use both of these eyes together" (Bartlett, Marshall, & Marshall, 2012, p. 335). A Two-Eyed Seeing approach, ideally utilizing both quantitative and qualitative methods, within a community-based participatory research (CBPR) framework represents a research strategy that considers best practices in both Indigenous and Western settings and can account for the complex relationships between variables of interest and the unique contexts of Aboriginal communities in Canada. This approach assists in negating the power differential inherent in Western and Indigenous ways of knowing, at least from the point of view of the academy, where standardized, quantitative data are valued over all other forms (Hall et al., 2015). Two-Eyed Seeing allows researchers to see the value in Indigenous methods and can also provide context for narrow, quantitative data, as Indigenous methods often emphasize the wider relationships between relevant variables and community (Hall et al., 2015).

Researchers utilizing data from Aboriginal communities, both small- and large-scale, should strive to have the benefits of their research go beyond the dissemination of knowledge to the academic community, which has access to conferences and journal subscriptions. Research can be viewed as a source of healing in Aboriginal communities, and contemporary investigators should collaborate with communities to ensure their research meets the needs of the individuals within the community and the community as a whole and also works to undo the colonial-style research projects of the past that affected many communities negatively (Hall et al., 2015). Western researchers customarily took a "helicopter" approach to research in Indigenous communities in which they would arrive, take data in whatever form they required, and then leave and never return to share the results of their project (Ferreira & Gendron, 2011). Applying a CBPR design ensures that communities are involved in all steps of the research project, from conception through to dissemination of results, and that community members have the opportunity to refine the research question to ensure that the work benefits the community.

CBPR can provide a framework within which a researcher can utilize Two-Eyed Seeing and/or a mixed-methods approach. CBPR is also likely to reduce the risk of a researcher overlooking the complexity of the relationships inherent in Aboriginal communities. This framework not only considers who is involved (i.e., the sample), but also requires researchers to carefully reflect on how these individuals and communities are involved in each step of the project, from data collection through to knowledge translation and dissemination (Castleden, Morgan, & Lamb, 2012). The three main Canadian federal funding agencies have devoted an entire chapter of their *Tri-Council Policy Statement (TCPS2): Ethical Conduct for Research Involving Humans* (CIHR, NSERC, & SSHRC, 2014) to "Research Involving the First Nations, Inuit, and Métis Peoples of Canada." This document clearly lays out the expectation that

researchers will engage with Aboriginal communities that may be affected by their research, utilize a collaborative method, and ensure that the outcomes of the research project will benefit the communities in addition to the researcher (i.e., use a CBPR framework; CIHR, NSERC, & SSHRC, 2014). More importantly, researchers are encouraged to include community members in both the interpretation and dissemination of the results of the study (CIHR, NSERC, & SSHRC, 2014). This approach is invaluable in terms of identifying potential confounds and ensuring that the research does in fact benefit the relevant communities. Any researcher engaged in a truly collaborative research project would have formal and informal advisors available to consult regarding their findings, including any potentially harmful research outcomes.

Conclusion

This paper respectfully offers a cautionary note to colleagues interested in the use of large data sets, particularly when data analytic methods may lack the sophistication to account for complex relationships between variables. We offer recommendations to help ensure that data analyses and interpretations are appropriate.

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