A Community-Based Mixed Methods Approach to Developing Behavioral Health Interventions with Indigenous Adolescent Populations

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UMMARY

In the United States, the American Indian (AI, Native, Tribal) population suffers the largest behavioural health disparities of any ethnic group. Within Native communities, adolescents are the most disproportionately impacted by substance use, suicide, and sexually transmitted infection (STI). A devastating historical legacy has created a context in Native communities of poverty, unemployment, and a service delivery system that is under-equipped to meet behavioural health prevention and treatment needs. Disparities are further compounded by a dearth of Native peoples trained in the behavioural health arena.

In the face of these challenges, Native communities are extraordinarily resilient and have sustained the well-being of Tribal members for generations. Tribal communities are self-governing and considered independent nations by the United States government. Sovereignty, coupled with an abundance of individuals who can be trained as Community Health Workers (CHW) to meet the unique aspects of behavioural health problems suggest Native populations have great aptitude for uptake and rapid dissemination of promising prevention and intervention strategies.

Despite existing disparities, there is a lack of behavioural health interventions developed with and for Native adolescents using participatory approaches. While some participatory approaches exist, they have not been accompanied by a requisite stage-based strategy supported by scientific investigation to obtain the knowledge and data necessary for developing, adapting and evaluating interventions. Community Based Participatory Research (CBPR) is a successful way to facilitate the cultural adaptation and fit of evidence-based behavioural health interventions for and with Native and other indigenous communities. Further, there is strong evidence in the literature supporting the utility of stage-based models for culturally adapting interventions. Cultural adaptation stage models may represent the best of all worlds for addressing behavioural health disparities among racial/ethnic minorities, by incorporating elements of rigorous prevention research as well as that of culturally-grounded approaches. Adaptations take advantage of the theory and research rigor that established the original intervention and add qualitative research components to incorporate community input and ensure cultural congruency.

To date, there has never been a rigorous evaluation of a culturally adapted evidence-based intervention conducted with an exclusive sample of Native American adolescents. This dissertation directly addresses this gap in the literature by answering the following research question: Can a stage-based research model rooted in both rigorous scientific methodologies and unique cultural understanding within Native communities inform the design, adaptation, implementation, and evaluation of behavioural interventions targeting disparities among adolescents?

This dissertation reports on a series of studies conducted in partnership with a rural, reservation-based American Indian community in the United States. The formative, pilot and efficacy studies presented flow from a stage-based model developed by the Johns Hopkins Center for American Indian Health to the development and adaptation of interventions targeting the most marked behavioural health disparities experienced by Native adolescents: substance use, suicide and sexually transmitted infection. The dissertation describes the studies from each stage of the

model with a special focus on the evaluation of a culturally adapted evidence-based intervention for HIV risk reduction. It concludes with implications of the methods and results as well as recommendations for future research.

Chapter 1 provides additional background on: a) American Indian populations, b) Native adolescent behavioural health disparities, c) the problem and opportunity addressed by this research, d) a review of the relevant literature, e) a description of the Center's stage-based approach including theoretical framework, and f) an outline of the remaining dissertation chapters.

Chapter 2 describes the methods and results of a qualitative study conducted with Native adolescent focus (N=58) groups exploring the intersection of substance use and self-injury. The study sought to gain insight regarding how binge substance use functions as a potential form of intentional self-injury and to identify the community's perspective on dual prevention strategies. Qualitative data collection allowed investigators to identify shared root causes, precipitants and social influences for substance use and self-harm behaviours and potential prevention approaches.

Chapter 3 presents the methods and results of qualitative interviews completed with n=22 American Indian adolescents who attempted suicide. The data collected helped hone a Tribal-specific conceptual model for adolescent suicide risk. This chapter describes risk and protective factors unique to this sample of American Indian adolescents, organized at individual, family, community and societal levels. Study results provide practical implications for research and development of suicide prevention programs

Chapter 4 reports quantitative data from a Tribally-mandated surveillance system to explore the co-occurrence of substance use and self-injury among Native youth over a four-year period (2007-2010). Results show nearly half of adolescents are "drunk or high" at the time of suicide ideation and the majority are "drunk or high" at the time of suicide attempt and death. The high co-morbidity of these behaviours highlights the importance of behavioural health science to understand the relationship between substance use and self-injury to design targeted and integrated interventions.

Chapter 5 presents the methods and results of a cross-sectional study of n=71 Native adolescents who attempted suicide. We collected quantitative data to explore participants' patterns of medical care utilization in the year prior to their attempt. Results showed the majority of adolescents visited their local emergency department at least once in the year prior to attempt, over a quarter of which were for psychiatric reasons. The discussion concludes that reservation-based emergency departments are ideal locations for screening and potential intervention with Native adolescents at risk for suicide.

Chapter 6 reports the results of a pilot trial conducted with n=32 Native adolescents to evaluate the feasibility and acceptability of self-administered urine sample collection for screening of sexually transmitted infection. The majority of adolescents was comfortable with screening procedures, preferred this method over clinic-based testing and would recommend it to their friends. Results imply that a self-administered method of screening is feasible in a rural,

reservation-based context with barriers to clinic-based screening, acceptable to a Native adolescent population, can triangulate self-reported outcomes in behavioural health intervention trials, and holds promise for screening uptake and scalability.

Chapter 7 and 8 present the first rigorous evaluation of a culturally adapted evidence-based intervention conducted with an exclusive sample of American Indian adolescents.

Chapter 7 describes the study rationale, methods, theoretical basis and baseline characteristics of the randomized controlled trial of "Respecting the Circle of Life:" a culturally adapted evidence-based intervention for HIV/AIDS risk reduction. This chapter provides in-depth information on the community-based participatory research process that shaped the Respecting the Circle of Life intervention adaptation and trial design. It also provides detail on the Respecting the Circle of Life implementation structure, content and theoretical foundation. The trial enrolled n=267 Native adolescents who received either Respecting the Circle of Life or a control program. Participants were assessed at baseline, 6-months and 12-months follow-up. Baseline data for the sample are reported. The discussion articulates the need for HIV/AIDS prevention interventions like Respecting the Circle of Life, to break the cycle of behavioural health disparity among American Indian adolescents.

Chapter 8 presents the one-year outcomes from trial of the Respecting the Circle of Life intervention. We assessed the intervention's impact on: 1) improved condom use self-efficacy, 2) enhanced HIV prevention knowledge, intention and perceptions, 3) increased partner negotiation skills related to sex and substance use, 4) increased condom use, 5) decreased frequency of sex with substance use, and 6) delayed sexual initiation. Results concluded the Respecting the Circle of Life intervention had short- and medium-term impacts on the outcomes of interest. Impacts on the trial's main outcome of interest (condom use self-efficacy) were sustained at 12 months follow-up. The study employed a novel retention strategy through incorporating the trial into a two-week summer basketball camp. The low attrition rate (10%) at 12 months follow-up among this community-based sample lends to the likelihood of success of implementing Respecting the Circle of Life in other rural, reservation-based communities. The discussion provides further detail about the effectiveness of American Indian community health workers delivering sensitive behaviour change information through the Respecting the Circle of Life intervention and the need for additional study of the program to sustain intervention impacts.

The final Chapter 9 summarizes the findings and discusses the methodological strengths and limitations of this body of research. Implications of the study methods and results are reviewed, with a particular focus on replication and scale-up of similar stage-based approaches to cultural adaptation, implementation, and evaluation of behavioural health interventions with other Native and indigenous adolescent populations. Recommendations and directions for future research are described.

There are several strengths to the research comprising this dissertation including: 1) fidelity to a community-based participatory research approach; 2) intervention delivery and data collection conducted by trained Native community health workers (paraprofessionals); 3) exclusive samples of adolescents and young adults of American Indian race/ethnicity; 4) mixed-methods

(quantitative and qualitative) evaluation; and 5) rigorous quality assurance and participant safety strategies.

The studies presented in this dissertation represent the first stage-based model of community-based participatory research that respond to the unique profile of risk and resilience in Native communities, as well as the adaptation, implementation and evaluation of an evidence-based intervention for HIV/AIDS risk reduction among Native adolescents. The randomized controlled trial presented in Chapters 7 and 8 shows efficacy for the impacts of the Respecting the Circle of Life intervention on adolescents' behavioural health outcomes at 6 and 12 months post-intervention. The behavioural health research model underpinning the intervention and evaluation design has relevance and application in other Native and indigenous communities suffering from similar disparities.