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

Lauren
LaRue
Tingey



A Community-Based MIXED METHODS APPROACH

TO
*Developing Behavioral
Health Interventions
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Lauren LaRue Tingey

The studies presented in this thesis have been performed at the Johns Hopkins Center for American Indian Health. The Center is part of the Johns Hopkins Bloomberg School of Public Health, a division of Johns Hopkins University in Baltimore, Maryland, USA.

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**A COMMUNITY-BASED MIXED
METHODS APPROACH TO
DEVELOPING BEHAVIOURAL
HEALTH INTERVENTIONS
AMONG INDIGENOUS
ADOLESCENT POPULATIONS**

ACADEMISCH PROEFSCHRIFT

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aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
prof. dr. D. C. van den Boom
ten overstaan van een door het College voor Promoties ingestelde
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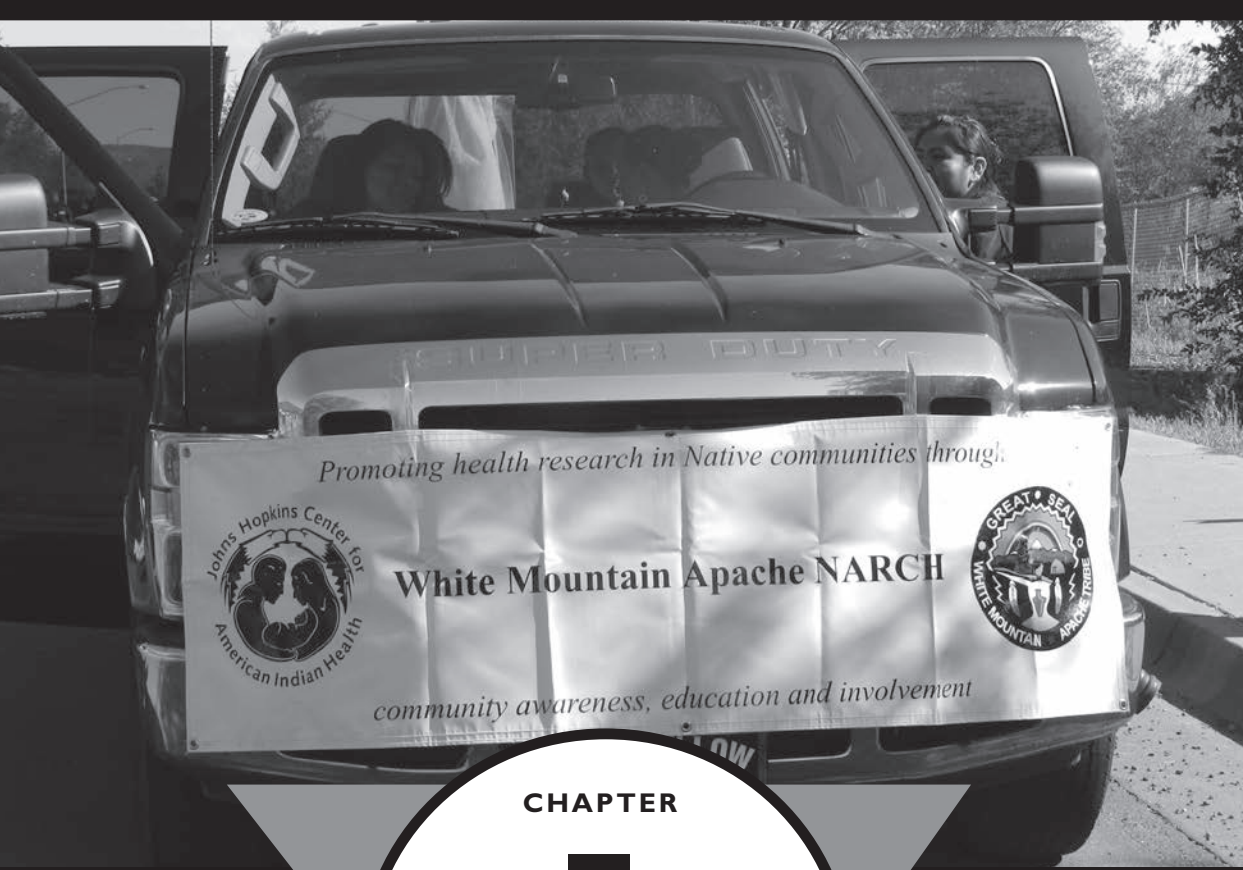
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Introduction



CHAPTER

I

I. General Introduction

American Indian (AI, Native) populations experience the greatest behavioural health disparities of any U.S. racial group. A constellation of factors impacting Native communities preclude access to and use of available prevention and intervention programs, and contribute to high rates of co-morbidity. Within Native populations, adolescents are particularly affected, specifically in the areas of mental health, sexually transmitted infection (STI), and substance use. Suicide is sometimes an outcome of complex and unresolved problems, and Native adolescents have the highest suicide rates in the U.S. The Native American population is diagnosed with STIs at four times the rate of Whites and has twice the rate of teen pregnancies, in addition to being the only U.S. racial group in which HIV rates are increasing. Furthermore, substance use is a known risk factor for suicide and HIV/STI transmission, and Native adolescents have the highest substance use and related morbidity and mortality in the U.S.

Despite these marked disparities, there is a lack of behavioural health interventions developed with and for Native adolescents that employ mixed-methods (qualitative and quantitative) designs with demonstrated impacts on behavioural health targets. Various participatory approaches have been described in the literature on prevention and intervention with Native communities however they have not been supported with scientific evidence of their utility and appropriateness for intervention development within the behavioural health arena. This dissertation presents a mixed-methods community-based research model developed by the Johns Hopkins Center for American Indian Health. It reviews a selection of formative, pilot, and efficacy studies that comprise a stage-based approach to behavioural health intervention development with American Indian adolescents. It also includes evaluation methods and findings, relevance of the results to American Indian and other indigenous adolescents, and recommendations for future research and intervention approaches.

This introductory chapter 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 stage-

based approach including theoretical framework, and f) an outline of the remaining dissertation chapters.

2. Overview of American Indian/Alaska Native Population: Behavioural Health Status, Risk and Contextual Factors

There are an estimated 1.9 million American Indian/Alaska Natives (AI/AN) currently residing on reservation or trust lands in the U.S. (1). The death rate among AI/ANs is 20% higher than the U.S. All-Races rate with some Native communities experiencing double the U.S. death rate (1, 2). There has been a long history of infectious disease disparity between the general U.S. and Native populations particularly with regards to tuberculosis, pneumonia, and influenza however this burden is shifting to the behavioural and mental health arenas, reflecting similar epidemiologic transitions worldwide (1, 2).

2.1 Historical Trauma. The behavioural health of Native communities is impacted by historical trauma and a legacy of oppression by the U.S. government. Historical trauma can be defined as: mass trauma deliberately and systematically inflicted upon a target population by a dominant population, the experience of trauma not limited to a single event but experienced over generations, the traumatic events reverberating through a population creating a universal experience, and the magnitude of the trauma derailing the population from its natural, projected historical course resulting in physical, psychological, social and economic disparities across generations (3). Explanatory models of historical trauma link behavioural health disparities to both physical and psychosocial stress from the social environment, where psychosocial stressors create susceptibility to disease and also act as a direct pathogenic mechanism (3).

2.2 Poverty & Unemployment. History has created a context in Native communities that contributes to and exacerbates behavioural health disparities including poverty, un- and under-employment and a lack of available prevention and intervention resources. Native communities have the highest poverty rates of any U.S. racial group, with nearly 30% of the entire population living below the federal poverty line (4). For the tribal community participating in this research, 57% of all children between the ages of 0 and 5 are living in

poverty (5). Also in this community, 61% of those aged >16 years or older are either “Not in Labor Force” or unemployed; 47% aged ≥ 25 have not received a high school diploma, and the median household income is \$14,496, compared with \$62,982 for U.S. All Races (4). Over half (53%) of homes are led by single mothers and 75% of children are born to unwed mothers (6).

2.3 Barriers to Mental and Behavioural Health Intervention.

Failure by the U.S. government to appropriate adequate federal funds in Native communities also creates a weakened prevention, treatment and service delivery system (2). Disjointed efforts to meet identified needs, western-dominated diagnostic methods and treatment plans, and high staff turnover are the result (2). Access to prevention and treatment is further compounded by a dearth of indigenous peoples trained in mental and behavioural health care. Low availability of reservation-based specialty services precludes prevention, early intervention and continuity of care (7, 8).

3. Adolescent Behavioural Health Disparities

3.1 Mortality. Within Native communities, adolescents and young adults are disproportionately affected by behavioural health disparities, namely substance use, suicide, and sexually transmitted infection. The death rate for AI/ANs ages 15-24 is 2.3 times that of the general population, with the first and second leading causes of death being unintentional injury and suicide, respectively (1).

3.2 Suicide. Native adolescents have the highest suicide rate in the U.S. at 29.6 suicides per 100,000, roughly 3.5 times the U.S. average (9). In 2013, the proportion of Native high school students was higher than the proportion of total U.S. students for having serious thoughts of suicide (21.8% vs. 15.8%), making suicide plans (17.7% vs. 12.8%), attempting suicide (14.7% vs. 7.8%) and receiving medical attention for a suicide attempt (6.1% vs. 2.4%) (10).

3.3 Sexual Health. American Indians and Alaska Natives are diagnosed with HIV at a rate 30% higher than Whites and with STIs at a rate ~400% higher than Whites (11). Between 2007 and 2010, AI/ANs were the only racial/ethnic group in the U.S. experiencing an increase in HIV diagnosis (12). Native adolescents compared with the

general U.S. population are more likely to have ever had sex (69% vs. 47%); had sex for the first time before age 13 (11% vs. 6%), had sex with four or more persons during their life (22% vs. 15%), and drank alcohol or used drugs prior to last sex (32% vs. 22%) (1, 2, 12). Native adolescents also have the highest rates of teen pregnancy with nearly half (46%) of Native females giving birth in adolescence and bearing twice as many children than in the general U.S. population (1, 2, 12).

3.4 Substance Use. Native adolescents have the highest substance use and related morbidity and mortality of any U.S. racial group, and are more likely than U.S. All Races adolescents to engage in past-month binge drinking (30% vs. 24%), marijuana (32% vs. 21%) and cocaine use (6% vs. 3%), and lifetime methamphetamine use (11% vs. 4%) (12, 13). It is well established in the literature that substance use significantly impacts the behaviour of suicide and incidence of STIs, suggesting shared risk and contextual factors for these behaviours as well as potential root causes (14-16).

4. Protective Factors in Native Communities

4.1 Cultural Wisdom & Tradition. Despite these challenges, Native communities are resilient and have sustained the well-being of their members in generations of hardship through traditional knowledge and practices that intrinsically promoted behavioural health. Traditional world views are often relational or circular and conflict with western linear, cause and effect views (17, 18). Mental illness and behavioural health problems in indigenous cultures often attribute to being “out of balance or harmony” with mind, body, spirit and creator and not just an issue with the psyche alone (18, 19). Disruption in harmony from external variables such as curses or evil spirits, black magic, and oversight of traditional practices, contrast with internal variables like genetic background and chemical imbalances (18, 19). Many indigenous treatment models call for traditional ceremonies, rituals, and connectedness with one’s environment, rather than individualistic, psychotherapeutic modes (17, 20, 21). As such, behavioural health care systems in Native communities should operate from a foundation in indigenous etiology and treatment; several examples illustrate this point.

Peacemaking ceremonies in Dine culture treat interpersonal and family-based conflict, antisocial law-breaking behaviour, substance use as well as child neglect (21). Peacemakers mediate by defining the problem, identifying causes of disharmony, and helping those involved to agree on action for restored balance (21). Peacemaking has been shown to improve substance use-related dysfunction, anxiety, as well as social, occupational and school functioning (21). Other treatment models for substance abuse include sweat lodge ceremonies--or ceremonial saunas-- used in Navajo communities to cleanse the mind and body and facilitate return to balance (21).

The Kashaya Pomo look to herbal ceremonies for healing. Sacred herbs and plants are gathered including teas, pine, and various grasses. Herbs are ingested to represent all that is consumed by the body and to alert the herbs to whom the ceremony is dedicated; ingestion helps herbs recognize the person when called upon for healing (21). Herbs are then burned to unlock their healing energy and power (21). Traditional songs accompany ceremonial herb burning to invoke a trance-like state enabling the person to go back in time and experience the natural world; without involvement in herb ceremonies a person's spirit can become disconnected from the universe and at-risk for disharmony and imbalance (21).

The Western Apache invoke oral narratives to impact a person's psychological state and motivate behaviour change (22). Metaphorically referred to as "shooting someone with an arrow," historical narratives are told to improve anxiety, sadness, despair, and cognitive distortion (22). Once the "arrow" (narrative) has been "shot" (told to the person), it goes to work by changing their thoughts. If the narrative (arrow) is strong enough, it will motivate the person to change their actions, referred to metaphorically as "pulling the arrow out" (22). Narratives are tied to the physical places they occurred within the land, for example when a person encounters a spot along a river from a narrative it enables them to "travel in their mind" to recall the event, the knowledge they acquired through story, and encourage sustained behaviour change (22). Accounts from Apaches receiving this practice include feelings of smoothness or softness, inner quiet, hopefulness, a restored relationship between self and surroundings, reestablishment of psychological balance, and healing of sickness (22).

4.2 Tribal Sovereignty. In the U.S., tribal communities are self-governing and considered independent nations by the federal government, with great aptitude for uptake and rapid dissemination of promising behavioural health intervention strategies to improve the health and well-being of their Tribal members. The Indian Health Care Improvement Act (IHCIA), originally enacted in 1976, was established to improve the health of American Indians/Alaska Natives as required by the federal government's historical and legal relationship with as well as responsibility to Native people (23). It authorizes the delivery of health care services by the Indian Health Service, within the U.S. Department of Health and Human Services. The recent reauthorization of the IHCIA through the Affordable Care Act (H.R. 2708) contains provisions which offer opportunity for improved behavioural health outcomes including preventative services to cover cancer screenings, diabetes screening and prevention activities through culturally appropriate programs, the consolidation of existing authorities to provide behavioural health assessment, treatment and prevention, and the expansion of grant opportunities addressing youth suicide (23).

4.3 Community Health Workers. Native communities have an abundance of individuals with capacity to be trained as Community Health Workers (CHW). Consensus has not been reached on the definition of a CHW; they can be young, old, vary in literacy levels, peers or non-peers, generalists or specialists and play preventive, curative or developmental roles (24). Membership in the same ethnic group, peer-status, past experience, social position, and knowledge of community may enable CHWs to act as a bridge between individuals and service providers (25-27). CHWs can meet unique cultural aspects of behavioural health problems and reinforce protective factors, and this common ground helps establish rapport, trust and facilitates health improvements (7, 25, 28-30). There is mixed evidence for the utility of CHWs in behavioural health intervention (31, 32). A review conducted in 22 developing countries concluded that CHWs, compared with usual health care services, can reduce symptoms of depression, anxiety and post-traumatic stress disorder, improve dementia symptoms, and decrease problem drinking, however the evidence was of low-quality in some areas (31, 32). Other behavioural health intervention research suggests CHWs can motivate behaviour

change for screening, testing, and health promotion among at-risk groups including exclusive breast-feeding and communication skills of new mothers, Type I diabetes control, diet and exercise, in addition to goal-setting and self-monitoring (33-37).

However researchers agree that CHWs are suited for delivering behavioural health interventions; people relate to someone of their own ethnic background familiar with community dynamics, values, attitudes, and communication styles (28, 38). Specific responsibilities of CHWs in behavioural health prevention and intervention could include screening and assessment, crisis management, psychoeducation, addressing stigma, bridging cultural beliefs and language barriers, developing culturally-appropriate coping and problem-solving skills, providing social support, goal setting, and connecting to treatment and resources (39-41, 41).

5. Problem and Opportunity Addressed by This Research

There has been a lack of behavioural health interventions developed with and for Native communities using participatory research approaches that employ mixed methods designs (formative, qualitative and quantitative studies) and a staged approach to cultural adaptation, with demonstrated impacts on targeted behavioural health risks among adolescents. Various participatory research approaches have been described in the literature on prevention and intervention with Native communities, however the presentation of these approaches has not been accompanied by corresponding studies illustrating the specific method of scientific investigation that was utilized to obtain the knowledge and data necessary to inform the development, adaptation, and evaluation of the behavioural health intervention. More specifically, while participatory research models have been described for conducting research with Native adolescents, they have not been supported with scientific evidence of their utility and appropriateness for intervention development, specifically within the behavioural health arena. Therefore the central question of this research is: 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?

6. Review of the Literature

6.1 Participatory Research Approaches. Various participatory research approaches have been described in the literature on prevention and intervention with Native communities, including Community-Based Participatory Research, Participatory Action Research, and Tribal Participatory Research (42). In Community-Based Participatory Research, emphasis is placed on the empowerment of the community itself through the research, because community members are involved in all aspects including design, implementation and evaluation (42). Value is placed on the co-construction of meaning by community members and researchers, the requirement of collaboration for a successful outcome, and cycles of action and reflection (42). Community-Based Participatory Research incorporates values from Participatory Action Research, where research is conceptualized as increasing research participants' self-determination and whose goals revolve around change at the individual level, and from Tribal Participatory Research, which emphasizes collaboration between researchers and community members and formalizes an infrastructure within the Tribe to conduct the research (42-44).

6.2 Cultural Intervention Adaptation. Participatory approaches, especially Community Based Participatory Research (CBPR), can facilitate the cultural adaptation and fit of behavioural health interventions to Native and indigenous contexts (42). Deep-structure cultural adaptation can be defined as: "using systematic methods to infuse the unique cultural worldviews, beliefs, values and behaviours of a population into a prevention curriculum that has been developed and normed on a different population" (45, 46). To be considered rigorous, cultural adaptations must maintain fidelity to the core elements of the original intervention while also adding specific cultural content to the intervention or its strategies for engaging participants (47). In the process of cultural adaptation, fit to the community of interest is the central focus of development activities, while also taking advantage of the original intervention's foundational

theory, basic and efficacy research (48). There is consensus in the literature that the use of formative studies can determine how well an original intervention would fit the needs and preferences of a specific racial/ethnic group, especially in terms of differences in community-specific factors related to the outcome, and that quantitative and qualitative methods should be combined to inform modifications.

Cultural adaptations are justified under the conditions of 1) non- or under-involvement of the target population in the original intervention, 2) unique population-specific risk and resilience factors, 3) behaviours as they are manifested by members in the community that the original intervention was not designed to influence, and 4) poor intervention effectiveness (49). Cultural adaptations are also justified when there are mismatches between program conditions that existed during the original intervention validation research and what might exist during application to a different racial/ethnic group, including a) group characteristics, b) program delivery staff, and c) administrative/community factors (50).

Deep-structure cultural adaptation requires time and close collaboration with the targeted community while balancing the necessary cost to create a culturally focused intervention for a unique group while maximizing the likelihood for achieving desired intervention effects and potential program scalability (45, 46). Deep-structure adaptations are a good fit for Native populations with immediate behavioural health-related needs and a lack of prevention research (45).

6.3 Stage-Based Approaches to Intervention Development.

There is agreement in the literature that the process of cultural adaptation can be organized into five distinct stages, including: 1) information gathering, 2) preliminary design, 3) preliminary testing, 4) refinement, and 5) final trial (51). Several staged models currently exist to inform the process of cultural adaptation (52-56). Although these models were developed separately, they demonstrate considerable agreement. A critical aspect of all staged models are that they contain concrete steps to guide intervention developers in using qualitative and quantitative data to determine the need for cultural

adaptation, intervention elements to change, and estimates of the effects of intervention alterations (49).

Confidence in the validity and utility of staged models to inform the cultural adaptation of interventions is supported by similarity shown between models, but also by budding evidence for their effectiveness in targeting behavioural health disparities (52, 54, 56, 57). 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 (48). Cultural adaptation stage models resolve the tension between “top-down” universal approaches that view the original intervention content as applicable to all other groups and not in need of alterations, and “bottom-up” approaches that emphasize culturally grounded content consisting of the unique values, beliefs, traditions and practices of a particular group, through the integration of a series of adaptation stages (47, 51).

6.4 Behavioural Health Intervention with Native

Adolescents. While a number of reviews exist in the literature of adolescent behavioural health prevention interventions including meta-analyses, they have generally not focused on intervention efficacy for racial/ethnic minority groups with the exception of those for HIV prevention, and in this case, not with Native Americans (47, 51). Meanwhile, Native Americans have been included as a very small proportion of the total sample in a few efficacy trials in the areas of type II Diabetes (adults), substance use (adolescents) and conflict resolution (adolescents) (58-62). The behavioural health disparities experienced by Native Americans cannot be addressed unless they are participants in related evaluation research (63). Furthermore, evaluations of behavioural health interventions involving exclusive samples of Native Americans, and specifically reservation-based Native American adolescents, while they would be the gold standard, are scarce (64-67). Native American and other minorities continue to be underrepresented not just in prevention efforts but across the

research spectrum including theoretical frameworks, design, implementation and evaluation (68, 69).

6.4.1 Adolescent Development. Adolescence is typically marked by a period of identity exploration, instability, and a focus on one's self (69). For Native adolescents, this transition may conflict with notions of the collective self, a value upheld in many Native cultures (69-72). Research suggests that this unique situation faced by many Native adolescents creates additional tension and barriers to the development of targeted behavioural health risk reduction strategies (69, 73). Yet, little is known about the contemporary expectations, pressures and norms that influence Native adolescents' decision making regarding health, or how those experiences contribute to their engagement in risky behaviour. Therefore, it is essential in research with Native adolescents to more deeply understand these connections and precipitants impacting behaviour change.

HIV/AIDS has been the subject of more stage models for the cultural adaptation of interventions than any other health condition, but there has never been an adaptation and evaluation conducted with an exclusive sample of reservation-based Native American adolescents (55, 56, 74-80). Furthermore, adapted interventions with younger participants have produced somewhat smaller effect sizes than those with older participants and the literature argues for more evaluation of systematic cultural adaptations on interventions directed at youth (49, 51). This thesis will directly address these gaps in the literature.

7. Rationale and Theoretical Background of Methodological Approaches Used in this Research

7.1 Quantitative Data Collection. There is substantial need for community-based Native-adolescent-specific research on precipitants, risk and population-focused strengths due to the: 1) public health magnitude of Native adolescent behavioural health, 2) the paucity of studies and their methodological limitations, 3) unique opportunities in tribal contexts for behavioural health intervention, and 4) the potential to reduce marked disparities among Native adolescents. Quantitative descriptive studies need to be conducted to learn directly from Native adolescents engaging in high-risk behaviours about potential risk and protective factors including socio-demographics, cultural

characteristics, behavioural history and connections to treatment, adverse life events, and psychosocial functioning, in addition to the relationships of these variables to the frequency of problematic behaviours. These studies should also explore settings in which to identify high-risk adolescents and novel intervention approaches that respond to the specific context and parameters in tribal communities.

7.1.1 Behavioural Health Surveillance. Reservation-based tribal communities offer a unique opportunity to collect surveillance data in real-time to track trends and patterns in health behaviours of individual tribal members due to: a) geographically defined boundaries, b) relatively small population sizes, c) racial/ethnic homogeneity, and d) tribal sovereignty to advance tribal-specific research targeting known behavioural health disparities. Toward this end, one tribal community, with technical assistance from the Johns Hopkins Center for American Indian Health, has implemented the first and only community-based, mandated, surveillance system of suicidal and self-injurious behaviours (81).

This tribe mandated reporting to a locally appointed Surveillance Team of any known incident of suicidal ideation, attempt or death, in addition to other intentional self-injury such as cutting or burning, and severe life-threatening episodes of alcohol or drug intoxication. Reports are made using a standardized tribally-approved set of forms, and data are entered on an on-going basis into a secure web-based database. Surveillance team members are authorized by tribal law to follow-up in-person on every incident reported through the system to confirm the report, gather more detailed information, and triage the individual and their families to appropriate available care. This system has enabled the tribe to accurately characterize the problem of suicide, self-injury and binge substance use as it is experienced by their community members, rather than on larger cross-population studies with varied sampling methods of Native participants to substantiate community-specific rates (9, 82, 83).

7.2 Qualitative Data Collection. Behavioural health research predominately utilizes quantitative methodologies which can provide knowledge and risk factors both universal and culture-specific, but how these risk factors lead to specific behaviours is not yet completely

understood. Qualitative approaches are essential to deepening how we understand risk, facilitating understanding of relationships between variables identified by quantitative approaches, and for moving the field of behavioural health science forward (84). Specifically, a qualitative approach presents behaviour in the language of the participant and an accurate account of the meaning attributed, in contrast with phenomenological, theoretical, or ethnographic descriptions in which researchers may infuse their own interpretation (85).

7.3 Cultural Adaptation of an Evidence-Based Intervention.

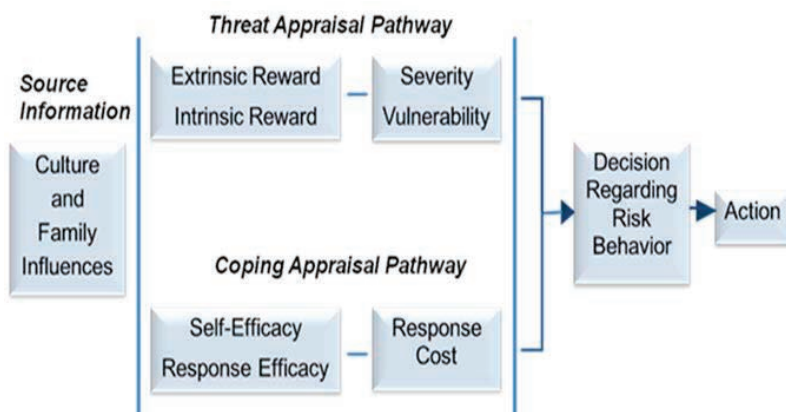
This dissertation presents a staged model of the cultural adaptation and evaluation of an HIV risk-reduction intervention for adolescents conducted by the Johns Hopkins Center for American Indian Health in partnership with its longest standing research collaborators, the White Mountain Apache Tribe (Apache).

7.3.1 Community Based Participatory Research. As described previously, a Community Based Participatory Research (CBPR) process, which builds trust and increases likelihood that programs are conceived sensitively and appropriately, was utilized to guide selection of an evidence-based intervention (EBI), processes and key targets for adaptation, implementation and evaluation, and included the formation of a community advisory board (86-89). Our CBPR process identified the absence of sex education in schools as contributing to high rates of STIs and teen pregnancy among Apache adolescents. Community Advisory Board members and community feedback indicated preference for an intervention inclusive of protective factors that was experiential, and taught concrete skills. This process also identified Apaches aged 13 to 19 to be the most important population to initiate prevention and intervention, and to recruit youth both in and who have dropped out of school. Community Board Members members and focus group respondents preferred Apache paraprofessionals with health education experience and fluency in English and Apache as interventionists, understanding that intervention topics could be sensitive and interventionists must be trusted, and comfortable interacting with youth. Study partners agreed this was essential to replication and sustainability in other Native communities.

7.3.2 Intervention Selection. The EBI “Focus on Youth” was selected from the Centers for Disease Control and Prevention Compendium for adaptation due to its targeted age group (adolescents), skills-focused curricula, theoretical underpinnings promoting protective factors, capacity for delivery by trained community members, and track-record of successful cross-cultural replication (90-92).

7.3.3 Focus on Youth Theoretical Model. The Protection Motivation Theory is the foundation of Focus on Youth and posits that the perceived threat of HIV infection initiates two cognitive pathways: 1) threat-appraisal (risk) balances the threat of contracting HIV including intrinsic/extrinsic rewards versus the severity of HIV and one’s perceived vulnerability; 2) coping-appraisal (protective) balances one’s ability to avoid the threat through self-efficacy and response efficacy versus the relative cost of the adaptive behaviour. These combine to create protection motivation: the intention to respond by either engaging in the risky or protective behaviour (93).

Figure 1. Protection Motivation Theory (94)



7.3.4 Focus on Youth Curriculum. Focus on Youth initially targeted low-income, urban, African-American adolescents and has been previously adapted for various populations around the world (95). Eight sessions are delivered weekly by pairs of adult interventionists from the community to peer groups of the same sex and age in a community-based setting, typically a community center (96). Activities include discussion, lectures, videos, games, role

playing, storytelling, and arts and crafts (96). Sessions focus on: (a) extrinsic rewards, by teaching decision-making related to communication and negotiation skills, and information regarding condom use, and (b) intrinsic rewards, by emphasizing values clarification and goal setting. Facts regarding HIV/AIDS, STIs, contraception and human development are presented. In the last two sessions participants develop targeted community projects and a ‘graduation’ ceremony is held (96). Participation in at least six of the eight Focus on Youth sessions is considered the minimum for adequate intervention dosage.

7.3.5 Adaptation. To adapt Focus on Youth to the Apache context we conducted fourteen focus groups, nine with youth and five with parents, and three Community Advisory Board meetings. These explored content and format changes essential for community acceptance and impact, behaviours that elicit intrinsic/extrinsic rewards, perceptions of HIV severity and vulnerability, relative costs in choosing protective behaviours, relevant examples and language (92). Our Community Based Participatory Research Process (CBPR) elucidated the need to adapt the Focus on Youth intervention schedule and delivery mechanism. Feedback revealed that retention of youth for eight weeks would be unlikely and the community lacked available centers with necessary capacity.

Due to basketball’s widespread popularity, an eight-day competitive summer basketball camp was brainstormed as a potential vehicle for implementation as it would a) capitalize on availability (i.e. not compete with school-based activities), b) be viewed as a positive recreational outlet by youth and families, c) attract both genders equally, d) be inclusive of adolescents who had dropped out of school, and e) maintain attendance with daily basketball culminating in competitive tournament play. Study partners agreed and developed a camp for this study that was free for participants.

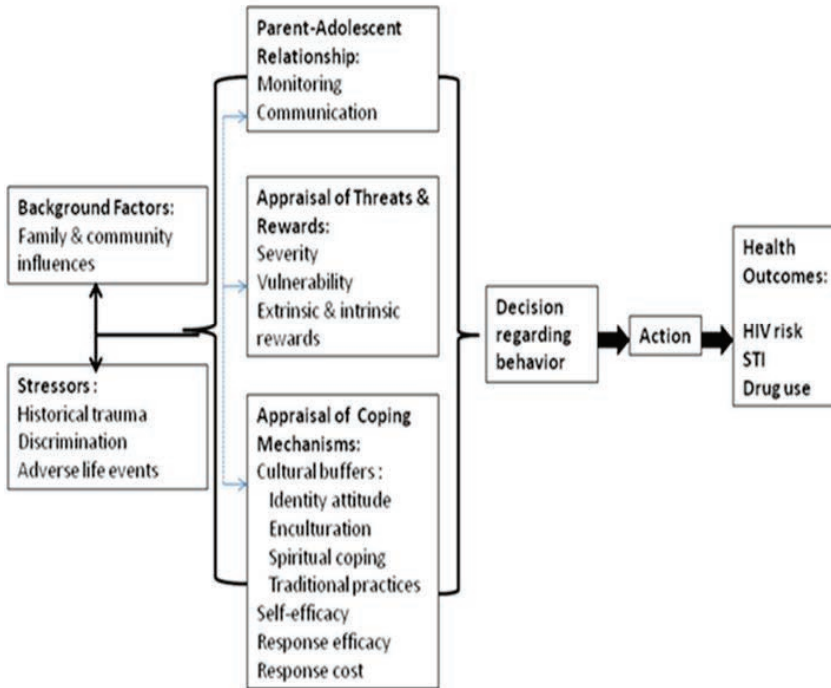
Several adaptations were made to Focus on Youth curriculum content. One example was expanding the human anatomy and development lesson and adding a second related skills-based activity (reflecting the lack of sexual health education taught in Apache schools). The adapted intervention was renamed locally “Respecting the Circle of

Life: Mind, Body and Action.” Respecting the Circle of Life is multilevel and community-based, targeting behaviour change for youth through a camp as opposed to in schools. The choice of this setting (camp vs. school) increases the likelihood of recruiting a wider sample of youth (those in and out of school), sustaining the intervention over time in the Apache community (without dependence on the public school system), and successful dissemination to other Native populations.

7.3.6 Respecting the Circle of Life Behaviour Change

Framework. The Respecting the Circle of Life Behaviour Change Framework was developed during our CBPR process and is based on an understanding that the Apache people, like other Native groups, have a concept of health that is broader than the definition of absence of disease and that behaviour change is a result of interaction between individual, family and community levels. We used the Walters & Simoni (97) Indigenist model of trauma, coping, and health outcomes to adapt and enhance Protection Motivation Theory by illustrating how Apache cultural concepts of health operate together to impact health behaviour decision-making and, ultimately, behavioural health outcomes (Figure 2) (94, 97).

Figure 2: Theoretical Behavior Change Model for RCL



7.3.7 Respecting the Circle of Life Structure. Camp consists of eight consecutive four-hour days. Youth participate in 90 minutes of basketball, 30-minute lunch and a 90-minute educational session. The last day includes an extra 180 minutes to accommodate a graduation ceremony and tournament.

7.3.8 Respecting the Circle of Life Interventionists. Renamed Respecting the Circle of Life Facilitators, interventionists were male and female Native paraprofessionals from the community trained and employed by Johns Hopkins. All facilitators had at least a high school diploma while some had two- and four-year college degrees. All were bi-lingual in their Native language and English and had previous health education and/or teaching experience. All were paid a salary commensurate with their education and job requirements in the Apache community.

8. The Present Research

This research is the first illustration of a staged-based model rooted in community-based participatory values to the development of behavioural health interventions targeting Native American adolescent disparities, with a special focus on the evaluation of a culturally adapted EBI for HIV risk reduction.

8.1 Study Population. The White Mountain Apache (Apache) (~17,000 population) reside on the Fort Apache Indian Reservation in northeastern Arizona (see Figure 3). Apaches were once nomadic people, roaming land that includes their current reservation and as far south as northern Mexico. Apaches' first contact with white settlers, primarily mountain men and traders, was in the early to mid-1880s. Their subsequent history included strong resistance to federal subjugation of original lands and acculturation in the late 19th century, and eventual accommodation and cooperation with federal authorities as a survival strategy (98).

The reservation consists of 1.6 million acres, geographically isolated from other population centers. The nearest major airport is in Phoenix, 200 miles away. Although paved highways connect the reservation overall it remains isolated from surrounding communities. There are twenty-five major reservation communities; the largest population centers are within a 7-mile radius of the capital of Whiteriver (65%) and in an outlying community called Cibecue (16%). The Apache Tribe is governed by an elected 11-member Tribal Council comprised of a Chairman, Vice Chairman and nine Council members representing each community.

Major industry includes a timber mill, tourism including a Casino, ski resort, historical museum, and agriculture and livestock enterprises. However, between 2007 and 2010, the number of unemployment claimants living in the region increased 320% (5). The tribally-owned lumber and saw mills have closed due to recent forest fires, causing hundreds of lay-offs, and the recession caused the Tribe to furlough numerous tribal employees.

Figure 3. Fort Apache Indian Reservation



In the Apache community, healthy adolescent development is threatened by these social and economic challenges, and, in the absence of community-based interventions, more than half of Apache youth resort to school drop-out, substance use, intentional injury, and high risk sex during adolescence. Recent studies conducted by Apache-Johns Hopkins research partners have yielded important preliminary data. Between 2006-2011 study partners recruited ~60% of the total Apache teen mother population for a home-visiting intervention.

At baseline: 1) 32% reported a lifetime STI diagnosis; 2) the average age of sexual intercourse initiation was 15.4 years (SD=1.6); and 3) 53% reported that they had not used a condom at last sex, a higher percentage compared with 2011 YRBS data on all Native youth (34%), all Arizona youth (41%) and U.S. All Races youth (40%)(99). A concurrent study with male and female adolescents (mean age 16) who had exhibited recent suicidal behaviour revealed high rates of lifetime drug use: 92% for alcohol, 88% for marijuana, 38% for crack/cocaine, and 35% for methamphetamines, which is 3 times that of all Native adolescents in 2009. Drugs were initiated early in this sample with 40% using marijuana and 37% using alcohol at <12 years of age.

Since 1990, the Apache tribe has experienced suicide rates among 15-24 year olds that are up to 10-13 times higher than rates for U.S. All Races in this age group, and 5-6 times the rate for Natives (100). Although the health, social and economic challenges noted above have at times threatened the very survival of the White Mountain Apache, the Tribe has not fallen victim to bitterness or isolation. Indeed Apache people continue to demonstrate vast cultural and communal strengths that lend promise to the continued success of their behavioural health research endeavors.

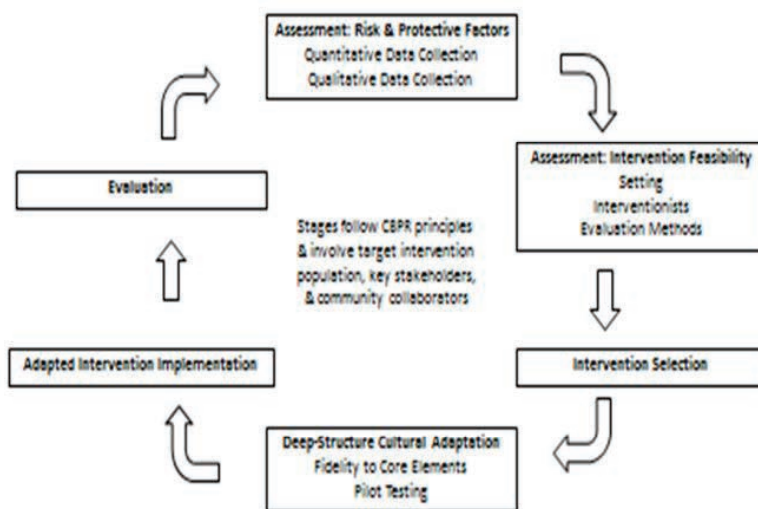
8.2 Human Subjects Research Review Procedures. All research reported in this dissertation was reviewed and approved by the White Mountain Apache Tribal Council and Health Advisory Board, and the Johns Hopkins University and Phoenix Area Indian Health Service Institutional Review Boards. All related manuscripts were reviewed and approved by the White Mountain Apache Tribal Council and Health Advisory Board. Serious adverse events were reported in real-time to participating Institutional Review Boards. There was no Data Safety and Monitoring Board for any of the studies conducted. All study participants were voluntarily consented (ages 18 and older) or assented (ages 17 and younger with parent/guardian consent) to participate in these studies.

8.3 Study Hypotheses. This research answers the following questions: Core Question: Can a stage-based research model rooted in rigorous scientific methodologies and which responds to the unique cultural considerations in Native communities inform the design, adaptation, implementation and evaluation of behavioural interventions targeting disparities among youth? Sub-Questions: 1) What type of data can be collected in Tribal communities to measure baseline behavioural health risks among youth? 2) How do community members and youth themselves describe and understand youths' behavioural health risks? 3) What family and community-specific risk, protective and contextual factors impact youths' behaviour change at the individual level? 4) What limitations and opportunities exist in rural, reservation-based communities for behavioural health intervention delivery? 4a) What settings are ideal for delivery of behaviour-change messages to youth? 4b) What type of interventionist is suited for delivery of sensitive behaviour-change messages? 5)

What types of interventions can be successfully adapted for implementation with Native youth? 6) How can behavioural health interventions be rigorously evaluated in a community-based context? 6a) What strategies can be used to retain youth in study participation over time? 7) What is the impact of an adapted evidence-based intervention on behavioural health outcomes among Native youth?

8.4 Summary of Potential of Research. This thesis has potential to make significant contributions to the existing literature. The combination of qualitative and quantitative data will provide the first evidence for a stage-based model of community-based participatory research that responds to the unique profile of risk and resilience in a Native community, and for the adaptation, implementation and evaluation of behavioural health interventions with adolescents (see Figure 4).

Figure 4: A Stage-Based Approach to Cultural Adaptation & Evaluation of Behavioural Health Interventions for Native Adolescents*



*Adapted from Wingood & DiClemente, 2008 and Okamoto, 2014

The randomized controlled trial presented is the first evaluation of an adapted evidence-based HIV intervention for a Native adolescent population, and provides evidence of impact on youths' behavioural outcomes at 6 and 12 months post-intervention. Despite marked disparities in rates of STIs, teen pregnancy and risk for HIV/AIDS compared with other U.S. racial groups, no evidence-based intervention has been culturally adapted and rigorously evaluated with a Native community; to our knowledge this was the first. By exploring behavioural health disparities and possible solutions from the standpoint and language of community members themselves and combining this with rigorous scientific methodologies, the Center has produced a behavioural health research model with relevance and application to other Native and indigenous communities suffering from similar disparities.

9. Outline of Thesis by Chapter

The research questions in this dissertation are investigated in subsequent empirical chapters. Chapters 2-8 comprise a series of published manuscripts. Since each chapter was published independently, there is some overlap in content between chapters.

Chapter 2 (101) reports the methods and results of a qualitative study conducted with n=58 Apache adolescents ages 12-19 exploring the intersection of substance use and self-injury. The main research question was to gain insight regarding how binge substance use functions as a potential form of intentional self-injury and to identify community-based ideas for dual prevention strategies. The use of qualitative focus group data collection allowed investigators to identify shared root causes, precipitants and social influences for these behaviours as well as possible prevention approaches and target settings for intervention.

Chapter 3 (102) presents the methods and results of a qualitative study conducted with n=22 Apache adolescents ages 13-19 who had made a recent suicide attempt. Investigators sought to further hone a Native-specific conceptual model for adolescent suicide risk with data collected through a series of longitudinal interviews. This chapter describes risk factors unique to this sample of Native American adolescents, organized at the individual, family, community and

societal level. The discussion of the results provides practical implications for research and suicide prevention intervention development.

Chapter 4 (83) reports quantitative data from the Apache tribally-mandated surveillance system to explore the co-occurrence of substance use and self-injury among Apaches ages 15-24 over a four-year period (2007-2010). Results indicate nearly half of adolescents are “drunk or high” at the time of suicide ideation or non-suicidal self-injury and the majority are “drunk or high” at the time of suicide attempt and death. The high co-morbidity of these behaviours among Apache adolescents highlights the importance of behavioural health science to understand the relationship between these behaviours to design targeted and integrated interventions.

Chapter 5 (103) presents the methods and results of a cross-sectional study of n=71 Apache adolescents ages 13-19 who had made a suicide attempt. The main research question was to understand their 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 (104) describes the results of a pilot trial feasibility trial conducted with n=32 Apache adolescents ages 18-19. The main research question was whether self-administered urine sample collection for screening of sexually transmitted infection was an acceptable method in a rural, reservation-based context with limited access to clinic-based screening. Results showed the majority of adolescents were comfortable with screening procedures, preferred this method over clinic-based testing and would recommend it to their friends. The discussion concludes that a self-administered method of screening is feasible among a Native adolescent population, can triangulate self-reported outcomes in behavioural health intervention trials, and holds promise for screening uptake and scalability.

Chapter 7 (105) describes the study rationale, methods, theoretical basis and baseline characteristics of a cluster-randomized controlled trial of the Respecting the Circle of Life intervention with n=267 Apache adolescents ages 13-19 who were intervened with and assessed from baseline to 12-months follow-up. This chapter provides in-depth information on the community-based participatory research process that shaped the Respecting the Circle of Life intervention design and evaluation. It also provides detail on the Respecting the Circle of Life intervention structure, content and theoretical design. Finally, baseline data are reported. The discussion articulates a distinct 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 (106) reports one-year outcomes from the cluster-randomized trial of the Respecting the Circle of Life intervention. Primary study aims were to assess intervention 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 drug use, 4) increased condom use, 5) decreased frequency of sex with substance use, and 6) delayed sexual initiation. Primary outcome measures included condom use self-efficacy, HIV/AIDS prevention knowledge, and sexual and substance use behavioural outcomes. Results concluded the Respecting the Circle of Life intervention had short- and medium-term impacts on the behavioural health outcomes of interest. The study employed rigorous research methods including novel recruitment, sample maintenance and retention strategies. The discussion of the results provides further detail about the feasibility of conducting a community-based behavioural health intervention trial for HIV/AIDS prevention among Native adolescents and the need for additional study to sustain intervention impacts.

Chapter 9 summarizes the empirical 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 and implementation of behavioural health interventions with other Native and indigenous adolescent

populations. This chapter concludes with recommendations and directions for future research.

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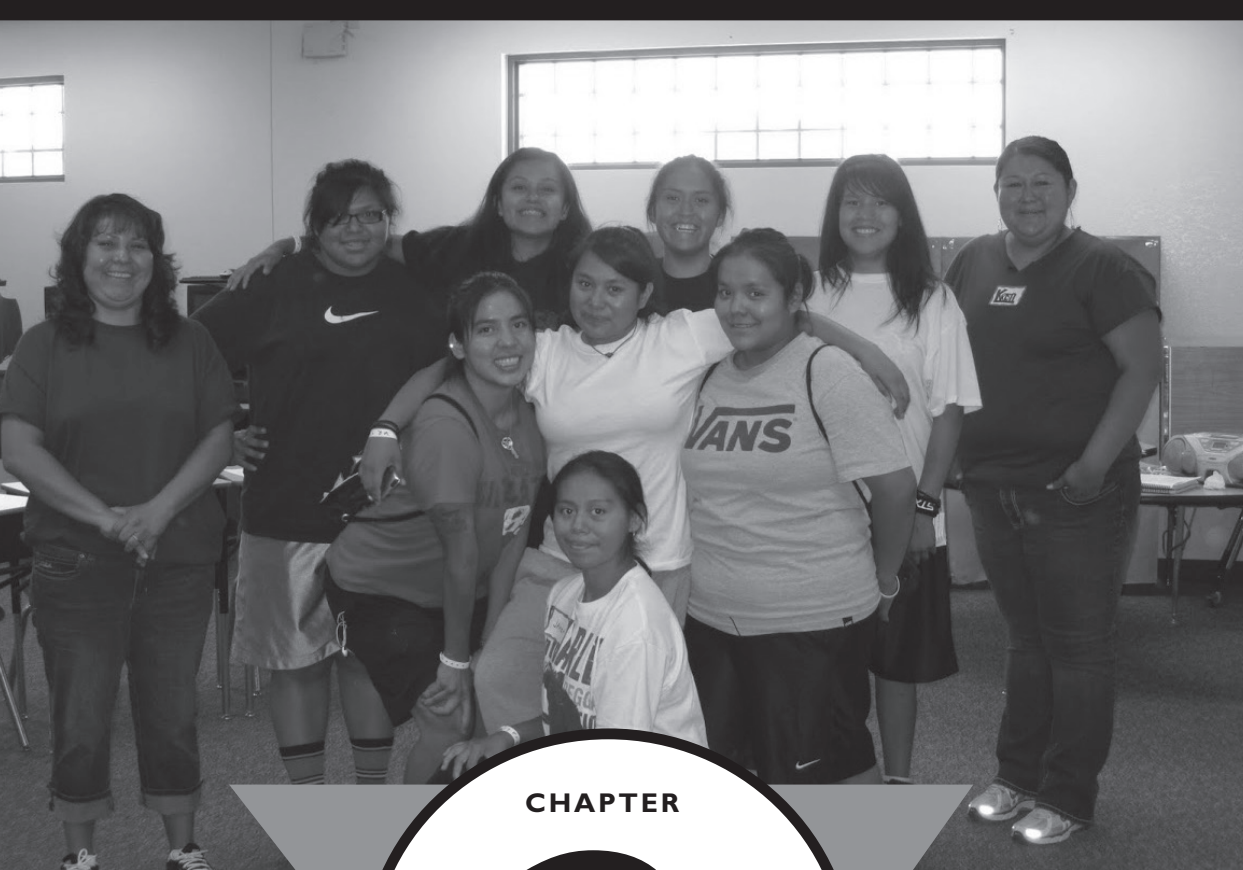
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**Exploring Binge Drinking
and Drug Use Among American Indians:
Data from Adolescent Focus Groups**



CHAPTER

2

ABSTRACT

Background: Risk factors for binge substance use and non-suicidal self-injury (NSSI) are similar, suggesting the importance of exploring how binge substance use and self-injury interrelate.

Objectives: To gain insight from a sample of American Indian (AI) adolescents regarding how binge drinking and drug use function in their lives, including as overlapping forms of self-injury, and to identify community-based ideas for dual prevention strategies.

Methods: N=58 White Mountain Apache (Apache) adolescents participated in ten mixed gender (n=33 males, 55.9%) focus group discussions. Results were interpreted and categorized by Apache researchers, and compared to Nock's behavioral model of NSSI. Results: Participants reported substance use most commonly with "family" and "friends," "at a house" or "around the community." Substance use was not confined to a particular time of day, and often occurred "at school." Commonly endorsed reasons fell into two main categories: "to avoid problems" or "to reduce negative feelings," versus "to be cool," or "to feel part of a group." All adolescents but one thought that some youth use substances excessively as a way to harm/injure themselves (n=25 responses). Prevention approaches included: encouraging healthy relationships, teaching about consequences of use, providing alternative recreation, and changing/enforcing laws on the reservation.

Conclusion: Tribal-specific data support the idea that binge substance use sometimes functions as a form of self-injury. Home/school environments are critical prevention settings, in addition to improved law enforcement and increased recreation.

Dissertation Relevance and Significance: This article illustrates the stage: assessment of risk and protective factors through qualitative data collection, of the approach described within this dissertation. Results advance understanding, possible shared root causes and functions of binge substance use and self-injury, which argue for utilization of integrated interventions for American Indian adolescents.

INTRODUCTION

Binge-drinking is related to a substantial proportion of alcohol-related deaths (1), nonfatal injuries and negative psychosocial outcomes (2, 3). Among all U.S. adolescents (<21 years old), nineteen percent (7.2 million) of those with past month alcohol use were classified as binge drinkers. Higher rates of alcohol and drug use among American Indian (AI) adolescents and research specific to AIs suggest they are more prone to binge drinking (4).

Binge substance use and non-suicidal self-injury (NSSI) share common risk factors (5, 6). NSSI is characterized by self-inflicted harm (e.g. cuts and burns) without expressed intent to die, is associated with other high-risk behaviors including suicide attempts (7-11), and is increasing among adolescents. NSSI is currently a sizable source of morbidity among the White Mountain Apache Tribe (WMAT/Apache) with rates higher than the general population at 600/100,000 for all ages and 3,000/100,000 for 10-14 year olds (5, 10, 11). Many Apaches are intoxicated or high during NSSI, contrasting with reports in other populations (5, 12, 13). Substance use is the second most prevalent self-reported “method” of NSSI by Apaches (5).

Comparable explanatory models exist for alcohol misuse and NSSI (14-16). In addition, the functions of both have been conceptualized as internal (intrapersonal) or external (interpersonal), and as negatively or positively reinforcing. Examples of internal functions are to reduce stress (negative reinforcement), and to feel more autonomous or alive (positive reinforcement). Examples of external functions include to provide distance or isolate oneself from others (negative reinforcement), and to enhance peer group status or strengthen friendships (positive reinforcement). In young people, external motives are associated with moderate alcohol use and internal motives with alcohol-related problems (17). Most adolescents engage in NSSI for internal functions, but a substantial proportion also report external functions (14, 17). Binge substance use also shares common risks with NSSI among U.S. and Apache adolescents, but rarely has this behavior been conceptualized as a possible form of self-injury or on the spectrum of suicidality (5, 6).

Background

The White Mountain Apache Tribe (Apache), with a population of ~15,500, resides on the Fort Apache Indian Reservation in Northeastern Arizona. The Apaches have an internationally renowned track record of innovative public health research to address difficult health problems, including infant mortality, adolescent pregnancy, and youth suicide (18-22). Their attention to current health disparities affecting tribal members and determination to employ Community Based Participatory Research (CBPR) to solve problems distinguishes their community.

To better understand self-injury, in 2001 the Tribal Council mandated a unique Apache suicide and self-injury surveillance system (described in detail in previous publications) (5, 23). The original mandate required reporting of suicide deaths, attempts and ideation. In 2004, it expanded to include verification of all reported incidents through in-person follow-up. This process identified that some incidents of intentional self-injury were non-suicidal and binge substance use was frequently co-occurring with intentional self-injury. Therefore, in 2007 data collection expanded to include NSSI, and in 2010, binge substance use was added as a discreet reportable behavior.

The addition of new, self-injurious behaviors of concern to the community occurred with guidance and input from Apache key stakeholders, including representatives from the Elders Council, Apache Community Advisory Board (CAB), three High Risk Coalitions (comprised of Apache service providers) and Tribal Health Departments. These groups hold regular meetings where a common vocabulary for observed behaviors has developed, blending both community and scientific terminology, that is used to inform surveillance data collection and interpretation.

The addition of binge substance use to the system reflects local understanding that self-injury and substance use are on a common spectrum of maladaptive behavior. This is a preliminary qualitative study to elucidate possible internal and external functions of binge substance use among Apache adolescents. To interpret our findings, we employed Nock's Four Function Behavioral Model of NSSI (24).

METHODS

CBPR

This study was designed employing a CBPR approach; tribal leaders and the Apache CAB were involved in every aspect of conception and implementation. This study was motivated by a community survey ranking alcoholism as the most troubling health problem, school concerns about student bingeing, and corroborating surveillance system data.

Definitions & Terms

We utilized Apache surveillance system terminology/definitions. Self-injurious behavior is defined as direct and deliberate infliction of injury upon the self, and includes both suicidal and non-suicidal self-injury (16). “The intent of the [non-suicidal] self-injuring person is not to terminate consciousness, as in suicide, but to modify it; those who engage in non-suicidal self-injury typically have thoughts of temporary relief” [as opposed to permanent relief in suicide] (25, p.130). Binge substance use is defined as consuming substances with the intention of modifying consciousness that results in severe consequence(s) (e.g. passing out, found unresponsive, and requiring treatment in Emergency Department). Note that this differs from the commonly accepted western scientific definition of >5 drinks for men and >4 drinks for women in <2 hours. The commonalities between NSSI and binge substance use definitions, particularly the focus on intentionally modifying consciousness, reflect Apache stakeholders’ view that binge substance use is a potential form of self-injury with physical consequences just as harmful and ‘direct’ as cutting one’s arm with a razor.

Participants

AI adolescents aged 12-19 living on the Apache Reservation were eligible. This age group was selected to inform prevention strategies as Apache surveillance data indicate both behaviors are initiated at this age.

Sampling & Recruitment

Adolescents were recruited from three collaborating schools. Purposive sampling allowed for heterogeneity on risk and protective factors, such as age, gender, school performance and past alcohol/drug use. Participants were identified and recruited by counselors and school administrators. Using a standard script, Apache researchers explained the study purpose, associated risks, and benefits of participation. Adolescents aged 12-17 were required to have parent/guardian consent and 18-19 year olds consented themselves.

Design

Ten focus groups (~1 hour each) were facilitated in local, private classrooms. Apache community mental health specialists, who are bilingual, respected members of their community, knowledgeable in surveillance system terms/definitions and trained by JHU mental health professionals, facilitated focus groups.

This study and manuscript was approved by the Apache Health Advisory Board and Tribal Council. The study also was approved by the Phoenix Area Indian Health Service and Johns Hopkins Institutional Review Boards.

Focus Group Guide

The focus group guide was developed in collaboration with the CAB and Apache community mental health specialists, semi-structured and utilized surveillance terminology/definitions. Facilitators used the guide as a general outline for discussion and to probe respondent's explanatory and conceptual understanding of how binge substance use functions for Apache adolescents. Participants were asked about general drinking scenarios, context for behaviors, why adolescents engage in binge substance use, agreement/disagreement with tribal stakeholders' belief that binge substance use functions as a form of self-injury, and prevention ideas. Participants were not asked about personal substance use. Focus groups were audio recorded and transcribed.

Analysis

Data analysis was conducted iteratively. Researchers read transcripts and identified major themes. A code book with definitions was developed and applied to all transcripts manually. Emergent codes were added as themes, followed through focus group texts, and new phenomena were identified. Themes were redefined and re-categorized as transcripts were continually reviewed. Data tables and matrices were developed and discussed at team meetings throughout analysis to allow comparison of themes across categories and to ensure consistent and reliable coding. Results are organized in the following domains: 1) the context of binge use, 2) reasons for adolescent substance use categorized according to Nock's model (24), 3) ideas about binge behavior as a potential form of self-injury, and 4) ideas for substance use prevention. (One of ten transcriptions was eliminated due to poor sound quality and limited field notes).

RESULTS

Sample

N=58 adolescents participated in ten mixed gender (n=33 males, 55.9%) focus groups.

Context of Binge Use

In response to "who do youth usually use drugs or alcohol with?" the most frequent response categories were "family," specifically siblings, cousins and "friends."

"They drink with their friends. I guess their closest friends or their family members because their family members can give them the drinks also...especially if they are too intoxicated they can just hand it to them and they drink with them."

"Sometimes new friends that you meet and old friends that introduce you have alcohol with them...they give you some and it just starts out like that with a friendship, so-called friendship from binge drinking."

Participants were asked “where do youth usually use drugs or alcohol?” The most frequent response category was "at a house," which included their home and friends' houses. The second most frequent response category was "around the community," such as "outside," "in the mountains," "playground," "parks," "stores," "on the road," and "around."

“You have two options: one, out where nobody can see you where guys are hanging out; two, just go to someone’s house where they don’t mind guys drinking there....”

"School" also was a frequently cited location.

“I’d say usually people have been drinking in the school.....there was this incident where 10 people got suspended for drinking last month.”

“It could be seeped through a Gatorade.....or water bottle...one of them got caught and it was happening in the classroom, while the teacher was teaching.”

Participants were asked “when do youth usually use drugs or alcohol?” The two most frequently reported answers were "at night" and "after school." The next most frequent set of responses was: “anytime,” “in the morning” and “during school.”

“It can actually happen anytime, anywhere, anyplace. It doesn’t matter where, doesn’t matter when, it will always happen.”

Table 1: Who, Where, and When of Binge Drinking and Drug Use

With Who? (N=49)	N	Where? (N=54)	N	When? (N=45)	N
Family	2	House	1	Time of Day	3
	3		3		0
Brothers/sisters	7	Their house	5	Night	9
Relatives	7	Friend's house	5	Afternoon (after school)	7
Cousins	5	House-Other	3	Anytime	6
Parents	2	Around the	1	Morning (before school)	5
		Community	1		
Family-Other	7	School	9	During school	3
Friends	1	Special Events	8	Special Occasions	1
	7				1
Older Kids	2	School-related	4	Holidays	6
Alone	2	Community-related	4	When they have money	3
Other	6	Away From	8	When no one is home	2
		(Parents/Police)			
		Anywhere	4	Other	3
		Parties	3		
		Other	3		

Reasons for Adolescent Substance Use

Participants were asked, “why do you think youth start using drugs or alcohol?” The most frequently reported reasons were (total reasons=105): “to avoid problems (n=25),” “to be cool (n=15),” “to feel part of a group (n=14),” “to reduce negative feelings (n=14),” “to feel good (n=11)” and “to feel strong or better than someone (n=10).” Other less common responses included “to start a confrontation (n=4),” “to get attention (n=4),” to gain respect (n=3),” “to get a reaction from someone even if it’s negative (n=3),” and “because they feel numb (n=2).”

We categorized these codes into a behavioral model of NSSI, based on Nock’s and colleagues’ theory and research (12, 16, 24), comprised of four functions along two dimensions: 1) automatic (internal) vs. social (external) motivation, and 2) positive reinforcement vs. negative reinforcement (see Table 2). The majority of our coding categories mapped onto the four different functions. Reasons that were coded

into social, positive reinforcement functions included “to feel part of a group,” “to be cool,” “to gain respect,” and “to get attention.”

:They probably don’t get enough attention from their parents or family members... they probably just want to black out and get hurt so that somebody will be there to take care of them and actually notice what they are doing, to give them the attention that they need or wanted for so long.”

Social, negative reinforcement functions included “to avoid problems with school and family.”

“Certain students who have problems in their lives with relationships or family...they just drink to put the problem away.”

Response categories that were coded into automatic, positive reinforcement included “to feel good,” and “thrill of being high.”

“Most of them just want to act like everything is ok, and drinking...gives them a good feeling.”

Automatic, negative reinforcement functions included “to reduce negative feelings like stress and depression.”

“Usually it starts with problems, problems in your family...you try to numb somewhat the pain...”

Table 2: Four-Function Behavioral Model of Binge Drinking and Drug Use

	Negative Reinforcement	Positive Reinforcement
A u t o m a t i c	<p>Quotes:</p> <ol style="list-style-type: none"> 1. When they don't have more, or when they don't have control over anything, that's when they just let go and they just let the binge drinking take over... and when they can't control it, the more you get the more you want, so after you get to that point when you really have that need. 2. When they are at their breaking point...some stress and personal issues and parents, school and grades; they can't take it and so they just start drinking, drinking, drinking. 3. Everybody on the reservation has some type of problems, even some small spark can push them there, to that limit. 4. Probably to take away the pain because they are not feeling good, and [if] it felt like the way they felt the last time, they'd do it again. 5. We all go through problems that burden us in our backs, and there is only a few of us that probably find solutions to get away from it; few of the solutions turn to alcohol and drugs, thinking that is the only alternative. 6. Some are too stressed from the teachers that give them problems or their grades if they are not doing well, and if their parents are constantly at them. 7. It's because of the grades and how their parents are always nagging at them to get a better grade and it just gets to them. 	<p>Quotes:</p> <ol style="list-style-type: none"> 1. Some people say they don't know, that [they] can't describe that feeling; it's like something they want to be the rest of their life. 2. Some like the thrill of being high. 3. People try to show off sometimes, that they can be more than another person. 4. Because they are mad at someone.
S o c i a l	<p>Quotes:</p> <ol style="list-style-type: none"> 1. Family problems...they just don't like being around it...maybe they start drinking as a way out. 2. I am not sure how to say this.... just like a mask or something...it kind of hide[s] your brain until you are out of it, like all of your problems. 3. When they have a problem they can't control anymore or when they get to the point where they can't have enough and when they get pressured by friends. They are saying that it'll make your problems go away. 4. Sometimes one of the older family members you know is drinking...that's why some people just want to get away from whatever. 5. They'll probably call them names or make fun of them because they don't do it [binge drinking], so they probably don't want [it] to go like that. 6. They think it is pretty awesome and amazing just to get out of whatever situation they are in for the time being. 	<p>Quotes:</p> <ol style="list-style-type: none"> 1. Most of them probably think it's cool and my friends do that so I think I am going to do that. I want to be cool...I want to be where people know me and be popular, so just for pride. 2. Peer pressure;--[they're] feeling like they have no friends. They probably just do it just to get accepted by other people. 3. They do it because they see the other kids doing it and they don't want others to think they are not one of them. 4. Most of them think it's cool the way they are around their family and friends; they try to be normal, but around other relatives and friends they act cool... 5. To feel more respected. 6. Because they probably grew up in an unstable house and they were just not getting accepted by people. The only way is [by] binge drinking. Then you think nobody wants to stop me, nobody cares about me, especially if it's a family problem. They do it to make people feel sorry for them.

Ideas about Substance Use as Self-injury

Participants were asked, “what do you think about the idea that some youth use alcohol and drugs excessively as a way to harm or injure themselves?” N=25 youth gave verbal responses to this question. Responses were coded into “agree” (n=21), “disagree” (n=1), and “maybe/sometimes” (n=3).

“They want to seek attention, most of them feel neglected, like nobody is really listening to them...to get the attention they need by hurting themselves, by destroying their body, here and there, to and from, never ending.”

Participants also talked about the relationship between binge substance use and suicide.

“There is always a point in life when you don’t care about anything anymore...you just want to give up, drinking until they die or they just want to attempt....”

Ideas About Prevention of Binge Substance Use

Participants were asked what could be done to prevent Apache adolescents from engaging in binge substance use. Much of the conversation centered on community-wide prevention in the following domains: 1) providing activities, 2) creating programs to encourage healthy family and peer relationships, 3) teaching adolescents about binge substance use consequences, and 4) changing or enforcing local laws regarding drugs and alcohol.

“I would say programs that bring friends and family together and help them work with one another.”

“Show them the path of people that were involved in drugs or alcohol and tell them their experience...how it ended up bad for them... or it ruined their chances of going to a good college.”

“The penalties for bootlegging don’t seem like anything at all because I know someone that got busted...they didn’t really do anything to her...she just got a slap on the hand and she was set free again.”

DISCUSSION

This study has several limitations: 1) Representation from only one tribe limits generalizability. 2) The sample was school-based, representing adolescents less at-risk for substance use or NSSI. 3) Utilization of a community-based definition for binge substance use limits comparisons to studies using other definitions. 4) Tribal stakeholders' hypothesis about binge substance use as potential self-injury framed focus group discussions to elicit common or contrasting ideas, but the frame itself may have biased participants than if discussion were completely open-ended.

Several themes emerged: 1) Adolescents report binge substance use can occur anytime, in any place and with anyone. 2) Adolescents report some binge substance use occurs during school hours and on school property, highlighting the seriousness of the problem and that school may be an important setting for future prevention efforts. 3) Many reported reasons for bingeing fit into an accepted behavioral model of NSSI. 4) Some adolescents clearly view binge substance use as a form of non-suicidal and suicidal self-injury, which may necessitate tailored interventions addressing these functions. 5) Adolescents were insightful about public health-focused prevention strategies including ideas to increase recreation, improve family and peer relationships, teach about consequences, and increase law enforcement.

Past cross-cultural studies with adolescents and young adults exploring motivation for substance use are mostly quantitative and utilize the Drinking Motives Questionnaire (DMQ) (17, 26-29). DMQ constructs map to Nock's model and several studies indicate participants use primarily for "social" reasons: to celebrate, be sociable (Positive/Social), followed by "coping" reasons: helps with depression/anxiety, relax (Negative/Automatic), then by "enhancement" reasons: like feeling, exciting/fun (Positive/Automatic), and finally by "conformity" reasons: external pressures (Negative/Social) (17, 26-30). Few studies are qualitative and none has directly investigated binge substance use as a potential form of self-injury (31,32). This hypothesis warrants further research given the large disparities and co-occurrence of self-injury and binge


substance use among AI adolescents. Intervention approaches that target common motivations and promote culturally-based protective factors hold promise (33-35).

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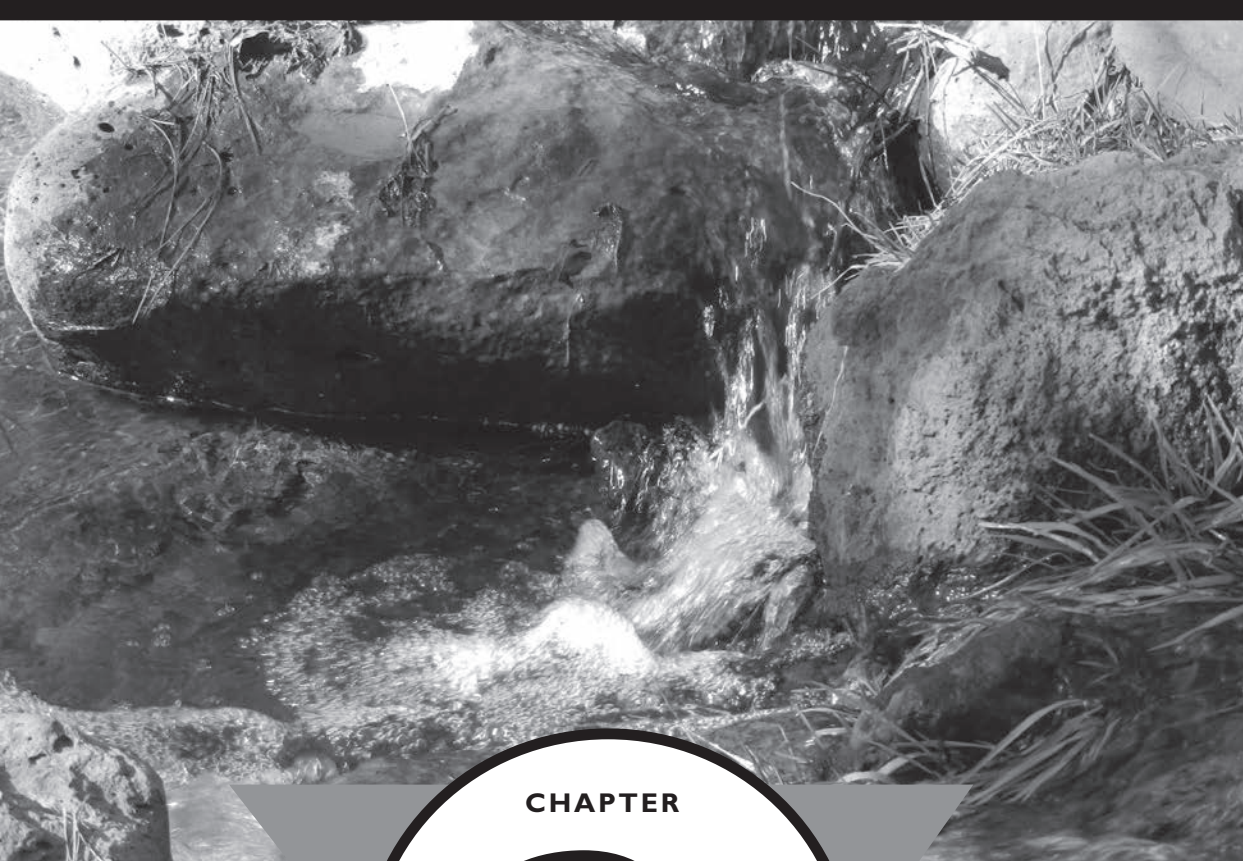
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**Risk Pathways for Suicide
Among Native American Adolescents**



CHAPTER

3

ABSTRACT

Native American (Native) adolescents have the highest suicide rates in the United States, yet no conceptual models describing risk factors specific to this population exist. We sought to further hone a Native-specific conceptual model developed from quantitative data with qualitative data collected from a longitudinal series of interviews with (N = 22) Native adolescents who had attempted suicide. Four levels of suicide risk emerged, detailing individual, family, community, and societal factors that affect youths' pathways to suicide, along with a variety of subthemes and constructs. Some themes parallel established models of suicide risk, however, others are unique to the experience of this sample, including the impact of overtaxed households and family composition, significant grief burden, contagion, and stigma surrounding treatment seeking. We suggest adaptations of existing themes and constructs in the model. We discuss practical implications for research and intervention development, along with strengths and limitations of the study.

Dissertation Relevance and Significance: This article illustrates the stage: assessment of risk and protective factors through qualitative data collection, of the approach described within this dissertation. Results deepen our understanding of risk and protective factors for youth suicide at individual, family, community and societal levels for cultural tailoring of interventions for American Indian adolescents.

INTRODUCTION

Native American (Native) adolescents have the highest suicide rate in the nation at 29.6 suicides per 100,000 youths, roughly 3.5 times the U.S. average (1, 2). However, among Native adolescents, suicide rates and patterns vary widely, with some tribes having rates as high as 15 times the national average (1, 2). Known risk factors for suicide across ethnic groups include depression, hopelessness, substance use, access to lethal means, history of suicidal behavior, physical or sexual abuse, and stressful life events (3, 4). The few studies attempting to understand the inexplicably high rates of suicide in Native communities identified loss of ethnic identity and language, frequent exposure to suicide and other premature deaths, and binge substance use as specific risk factors (4-6).

Intervention with those at highest risk for suicide requires refining and organizing risk factors into coherent conceptual models that address common risk factors for suicide as well as those that might be specific to Native teens and their communities. A variety of conceptual models of suicide have been developed with implications for suicide prevention, such as those that focus on psychopathology (7), sociology (8), cognition (9), and behavior (10). However, none of these models have taken an ecological approach to understanding suicide, nor were they developed specifically by and for suicidal behavior as it is experienced in Native communities.

Qualitative studies of youths who have attempted suicide could be useful in understanding relationships between variables identified by quantitative approaches and to hone an ecologically based, Native-specific suicide risk model. Applying such a model to understanding risk pathways to suicidal behavior among Native youths can enlighten culturally anchored prevention approaches that might be relevant to other Native communities with high suicide rates.

The White Mountain Apache Tribe (Apache) and Johns Hopkins University have a 20-year collaboration to reduce youth suicide. The primary strategy to understand suicide in this community is the tribally driven Apache Suicide Surveillance and Prevention System, in place since 2001. To date, the surveillance system has been instrumental in identifying high rates of youth suicide (2), suicide attempts (5), and nonsuicidal self-injury (11). Quantitative data from the surveillance system have yielded patterns of suicidal behavior and provided the foundation for a preliminary Apache conceptual model of youth suicide.

In this article, we further develop the Apache conceptual model of youth suicide with qualitative data from a community-based sample of Apache adolescents ($N = 22$) who have attempted suicide (12). Qualitative approaches are essential to deepening how we understand suicide risk unique to a community and for moving the suicide prevention field forward (13, 14). We sought to obtain in the participants' own language an account of their experiences prior to and following their suicide attempts (15). Results suggest that existing themes and constructs in the model should be adapted to illuminate possible intervention approaches. To our knowledge, this is the first qualitative study of an exclusive sample of Native adolescents who had made a recent suicide attempt (16).

METHODS

Community-Based Participatory Research Approach

The community-based participatory research approach (CBPR) is defined as that which engages community members, employs local knowledge in the understanding of health problems and the design of interventions, and invests community-members in the processes and products of research (17). A collaboration between Native and non-Native researchers, community leaders, members of the Elders Council, key stakeholders, and a community advisory board utilized a CBPR process to develop all aspects of the study design. This included identifying the study population, developing topics for exploration, designating data collection methods, and interpreting and disseminating results.

Sample

We recruited participants from a community-based descriptive study of $N = 71$ Apaches (aged 13–19 years) with a recent suicide attempt who had completed a cross-sectional quantitative assessment battery (6). We selected participants from the larger sample to be approached using a randomization sequence created by the study data manager using Stata 9.0 (18). We used random selection to gain a more representative sample, avoid privacy concerns in a small community, and distribute enrollment across time based on available resources. Participants aged 18–19 years provided written informed consent, and we obtained parental consent for participants aged 13–17 years.

Data Collection

We collected data through in-depth individual interviews using a semistructured guide to ensure every participant was asked about all topics in the Apache conceptual model. The guide focused on what the participant considered most important to his or her own unique pathway to suicide and covered all key model categories, with open-ended topical questions followed by relevant probes (12).

Topics included (a) individual factors, such as personal identity and thoughts about self, spirituality, emotional state during the suicide attempt, and current well-being; (b) experience in the family, including household composition, residential status and mobility, kinship ties, deaths of family members, relationships with caretakers, caretaking responsibilities, and impact of the suicide attempt on family and household; (c) experience in the community, including social networks, intimate relationships, academic achievement, extracurricular activities, community and tribal activity involvement, and impact of the suicide attempt on these networks; and (d) social circumstances surrounding the suicide attempt, including events or forces that led to the attempt, help seeking and sources of mental health care, treatment history, and beliefs about preventing a re-attempt.

Participants completed up to five interviews over the course of 1 year, approximately every 2 months from the date of enrollment. We designed the prospective schedule of interview administration to establish trust and facilitate increased sharing over time as well as to track attitudes, suicidal behavior, and service utilization for a critical risk period post-attempt. We collected data from February 2007 to September 2009. Apache research assistants (RAs) conducted in-person interviews in a private setting selected by the participant, which could include the research office, the participant's home, or another private location, and recorded the interviews using hand-held digital audio recorders. RAs conducted interviews in English or Apache, according to participant preference, which, for the vast majority, was English. Each interview lasted approximately 60–90 min. Participants received a \$20 Wal-Mart gift card for each interview.

Quality Assurance. We took several steps to ensure quality and confidentiality of the data collection process. RAs underwent intensive training in qualitative data collection, human subjects research, and ethics prior to data collection. To ensure high-quality interviews, we randomly selected and reviewed 25% of audio files and provided RAs

with feedback when necessary. The study team held weekly conference calls to discuss study progress, provide supervision, and address additional training needs.

Risk Protocol. In the interview, the RA asked about the participant's suicide attempt and other potentially sensitive issues. We trained RAs to respond to participants who became distressed and refer to the local community mental health center as necessary. To assess for imminent suicide risk, RAs completed the Suicide Ideation Questionnaire (SIQ) or the Suicide Ideation Questionnaire JR (SIQ-JR; 19) with participants at the end of each visit. If the participant scored ≥ 30 on the SIQ or ≥ 23 on the SIQ-JR, the RA followed the established study risk protocol.

Data Management. We labeled audio files, transcripts, and study files with unique participant identification, and we removed identifying information from interview transcripts. We password protected all computers and maintained copies of interviews in locked cabinets accessible only by the study team. The Johns Hopkins School of Public Health and Phoenix Area Indian Health Service Institutional Review Boards as well as the Apache Tribal Council and Health Advisory Board approved the study. The Apache Tribal Council and Health Advisory Board approved this manuscript.

Data Analysis

We utilized a qualitative descriptive approach. We described the data in terms of the existing Apache conceptual framework and presented results in the everyday terms and language of the events as participants described (15). Our analysis remained close to the surface of words and experiences participants described using language as the vehicle of communication as opposed to a highly interpretive approach (15). We audiotaped and transcribed interviews verbatim (translation from Apache to English occurred when indicated). Two independent coders imported transcripts into Atlas.ti version 6 (20) for coding. We analyzed completed interviews at the end of data collection and did not group them by participant.

The study team used a directed method of qualitative content analysis because the existing Apache model of youth suicide would benefit from further description to extend this conceptual framework (12). With directed content analysis, our goal was to offer supporting and non-supporting evidence for the Apache model of youth suicide (12). Therefore, we developed some codes before analysis based on the

Apache conceptual model and risks identified in the literature, and we generated others from the data themselves (12, 15).

Coding was inclusive, and we added as many codes as possible so as not to limit ideas; the same statement could be coded into multiple themes (21, 22). We operationalized coding definitions to ensure that each code was clearly distinguished from the others and systematically applied to transcripts (15). We conducted constant comparisons of data pertaining to emerging themes to identify similarities and differences and to further refine coding categories, to produce major themes, and to identify corresponding illustrative quotes. This analysis process resulted in 60 separate codes and 1,853 quotes. Analysis continued to the point of data saturation, when additional transcripts failed to identify new themes.

We took several steps to maintain the validity of the data, including team data coding with ongoing reliability checks and refinement of the coding system, triangulation through multiple researcher perspectives and examination of interpretations that did not fit emerging themes, cultural auditing of the coding and interpretive process, and team-based consensual analysis (21). We did not conduct member checking as a form of validation for two reasons: (a) suicide is a very sensitive topic, and authors agreed it was not appropriate to go back to participants to confirm our results, and (b) member checking is not always recommended because it can lead to false confidence or potentially derail good analytic interpretation (23).

Alternatively, we conducted repeat interviews (up to five over 1 year) as a mechanism for confirmation, clarification, and elaboration of themes that emerged (23). University researchers (Native and non-Native) discussed the data and reconciled divergence through refinement of coding categories, continued open coding, and revision to the codebook. Study team members achieved final agreement regarding all coding, interpretation, and comparison of data with the Apache model. We assessed 34% of interviews for intercoder reliability and achieved 95% agreement.

RESULTS

We randomly selected 34 participants to be approached. Ten participants declined participation, 6 for “noninterest” and 4 because they were moving out of state. Twenty-four participants consented; the study team dropped 2 participants, 1 because of a learning disability

that would preclude interview completion and 1 for non-adherence with study visits. The final sample consisted of 22 participants, who completed a total of 74 interviews. The mean number of interviews was 3.7/5 (range 1–5). The small sample size precluded a full sub-analysis by age group (13–15 vs. 16–19). However, a cursory review by the study team of each age group did not yield differences in response, with the exception that a greater number of older participants endorsed interpersonal conflict with family members and other adults as a precipitant for their attempts. Results are a descriptive summary organized by themes and situated within the four risk categories of the Apache model (individual, family, community, society).

Individual Factors

Two themes to emerge in this category were related to adolescents' emotional state surrounding the event and the amount of planning or forethought that went into their suicide attempts.

Emotion Recognition and Dysregulation. Some participants were not able to clearly describe their feelings leading up to their attempt and when interacting with friends post-attempt, as one participant indicated, who said, "I didn't feel anyhow." Another answered, "I felt somehow" when asked how the participant felt seeing friends when the participant came back to school. When participants were asked how they felt prior to their attempt, another had a lot to say but was unable to articulate the specific emotions they were feeling:

"What's my purpose in life, you know what am I doing here? My youth is wasting away. I can't do what I wanted to because I am not really smart enough. . . . I started to feel like I wasn't important as a human anymore. I was thinking that maybe death was the perfect opportunity for me because I won't have to worry about what was coming in the future."

In contrast, other participants were able to identify feelings of sadness and worthlessness. When asked about the participant's feelings on the day of the attempt, one participant said, "I felt sad and like nobody needed me around. Why was I even put on earth, is there really a reason? I felt like I was lost, like I wasn't needed anymore, that I didn't even exist." Despite an inability to recognize their emotions and emotional dysregulation experienced by some, other participants clearly described coping strategies they had used in the past, including

talking with friends and family, going for a walk, writing and listening to music, thinking about their families, sobering up, and being around friends.

Impulsivity and Reactivity. Many participants described their suicide attempts as impulsive or sudden. “It just happened out of nowhere,” said one participant. “It was just something that happened I guess,” said another. Sometimes participants described their attempts as a swift reaction to an experience or feeling. Often participants said they were not thinking about the attempt ahead of time and did not prepare for it. Some even said they did not know they were going to attempt that morning, and looking back on it, they did not actually want to die. As one participant said, “I didn’t really think about it. I just took off and tried to look for that rope, but that rope wasn’t there and so I was like, why am I even going to do this?”

Family Factors

Major family-level themes included a dynamic characterized by conflict, multifamily household composition, substance use, and social support.

Family Dynamics. Some participants described their home lives as tumultuous and involving frequent interpersonal confrontation. One participant described this dynamic as contributing to the participant’s attempt:

“I kept telling everyone that it [the suicide attempt] was mostly because my brother and sisters really get to me. They just keep taking my stuff so I got real mad and stayed in my room. I don’t really trust anybody.”

Another participant painted a vivid picture of the participant’s strained relationship with the participant’s mother:

“Our relationship is a boat and it’s got holes in it and we’re both trying to haul out the water. The only time we talk is when I’m going to tell her where I am going and who I am going with and that’s it.”

Some adolescents described their suicide attempts as a means to receive more attention within the family, as one participant described in reference to his own suicide attempt:

“What really gets me mad was like when someone else did suicide, they’re all there and when my cousin tried suicide, everybody was there, even my mom. When I did it [attempted suicide] my mom wasn’t even there, like my family doesn’t really care about me.”

Another participant said, “Ever since I did it [attempted suicide] they started paying more attention to me or something, like finally caring about me more.”

Household Composition. Several participants described households in which multiple families lived together out of necessity. This created conflict because of shared space and lack of privacy, as one participant described:

“I live with my mom and her boyfriend, his annoying brother and his dad. I try not to stay at home most of the time. Usually my boyfriend does help because I go see him and it gets me out of the house. But I guess you could say home life, it sucks.”

Another participant described limited resources and an uneven division of labor at home:

“Our family doesn’t do much to help my grandma. And, my sister, she’s twenty-one and she just stays around here and she doesn’t even do anything, she’s hardly ever helping. She gets mad when people tell her to get a job, she doesn’t like anyone telling her what to do, because it’s her life, and all she does is drink.”

Substance Use. Some participants described a heavy burden of substance use within the family and how it exacerbated an already negative interpersonal dynamic. Many named multiple family members who used substances. One participant described a history of parental substance abuse and how it impacted the participant’s current relationship with the participant’s mother:

“My mom was hardly ever around. I always knew what she was doing even when I was about four years old and stayed with my grandma. I only wanted to be around my mom when I knew she was trying to quit, or trying to be around us . . . and it wasn’t that long before she would take off and drink more.”

Family Support. Despite the circumstances described in some families, nearly all participants indicated they and other family members turned to immediate and extended family when help or psychosocial support was needed. Most participants said that “family comes together.” Almost all participants said that “family talks to each other,” in at least one interview. Participants also said that their cousins “are really more like sisters” or brothers, because they were often raised together in the same home. These close relationships provided important support for participants. As one participant described:

“My relationship with her [cousin] is better than any friend that I have ever had. She’s always there to talk, she doesn’t like it when I try and do that stuff [attempt suicide]. She doesn’t like it when I drink. She talks to me and guides me though life, and helps me with any problems that I have. She helps me money-wise, with family matters, and relationships . . . and if anything happens, she says don’t do anything crazy.”

Community Factors

Community-level themes included significant grief burden and stigma about suicide and help seeking.

Grief burden. Participants described frequent and recent exposure to deaths from suicide and other causes (accidents, trauma, severe illness) occurring among family members and close peers. One participant described a series of deaths impacting the participant’s life. “I just thought I’m losing everybody. I lost my cousin, I lost my grandma, and now I lost my boyfriend, what am I going to do now?” Several youths described these losses happening close in time, which afforded them little time to grieve and created a challenging context in which to enlist coping strategies.

Stigma. Several participants described being stigmatized for their attempts. One participant talked about experiencing extreme stigma prior to returning to school:

“I wanted to go to back to school after I came back from the hospital, but I started hearing stories around, saying that I was a crazy person and a psycho . . . so I knew if I went back to school there was going to be trouble, so I’m just going to wait for a while.”

Other participants described stigma associated with needing help and treatment seeking. One participant said, “Everybody used to laugh about me like you’re just turning into a psycho. You have to have all the help now. So I thought to myself, I think it is too much help, I am turning into a psycho.”

Societal Factors

Adolescents described two main societal factors that affected their suicide attempts, including the process of imitation and pressure to minimize the seriousness of the event and its related implications.

Imitation. Some participants described imitation as a factor influencing their suicide attempts, specifically mimicking the suicidal behavior of a peer. “I kind of think it just rubbed off on me, because I always hung out with him.” Another participant articulated the role of copying when discussing the participant’s suicide attempt with a friend: “It was awkward . . . it was weird to tell her I tried suicide because she might just be thinking I’m copying her.” Yet another participant referenced the process of contagion when talking about suicide. “Maybe if I said I ran away it would be a whole different story, but its suicide it’s just like oh you are trying to be like me.”

Minimizing. To illustrate the complete experience of a suicide attempt, several participants described trying to downplay or diminish the significance of the attempt after it happened. This was described when seeing their friends after the attempt: “It was just like seeing them every day, normal like any other day.” It was also described in how their friends reacted to the news of their suicide attempts: “They didn’t really have like a big shock or anything.” Some participants described minimizing their attempts as a way to avoid talking about them in detail, the problems that led to the attempts, and in an effort to get their lives back to normal. One participant said, “I told her and it was just a normal day again. She asked me a couple of questions, like why, but she was laughing the whole time so I don’t really think it’s serious.”

DISCUSSION

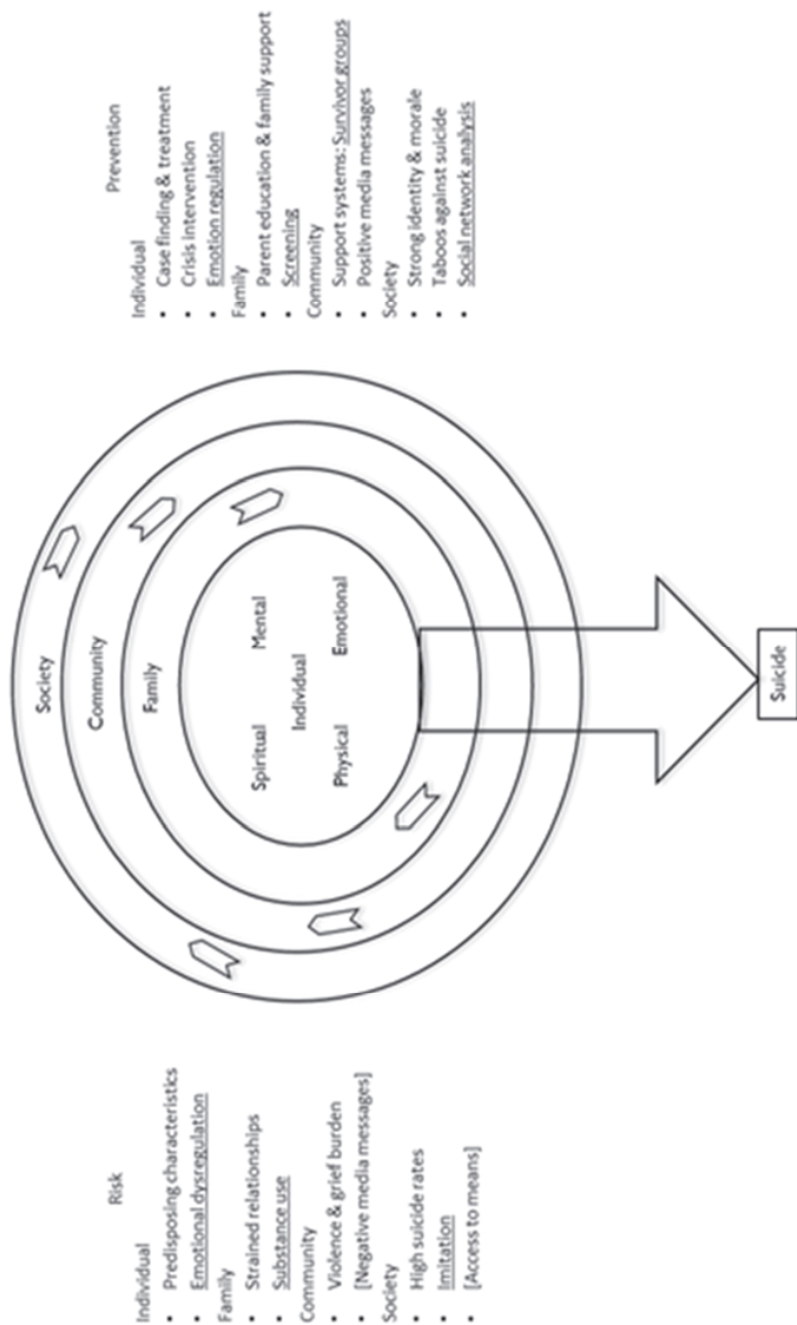
Key themes situated within four primary categories emerged from this in-depth study of Apache youths who attempted suicide. Individual-level factors, including negative emotion and an inability to express emotion, contributed to reactivity and dysregulation. Impulsivity

might build on heightened feelings, leading to an acute combination that could accelerate the pathway toward suicide. Family-level factors, including multigenerational overburdened households challenged by lack of privacy, sharing of limited resources, and confusion around the division of labor, caused confrontations to elevate quickly and be further intensified by substance use. A tumultuous shared environment, modeling, and intergenerational substance use indicated some families might be considered high risk.

Community-level factors, such as name calling and inciting shame by peers and classmates, as well as stigma around needing help, complicated treatment seeking. Participants recalled social pressure to minimize the seriousness of their attempts and to describe the attempts as isolated events. Also, imitation of suicidal behavior between peers, family members, and the community at large is symptomatic of the social process of contagion.

Study results led to changes in the original Apache model (refer to Figure 1, in which themes for potential removal are in brackets and those to add are in boldface). We included all original themes in the model, based on local data and input from key tribal stakeholders, and explored them throughout the qualitative interviews. Themes to potentially be removed, including negative media messages and access to lethal means, were deemed no longer relevant by study partners because participants did not endorse them as impacting or contributing to their attempts in a significant way. Themes to be added to the model, including emotional dysregulation, substance use, and imitation, were warranted based on the frequency and depth in which they were described by participants as central to influencing their suicidal behavior.

Figure 1: White Mountain Apache
Descriptive Model of Youth Suicide



Some key themes are worthy of discussion because they relate to other models of suicide risk and the extant research literature. First, Apache participants had been exposed often and recently to suicide attempts and deaths from suicide and other causes. For these adolescents, grieving was not rare, and little time was afforded for recovery. A family history of suicide and suicide attempts is described extensively in the literature as contributing to suicidal behavior among both Native and non-Native adolescents and is central to Schaffer's model (7, 24-27).

Second, descriptions of participants' suicidal behavior as a form of copying or imitation showed that suicide might be learned through social modeling; this is also highlighted in Schaffer's model (7) and in the dynamic of acquired capability in Joiner's (28) interpersonal theory of suicide.

Third, family life can be characterized by turmoil and aggression, in some cases the primary precipitant for the attempt, and several quotations about family relationships aligned with thwarted belongingness (28, 29). Fourth, participants described significant sadness, hopelessness, and anger and feelings that their deaths were worth more than their lives, which resonated with the self-hate and liability components of perceived burdensomeness (28, 29). Fifth, the state of emotional confusion and inability to articulate emotions some participants described is consistent with the concept of emotion dysregulation that Linehan (10) posited.

There are limitations to this study. First, although a small qualitative sample was appropriate at this stage of research, results should be balanced with those from the larger quantitative study to better generalize findings (11). Second, the experiences of participants might differ from those who declined participation, and our sampling method might have precluded selection of participants who were more willing to share and go into depth about their experiences. Third, adolescents provided retrospective accounts of their suicide attempts, which could have been affected by their current mental health status and/or other factors occurring since the time of interview and index attempt. Fourth, this analysis did not examine differences in themes between genders, which necessitate further investigation.

Finally, the interview guide asked about the role of traditional values and practices in impacting the youths pre-attempt and as a source of prevention or post-attempt intervention. However, none of the participants answered these questions in depth, leaving this an

additional area for further exploration. Limitations aside, in this study, we provide firsthand experience directly from an exclusive sample of Native adolescents who had attempted suicide.

The richness of these qualitative data and refinement of the Apache conceptual model enable the tailoring of prevention and intervention approaches that respond to this profile of suicide risk and might be relevant for other Native communities experiencing similar risks. At the individual level, the combination of failing to recognize and regulate emotional distress and the sense of impulsivity or suddenness indicates a narrow window of opportunity for crisis intervention. This short and rapid pathway to suicide would benefit from programs that teach identification of negative emotions and situations that put the adolescent at risk to help naturally link to coping strategies, including managing impulsivity.

At the family level, detailed descriptions of family-based psychosocial support suggest family is important to strengthen as a primary platform from which to intervene (7, 28, 29). Family-based approaches can capitalize on the importance of family in Native communities, and existing trust and comfort among family members, to teach communication skills, anger management, and conflict negotiation (30, 31). Innovative methodologies, such as screening for violence or abuse, might be utilized to better address at-risk families.

At the community level, stigma surrounding suicide and help-seeking presents an opportunity to focus on positive protective factors, such as Apache beliefs about the sacredness of life and traditional pathways to healing, a significant source of strength and resilience in this and other Native communities. Interventions for youths who make suicide attempts, survivor support groups, and enhanced connection to care are also necessary. Finally, at the societal level, a multidisciplinary universal awareness campaign might help suicidal behavior to be taken more seriously. Proactive identification of and interventions with high-risk networks within a comprehensive plan for handling the spread of contagion would also be important in this and other Native, reservation-based and rural communities, with suicidal behavior and deaths occurring close in time and space.

With this study, we move current research in the direction of honing a culturally and contextually based explanatory model of suicide among American Indian youth because it came directly out of their own life experiences, and a collaborative analysis process that includes non-Native and Native researchers and the Apache community. Findings


support the critical role qualitative data collection plays in suicide prevention research. Direct quotes illuminate how variables of risk existing at different levels create a pathway to suicidal behavior, enhanced the Apache conceptual model, and deepen understanding for the field. The emergent nature of qualitative research allowed for generation of themes from participants themselves, an inductive approach to developing suicide prevention theory and intervention approaches.

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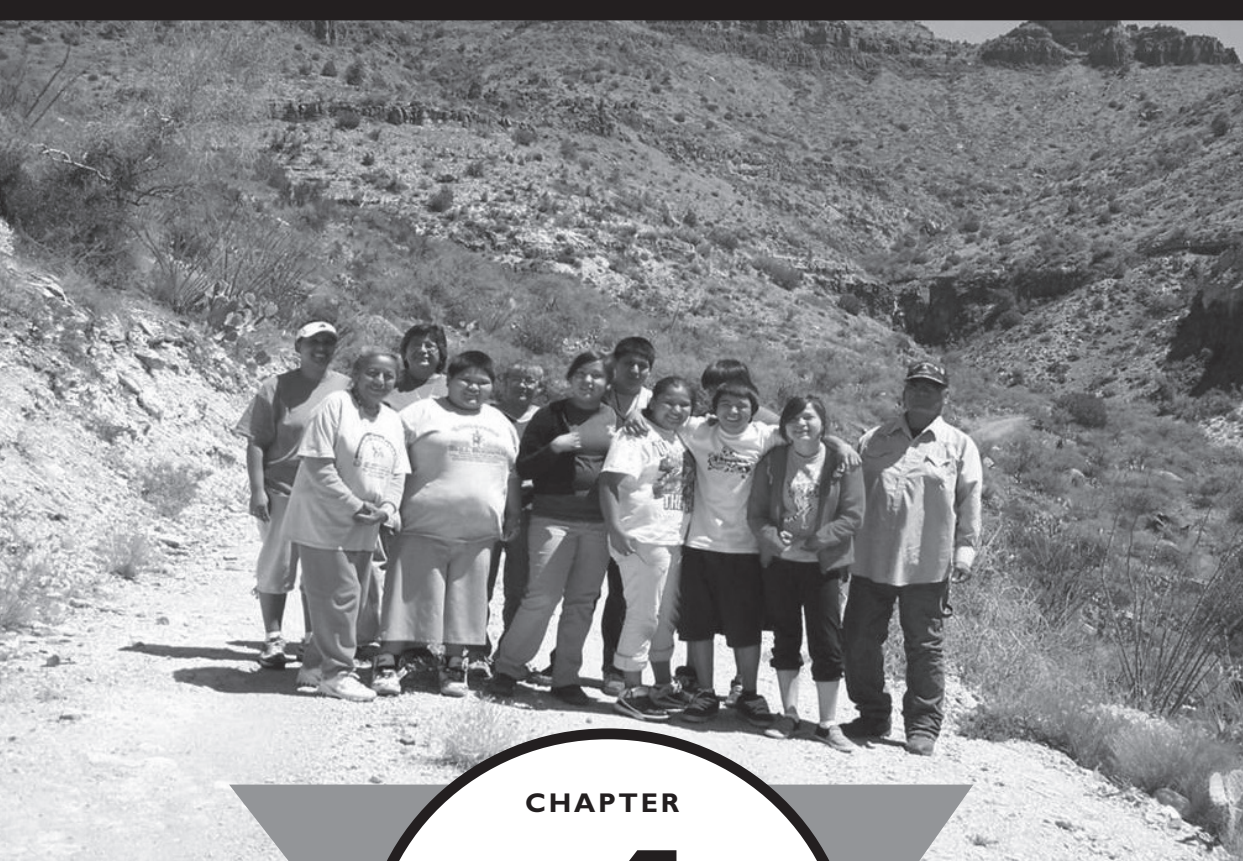
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Understanding the Relationship Between Substance Use and Self-Injury in American Indian Youth



CHAPTER

4

ABSTRACT

Background: American Indian communities compared to other US populations are challenged by the largest health disparities in substance abuse and suicidal behavior among youth ages 15-24.

Objectives: This paper examines the co-occurrence of substance use and self-injury among reservation-based youth in the U.S.

Methods: White Mountain Apache tribal leaders and Johns Hopkins University formed a partnership to address self-injury and substance abuse among Apache youth. Data on suicide (deaths, attempts, ideation), non-suicidal self-injury and substance use was analyzed from the White Mountain Apache tribally mandated self-injury surveillance registry from 2007-2010, including 567 validated incidents from 352 individuals, 15-24 years old. Findings regarding characteristics of co-occurrence—including differences in type of self-harm behavior, gender, and reported reasons for act—were interpreted through a community based participatory research process.

Results: From 2007-2010, 64% (n=7/11) of Apache youth ages 15-24 years old were “drunk or high” at time of suicide death with data missing for 2/11 deaths; 75.7% (n=118/156) were “drunk or high” during suicide attempt; 49.4% (n=83/168) during suicidal ideation; and 49.4% (81/166) during non-suicidal self-injury. Co-occurrence of substance use was higher for more lethal acts and among males.

Conclusion: High rates of co-occurring self-injury and substance use within this population highlight the importance of research to understand relationships between these behaviors to design pre-emptive and integrated interventions.

Dissertation Relevance and Significance: This article illustrates the stage: assessment of risk and protective factors through quantitative data collection, of the approach described within this dissertation. Tribal-specific data on the co-occurrence of self-injury and substance abuse corroborate and extend qualitative results collected through this stage-based approach and further support the interconnectedness of high-risk behaviors among American Indian adolescents.

INTRODUCTION

Unique to American Indian (AI) populations, the developmental trajectories for substance abuse and suicide behavior are parallel, peaking in adolescence through young adulthood. A broad literature supports that suicide and substance use co-occur (1). However, the relationship and possible shared causes are unknown (2).

While binge drinking and heavy alcohol use peaks in 15-24 year olds in the general US population (3); AI youth are disproportionately affected. Rates of substance dependence and abuse are higher and start younger (3) among AI youth, and the age-adjusted alcohol-related death rate for 15-24 year olds is 12-fold higher compared to U.S. All Races (4.0/100,000 vs. 0.3/100,000) (4).

Suicide death rates for AI youth and young adults also exceed other racial and ethnic groups, 17.9/100,000 vs. 10.8/100,000 U.S. All Races, with youth disproportionately affected (4). AIs ages 15-34 years old have the highest suicide death rates (34.2/100,000 for 15-24 and 37.5/100,000 for 25-34 vs. 9.7/100,000 for US All Races), while suicide deaths in the U.S. population rise in the 45-54 year old age range (15.9/100,000) and are highest among 75+ year olds (16.4-16.9/100,000) (4).

It is unknown whether among AI youth suicidal behavior and drug use are occurring together in the same population or whether rates of each are high but not necessarily co-occurring in the same youth. If suicidal behavior and drug use are occurring together, it is important to understand the nature of the relationship to develop effective interventions.

Three dominant western hypotheses about the co-occurrence of suicidal behavior and substance abuse include: 1) both behaviors are motivated by a single cause such as unbearable stresses, a sense of inadequacy or unmet expectations, or an attempt to “escape” life’s difficulties; 2) both behaviors are an expression of a third factor, such as other psychiatric conditions (i.e., depression or disruptive behavior disorders), poor impulse control (2) or negative life experiences (abuse or trauma); and 3) chronic or episodic substance abuse has biological, legal, emotional and physical consequences that increase risk for suicide in vulnerable populations (1).

To gain a clearer and culturally informed understanding of how AI youth’s suicidal behavior and substance abuse co-occur, this paper

explores data from a unique tribally mandated self-injury surveillance system created by the White Mountain Apache Tribe (WMAT) to track community-based data on intentional self-injury and substance use. The White Mountain Apache Tribe has approximately 15,500 enrolled tribal members who live on the Fort Apache Reservation in rural east-central Arizona. The surveillance system was created by Tribal Resolution in 2001 following a cluster of youth suicide deaths, and has been described in detail in previous publications (5, 6). The original tribal mandate required community-based reporting of suicide deaths, attempts and ideation by all health and human service agencies and tribal citizens to a centralized suicide prevention data management team.

In 2004, the Tribe partnered with Johns Hopkins University (JHU) to refine and expand the surveillance outreach protocol, including a process to validate reported incidents through in-person follow-up by Apache community health specialists trained by Johns Hopkins mental health professionals. The follow-up process identified that substance abuse was frequently co-occurring with intentional self-injury, and some incidents of intentional self-injury were non-suicidal. As a result, in 2007, tribal leadership expanded the surveillance mandate to include collection of data on non-suicidal self-injury (NSSI), and in 2010, binge substance use was added as discreet reportable behaviors with or without co-occurrence of other forms of self-injury. This change reflected local understanding that suicidal and substance abuse behaviors are alien to Apache traditions and may share common root causes residing in a multigenerational history of trauma that eroded protective factors embedded in Apache culture. Tribal stakeholders seek understanding as to whether both behaviors may function as self-annihilation that arises in adolescence when vulnerable youth struggle to consolidate their identity and transition to adulthood.

As a first step, using data from the WMAT surveillance system from 2007-2010, the tribal and university investigators applied a community-based participatory research process to observe and interpret the degree of overlap between self-injury behaviors and substance abuse among Apache youth ages 15-24, the population at highest risk for both behaviors. The analysis focused on: to what degree intentional self-injury and binge substance use co-occur, and if there are differences in co-occurrence across self-injury categories (death, attempt, ideation vs. non-suicidal self-injury), gender, and reported reasons for self-injury. The ultimate goal of this line of research is to produce data to inform culturally tailored prevention

interventions for co-occurring self-injury and substance use within American Indian populations.

METHODS

Design

Apache community mental health specialists indigenous to the local community were hired and trained to: 1) educate community members regarding the suicide surveillance system and completion of the data registry forms, 2) validate and enter data from registry forms, 3) follow up on registry cases and facilitate referral, and 4) help interpret data in order to develop prevention strategies. As reporting and participation is mandated by tribal law, no informed consent/assent is required to collect surveillance data.

The tribally mandated registry form collects data regarding: name, age, sex, tribal affiliation, type of self-injurious behavior (including suicide death, attempt, ideation and non-suicidal self-injury, binge alcohol or drug use), method, date and location, history of previous suicidal behavior, reported reason for act, and referral information. Registry forms are completed by police, fire, medical, school and social service personnel, religious leaders, family members and peers of suicidal individuals. Forms are collected and data-entered by Apache community mental health specialists. A secure electronic database is used to store and manage data.

Definitions

Definitions of events for completing the suicide registry form and validation process are modeled on the Columbia Classification Algorithm for Suicide Assessment (C-CASA) (7). A *suicide* is defined as a death resulting from intentional self-inflicted injury as determined by the local medical examiner or authorized law enforcement official. A *suicide attempt* is defined as intentional self-injury with intent to die. Aborted and interrupted suicide attempts are included as part of the “suicide attempt” categorization. *Suicidal ideation* is defined as thoughts to take one’s own life with or without preparatory action. *Non-suicidal self-injury (NSSI)* is defined as intentional self-injury without intent to die. *Binge substance use*—not part of the CASA system—is defined as consuming substances with the intention of modifying consciousness and resulting in severe consequence, including: blacking/passing out, found unresponsive,

requiring treatment in the Emergency Department. “*Other*” events include incidents that are validated as “no deliberate” or “indeterminant” self-harm with unknown intent to die.

Sample

Data include all events reported to the White Mountain Apache self-injury surveillance system from January 2007-December 2010 for tribal members ages 15-24 years old and validated as suicide death, attempt, ideation, non-suicidal self-injury (NSSI) or binge substance use through in-person follow-up (see “*Validation Process*” below). Events coded as “other” were excluded from this analysis.

Validation Process

Suicide deaths were validated through several sources including tribal police, Bureau of Indian Affairs investigators, Indian Health Service records, a local high risk task force, and family members and peers of the deceased. Substance use at the time of suicide death was verified by Tribal police, medical charts or significant others (e.g. family, friends, neighbors, school mates, etc). All other self-injury events were confirmed by Apache community mental health specialists during in-person follow-up with reported individuals. Follow-up procedures assessed intent to die, and validated categorization of reported behavior, self-injury method, “reason for the act,” and substance use at the time of act.

Analysis

Data for Apaches aged 15 to 24 are presented by year, self-injurious behavior (death, attempt, ideation, NSSI, and binge substance use), co-occurrence of substance use, and gender (Table 1). The individual’s reported reason for the act is also presented by type of behavior (not available for suicide deaths) (Table 2). Only validated, double-entered data are included in the analysis. All data were analyzed with Stata version 11 (14). This manuscript was reviewed and approved by the White Mountain Apache Tribal Council and Health Board.

RESULTS

Self- Injury Events

Between January 2007 and December 2010, a total of 1,230 self-injury events from 699 individuals were validated from the White Mountain Apache surveillance system for tribal members of all ages. Among 15-24 year old youth, there were 567 events from 352 youth, representing approximately 11% of this age group over a four-year period. Youth ages 15-24 (who comprise approximately 20% of the population) accounted for 65% of all deaths (11/17), 53% of all suicide attempts (156/294), 44% of all ideation, (168/382), and 43% of all NSSI (81/232).

Alcohol and Drug Use-Related Events

Substance use was known to co-occur in 64% of youth deaths (7/11); however substance use data were not available for 2/ 4 suicide deaths. Among attempts, 75.7% (n=118 of 156) were “drunk or high” at time of attempt, including 32.1% (n=50) who used overdose as their method; 49.4% (83 of 168) at time of suicidal ideation; and 34.9% (81 of 232) at time of NSSI. In 2010, when the surveillance system expanded to include binge substance use as a form of self-harm, 53 incidents of binge substance use were reported and validated.

Substance Use Type and Self Injury

When youth reported “being drunk or high” at time of self-injury, alcohol was the primary substance to co-occur with self-injury events—97.1% for suicide attempt; 91.6% for ideation; and, 48.2% for NSSI. Marijuana was the next most common drug to co-occur with self-injury—17.7% for attempt; 10.8% for ideation; 4.8% for NSSI. When overdose was reported as the primary method of suicide attempt, prescription drugs were most common (52%) followed by over-the-counter drugs (34%), illicit drugs (8%), then alcohol (6%). In 2010, when binge substance use was added as a reportable self-injury, alcohol (96.2%) was predominantly reported.

Gender Differences

Of the 567 total youth self-injury events, the male to female ratio was 1:1 (289 males vs. 278 females). Of all youth deaths, 73% (8/11) were male vs. 27% (3/11) females. Substance use was known to co-occur in 50% (4/8) of male deaths (and “unknown” for 2/8 males) and 100%

(n=3) of females. None used overdose as a method (hanging was the primary method—data not shown) (see Table 1). During youth attempts, two-thirds of males (67%) were drunk or high at the time (51/76), compared with 59% of females (47/80). However, only 12% of males chose overdose as their method compared with 52% of females. During ideation events, males were more often drunk or high than females (61% vs. 33%); however, females increasingly endorsed co-occurring substance use between 2007 and 2010 (29% to 56%). For NSSI not including binge substance use, males were drunk or high 57% of time compared with 42.7% of females. Similar to trends with suicide ideation, females' co-occurrence of substance abuse with NSSI increased during this time period (21% to 63%). In 2010, when binge drinking and drug use was added to the tribal surveillance system as a category of self-injury, binge substance use was reported nearly two times more for males than females (n=37 males vs. n=16 females).

Reported Reason for Act

Table 2 presents reason for act by behavior—including suicide attempts, suicidal ideation, NSSI and binge substance use. The most similar reported reasons for self-harm across suicide and binge behaviors was: fight/argument with boy/girlfriend; fight argument with parent/relative and family or home situation problems. The most dissimilar reported reasons across types of self-injury were death of loved one and depression, with binge substance users reporting less depression as reason for act and no “death of loved one.” Conversely, binge users more frequently reported peer pressure as reason for act. There was also a higher proportion of unspecified data for “reason for the act” for binge incidents—including “no reason in particular.”

**Table I: Suicidal and Self-Injury Events Among Apaches
Aged 15-24: 2007-2010** (* added to registry in 2010)

n (%)	2007		2008		2009		2010		Total		
	M	F	M	F	M	F	M	F	M	F	
Suicide Deaths	n=69	n=86	n=56	n=69	n=64	n=51	n=100	n=92	n=289	n=278	All n=567
Drunk or high at time of death (not primary method)	0	0	1	0	2	3	1	0	4 (50%)	3 (100%)	7 (63.6%)
Overdose was primary method	0	0	0	0	0	0	0	0	0	0	0
Unknown/missing alcohol or drug use	0	0	0	0	1	0	1	0	2 (25%)	0	2 (18.2%)
Suicide Attempts	n=19	n=16	n=20	n=26	n=23	n=20	n=15	n=17	n=77	n=79	n=156
Drunk or high at time of attempt (not primary method)	12	6	11	7	14	4	9	5	46 (59.7%)	22 (27.8%)	68 (43.6%)
Overdose was primary method	3	9	4	14	1	11	1	7	9 (11.7%)	41 (51.9%)	50 (32.1%)
Alcohol	0	0	0	0	0	0	1	2	1 (1.1%)	2 (4.9%)	3 (6%)
Illicit Drug	0	1	0	0	1	1	0	1	1 (1.1%)	3 (7.9%)	4 (8%)
Prescription Drug	1	4	4	8	0	7	0	2	5 (55.6%)	21 (51.2%)	26 (52%)
Over Counter Drug	2	4	0	6	0	3	0	2	2 (22.2%)	15 (36.6%)	17 (34%)
Suicide Ideations	n=24	n=15	n=20	n=24	n=25	n=11	n=25	n=24	n=94	n=74	n=188
Drunk or high at time of ideation (not primary method)	18	3	13	8	14	3	13	11	58 (61.7%)	25 (33.8%)	83 (49.4%)
Non-Suicidal Self-Injuries (NSSI)	n=27	n=33	n=14	n=19	n=14	n=16	n=59	n=50	n=114	n=118	n=232
Drunk or high at time of NSSI (not primary method)	12	3	8	7	7	9	13	22	40 (35.1%)	41 (34.7%)	81 (34.9%)
Binge Substance Use*	-	-	-	-	-	-	-	16	n=37	n=16	n=53
Alcohol	-	-	-	-	-	-	-	16	35 (94.6%)	16 (100%)	51 (96.2%)
Illicit Drug	-	-	-	-	-	-	1	0	0	0	0
Prescription Drug	-	-	-	-	-	-	1	0	1 (2.9%)	0	1 (1.9%)
Over Counter Drug	-	-	-	-	-	-	-	0	1 (2.9%)	0	1 (1.9%)

Table 2: Reason for the Act: Suicidal and Self-Injury Events Among Apaches Aged 15-24: 2007-2010

Reason N (%)	Suicide Attempts N=156	Suicide Ideations N=168	NSSI (Non- Substance Use Method) N=166	Binge as NSSI (Substance Use Method) N=66	Total N=556
Suicide/death of loved one/friend/relative	6 (3.9%)	3 (1.8%)	8 (4.8%)	0	17 (3.1%)
Fight/argument with boy/girlfriend/spouse	25 (16%)	22 (13.1%)	25 (15.1%)	6 (9.1%)	78 (14.1%)
Fight/argument with parent/relative	31 (19.9%)	38 (22.6%)	24 (14.5%)	5 (7.6%)	98 (17.6%)
Fight with other	1 (0.6%)	2 (1.2%)	6 (3.6%)	0	9 (1.6%)
Trouble with the law	1 (0.6%)	4 (2.4%)	0	0	5 (0.9%)
Family or home situation/problems	5 (3.2%)	2 (1.2%)	6 (3.6%)	3 (4.5%)	16 (2.9%)
Trouble at school	0	1 (0.6%)	3 (1.8%)	0	4 (0.7%)
Depression	12 (7.7%)	17 (10.1%)	18 (10.8%)	1 (1.5%)	48 (8.6%)
Stress/a lot on the mind	6 (3.8%)	12 (7.1%)	9 (5.4%)	2 (3%)	29 (5.2%)
Peer pressure/copying	1 (0.6%)	0	2 (1.2%)	5 (7.6%)	8 (1.4%)
No reason in particular	1 (0.6%)	4 (2.4%)	7 (4.2%)	9 (13.6%)	21 (3.8%)
Can't remember much about the event	3 (1.9%)	4 (2.4%)	2 (1.2%)	2 (3%)	11 (2%)
Other	12 (7.7%)	11 (6.5%)	20 (12.1%)	5 (7.6%)	48 (8.6%)
Unknown/Unspecified	52 (33.3%)	48 (28.6%)	36 (21.7%)	28 (42.4%)	164 (29.5%)

DISCUSSION

Our data show high frequency of substance use co-occurring with self-injury among Apaches aged 15-24. While Apache males were drunk or high 50-60% of the time for all forms of self-injury, co-occurrence of substance use among females increased over the study period, reaching or exceeding male rates across injury categories by 2010. Other studies have indicated a climb in AI female substance use during this period (8). Apache females also choose overdose as their primary method of attempt (51.9%; n=41/79 female attempts) compared to only 12% of Apache males. This female preference for overdose is similar to other U.S. populations, while Apache female suicide death and attempt rates have been found to be higher in previous studies (5).

The greatest co-occurrence between substance use and self-injury was among those who died by suicide (7/9; 77.8%) that could be validated (2 males who died had unknown substance use), followed by suicide attempt (75.6%; n=118/156); suicide ideation (49.4%; n=83/168); and NSSI (48.8%; 81/166). Thus, it appears the more lethal the behavior among the Apache, the greater co-occurrence with alcohol and drug use. While explanations from the literature could attribute this fact to the loss of impulse control that comes with substance use (2, 9), Apache collaborators seek more culturally relevant explanatory models that posit substance abuse as a co-occurring form of adolescent self-injury that amplifies results of intentional self-harm. This idea is in contrast to dominant western models of suicide, such as Joiner's (2005) (10) and Mann's (2005) (11), which do not include binge substance use on the spectrum of self-injury.

In order to shed light on the Apache hypothesis that adolescent binge substance use is functioning as a maladaptive form of self-injury, we explored similarities and differences in reported reasons for act in Table 2. The most commonly reported reasons for self-injury across suicide and binge categories were partner conflict, family conflict, and family problems. However, youth identified for binge substance use were less likely to report death of a loved one or depression as a reason for their act and more likely to report peer pressure. Due to study limitations, we could not clarify inferences regarding substance use function when substance use co-occurred with suicide attempts or ideation. Further research is needed to determine if alcohol or drug use preceded ideation or attempt consciously or unconsciously, intentionally or unintentionally. In addition, the fact that when overdose was the method of attempt, prescription and over the counter drugs were the favored substance choice, may indicate a stronger intention to self-harm. Nonetheless, alcohol co-occurring with Apache self-injury behavior was a pervasive phenomenon.

Ultimately important in understanding alcohol use among AIs is the historical literature which charts a course whereby alcohol was inflicted by the dominant society as a tool of economic, political, moral and social subjugation of American Indians (see Mancall 1995 and MacAndrew 1969) (12,13). Before the arrival of European explorers, fermented substances were generally unknown and taboo to indigenous North Americans. As the new colonies formed, alcohol became an instrument used by settlers to coerce tribes into signing treaties, conduct unfair trades of furs, food and other resources, and denigrate and stereotype the "drunken savage" in the colonial consciousness (12, 13).

In this light, the Apache's modern day hypothesis begs many questions regarding the lasting role of alcohol (and other non-ceremonial drugs) on collective Indian psyche and society. Are alcohol and illegal drugs continuing to function as a direct form of individual, family, and community self-destruction? Could this cultural understanding better equip tribes to address the dual problems of suicide and binge substance use among youth attempting to transition to productive adulthood?


There are several limitations to this study. The co-occurrence of substance use with self-injury events may be under-reported due to individual's and families' reluctance to report binge and illegal substance use among their youth, social undesirability, stigmatization or fear of legal consequences, in spite of the fact surveillance information is protected from legal investigation. In addition, self-injury data in this analysis included only validated events, which could create a bias toward reporting individuals who were easier to find and potentially less challenged than those whose reports were not validated. Expansion of the surveillance data collection system over time (i.e., the inclusion of binge drinking and drug use as a reportable act in 2010) changed data trends—with more binge substance use incidents ascertained in 2010; however, the addition of this data category provided increased opportunity for exploring shared characteristics of suicide and substance abuse behaviors in this setting. Finally, while the data collection was prospective, the analysis is cross-sectional. Therefore, we cannot discern the extent to which substance use preceded or prompted suicide or other self-harm behaviors.

The White Mountain Apache tribally sanctioned surveillance system presents a unique platform to examine self-injury within a reservation setting. Its parameters for data collection reflect distinct tribal understanding of the relationship between suicide and substance abuse as part of the continuum of self-injury. Apache community mental health specialists' in-person follow up to validate specific intentions (suicidal vs. non-suicidal) and reported reason for the act, the primary method (i.e., hanging involving intoxication vs. overdose), and the role of substance abuse produced preliminary insights into how substance abuse may function on the spectrum of self-harm. This line of research has high import to AI communities who suffer a large burden of years of productive life lost (YPLL) due to these acute behavior problems converging in adolescence.

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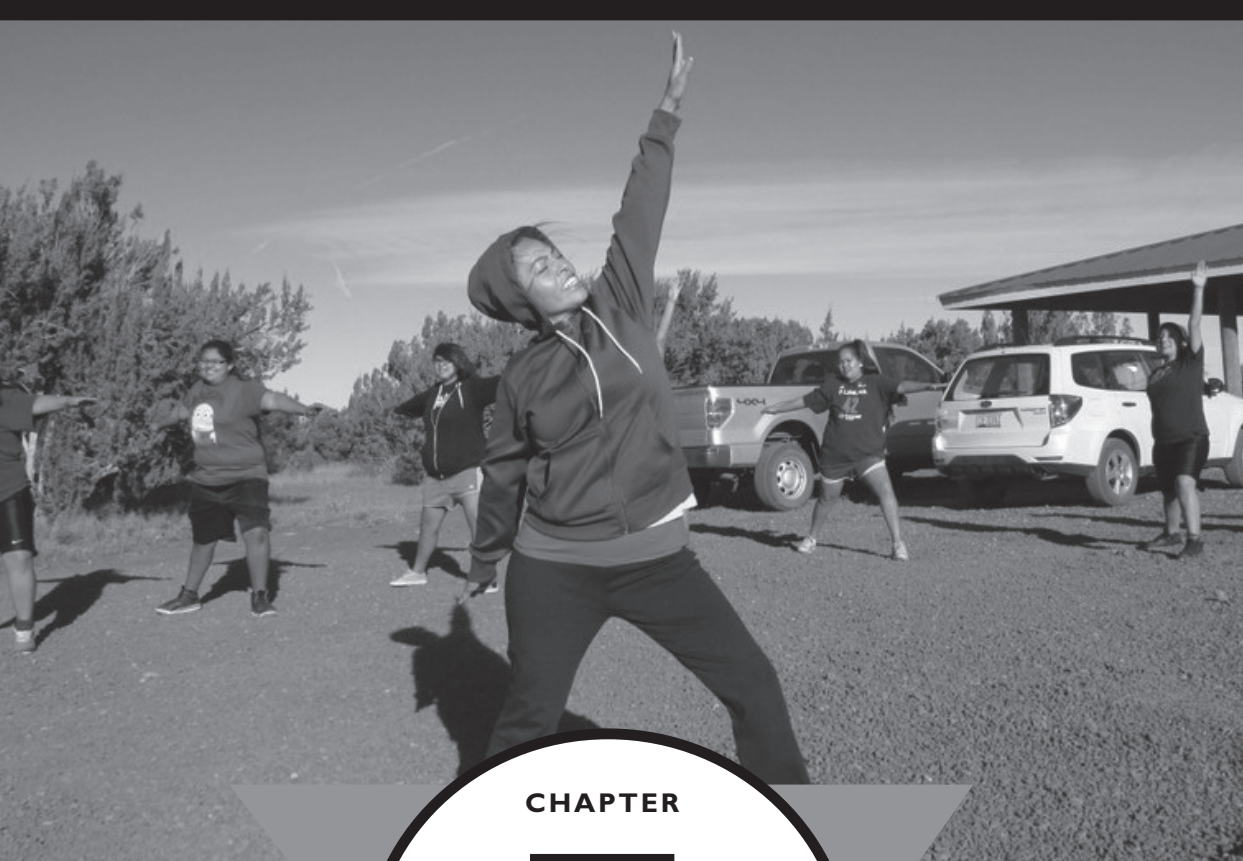
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Emergency Department Utilization Among American Indian
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**Emergency Department Utilization
Among American Indian Adolescents
Who Made a Suicide Attempt:
A Screening Opportunity**



CHAPTER

5

ABSTRACT

Purpose: Reservation-based American Indian adolescents are at significant risk for suicide. Preventive approaches have not focused on medical service utilization patterns on reservations, which are typically limited to one local emergency department (ED). Patterns of ED utilization prior to suicide attempt were evaluated to identify opportunities for screening and intervention.

Methods: Cross-sectional study of Apache adolescents (aged 13-19) who attempted suicide and consented to medical chart review. Lifetime presenting complaints for Indian Health Service ED visits prior to the index suicide attempt were extracted and coded.

Results: 1424 ED visits from 72 Apache adolescents were extracted (median lifetime visits, n=18). In the year before attempt, 82% (n=59) of participants had an ED visit for any reason and 26% (n=19) for a psychiatric reason, including suicidal thoughts or self-harm.

Conclusion: Service utilization data suggest EDs are critical locations for reservation-based suicide prevention. Suicide screening for all ED patients could increase early identification and treatment of this at-risk group.

Dissertation Relevance and Significance: This article illustrates the stage: assessment of intervention feasibility, specifically potential settings for intervention delivery, of the approach described within this dissertation. Medical chart review data indicate emergency departments are an important setting for connecting with at-risk American Indian youth and conducting both screening and behavioural health interventions.

INTRODUCTION

Reservation-based American Indian (AI) adolescents have suicide rates 4-15 times that of national samples (1). AI adolescents experience notable health care disparities, including decreased access to well-child visits (2) and mental health treatment (3), as well as increased visits to emergency departments (EDs) (4) and injury-related hospitalization and death (5). On reservations, the ED is often the primary source of medical care. Consequently, screening in ED settings may be a critical strategy to increase identification of individuals at risk for suicide and decrease suicide attempts and deaths (6, 7). However, there are no known studies on ED utilization among AI adolescents at risk for suicide.

The current study is the first of its kind to investigate reservation-based ED utilization in a sample of AI adolescents who attempted suicide. Patterns of ED utilization in the time before suicide attempt were explored to illuminate specific opportunities for screening and early identification.

METHODS

Study Procedures

Participants were White Mountain Apaches (Apache) aged 13-19 who made a suicide attempt within the past 3 months. Participants were identified by the tribally mandated Apache Suicide Surveillance and Prevention System (1, 8) and consented to a series of studies examining suicide risk factors and brief intervention approaches. Participants (aged 18 to 19) or a legal guardian (for participants aged 13 to 17) consented to an Indian Health Service (IHS) medical record review; 22/94 (23%) of those approached declined participation. Apache Research Assistants used a form created by the study team to extract medical record data including ED presenting complaints and dates of service. The study protocols were approved by relevant tribal, Indian Health Services, and University research review boards.

Data Analysis

The first three ED visit presenting complaints were coded using the diagnosis grouping system developed by the Pediatric Emergency Care Applied Research Network Core Data Project, based on ICD-9 codes (9). Imprecise or invalid complaints (40/1582, 3%), as well as

patients leaving against medical advice (118/1582, 7%), were excluded from final analysis. Codes occurring in less than 20 ED visits in the total sample were coded as “Other.” E-codes, which designate external causes of injury, were included as “Psychiatric” when the visit was for deliberate self-harm; all other E-codes were coded as “Trauma.” All visits with a “Psychiatric” code were further coded for suicidal ideation or self-harm. ED visits before, but not including, the date of the index suicide attempt were analyzed using univariate statistics in IBM SPSS 21.

RESULTS

Medical records for 72 participants were analyzed. 60% were female with a mean age of 16.7 years (SD: 0.9). 1424 ED visits were coded. Lifetime ED visits per participant ranged from 2 to 52 (median: 18). The Table displays frequency of presenting complaints in each category by year prior to index attempt (designated by first complaint in the medical record). Most common primary presenting complaints in the year prior to index attempt were Trauma (28%, n = 47), Ears, Nose and Throat (ENT) (21%, n = 35) and Psychiatric (8%, n = 14). These presenting complaints were common across all time periods, with the exception of early childhood.

Table: ED Visit Primary Presenting Complaint by Year Prior to Index Suicide Attempt

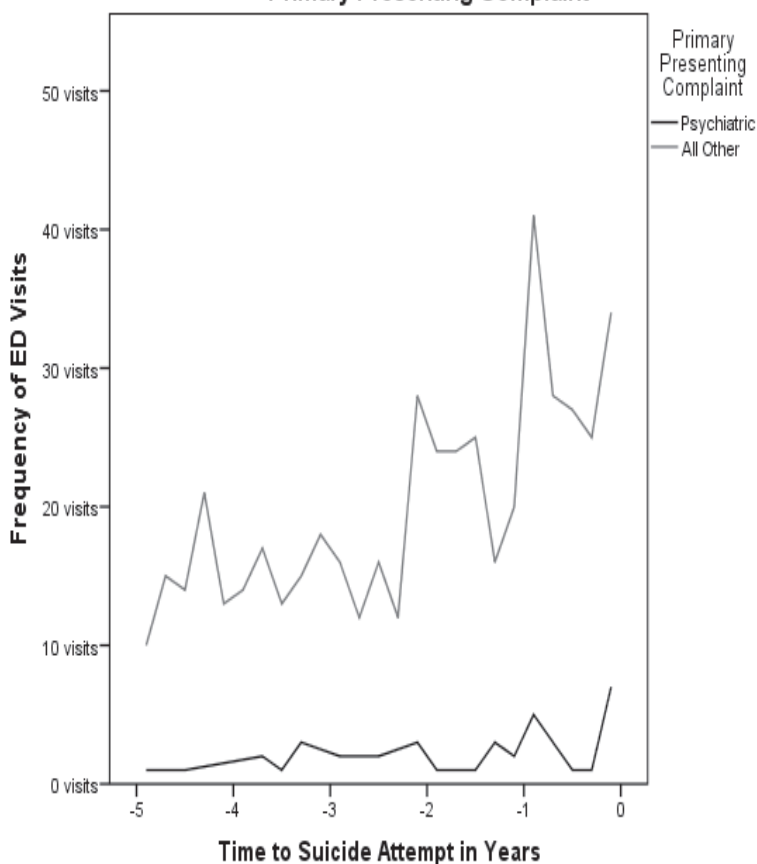
Presenting Complaint, N (%)	Total	<1	1-5	5-10	10+
ENT, Dental and Mouth	404(28)	35(21)	83(23)	70(26)	216(35)
Trauma	324(23)	47(28)	105(29)	84(31)	88(14)
Gastrointestinal	109(8)	7(4)	17(5)	17(6)	68(11)
Respiratory	106(7)	2(1)	10(3)	7(3)	87(14)
Dermatologic	96(7)	13(8)	35(10)	22(8)	26(4)
Psychiatric	40(3)	14(8)	23(6)	2(1)	1(<1)
Systemic States	86(6)	4(2)	10(3)	19(7)	53(9)
Urinary Tract	30(2)	3(2)	6(2)	13(5)	8(1)
Musculoskeletal	24(2)	6(4)	15(4)	2(1)	1(<1)
Diseases of Eye	20(1)	5(3)	9(2)	1(<1)	5(1)
Other*	185(13)	33(20)	54(15)	34(14)	61(10)
Total	1424	169	367	274	614

*“Other” category included presenting complaints that occurred in less than 20 visits and included: Toxicologic Emergencies, Genital and Reproductive Diseases, Fluid and Electrolyte Disorders, Hematologic Diseases, Allergic, Immunologic and Rheumatologic Diseases, Neurologic Diseases, Child Abuse, Circulation and Cardiovascular Diseases, Endocrine, Metabolic and Nutritional Diseases.

The Figure presents the frequency of ED visits across the five years prior to index attempt. Two categories of ED visits are plotted using linear interpolation: 1) Psychiatric visits, which included visits for self-harm; and 2) All other ED visits.

In the year before the index suicide attempt, 82% (59/72) of participants had an ED visit for any reason with no significant difference by gender ($\chi^2 = .02, p = .88$). 34 participants (41%) had an ED visit with “Trauma” and 19 (26%) had an ED visit with “Psychiatry” coded in the first three presenting concerns in this time period. Suicidal thoughts or self-harm were coded for five of these participants (7%, 4/5 were female).

Figure: Frequency of ED Visit in the Year Prior to Index Suicide Attempt by Primary Presenting Complaint



DISCUSSION

Data from Apache adolescent medical records indicate substantial contact (82%) with the local ED in the year before a suicide attempt. In comparison, according to the National Health Interview Survey, just 22% of AI/Alaska Native youth (under 18) made an ED visit in 2011 (10) and 65% of Apache children (aged 9 to 17) made an ED visit in 2012 (IHS, personal communication). Therefore, Apache adolescents who make suicide attempts appear to be a population with increased ED utilization, particularly in the year preceding a suicide attempt. Trauma and injury-related ED visits were the most common presenting complaints during this time period.

Results suggest that screening AI adolescent patients in ED settings may proactively identify those at risk for future suicidal behavior. Implementation considerations include appropriate patient selection, the availability of validated screening instruments and training of non-mental health personnel. The majority of ED visits in the five years before suicide attempt were for non-psychiatric reasons and few were for suicidal thoughts or behavior. Screening all adolescent patients, regardless of complaint, could have substantially increased identification in this sample. The sensitivity and specificity of the screening instrument would impact resulting burden on ED resources, highlighting the need for appropriate screening instruments for reservation-based AI adolescents.


Limitations to this study include small sample size, absence of a control group and imprecision in coding of presenting complaints; 7% of the codes were invalid and distinctions between suicide attempts and non-suicidal self-injury could not be made (118). Psychiatric presenting complaints could also have been underestimated by medical staff without extensive psychiatric training. These limitations are outweighed by the exclusively AI sample within a population experiencing significant suicide burden and healthcare disparities, and who are rarely the focus of ED research. Additionally, the majority of lifetime service use was captured since there are no other primary care facilities on the Apache reservation.

The 2012 National Strategy for Suicide Prevention advocates early identification and management of suicidal patients in ED settings (6). Future directions should include prospective investigation of ED utilization among AI adolescents who have attempted suicide with a non-attempter comparison group. AI reservation-based populations

may benefit from further research to develop and evaluate appropriate ED-based suicide screening instruments and brief interventions.

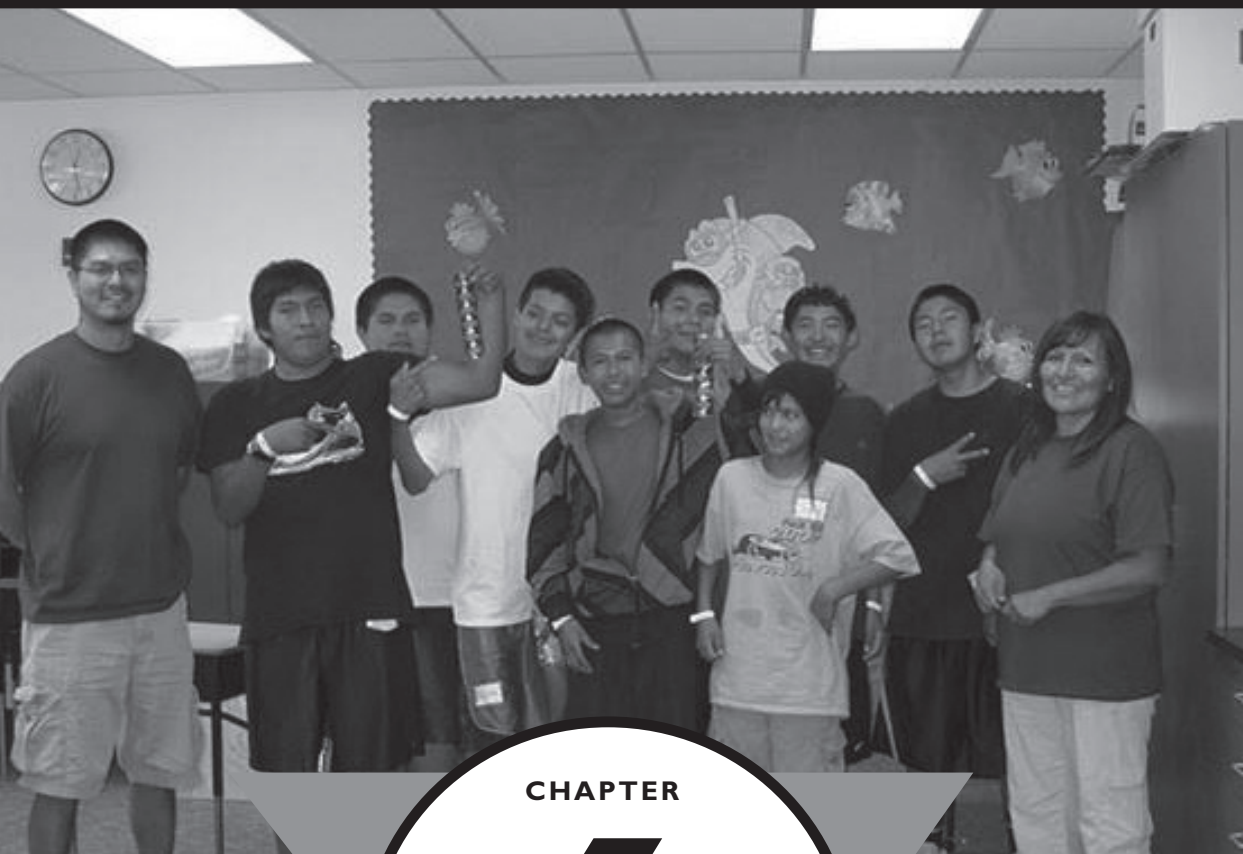
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Self-Administered Sample Collection for Screening of Sexually Transmitted Infection Among Reservation-Based American Indian Youth



CHAPTER

6

ABSTRACT

Background: American Indians suffer a disproportionate burden of sexually transmitted infection, particularly adolescents. Screening access barriers in rural and reservation-based communities necessitate alternatives to clinic-based options.

Methods: Self-administered screening for three sexually transmitted infections was piloted among 32 American Indian adolescents aged 18 to 19. Participants self-collected in a private location; specimens were processed by trained, American Indian paraprofessionals and analysis was conducted by an outside laboratory. Participants testing positive were treated by a Public Health Nurse from the Indian Health Service.

Results: Results suggest high overall acceptability: 69% preferred a self-administered method over clinic-based screening, 75% would encourage their friends to use this method and 100% would use it again.

Conclusions: A self-administered screening method has the ability to reach this and other high risk populations that might not otherwise access screening, with added potential within the Indian Health Services system for uptake and dissemination in rural, reservation communities facing significant screening barriers.

Dissertation Relevance and Significance: This article illustrates the stage: assessment of intervention feasibility, specifically interventionists and evaluation methods, of the approach described within this dissertation. Results demonstrate self-administered sample collection for STI screening is feasible and accepted in reservation-based communities, can help triangulate self-reported outcomes in behavioural health intervention trials, and is an important strategy for increasing uptake of screening behaviours. Further, American Indian paraprofessionals were found acceptable among participants and hold promise as behavioural health interventionists.

INTRODUCTION

American Indians and Alaskan Natives (AI/AN) suffer a disproportionate burden of Sexually Transmitted Infection (STI) morbidity compared with other racial/ethnic groups (1). In 2011 AI/AN chlamydia and gonorrhea rates were the second highest among all races/ethnicities and were four and five times the rate among Whites, respectively (1). Among AI/ANs, the majority of STIs occur among adolescents and young adults (2, 3). In 2011, 67% of all AI/AN chlamydia cases and 57% of all AI/AN gonorrhea cases were among those aged 15-24 (1). AI/AN female adolescents are disproportionately affected; in 2011, chlamydia and gonorrhea rates among AI/AN female adolescents were 3.9 and 2.2 times that of AI/AN male adolescents (1). Although screening of all sexually active women under age 25 for chlamydia and gonorrhea is recommended annually by the Centers for Disease Control and Prevention (CDC) (4, 5) data suggests chlamydia screening coverage rates among sexually active female adolescents is less than 60% in many states (6) and in spite of national screening guidelines and disproportionate STI morbidity (7) even lower among AI/AN female adolescents.

Among American Indians living in Arizona in 2011, the state-wide ratio of chlamydia infection between females and males was 4.7:1 (8). However, recent studies indicate young male partners who have not been diagnosed or treated for chlamydia may contribute to high re-infection rates among young females previously diagnosed and treated (9, 10). This research suggests that in addition to young females, there is a significant STI screening gap especially with regards to chlamydia, and possibly other STIs among young AI males (9, 10).

There are numerous barriers to clinic-based screening. Confidentiality and stigma-related concerns arise in rural, reservation communities with few or one health care facility where individuals are likely to encounter a friend or relative (11, 12). Screening practices in reservation-based clinics may also be suboptimal; a recent review of medical records at one Indian Health Service facility indicated considerable missed STI screening opportunities, even among pregnant females (13). Geographic isolation, long travel distances and limited transportation are additional screening obstacles on reservations (14, 15).

Alternatives to clinic-based STI screening are necessary to increase screening uptake and reduce disease burden among high-risk, reservation-based AI/AN adolescents. Self-administered sample

collection for STI screening has been demonstrated efficacious in reaching other high-risk groups to detect STIs, and an acceptable screening method among males and females (16, 17).

In this study, we evaluated the feasibility and acceptability of self-administered sample collection for screening among sexually active American Indian adolescents in a rural Southwest reservation community. Implications for clinical and public health practice are discussed.

METHODS

A community-engaged participatory research process was utilized by a team of Native and non-Native researchers to develop the study design. Garnering community input builds trust and increases the likelihood that programs are conceived sensitively and appropriately (18-21). Our community-informed research process included ongoing collaboration with a Community Advisory Board (CAB) comprised of key stakeholders and leadership from the Indian Health Service, as well as 14 focus groups conducted with youth (n=9) and parents (n=5) from the participating community. Community input guided selection of a screening method for piloting, processes and key targets for necessary adaptations to the screening method implementation and evaluation procedures, as well as protocols for follow-up and treatment of participants screening positive. This process identified the self-administered screening-method “I Want the Kit” (iwantthekit.org [IWTK]; described in detail elsewhere) for adaptation and feasibility piloting (17-22).

IWTK is a website where self-administered STI screening kits can be ordered free of charge and mailed to an individual’s home. Individuals self-collect specimens (urine or vaginal/penile swabs) and mail to a laboratory for processing; results and treatment referral (if necessary) are provided by phone. CAB and focus group feedback elicited several issues with IWTK implementation procedures including 1) inconsistent internet access on the reservation which would preclude access to ordering screening materials; 2) privacy concerns with having screening materials mailed to homes, especially in multi-generational households where parents and/or other family members may be residing; and 3) preference for in-person results disclosure (as opposed to over the phone). Community input also identified youth ages 18 to 19 to be the most important and appropriate sub-group in the community to pilot the screening method.

To address these identified issues, a key adaptation to the original IWTK protocol included in-person delivery of screening materials, sample collection, as well as results disclosure and treatment (if indicated). CAB members preferred AI paraprofessionals with public health experience and fluency in English and the Native language to act in this role, understanding that STI screening is sensitive and paraprofessionals must be trusted members of their community, and comfortable interacting with youth. Study partners agreed these screening method adaptations were essential to replication and sustainability in other AI communities. Individuals were eligible if they were male or female, a resident of the participating AI reservation and were between the ages of 18 and 19 at the time of consent.

Convenience sampling was used to recruit participants during a summer basketball camp hosted by the local study team in July 2011 and June 2012. Camp participants (n=267) were males and females ages 13 to 19 and residents of the participating AI reservation. CAB members believed it would not be culturally appropriate for study staff to ask if potential participants had ever had sexual intercourse; therefore ever having engaged in past sexual intercourse was not a study exclusion criterion. Eligible participants were approached by study staff that explained the study, delivered informed consent and scheduled a separate time and location for specimen collection.

Native paraprofessional study staff met participants at a private location of their choosing with a bathroom (typically their home or local study office), gave hard-copy instructions describing the self-administered screening process, and verified understanding. Study staff was present to address questions about instructions or problems with collection. Participants independently self-collected their urine sample and transferred it to a secure transport tube. Participants handed the transport tube to the study team member who deposited it into a biohazard bag and mailing envelope. Study staff compiled mailing envelopes with collected specimens in a temperature controlled container and shipped to an off-reservation CLIA-certified laboratory that processed IWTK samples in Baltimore, Maryland. Urine samples were tested by transcription mediated amplification assays (APTIMA Combo 2) for chlamydia and gonorrhea (23) and the APTIMA *Trichomonas vaginalis* (ATV) assay for trichomoniasis (Gen Probe, San Diego CA) (24, 25).

The laboratory furnished results to the study team within two business days. STI positivity was determined as a positive test by urine for any one of chlamydia, gonorrhea or trichomoniasis. Participants with

negative test results by urine for all three STIs were considered negative. For negative results, trained Native paraprofessional study staff met privately with the participant for disclosure. For positive results, study partners collaborated with Public Health Nurses at the (PHN) local Indian Health Service (IHS) Hospital; whereby a referral was made to a PHN who met with the participant (in their home or another private location) for disclosure and treatment initiation. The PHN also fulfilled state and federal surveillance reporting, provided counseling and education, and followed-up again with each participant to complete a test of cure.

Data on demographics, STI outcomes, and participant comfort, acceptance, and likelihood of future use of the self-administered screening method were collected immediately post-screening and again after results disclosure through a self-report questionnaire created by the study team. Participants were given a \$15 Wal-mart gift card if they completed the second assessment administered post-results disclosure. Likert response categories were dichotomized and data were analyzed using Stata 11.0 (27). The study was approved by relevant tribal, IHS and University research review boards. This manuscript was approved by the authorized tribal review board and Tribal Council.

RESULTS

We approached 68 youth for potential participation and 30 declined (n=17 males, 57%). Reasons for declining included because they were uncomfortable with screening for STIs (n=15), gave no specific reason (n=12), were scared of finding out result (n=1), were scared of parent finding out result (n=1), or said they had already been tested and treated (n=1). We consented 38 participants. At the first data collection time point post-sample collection, six participants indicated they had never engaged in sexual intercourse. We present results for participants who reported ever having engaged in sexual intercourse (n=32/38, 84%). The median age was 19 and 69% (n=22) were male. 81% (n=26) reported sexual intercourse in the past six months, with an average of 1.6 partners (range 1-3, SD 0.7). Of those screened, 44% (n=14) tested positive for at least one STI (50%, n=7 males); 10 were positive for chlamydia (70%, n=7 males), one for gonorrhea (female), two for trichomoniasis (both females), and one was co-infected with chlamydia and gonorrhea (female). Of those who tested positive (n=14), 64% (n=9) had never been screened in the past. All participants who tested positive were treated.

Table one summarizes participants' experience with self-administered STI screening. The majority (88%) reported test procedures were not difficult; a few had trouble urinating into the cup (n=3), using the dropper to suction urine (n=1), transferring urine into the collection tube (n=3), and adding urine to the correct level in the tube (n=2). 100% of participants were comfortable with the person who disclosed their results and nearly all (96%; n =24) felt their questions were sufficiently answered.

Table 1: Comfort with self-administered sexually transmitted infection screening procedures immediately

	Female (n=10)		Male (n=22)	
	Not at all/not very comfortable N (%)	Somewhat/very comfortable N (%)	Not at all/not very comfortable N (%)	Somewhat/very comfortable N (%)
Privacy of testing location	0 (0)	10 (100)	3 (14)	19 (86)
Feelings about taking the test	2 (20)	8 (80)	2 (9)	20 (91)
Understood test directions	10 (100)	0 (0)	20 (90)	2 (10)
Complete the test itself	9 (90)	1 (10)	19 (86)	3 (14)
Post Results Disclosure				
	No N (%)	Yes N (%)	No N (%)	Yes N (%)
Understood test results	0 (0)	10 (100)	1 (5)	21 (95)
Comfortable with person giving results	0 (0)	10 (100)	0 (0)	22 (100)
Questions were answered (n=24)	0 (0)	8 (100)	1 (6)	15 (94)
Diagnosis concerns addressed (n=22)	2 (29)	5 (71)	9 (60)	6 (40)

Table two summarizes participants' preferred method of future STI screening. The majority 69% (n=22) preferred a self-administered method over clinic-based screening and 100% would use the self-administered screening method again. Those that preferred IHS clinic-based screening indicated wanting direct access to a physician as the reason for this preference. Of those who had experienced clinic-based screening in the past (n=18), 78% (n=14) preferred self-administered over clinic-based. The majority (94%) reported they would access the internet to order the self-administered test.

Table 2. Future utilization of self-administered sexually transmitted infection screening (post results disclosure)

	Female (n=10)	Male (n=22)
	N (%)	N (%)
If you were at risk of contracting a STI in the future, would you:		
Take a self-administered test again	10 (100)	22 (100)
Prefer to (mutually exclusive):		
Take a self-administered test	8 (80)	14 (64)
Go to IHS clinic for testing	2 (20)	7 (32)
Neither	0 (0)	1 (4)
If test were free, available online and could be mailed, would you:		
Order this test	9 (90)	21 (95)
No (specify why)	1 (10)	1 (5)
No internet access	1 (100)	0 (0)
Don't trust internet	0 (0)	1 (100)

DISCUSSION

A self-administered STI screening method was found highly acceptable among rural, reservation-based American Indian adolescents. Participants felt comfortable with this method's privacy, non-clinic based option, in-person assistance from a Native paraprofessional, and in-person results disclosure and treatment from a local PHN. Participants understood testing instructions and were confident in their ability to complete the test independently. Importantly, the majority (69%) preferred this method over visiting the IHS clinic, 94% said they would order it online, and 75% (n=24) said they would encourage their peers to use this method. These results suggest high overall acceptability.

Self-administered STI screening, especially if provided free of charge, has potential to reach this high-risk population for testing and treatment referral, overcome barriers of stigma and confidentiality, and

reach those that might not otherwise access STI testing. Despite national screening recommendations focused on females of reproductive age, our majority sample of males with a high rate of positivity (all for chlamydia), and limited access to testing argue for targeted screening promotion among young AI males. Self-administered STI screening could be replicated and scaled-up in other AI communities through incorporation into the IHS standard of care, which has access to a ready infrastructure of two viable outreach work forces: Community Health Representatives (CHRs) and PHNs. CHRs could be trained to offer self-administered screening as an alternative to clinic-based testing and connect individuals to high quality follow-up, treatment and risk-reduction counseling already provided through the IHS-PHN system. Finally, since only 30% of our study sample was female, future directions should include additional piloting of self-administered STI screening methods with young AI females.


This study was exploratory, and results should be understood within the context of study limitations. First, limited resources including study staff availability and convenience sampling from a camp (as opposed to throughout the reservation) precluded recruitment of a large sample size; so the sample cannot be considered representative but appropriate nonetheless for a feasibility study. Second, the CDC recommends self- or clinician-collected vaginal swab as the preferred sample type and screening method for females (26). During our community-engaged research process however, community partners agreed this method would not be culturally acceptable and a first catch urine specimen was chosen instead. While considered acceptable by the CDC, first catch urine may detect up to 10% fewer infections when compared with vaginal swabs and may reduce user ease with specimen collection (due to necessary pipette of urine) (26). The proportion of those who tested positive cannot be extrapolated to population rates, and in general, would likely underestimate as the most at-risk segment of this population is highly mobile and hard-to-reach. Finally, this study was based on one IHS-catchment in a rural reservation area, and caution should be exercised in generalizing findings.

Limitations aside, to our knowledge this is the first study to explore a self-administered method of STI screening among AI adolescents in the United States and yielded important indications for other communities experiencing similar barriers. While our sample was not large enough to determine prevalence, the proportion of participants who tested positive (44%) sounds an urgent call to action.

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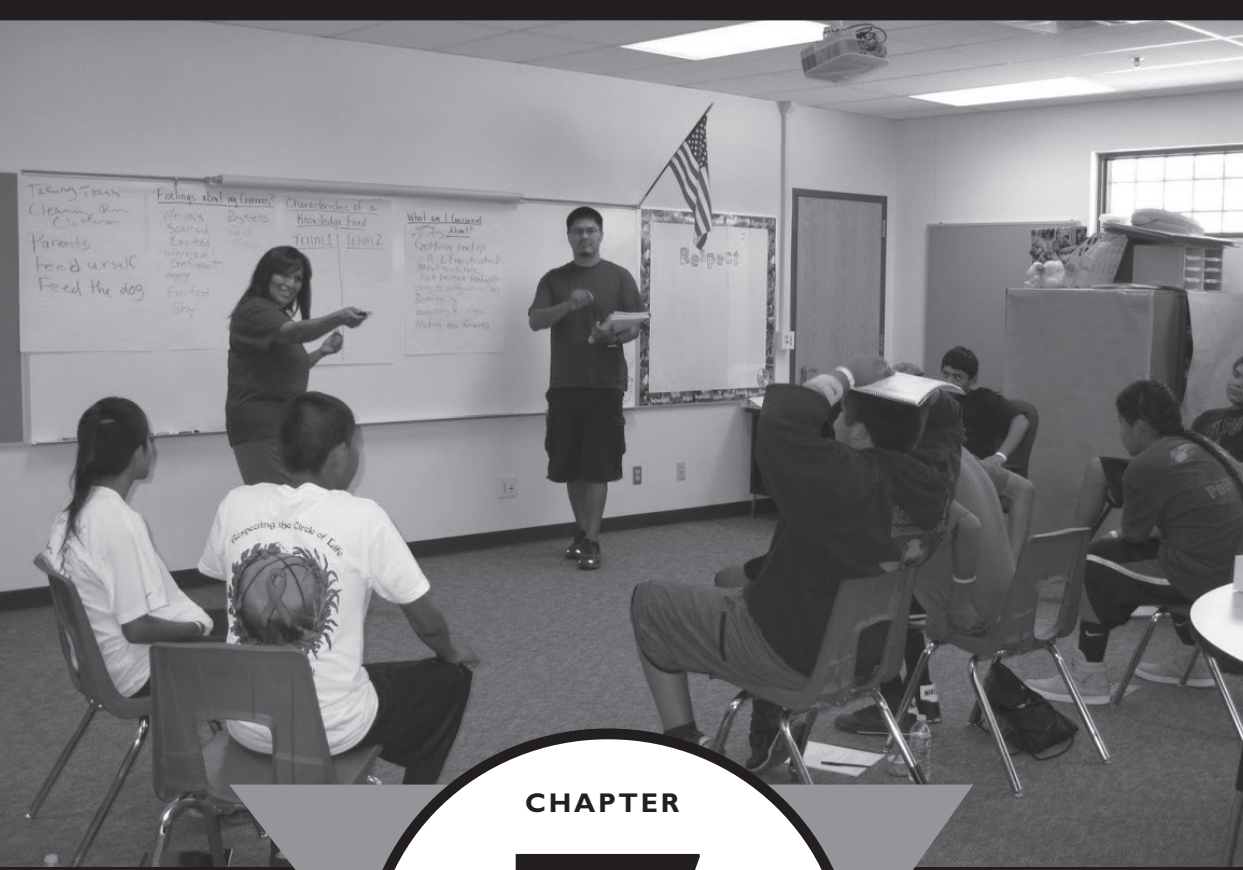
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The Respecting the Circle of Life Trial for American Indian Adolescents: Rationale, Design, Methods and Baseline Characteristics



CHAPTER

7

ABSTRACT

This paper describes the rationale, design, methods and baseline results of a randomized controlled trial to evaluate the impact of an adapted evidence-based intervention (EBI), “Respecting the Circle of Life” (RCL) to reduce behavioral risks of HIV/AIDS among American Indian (AI) adolescents. A participatory approach shaped intervention adaptation and study design. 267 participants (ages 13-19) were randomized by peer groups of the same sex to receive the RCL intervention or a control condition. Self-report assessments were administered at four intervals. The sample was predominately female (57%), had low HIV knowledge prevention scores, early sexual initiation (mean 14.6 years), and 56% reported intention to use a condom at next sex. Baseline characteristics were evenly distributed between groups with the exception of age and extrinsic reward scores. This is the first rigorous evaluation of an adapted EBI for HIV/AIDS prevention among AI adolescents, an at-risk and understudied population.

Dissertation Relevance and Significance: This article illustrates the stages: intervention selection and deep-structure cultural adaptation, of the approach described within this dissertation. The manuscript describes how an EBI for HIV/AIDS prevention can be successfully tailored for American Indian adolescents reflecting community-specific risk and protective factors following participatory research principles.

INTRODUCTION

HIV/AIDS is an emerging disease for American Indian/Alaska Native (AI/AN) populations. AI/ANs are diagnosed with HIV at a rate 30% higher than Whites and from 2007-2010, were the only racial/ethnic group in which HIV incidence increased (32). A constellation of HIV/AIDS risk and contextual factors affect AI/AN populations, namely high rates of unprotected sex and substance use (1, 2, 3). Stigmatization and concerns about privacy in rural reservation-based settings lead to poor testing, a lack of early identification of HIV, and shorter survival following diagnosis when compared to other U.S. groups (4).

Evidence-Based Interventions (EBI) for HIV/AIDS prevention have reduced behavioral risk among different adolescent racial/ethnic groups as documented by the Centers for Disease Control and Prevention's Compendium (5, 6). Adaptations of EBIs can take advantage of the research rigor that established the original EBI, add culturally-grounded community input, and may be best at addressing behavioral health disparities among under-represented groups in the EBI literature (7). While some HIV/AIDS prevention interventions have been designed for and evaluated among AI adolescent populations, none are cited in or have been adapted from an EBI in the CDC Compendium (5, 6, 8-14). Further, while there are several EBIs currently undergoing adaptation for AI/AN populations, results of trials evaluating their efficacy are not yet published.

This study is a randomized controlled trial of an adapted EBI conducted with a sample of reservation-based AI adolescents. This paper describes adaptation of the EBI, the study design evaluating its efficacy, and baseline characteristics of participants.

METHODS

Adaption of Evidence-Based Intervention

Selection. The EBI "Focus on Youth" (FOY) was selected for adaptation due to its targeted age group (adolescents), skills-focused curricula, theoretical underpinnings promoting protective factors (15), capacity for delivery by trained community members, non-school-based intervention setting, and track-record of successful cross-cultural replication (16-19). The Protection Motivation Theory (20) is the framework for FOY and posits that the perceived threat of HIV

infection initiates two cognitive pathways: threat-appraisal (risk) and coping-appraisal (protective) which combines to create the intention to respond by engaging in either the risky or protective behavior (20). Eight weekly sessions are delivered by pairs of adult interventionists from the community to peer groups of the same sex/age in community centers (21). Six FOY sessions are considered minimum intervention dosage.

Adaptation. The study team utilized a formative participatory research approach; we conducted fourteen focus groups, nine with youth and five with parents (34 males and 56 females), and three community advisory board meetings. Focus group discussions lasted 60-90 minutes and had an average of seven participants. Discussions explored intervention delivery and content changes essential for community acceptance and impact including behaviors that elicit intrinsic/extrinsic rewards, perceptions of HIV severity and vulnerability, relative costs in choosing protective behaviors, relevant examples and language (18).

Due to basketball's widespread popularity, an eight-day summer basketball camp was suggested for curriculum delivery as it would a) capitalize on availability (i.e. not compete with school-based activities), b) be viewed as a positive recreational outlet, c) attract both genders, d) be inclusive of adolescents who had dropped out of school, and e) maintain attendance. Concerns with adapting FOY from eight weeks to eight days (i.e. curriculum fatigue and less time to internalize behavior change messages) were outweighed by the potential benefits and endorsed by the architect of FOY, Dr. Bonita Stanton.

Formative research dictated content adaptations and addition of activities to address local teens' lack of knowledge about sexual risk behaviors, reproduction and sexual anatomy. A need for self-efficacy and communication skills among adolescents also prompted a deeper focus on communication-building activities and additional facilitator training related to forced sex. Local references were used in stories and scenarios where relevant. Activities where confidentiality or embarrassment was a concern were removed or adapted. Finally, due to feasibility concerns ongoing group projects (post program completion) were removed.

The adapted intervention was renamed by local partners "Respecting the Circle of Life: Mind, Body and Action" (RCL) to reflect Native beliefs in the connection between mental, physical, and spiritual health.

Respecting the Circle of Life Trial Design

The trial was a peer-group randomized controlled comparison of the RCL intervention vs. control and evaluated from baseline through twelve months follow-up (Figure 1). Two cohorts were recruited during two summer camps (each eight, four-hour weekdays), held approximately one year apart (2011 and 2012). The study site was a rural reservation in Arizona with a tribal population of ~15,500. A total of 475 AI teens ages 13-19 were eligible; N=267 completed the baseline assessment and attended camp. Participants formed self-selected same-sex peer groups/teams within the same age range (13 to 15 or 16 to 19) and were randomized. To reduce contamination, camp was held at separate gymnasiums for intervention and control groups. Each day consisted of 90 minutes of basketball, a 30-minute lunch and a 90-minute lesson (RCL or a non-competing educational control lesson).

Data were gathered through hard-copy via the self-report Youth Health Risk Behavior Inventory, which was adapted and pilot tested prior to use. Specifically we added questions assessing alcohol and drug use before/during sex and removed questions irrelevant to a rural setting measuring urban crime and weapon carrying. Confirmatory factor analysis (CFA) and examination of Cronbach α scores were conducted on all scale items to attain the most reliable variables for this sample (21, 22). CFA was used to generate loadings for individual items onto each factor and Cronbach's assessments were used to compare the reliability of different factor versions. Factors with low eigenvalues were removed when they did not significantly contribute to explaining the variance within a set of variables. Distribution of sociodemographic characteristics, psychosocial and behavioral risks, and PMT constructs were compared to determine quality of randomization by conducting chi-squared tests of association and t-tests for differences in means.

The study was approved by relevant tribal, Indian Health Service, and University research review boards. This manuscript was approved by the governing Tribal Council and Health Advisory Board. There was no Data Safety and Monitoring Board.

Baseline Results

Thirty peer groups/teams were randomized, 16 to the RCL intervention and 14 to the control condition (range six-twelve participants per group, average 8.9 participants). The total sample was

267 (138 RCL intervention, 128 control). The 2011 camp had 115 participants (43%) and the 2012 camp had 152 (57%).

Sociodemographics and Participation (Table I)

RCL intervention participants were significantly older (15.4 vs. 14.8 years, $p < 0.01$). Other key demographic variables were evenly distributed between intervention and control groups at baseline. Over half (56.2%) of participants were female and the majority (88.4%) were enrolled in school. A high proportion reported a history of school suspension (29.2%) and alcohol and marijuana use (19.9% and 22.1%, respectively). Over 80% of participants attended six or more camp days ($\geq 75\%$ of all lessons).

Table I: Sociodemographic characteristics and camp participation rates of youth at baseline, by treatment group

	RCL Intervention (n=138)	Control (n=129)	Total (N=267)
Sociodemographic Characteristics			
Age, Mean (SD) ^a	15.4 (1.7)	14.8 (1.5)	15.1 (1.7)
Gender, n (%)			
Male	59 (42.8%)	58 (45.0%)	117 (43.8%)
Female	79 (57.2%)	71 (55.0%)	150 (56.2%)
Currently in school, n (%)	123 (89.1%)	113 (87.6%)	236 (88.4%)
Ever been suspended from school, n (%)	40 (29.0%)	38 (29.5%)	78 (29.2%)
Currently have boyfriend/girlfriend, n (%)	50 (37.3%)	42 (33.3%)	92 (35.4%)
Drug use in past 6 months, n (%)			
Alcohol	30 (21.7%)	22 (17.2%)	52 (19.9%)
Cigarettes	15 (10.9%)	12 (9.3%)	27 (10.1%)
Marijuana	35 (25.4%)	24 (18.8%)	59 (22.1%)
Camp Participation			
Number of days attended camp, Mean (SD)	6.7 (2.0)	6.7 (2.0)	6.7 (2.0)
Attended six or more days of camp, n (%)	115 (83.3%)	106 (82.2%)	221 (82.8%)

^a $p < 0.01$ for test of between-group differences

Table 2: HIV-related behavioral risk profile at baseline, by treatment group

	RCL		
	Intervention (n=138)	Control (n=129)	Total (N=267)
Knowledge, efficacy & intention outcomes			
HIV-related knowledge, Mean (SD) (range 0-1)			
Prevention (Cronbach α = 0.62)	0.7 (0.3)	0.7 (0.2)	0.7 (0.3)
Transmission (Cronbach α = 0.72)	0.8 (0.2)	0.8 (0.2)	0.8 (0.2)
Total knowledge (Cronbach α = 0.73)	0.8 (0.2)	0.8 (0.2)	0.8 (0.2)
Believe condoms prevent HIV/STIs, n (%)	77 (55.8%)	67 (51.9%)	144 (53.9%)
Believe abstinence prevents HIV/STIs, n (%)	49 (35.5%)	54 (41.9%)	103 (38.6%)
Condom use self-efficacy	2.5 (1.0)	2.6 (1.0)	2.6 (1.0)
Mean (SD) (range 1-5) (Cronbach α = 0.83)			
Partner negotiation skills related to condom use	2.5 (1.0)	2.5 (1.0)	2.5 (1.0)
Mean (SD) (range 1-4) (Cronbach α = 0.94)			
Partner negotiation skills related to sex and drug use	4.5 (0.8)	4.5 (0.8)	4.5 (0.8)
Mean (SD) (range 1-5) (Cronbach α = 0.79)			
Intend to use condom at next sex, n (%)	76 (55.1%)	73 (56.6%)	149 (55.8%)
Sexual activity outcomes, among entire sample:			
Ever had vaginal sex, n (%)	37 (26.8%)	24 (18.6%)	61 (23.0%)
Age at sexual initiation, Mean (SD)	15 (1.7)	14 (1.4)	15 (1.6)
Had vaginal sex in past 6 months, n (%)	32 (23.2%)	19 (14.7%)	51 (19.1%)
Ever had anal sex, n (%)	5 (3.6%)	7 (5.7%)	12 (4.7%)
Diagnosed with STI in past six months, n (%)	1 (0.8%)	3 (2.4%)	4 (1.6%)
Contraceptive use in past 6 months, n (%)			
Condom	26 (18.9%)	18 (14.0%)	44 (16.5%)
Pill	3 (2.2%)	3 (2.3%)	6 (2.3%)
Depo	4 (2.9%)	3 (2.3%)	7 (2.6%)
RCL			
	Intervention (n=37)	Control (n=24)	Total (N=61)
Sexual activity outcomes, among youth that have ever had sex:			
Had more than one sexual partner in past 6 months, n (%)	10 (28.6%)	5 (21.7%)	15 (25.9%)
Talked about using condoms at last sex, n (%)	29 (78.4%)	16 (69.6%)	45 (75.0%)
Condom use at last sex, n (%)	26 (74.3%)	17 (77.3%)	43 (75.4%)
Ever use withdrawal during sex, n (%)	23 (65.7%)	10 (47.7%)	33 (58.9%)
Frequency of sex with substance use, n (%)			
Ever drink prior to sex	6 (17.7%)	8 (36.6%)	14 (25.0%)
Ever use drugs prior to sex	4 (11.8%)	7 (33.3%)	11 (20.0%)

Behavioral Risks (Table 2)

There were no significant between-group differences at the $p < 0.05$ level for HIV-related behavioral risks at baseline. Condom effectiveness knowledge for preventing HIV/STIs was low (~54%) and 56% said they intended to use a condom at next sexual intercourse. Almost one-quarter (23.0%) reported a history of vaginal sex, 19% in the past six months, with mean age of initiation of 14.6

years. Of those sexually active, three-quarters said they had both talked about and used a condom at last sex. The majority (~59%) of those sexually active had used withdrawal during sex; one-quarter (25.0%) reported alcohol and 20.0% illicit drug use prior to sex.

Protection Motivation Theoretical Constructs (Table 3)

Study groups were equal with regards to all seven theoretical constructs, with the exception of the intervention group scoring higher on extrinsic rewards (3.3 vs. 3.1, $p < 0.05$).

Table 3: Protection Motivation Theory construct scores at baseline, by treatment group

	RCL		Control		Total	
	Intervention		(n=129)		(N=267)	
	(n=138)					
Protection Motivation Theory outcomes (all range from 1-5)						
Coping Appraisal Constructs:						
Self-efficacy, Mean (SD) (Cronbach $\alpha = 0.66$)	4.3	(0.7)	4.2	(0.7)	4.3	(0.7)
Response efficacy, Mean (SD) (Cronbach $\alpha = 0.69$)	3.7	(0.7)	3.8	(0.8)	3.8	(0.7)
Response cost, Mean (SD) (Cronbach $\alpha = 0.58$)	2.8	(0.5)	2.9	(0.6)	2.9	(0.6)
Threat Appraisal Constructs:						
Intrinsic rewards, Mean (SD) (Cronbach $\alpha = 0.88$)	1.6	(0.7)	1.7	(0.8)	1.6	(0.7)
Extrinsic rewards, Mean (SD)* (Cronbach $\alpha = 0.72$)	3.3	(0.8)	3.1	(0.7)	3.2	(0.8)
Severity, Mean (SD) (Cronbach $\alpha = 0.42$)	3.7	(0.6)	3.6	(0.7)	3.6	(0.7)
Vulnerability, Mean (SD) (Cronbach $\alpha = 0.78$)	1.6	(0.8)	1.7	(0.8)	1.7	(0.8)

* $p < 0.05$ for test of between-group differences

DISCUSSION

Results demonstrate that participants have a risk profile appropriate for study aims. Compared to other US-based samples that received FOY, our sample had higher rates of truancy (e.g., 29% vs. 16%), history of alcohol use (20% vs. 14%) and drug use (22% vs. 7%) at baseline (19, 23, 21). Small proportions of youth believed abstinence and condom use prevent HIV/STIs (39% and 54% respectively). Relative to other FOY trials at baseline, this sample reported greater condom use self-efficacy, lower rates of sexual activity (23% vs. 36-37%), and higher condom use intention (56% vs. 36%) (16-19, 21, 23-25).

The customization of PMT constructs within this and other FOY samples make it difficult to draw direct comparisons. Generally, youth

in our sample scored better on self-efficacy, response efficacy, intrinsic rewards and vulnerability constructs and moderately on response cost, extrinsic rewards and severity constructs (16-19, 21, 23-25). Most of our scaled outcome measures had average to good Cronbach α scores with minimum values of 0.70, suggesting they will be effective markers of change over time in future analyses (26).

Statistically significant differences between RCL intervention and control groups at baseline including age and average extrinsic reward score, as well as peer group/team and camp cohort, will be adjusted for in the longitudinal analysis.

Conclusions

This trial is unique in its utilization of basketball camps as an implementation and retention strategy of a community-based sample in a hard-to-reach population. Reliance on AI paraprofessionals as interventionists was innovative; they comprised a ready workforce who illuminated culturally meaningful aspects of RCL content and addressed a lack of skilled health educators in an under-resourced community (27-31).

If RCL is demonstrated efficacious, tribes may have a novel approach that is practical, culturally and contextually appropriate, and evidence-based to prevent HIV/AIDS risk among adolescents. This is urgent for AI populations who are suffering from already high rates of STIs and related behavioral risk factors, the fastest increasing rates of HIV, and access barriers to treatment which contribute to higher case fatality due to AIDS.

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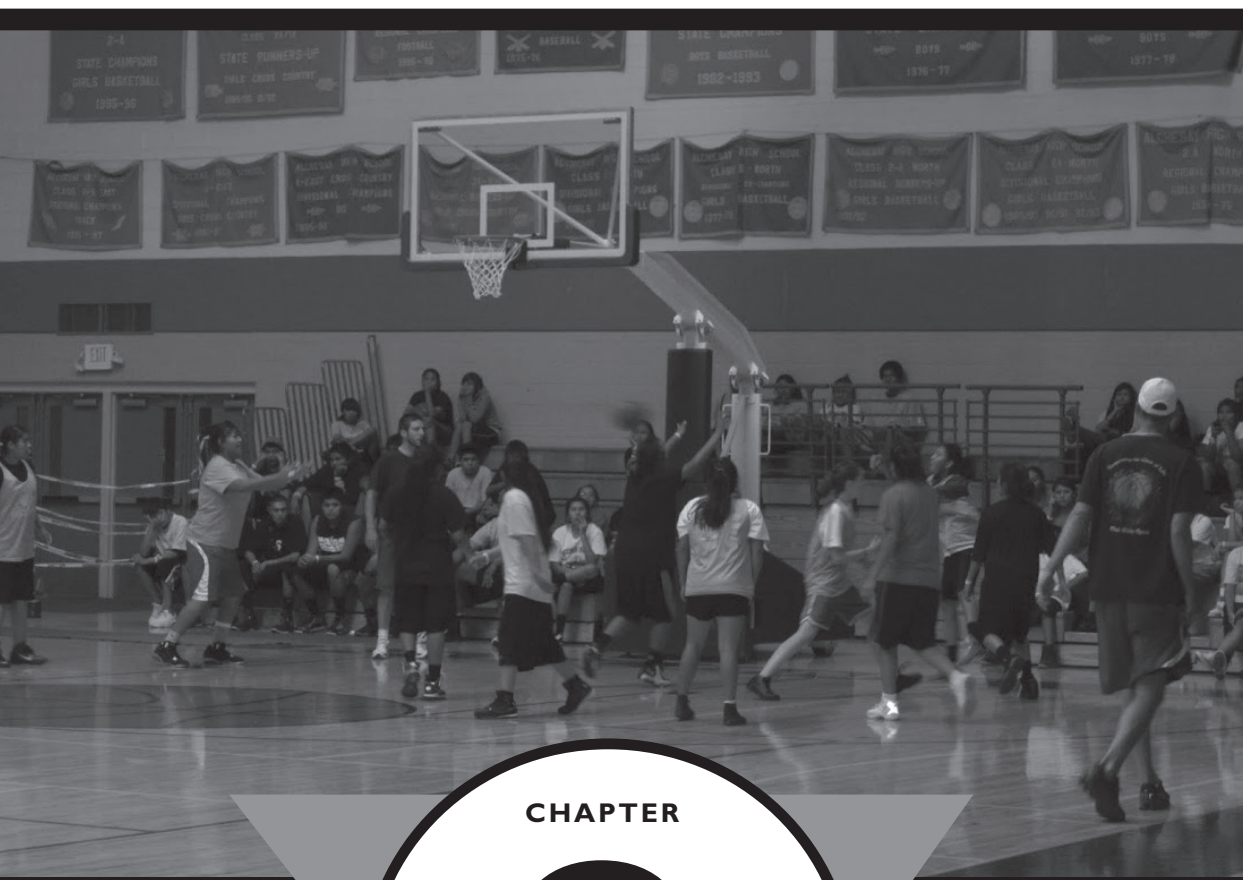
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Respecting the Circle of Life:
One Year Outcomes from a Randomized
Controlled Comparison of an
HIV Risk Reduction Intervention
for American Indian Adolescents



CHAPTER

8

Abstract

Potential for widespread transmission of HIV/AIDS among American Indian (AI) adolescents exists, yet no evidence-based interventions (EBIs) have been adapted and evaluated with this population. Intensive psychoeducation may improve knowledge and decision-making which could potentially translate to reductions in HIV risk behaviors. A peer-group randomized controlled comparison of an adapted EBI vs. control was delivered over an eight-day summer basketball camp in one reservation-based tribal community to adolescents ages 13-19. Outcome data were gathered immediately post-camp and at 6 and 12 months follow-up. Self-selected peer groups were randomized to intervention (n=138) or control (n=129) conditions for a total sample of 267 participants (56.2% female), mean age 15.1 years (SD 1.7). Intervention participants had better condom use self-efficacy post-camp (Adjusted Mean Difference [AMD]= -0.75, $p<0.005$) and at 6 (AMD= -0.44, $p<0.005$) and 12 months (AMD =-0.23, $p<0.05$) follow-up. Intervention participants also had higher HIV prevention and transmission knowledge (post-camp: AMD=0.07, $p<0.01$; 6 months: AMD=0.06, $p<0.01$), were more likely to believe condoms prevent STIs (post-camp: RR=1.41, $p<0.005$; 6 months: RR=1.34, $p<0.05$), to talk with an adult about HIV/AIDS (post-camp: RR=1.78, $p<0.005$; 6 months: RR=1.14, $p<0.005$), had higher partner negotiation efficacy related to substance use during sex (post-camp: AMD=0.37, $p<0.01$), and were more likely to intend to use a condom (post-camp: RR=1.39, $p<0.01$). The adapted intervention had short and medium-term impacts on AI adolescent risk for HIV/AIDS, but attenuated at 12 months. Intervention delivery through a community-based camp is feasible and acceptable with strong retention. Additional study is needed to evaluate the adapted intervention's impact on sexual risk behaviors and if booster sessions and parent involvement translate to long-term impacts.

Dissertation Relevance and Significance: This article illustrates the stages: adapted intervention implementation and evaluation, of the approach described within this dissertation. The manuscript describes how an EBI for HIV/AIDS prevention can be successfully implemented in an American Indian community with local paraprofessionals as interventionists. Results show a rigorous evaluation can be conducted in a unique camp-based setting with impacts on adolescents' behavioural health risks.

INTRODUCTION

American Indian adolescents are among the groups most vulnerable to sexually transmitted infections (STIs) including HIV/AIDS in the United States. According to recent surveillance (1), American Indian/Alaska Natives (AI/AN) were the only racial group in the U.S. in which HIV and AIDS incidence rates increased between 2007 and 2010. During this period AI/ANs also had the lowest survival rate compared to other races following a diagnosis of either HIV or AIDS (1).

Within AI/AN communities, adolescents are disproportionately impacted by behavioral risk factors for HIV/AIDS. AI/AN adolescents have the highest substance use and related morbidity and mortality of any U.S. group (2-6). They are more likely to initiate drug and alcohol use before the age of 13 and on average have higher rates of lifetime drug use than other adolescent groups (7). Substance use risk is compounded by risky sexual behavior and poor sexual health among AI/AN adolescents. In 2011, compared with all high-school aged U.S. youth, AI/ANs were more likely to have ever had sex, have had sex in the last three months and ever been forced to have sex (8). AI/ANs are diagnosed with STIs at four times the rate of Whites (9). Although declining from 1990 to the early 2000s, current data indicate that in the last decade, teen pregnancy rates have risen among AI/AN youth (10).

A shortage of healthcare providers, limited capacity of existing providers, and substantial access barriers to health care and education exacerbate HIV risk in rural, reservation-based populations. Recent reports indicate AI/ANs account for less than 1% of all HIV/AIDS cases nationwide (11). However due to racial misclassification and low HIV screening coverage rates, the actual number is likely higher (11).

In the broader U.S. population, several evidence-based interventions (EBIs) have been shown to reduce risk for HIV (12-15). However, no rigorous evaluations of the EBIs documented by the CDC (<http://www.cdc.gov/hiv/prevention/research/compendium/rr/complete.html>) have been conducted with an exclusive sample of American Indians. To avoid a potential HIV/AIDS epidemic in the AI/AN population, it is imperative to adapt or develop EBIs addressing the unique prevention needs in AI/AN communities.

The goal of this study was to adapt and evaluate an EBI for HIV/AIDS prevention for AI adolescents in partnership with one reservation-based tribal community. We hypothesized that intensive psychoeducation focusing on rewards and consequences of HIV-related risk behaviors and sexual health education as compared to a control condition would significantly (1) increase condom use self-efficacy (widely used as a proximal indicator of sexual behavior change, condom use self-efficacy is associated with one's ability to negotiate condom use with their partner, intention to use condoms and actual use of condoms) (16), and (2) improve HIV risk reduction knowledge, efficacy, and attitudes, as well as behavioral intent.

METHODS

Participatory Approach

We utilized a participatory research approach which builds trust and increases likelihood that interventions are conceived sensitively and appropriately (17-20). A participatory process guided the study team (comprised of non-AI and AI researchers and community partners) in the selection of an EBI for adaptation, identification of key adaptation targets, and implementation and evaluation methods. In the study's formative phase we established a community advisory board (CAB) and conducted 14 focus groups. We found that the community preferred an intervention that was inclusive of protective factors, experiential, and which taught concrete skills. CAB members and focus group respondents preferred paraprofessionals from the tribal community fluent in English and the local language as interventionists.

The EBI "Focus on Youth" (FOY), developed for African-American adolescents and successfully implemented in various populations around the world, was selected for adaptation (21-24). The Protection Motivation Theory (PMT) underpinning FOY posits that the perceived threat of HIV infection initiates two cognitive pathways: (1) threat-appraisal (risk) balances the threat of contracting HIV including intrinsic/extrinsic rewards versus the severity of HIV and one's perceived vulnerability; (2) coping-appraisal (protective) balances one's ability to avoid the threat through self-efficacy and response efficacy versus the relative cost of the adaptive behavior. These combine to create protection motivation: the intention to respond by engaging in either the risky or protective behavior (25).

EBI Adaptation

Based on the culture and context of this community, we made several adaptations to FOY curriculum content. Adolescents' lack of knowledge about sexual risk behaviors, reproduction and sexual anatomy prompted the addition of educational information and related skills-based activities. Formative research showed a need to improve self-efficacy and communication skills among youth which called for a deeper focus on communication-based activities and facilitator training related to forced sex. We removed from the curriculum any activities that the community felt would compromise confidentiality, and changed names, situations and other surface items to ensure lesson scenarios were relatable. AI study partners renamed the adapted intervention "Respecting the Circle of Life: Mind Body and Action" (RCL) to reflect local understanding of the connection between mental, physical and spiritual health.

Study Design

The study was a peer-group randomized controlled comparison of the RCL intervention vs. a control condition delivered over the course of a community-based eight-day summer basketball camp, and evaluated from baseline to 12 months follow-up (26, 27). We conducted the study over two cohorts through summer basketball camps (cohort 1 in Summer 2011 and cohort 2 in Summer 2012). Each camp consisted of eight consecutive four-hour weekdays and to reduce the possibility for contamination, utilized two separate school gymnasium facilities (approximately one mile apart). Each day, there was 90 minutes of basketball, a 30-minute lunch and a 90-minute educational lesson (RCL or control). The study was approved by relevant tribal, Indian Health Service (IHS), and University research review boards. This manuscript was approved by the Tribal Council and Health Advisory Board, the local governing bodies that provide regulatory oversight of all research conducted on the reservation. There was no Data Safety and Monitoring Board for this study.

Participants. The study was conducted in a rural and isolated reservation-based tribal community with a population of approximately 15,500. Participants were eligible if ages 13-19, American Indian, and residing in the participating community at time of consent. We recruited through local schools, IHS clinics, public events, and word of mouth. We provided written informed consent after participants received a complete description of the study. For

those under age 18, we obtained informed consent from a parent/guardian and assent from the participant.

Randomization. On the first day of camp, participants formed self-selected same-sex peer groups of 8 to 10 participants within the same age range (13-15 or 16-19 years). Groups were then allocated to the RCL intervention or control condition through a stratified randomization sequence created by the study data manager in Stata 9.0 (28). Stratification occurred by gender and age range.

Respecting the Circle of Life Intervention. RCL consisted of eight structured lessons delivered to peer groups of 8-10 participants of the same sex and age (29). Six RCL lessons was considered minimum for adequate intervention dosage.

Control Condition. The control condition consisted of eight educational lessons on topics not targeted by RCL (i.e. nutrition, fitness, tribal history, etc.), delivered in a large group setting (~50 participants) of mixed sex and age. Control content was taught through lecture and hands-on activities.

Quality Assurance

Three categories of research staffing included: (1) RCL Facilitators who delivered RCL and did not interact with control participants, (2) Control Facilitators, who were not trained in RCL and administered the control condition, and (3) Research Assistants who monitored participants' self-report assessments. All staff and participants were unmasked to randomization assignments. RCL Facilitators and Research Assistants were male and female AI paraprofessionals ages 25 to 50 from the community and employed by the partnering University. Control Facilitators were paid volunteers from local agencies and tribal departments.

RCL Facilitators completed a one-week, 40-hour training in the adapted curriculum for certification to facilitate, and the study team conducted booster trainings. A curriculum specialist observed 50% of RCL lessons during camp to ensure fidelity. We trained study staff in-person and through teleconferencing in study policies and procedures and certified them in research with human subjects.

Outcome Measures

We used the Youth Health Risk Behavior Inventory (YHRBI) to measure intervention outcomes; it measures psychosocial and behavioral intent outcomes and the seven theoretical constructs (self-efficacy, response efficacy, response cost, intrinsic reward, extrinsic reward, severity, and vulnerability). We selected it for its cross-cultural validity and strong psychometric properties across past evaluations of FOY with other populations (30). We adapted the YHRBI during our formative research; we modified five questions to include definitions and detail regarding sexual behaviors, added 11 questions about alcohol and drug use prior to and during sex, and removed 72 questions assessing urban crime, violence and weapon carrying. We pilot tested the adapted version with 15 local youth.

We administered the adapted YHRBI at four time points: (1) either upon signing consent or the first day of camp ('baseline'), (2) on the last day of camp ('post-camp'), (3) 6 months after camp, and (4) 12 months after camp. Baseline and post-camp surveys were administered at camp; follow-up surveys were administered in participants' homes.

We used confirmatory factor analysis (CFA) to examine and maximize the reliability of the YHRBI sub-scales for the study sample (Table 1). Specifically, we used CFA to confirm if individual scale items corroborated previously hypothesized constructs and to compare the reliability of different factor versions. If a particular item appeared to diminish the Cronbach's alpha value for a factor and did not contribute to its overall variance, we removed that item from that particular factor.

Statistical Methods

Condom use self-efficacy at 12 months follow-up was the study's primary outcome and was used to calculate the required sample size. In calculating our sample size, we aimed to detect with 80% power a 1-point between-group difference in the 5-point condom use self-efficacy scale. Assuming $\alpha=0.05$ and baseline mean (SD)=2.5 (2.5), we estimated a total sample size of $n=198$ at 12-months follow-up. Accounting for up to 25% attrition, we aimed to recruit a total of $n=265$ participants.

We fit population-averaged panel-data models to the data using generalized estimating equations (STATA's `xtgee` command). All models accounted for within-team correlation structures. Given

statistically significant differences in mean age and extrinsic rewards scale score between study groups at baseline, we adjusted models for these variables. Participants with complete data were similar to those missing data, with the exception of those missing the 12-month assessment being less sexually active and less likely to use alcohol. Findings are presented by study group and time point.

Table 1. Subscales for assessing Protection Motivation Theory constructs. (*values were re-coded in opposite direction)

Subscale	Scoring	Cronbach's α	Items within subscale
Coping appraisal: Self-efficacy (lower score = higher risk)	Range 1-5: 1 = Strongly agree 5 = Strongly disagree	0.87	I want to wait until I'm married before I have sex. If don't want to have sex with someone going out with, I would not be able to say no. If my sexual partner offers me drugs or alcohol I should take them. If my sexual partner uses drugs or alcohol before sex I should use them too.
Response efficacy (lower score = higher risk)	Range 1-5: 1 = Strongly disagree 5 = Strongly agree	0.85	If a girl says she won't have sex, a boy would say it's okay. Condoms are an important way to prevent pregnancy. Condoms are an important way to prevent you from getting a STD. Condoms are an important way to prevent you from getting HIV/AIDS.
Response cost (higher score = higher risk)	Range 1-5: 1 = Strongly disagree 5 = Strongly agree	0.81	My friends expect me to try drugs. My friends would think I was scared if I didn't try alcohol or drugs. If a girl carries condoms people think she is having sex. Condoms make sex hurt for a girl. Condoms make sex feel less good. When a guy and a girl are in a serious relationship they don't use condoms. Kids don't want other kids to think they are using condoms. Boys think it is important to have sex to feel like a man. Girls think it is important to have sex to feel like a woman.
Threat appraisal			
Intrinsic reward (higher score = higher risk)	Range 1-5: 1 = Very bad 5 = Very good	0.86	IF FOLLOWING HAPPENED IN THE NEXT 6 MONTHS, I WOULD FEEL... Smoke marijuana (pot, grass, weed). Get an HIV infection. Drink alcohol (beer, whiskey, liquor, wine). Get an STD (sexually transmitted disease, e.g., gonorrhea, herpes). Use cocaine. Get pregnant or get a girl pregnant. Get suspended from school. Have sex. I would like to know what it feels like to take drugs.
Extrinsic reward (higher score = higher risk)	Range 1-5: 1 = Strongly disagree 5 = Strongly agree	0.70	It is important that my friends respect me. Everyone my age has sex. My friends would lose respect for me if they thought I had an STD. How many of your close friends have sex? How many of the boys you know have sex? How many of the girls you know have sex?
Severity (higher score = higher risk)	Range 1-5: 1 = Strongly disagree 5 = Strongly agree	0.82	People who use drugs get HIV/AIDS. If two people are going together and one gets an STD, they would break up. If my mother knew I had an STD, she would be really upset.
Vulnerability (higher score = higher risk)	Range 1-5: 1 = No 2 = Probably not 3 = Don't know 4 = No, definitely 5 = Yes	0.79	IN THE NEXT SIX MONTHS I WILL... Smoke marijuana (pot, grass, weed) (including just trying it once). Become infected with HIV. Drink alcohol (beer, whiskey, liquor, wine) (including just trying it once). Get an STD (sexually transmitted disease, e.g., gonorrhea, herpes). Get pregnant or get a girl pregnant.

RESULTS

We recruited youth in May-July 2011 for the first camp and in March-June 2012 for the second camp. We approached a total of 475 youth and 208 were unable to participate due to summer scheduling conflicts (i.e. other commitments, not in town, etc.). A final sample size of 267 completed the baseline assessment and were randomized by peer-group to receive the RCL intervention (n=138) or control condition (n=129). Within the RCL intervention group, 115 participants (83%) received 6 or more lessons. Six month assessments were completed by 234 (88%) and 12 month assessments were completed by 239 participants (90%), resulting in 10% overall attrition.

At baseline (Table 2), the majority of participants had been enrolled in school the previous academic year (93%), and 30% reported past school suspension. More than half were female (56%), and mean age was 15.1 years (SD 1.7). Past sexual intercourse was reported by 22% and 35% reported a current boy/girlfriend. Participants in both study groups attended an average 6.7 days of camp. Study groups had similar socio-demographic characteristics at baseline with the exception of age (control participants were younger; $p < 0.001$). Participants receiving less than 6 RCL lessons were more likely to be sexually active and have used alcohol in the past 6 months.

Table 2. Baseline characteristics of participants, by randomization assignment and intervention dosage.

	Total	Randomization group		RCL session dosage (intervention group only)	
		Control (N=129)	RCL (N=138)	<6 RCL sessions	≥6 RCL sessions
Number (%)	267 (100)	129 (48.3)	138 (51.7)	23 (16.7)	115 (83.3)
Age, years - Mean (SD)	15.1 (1.7)	14.8 (1.5)**	15.4 (1.7)	16.3 (2.1)	15.3* (1.6)
Gender, n (%)					
Male	117 (43.8)	58 (45.0)	59 (42.8)	9 (39.1)	50 (43.5)
Female	150 (56.2)	71 (55.0)	79 (57.3)	14 (60.9)	65 (56.5)
Ever had sex, n (%)	59 (22.2)	23 (18.0)	36 (26.1)	10 (43.5)	26 (22.6)*
Have boyfriend/ girlfriend, n (%)	92 (35.4)	42 (33.3)	50 (37.3)	11 (47.8)	39 (35.1)
Currently in school, n (%)	236 (93.3)	113 (94.2)	123 (92.5)	20 (90.9)	103 (97.8)
Ever suspended school, n (%)	77 (29.8)	37 (29.8)	40 (29.9)	9 (39.1)	31 (27.9)
Drug use past 6 months, n (%)					
Alcohol	52 (19.6)	22 (17.2)	30 (21.9)	10 (43.5)	20 (17.5)**
Cigarettes	27 (10.1)	12 (9.3)	15 (10.9)	5 (21.7)	10 (8.7)
Marijuana	59 (22.2)	24 (18.8)	35 (25.4)	9 (39.1)	26 (22.6)
Number days attended camp, Mean (SD)	6.7 (2.0)	6.7 (2.0)	6.7 (2.0)	2.8 (1.5)	7.5 (0.7)**
Attended ≥6 days of camp, n (%)	221 (82.8)	106 (82.2)	115 (83.3)	-	-

* p<0.05, **p<0.01, ***p<0.001 for test of between-group differences

Condom Use Self-Efficacy

RCL participants had significantly improved mean condom use self-efficacy scores compared to controls at post-camp (range 1-5, lower score indicates higher efficacy; 1.69 v. 2.53, $p<0.005$), 6 months (1.78 vs. 2.34, $p<0.005$), and 12 months (1.67 vs. 2.01, $p<0.05$) (Table 3). Stratified analyses indicated improved self-efficacy scores among male intervention participants only immediately post-camp and improved scores among female intervention participants at all time points, suggesting a more long-term impact among girls.

Among participants ages 13-15, condom use self-efficacy scores were better in the RCL intervention group at post-camp (1.68 vs. 2.63, $p<0.005$) and 6 months (1.83 vs. 2.34, $p<0.005$), but not at 12 months. Among older participants (ages 16-19), RCL participants had improved condom use self-efficacy compared to controls at post-camp (1.72 vs. 2.13, $p<0.01$) and 12 months (1.45 vs. 1.80, $p<0.005$), but not at 6 months.

Knowledge

RCL intervention group participants had higher knowledge scores regarding prevention and transmission of HIV/AIDS than controls at post-camp (0.84 v. 0.76, $p<0.01$) and 6 months (0.84 v. 0.77, $p<0.01$), but not at 12 months (Table 4). They were also more likely to believe condoms prevent transmission of HIV and STIs at post-camp ($RR=1.41$, $p<0.005$) and 6 months ($RR=1.34$, $p<0.05$), but not at 12 months.

Behavioral Intent

RCL participants were more likely to have spoken with a family member or adult about HIV/AIDS at post-camp ($RR=1.78$, $p<0.005$) and 6 months ($RR=1.14$, $p<0.005$), but not at 12 months (Table 4). Several other behavioral intent risk variables were significantly improved among RCL participants post-camp, but not sustained through 6 or 12 months. RCL participants reported increased efficacy around partner negotiation skills related to substance use during sex (4.65 vs. 4.25 on a 5-point efficacy scale, $p<0.01$) and were more likely to intend to use a condom at next sex ($RR=1.39$, $p<0.01$) at post-camp, but not at later time points (Table 4).

Protection Motivation Theory

We observed significant between-group differences at post-camp for all three theoretical constructs comprising the coping appraisal pathway and none comprising the threat appraisal pathway (Table 5). Immediately post-camp, RCL participants had higher self-efficacy (range 1-5, 1=strongly agree, 5=strongly disagree; 4.46 v. 4.10, $p<0.01$), response efficacy (range 1-5, 1=strongly disagree, 5=strongly agree; 4.23 v. 3.66, $p<0.005$), and response cost (range 1-5, 1=strongly disagree, 5=strongly agree; 2.76 vs. 2.99, $p<0.01$). Significantly improved scores among RCL participants were only sustained for response efficacy at 6 months (4.03 vs. 3.76, $p<0.05$) and 12 months (4.08 vs. 3.80, $p<0.01$).

Table 3. Mean (SD) scores on condom use self-efficacy scale and adjusted mean differences, by time point and study group. (AMD=Adjusted Mean Difference)

Condom use self-efficacy (range 1-5; lower score = higher efficacy)	Baseline			Post-camp			6 month follow-up			12 month follow-up			Cronbach's α
	RCL Mean (SD) N=138	Cont. Mean (SD) N=129	AMD	RCL Mean (SD) N=131	Cont. Mean (SD) N=126	AMD	RCL Mean (SD) N=123	Cont. Mean (SD) N=111	AMD	RCL Mean (SD) N=124	Cont. Mean (SD) N=115	AMD	
Overall	2.54 (1.05)	2.60 (0.98)	0.0 (1.05)	1.69 (0.76)	2.53 (1.05)	0.75** (0.83)	1.78 (0.83)	2.34 (0.95)	-0.44*** (0.76)	1.67 (0.76)	2.01 (0.78)	-0.23* (0.78)	0.85
Male	2.40 (1.18)	2.43 (1.03)	0.01 (1.15)	1.68 (0.75)	2.45 (1.15)	0.86** (0.71)	1.70 (0.71)	2.13 (1.17)	-0.29 (1.17)	1.57 (0.68)	1.82 (0.83)	-0.12 (0.83)	0.90
Female	2.63 (0.94)	2.74 (0.93)	0.01 (0.96)	1.70 (0.76)	2.60 (0.96)	0.87** (0.91)	1.85 (0.91)	2.51 (0.70)	-0.58*** (0.70)	1.73 (0.81)	2.15 (0.71)	-0.33*** (0.71)	0.82
13-15 yr olds	2.74 (1.0)	2.71 (0.97)	0.15 (0.72)	1.68 (0.72)	2.63 (1.05)	0.85** (0.81)	1.83 (0.81)	2.34 (0.92)	-0.45*** (0.92)	1.94 (0.82)	2.12 (0.73)	-0.12 (0.73)	0.84
16-19 yr olds	2.16 (1.05)	2.19 (0.95)	0.05 (0.86)	1.72 (0.86)	2.13 (0.97)	0.54** (0.86)	1.72 (0.86)	2.34 (1.07)	-0.46 (1.07)	1.45 (0.63)	1.80 (0.84)	-0.36*** (0.84)	0.86

* $p<0.05$, ** $p<0.01$, *** $p<0.005$

Note: all models adjusted for group correlation and for age and mean score on extrinsic rewards subscale of PMIT at baseline

Table 4. HIV-prevention knowledge, efficacy, intention and behavioral intent outcomes, by time point and study group.

(AMD=Adjusted Mean Difference)

	Baseline			Post-camp			6 month follow-up			12 month follow-up			Cronbach's α
	RCL Mean (SD) N	Cont. Mean (SD) N	AMD	RCL Mean (SD) N	Cont. Mean (SD) N	AMD	RCL Mean (SD) N	Cont. Mean (SD) N	AMD	RCL Mean (SD) N	Cont. Mean (SD) N	AMD	
Knowledge of HIV prevention/transmission (range 0-1; higher score = higher knowledge)	4.48 (0.81) N=138	2.45 (0.97) N=129	-0.01 (0.12)	0.79 (0.17)	0.78 (0.16)	0.07**	0.84 (0.15)	0.76 (0.16)	0.06**	0.83 (0.17)	0.81 (0.16)	0.01	0.74
Partner negotiation on condom use (range 1-4; higher score = higher efficacy)	2.53 (0.98)	2.45 (0.97)	-0.03 (0.12)	2.60 (0.86)	2.63 (0.86)	-0.09 (0.17)	2.82 (0.86)	2.66 (0.90)	0.05 (0.16)	2.89 (0.89)	2.87 (0.78)	-0.08 (0.16)	0.93
Partner negotiation on drug use during sex (range 1-5; higher score = higher efficacy)	4.48 (0.81)	4.46 (0.79)	0.01 (0.12)	4.65 (0.71)	4.25 (0.98)	0.37** (0.17)	4.55 (0.76)	4.34 (0.90)	0.21 (0.16)	4.52 (0.82)	4.29 (0.94)	0.14 (0.16)	0.82
Belief condoms prevent HIV/STIs (Yes/No)	n (%) 77 (55.8)	n (%) 67 (51.9)	RR 1.00 (51.9)	n (%) 104 (79.4)	n (%) 67 (53.2)	RR 1.41** (53.2)	n (%) 89 (72.4)	n (%) 55 (49.6)	RR 1.34* (49.6)	n (%) 88 (71.0)	n (%) 69 (60.0)	RR 1.18 (60.0)	NA
Belief abstinence prevents HIV/STIs (Yes/No)	n (%) 49 (35.5)	n (%) 54 (41.9)	RR 0.78 (41.9)	n (%) 83 (63.4)	n (%) 49 (38.9)	RR 0.43 (38.9)	n (%) 58 (47.2)	n (%) 41 (36.9)	RR 1.21 (36.9)	n (%) 69 (55.7)	n (%) 45 (39.1)	RR 1.40 (39.1)	NA
Talked with family member/adult about HIV/AIDS in past 6 months (Yes/No)	n (%) 35 (25.6)	n (%) 30 (23.3)	RR 1.05 (23.3)	n (%) 57 (43.5)	n (%) 29 (23.0)	RR 1.78** (23.0)	n (%) 49 (39.8)	n (%) 14 (12.6)	RR 1.14** (12.6)	n (%) 49 (39.5)	n (%) 29 (25.4)	RR 1.51 (25.4)	NA
Intend to use condom at next sex (Yes/No)	n (%) 76 (56.7)	n (%) 72 (57.1)	RR 0.90 (57.1)	n (%) 92 (71.9)	n (%) 62 (49.6)	RR 1.39** (49.6)	n (%) 80 (66.7)	n (%) 60 (54.1)	RR 1.16 (54.1)	n (%) 85 (69.1)	n (%) 68 (59.7)	RR 1.09 (59.7)	NA
Had vaginal sex in past 6 months (Yes/No)	n (%) 29 (21.0)	n (%) 18 (14.2)	RR 0.90 (14.2)	n (%) 30 (22.9)	n (%) 17 (13.5)	RR 1.25 (13.5)	n (%) 34 (27.9)	n (%) 18 (16.2)	RR 1.08 (16.2)	n (%) 45 (36.6)	n (%) 24 (21.7)	RR 1.34 (21.7)	NA

*p<0.05, **p<0.01, ***p<0.005
 Note: all models adjusted for group correlation and for age and mean score on extrinsic rewards subscale of PMT at baseline

Table 5. Mean (SD) scores on Protection Motivation Theory constructs and adjusted mean differences, by time point and study group. (AMD=Adjusted Mean Difference)

	Baseline			Post-camp			6 month follow-up			12 month follow-up		
	RCL Mean (SD) N	Cont. Mean (SD) N	AMD	RCL Mean (SD) N	Cont. Mean (SD) N	AMD	RCL Mean (SD) N	Cont. Mean (SD) N	AMD	RCL Mean (SD) N	Cont. Mean (SD) N	AMD
Coping appraisal												
Self-efficacy	4.32 (0.68)	4.24 (0.69)	0.11	4.46 (0.67)	4.10 (0.81)	0.37**	4.33 (0.63)	4.17 (0.72)	0.19	4.33 (0.63)	4.13 (0.76)	0.16
Response efficacy	3.72 (0.73)	3.83 (0.76)	-0.14	4.23 (0.60)	3.66 (0.76)	0.55***	4.03 (0.67)	3.76 (0.80)	0.24*	4.08 (0.75)	3.80 (0.77)	0.26**
Response cost	2.96 (0.45)	3.00 (0.50)	-0.05	2.76 (0.58)	2.99 (0.48)	-0.22**	2.79 (0.54)	2.87 (0.42)	-0.08	2.84 (0.52)	2.92 (0.47)	-0.08
Threat appraisal												
Intrinsic reward	1.61 (0.68)	1.67 (0.78)	-0.06	1.55 (0.58)	1.64 (0.69)	-0.07	1.57 (0.69)	1.50 (0.58)	0.08	1.51 (0.55)	1.60 (0.57)	-0.07
Extrinsic reward	3.29 (0.78)	3.06 (0.73)	0.10*	3.30 (0.69)	3.11 (0.76)	0.11	3.42 (0.69)	3.10 (0.65)	0.22	3.46 (0.71)	3.28 (0.76)	0.12
Severity	3.65 (0.65)	3.64 (0.67)	-0.01	3.58 (0.73)	3.46 (0.67)	0.06	3.61 (0.63)	3.60 (0.53)	-0.02	3.54 (0.66)	3.49 (0.64)	0.01
Vulnerability	1.62 (0.75)	1.70 (0.80)	-0.14	1.66 (0.79)	1.70 (0.84)	-0.04	1.49 (0.68)	1.63 (0.80)	-0.13	1.55 (0.71)	1.68 (0.77)	-0.12

*p<0.05, **p<0.01, ***p<0.005

Note: all models adjusted for group correlation and for age and mean score on extrinsic rewards subscale of PMT at baseline

DISCUSSION

Implications

This is the first methodologically rigorous evaluation to indicate efficacy of an adapted evidence-based intervention to address risks for HIV/AIDS among a sample of exclusively American Indian adolescents. Results demonstrate the short and medium-term intervention impact of the RCL intervention on AI adolescents' risks for HIV across age groups, with greater response among females. This study also supports the innovation, feasibility and acceptability of conducting a randomized controlled comparison in a community-based setting (29). The study's overall strong retention rate (90%) and demonstrated knowledge gains among participants support acceptance of the RCL intervention.

The significant between-group differences observed on all coping-appraisal theoretical constructs reinforce past research suggesting promotion of protective factors may bear greater importance in AI populations than a focus on risk (31). These findings extend the literature on delivery of HIV/AIDS prevention interventions to self-selected groups of peers and further support the role of trained AI paraprofessionals in teaching sensitive behavior change information (32-40). Our evaluation shows that a behavioral health intervention rooted in Protection Motivation Theory and adapted for an AI community can improve condom use self-efficacy, but it does not provide evidence of long-term intervention impact on high-risk behaviors. Attenuation of initially strong intervention effects is consistent with past evaluations of the original EBI, Focus on Youth (21-24, 29, 41, 42).

Limitations

First, as in other HIV risk-reduction interventions, self-reported outcomes may not be accurate and/or may be impacted by participants' altering their responses based on social desirability. While the randomized design of this study helps mitigate this limitation, future studies could use data collection methods that decrease response bias such as Audio Computer Assisted Self Interview technology and biological outcome measures (43). Second, there is potential for attrition bias. The strong retention rate of participants seen in the study diminishes this concern. Intervention participants who received less than adequate RCL dosage were more likely to be sexually active and use alcohol at 12 months follow-up.

This challenge is faced in behavioral health intervention studies as those most in need of the intervention are difficult to retain.

Third, baseline inequalities between RCL intervention and control participants could theoretically confound results; statistical adjustment for these differences in the analyses minimizes this concern. Fourth, the intervention and control conditions differed in delivery format including group size and facilitator type (i.e., interventionists employed by the partnering University versus paid volunteers). Limited resources precluded our ability to determine to what degree differences in delivery mode versus actual program content resulted in RCL intervention impact. Also, despite using separate gymnasium facilities it is impossible to prevent all potential contamination between groups in a small, rural community. Finally, findings are not necessarily generalizable to the heterogeneous U.S. tribal population, as the RCL intervention was adapted for and evaluated in one tribal community. Limitations aside, behavioral health risks challenging the participating community also impact other rural and reservation-based AI populations; the RCL intervention may be more amenable to replication in these communities than other EBIs which have not been evaluated with AI/AN samples.

Future Directions

Booster sessions may be needed to sustain short- and medium-term intervention gains and would be feasible given the ability of local study staff to maintain contact with the majority of participants at later evaluation time points. Other evaluations of the original EBI which incorporated an additional curriculum lesson called ImPACT (Informed Parents and Children Together) demonstrated sustained and enhanced intervention impact at long-term follow-up (44, 45). In AI/AN communities, family has been shown to influence adolescents' behavioral health choices; therefore the addition of ImPACT may enhance the intervention impact of RCL (46, 47). Given known behavioral health disparities and increasing HIV rates in AI communities, advancing this and similar lines of research is urgent.

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Discussion



CHAPTER

9

9.1 INTRODUCTION

This Chapter will summarize the empirical findings and discuss 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 and implementation of behavioural health interventions with other American Indian and indigenous adolescent populations. Chapter 9 concludes with recommendations and directions for future research.

9.2 SUMMARY OF STUDIES AND MAJOR FINDINGS

Overview

The studies presented in this dissertation represent the first evidence for a stage-based model of community-based participatory research that responds to the unique profile of risk and resilience in a Native community, and for the adaptation, implementation and evaluation of behavioural health interventions with adolescents. The randomized controlled trial presented in Chapter 8 is the first evaluation of an adapted evidence-based HIV intervention for a Native adolescent population and shows efficacy for impacting 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.

9.2.1 Risk and Protective Factors

As the first step in the stage-based model, qualitative and quantitative data collection with Apache adolescents yielded important information about the risk and protective factors impacting the behaviours of substance use and self-injury and answered sub-questions one and two (what type of data can be collected in tribal communities to measure baseline behavioural health risks among youth; how do community members and youth describe and understand youths' behavioural health risks). Participants described in their own words how binge substance use occurs at any time of day, in a variety of settings including school, and in the presence of friends/peers and sometimes family. Adolescents endorsed binge substance use as a form of intentional self-injury; their reasons for engaging in the behaviour mapped onto an accepted theory of non-suicidal self-injury in the literature (1, 2).

Quantitative surveillance data corroborate and extend the qualitative findings by illustrating the co-occurrence of substance use and self-injurious behaviours, with the greatest co-occurrence among adolescents and young adults who died by suicide. Interpreted collectively, study findings demand more culturally relevant explanatory models that posit substance abuse as a co-occurring form of adolescent self-injury and reflect the distinct tribal understanding of the relationship between these behaviours on the self-injury continuum.

Building on these findings, Chapter 3 explored qualitatively an explanatory framework of adolescent self-injury, and illustrates through direct quotes how variables of risk existing at multiple levels create a pathway to self-harm. Chapter 3 also answered sub-question three (what family and community-specific risk, protective and contextual factors impact youths' behaviour change at the individual level). Individual-level factors such as reactivity and emotional dysregulation; family-level factors such as multigenerational overburdened households, sharing of limited resources, and confusion around the division of labor; community-level factors including name calling and inciting shame by peers, stigma and imitation are identified as important constructs in this framework of behaviour change. Together, the emergent nature of these three studies allowed for generation of behavioural constructs by participants themselves, inductive exploration of constructs through interviews and discussion, and comparison of themes with quantitative data.

In addition to risk and protective factor data, these studies produced important information for prevention and intervention development. Results call for the creation of integrated intervention approaches that target common motivations and functions of substance use and self-injury. Results also indicate a need for programs that teach identification of negative emotions and situations that put adolescents at risk. Family-based approaches can capitalize on this cultural value in Native and other indigenous communities, and provide a culturally relevant context to teach communication skills, anger management, and conflict negotiation (3, 4). The presence of stigma in the community around treatment drives an alternative focus on promoting positive protective factors such as Apache beliefs about the sacredness of life and traditional pathways to healing. Stigma also pushes capacity building of an additional tier of provider, namely paraprofessional community health workers, to navigate and enhance connection to treatment. Proactive identification of and interventions with high-risk networks are also important in this and other rural and

isolated communities, with high-risk behaviours occurring close in time and space.

9.2.2 Intervention Feasibility

After the stage of community-based qualitative and quantitative assessment, this dissertation investigated potential intervention settings and collection methods of behavioural health outcomes and answered sub-questions four and four-a (what limitations and opportunities exist in rural, reservation-based communities for behavioural health intervention delivery; what settings are ideal for delivery of behaviour-change messages to youth). Data from Apache adolescent medical records (Chapter 5) showed substantial contact (82%) with the local Emergency Department in the year before a suicide attempt and identified the Emergency Department as a key setting for early identification of and intervention with at-risk adolescents. The majority of Emergency Department visits in the five years pre- suicide attempt were for non-psychiatric reasons, thus screening all adolescent patients regardless of presenting complaint would increase identification and prevention efforts. The Emergency Department setting is especially relevant for behavioural health intervention delivery in this and other rural and isolated communities lacking alternative primary health care facilities and outpatient mental health clinics.

In addition to potential intervention settings, the method of self-administered sample collection to measure sexually transmitted infection as a proxy for sexual health behaviour was piloted among Apache adolescents ages 18-19. The results of Chapter 6 demonstrate this method of screening is highly acceptable. Participants felt comfortable with the privacy of self-administered testing, and preferred the non-clinic based option, in-person assistance from a Native paraprofessional, and in-person results disclosure and treatment. More specifically, the majority (69%) preferred this method over visiting a clinic; 94% said they would order it online, and 75% said they would encourage their peers to use this method. Results suggested high overall acceptability of self-administered screening and point to a method of data collection that can triangulate outcomes in behavioural health intervention trials.

Despite that condom use self-efficacy is a widely used proximal indicator of sexual behaviour change associated with both intention to use condoms and actual use of condoms (5), sexually transmitted infection incidence can more accurately track actual behaviour change

than a cognitive/attitudinal behaviour change construct. Self-administered data collection for sexually transmitted infection screening has relevance for behavioural health intervention evaluation in this and other high-risk adolescent populations with similar screening access barriers.

9.2.3 Intervention Implementation & Evaluation

The randomized controlled trial presented in Chapters 7 & 8 is the first rigorous evaluation of a culturally adapted evidence-based intervention (Respecting the Circle of Life) to address co-morbid risk for substance use, sexually transmitted infection, and HIV/AIDS, in a rural, reservation-based sample of Native adolescents. Chapter 7 described the cultural adaptation of the Focus on Youth intervention and answered sub-questions four-b and five (what type of interventionist is suited for delivery of sensitive behaviour-change messages to youth and what types of interventions can be successfully adapted for implementation with Native youth). Guided by thorough data collection, the study team made unique intervention delivery choices including condensing lesson administration, incorporation of basketball as an innovative implementation and retention strategy, and utilization of Native paraprofessionals as interventionists.

Baseline participant risk profiles were appropriate to the study aims including academic truancy, recent substance use, and current romantic relationships. Compared to other U.S.-based samples that received the original intervention (Focus on Youth), our sample showed higher rates of truancy and history of substance use (6-10). One-quarter of sexually active adolescents in our sample drank alcohol or used drugs prior to sex, supporting the intersection of these high-risk behaviours. A shortage of culturally adapted interventions, feasibility issues in rural and under-resourced reservation-based communities, and a lack of skilled interventionists have been barriers to scientific progress that were addressed through this trial.

Results of the Respecting the Circle of Life Trial (Chapter 8) answer sub-questions six, six-a and seven (how can behavioural health interventions be rigorously evaluated in a community-based context; what strategies can be used to retain youth in study participation over time; and what is the impact of an adapted evidence-based intervention on behavioural health outcomes among Native youth). Chapter 8 results demonstrate the short, medium, and long-term intervention impact of the adapted curriculum on Native adolescents' behavioural health outcomes, with greater response among females. Analysis

confirmed intervention impact at 12-months follow-up on the trial's primary outcome of participant condom use self-efficacy ($p < 0.005$) and response efficacy (theoretical construct) ($p < 0.01$). Several other significant between-group differences were found at six months follow-up including improved HIV/AIDS prevention knowledge ($p < 0.01$), belief that condoms prevent HIV/AIDS ($p < 0.05$) and speaking with an adult about HIV/AIDS ($p < 0.05$). Immediately post-camp, significant improvements were seen among participants' partner negotiation skills ($p < 0.01$), condom-use intention ($p < 0.01$), and all three theoretical constructs of the coping appraisal pathway (p range from < 0.05 to < 0.005); however, these differences were not sustained. Attenuation of initially strong intervention effects is consistent with past trials of the original intervention, Focus on Youth (6-12).

This study also verified the innovation, feasibility and acceptability of conducting a behavioural health intervention trial in a community-based setting (i.e. eight-day camps in the summer months) (7). The study's overall strong retention rate (90%) and demonstrated knowledge gains among intervention participants support: 1) community acceptance of the culturally adapted intervention, 2) Native paraprofessional facilitators' fidelity to intervention content and delivery of sensitive behaviour change messages and, 3) the use of peer groups for intervention delivery of HIV prevention information (13-16).

9.3 METHODOLOGICAL STRENGTHS AND LIMITATIONS

9.3.1 Strengths

Overview

The strengths of this research include: 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 evaluation; and 5) rigorous quality assurance and participant safety strategies. Each of these strengths is described in detail below.

9.3.1.1 Community-Based Participatory Research

As described in the Introduction (Chapter 1), a community-based participatory approach was utilized to design the studies comprising this research. The Johns Hopkins Center for American Indian Health

has an over 30 year relationship with the White Mountain Apache Tribe, wherein we have developed a unique partnership for our research that equitably involves community members, tribal leaders and researchers in all aspects of the research process (17). For each study comprising this dissertation (and all research endeavored by this partnership), we worked together to not only design, implement, and evaluate interventions but to also decide how results are disseminated in the community and through scholarly publications and presentations (17).

Community Advisory Boards were formed specific to each study that guided the selection of: study setting, target population, data collection procedures, and intervention administration including content and choice of interventionists. Community-based participatory research is a viable approach for countering the negative history of research conducted in Native and other indigenous communities because it engages researchers and communities in joint ventures that can help overcome past distrust and fear (17). Community-based participatory research is also widely viewed as especially relevant in culturally diverse contexts facing socioeconomic disparities (18).

9.3.1.2 Native Community Health Workers

This line of research has demonstrated American Indian community health workers to be an effective and culturally competent human resource to collect sensitive information from high-risk Native adolescents, to deliver behavioural health prevention interventions, enhance case management and continuity of care, and overcome cultural and transportation barriers in a rural and under-resourced community (19). They may also contribute to cost savings associated with early identification of mental and behavioural health needs and treatment-seeking, prevention of disease progression, and reduced reliance on acute, specialized, and inpatient care (20-22). Further, the employment of community health workers in under-resourced AI/AN and other indigenous communities with low employment rates builds human work-force capacity and economic development, which may indirectly improve health on a community-wide basis.

Like other public health strategies designed with AI/AN populations in the U.S., the incorporation of community health workers may have wide application for indigenous and developing populations across the globe (23). While this line of research does not intend to oversimplify by suggesting a “one-shoe-fits-all” approach in respect for the profound diversity across indigenous communities, shared socio-

historical contexts and complex behavioural health delivery environments support further exploration of the role of community health workers in these settings (24).

9.3.1.3 Exclusive Native Samples

Chapter 1 described a gap in the literature regarding evaluation conducted with exclusive samples of Native Americans and sounds an urgent call to action for their inclusion in the behavioural health research spectrum (25, 26). A strength of this line of research is the inclusion of exclusive samples of American Indians from one tribal community. While also potentially construed as a limitation (see section 9.3.2.1 below) the behavioural health disparities facing these communities cannot be addressed unless Native individuals are involved in evaluation research (25). Furthermore, these studies were comprised specifically of American Indian adolescents, the sub-group most disproportionately impacted by known behavioural health disparities. This dissertation contributes to the knowledge base for behavioural health intervention development, implementation by AI interventionists, and efficacy evaluation with AI/AN adolescents.

9.3.1.4 Mixed Methods

Our mixed-methods approach to data collection across studies included quantitative and qualitative evaluation comprised of participant self-report, structured clinical interviews, standardized measures, medical records review, focus group discussions and in-depth individual interviews. Assessments were selected based on their past use and validation with other AI/AN populations and cross-cultural utilization to enable sample comparison. All measures were adapted where necessary by community partners for cultural relevance and readability and pilot-tested prior to implementation. This mixed methods approach allowed for tailoring of data collection to study goals and objectives, identification of Apache-specific risk and protective factors and deepened our understanding of relationships between variables and complex mechanisms of behaviour change in a tribal community. This approach is relevant in other Native and indigenous populations suffering from behavioural health patterns impacted by community-specific contextual factors.

9.3.1.5 Quality Assurance and Safety

Across studies, strong quality assurance measures were employed. This included structured training and supervision of Apache

community health workers; a requirement that interventionists demonstrated mastery of curriculum through written and observational exams (score of 85% or higher) prior to administration; study-specific policies and procedures manuals; and intervention and assessment quality assurance checks through review of audio-taped study sessions. Apache community health worker training was didactic and included role playing, group discussions and hands-on exercises, mock scenarios and practical assessment. Trainings sought to teach skills associated with success in past trials with high-risk adolescents including: 1) developing rapport and trusting relationships, 2) showing empathy and interpersonal warmth, 3) good interviewing, communication and listening skills, 4) intervention and outreach techniques, and 5) boundary setting (27-31). Supervision of Apache community health workers was delivered consistently through weekly in-person meetings with field supervisors, and conference calls with study team leaders. Supervision included debriefing after stressful activities and strategies to deal with burn-out and job stress.

For the studies in which samples were comprised of Apache adolescents who had made a past suicide attempt (Chapters 3 and 5) Apache community health workers ensured the participant's safety by assessing current suicide risk at the close of each study visit. Staff completed the Suicide Ideation Questionnaire (32) and based on the participant's score and corresponding risk categories, in addition to other information shared during the visit, classified participant's level of suicide risk across a 4-point scale: 1) Does Not Appear at Risk, 2) At Some Risk, 3) At Medium to High Risk, or 4) At Very High Risk. The study safety protocol dictated study staff respond in a graduated fashion and contact study clinicians based on assessed risk, which ranged from making a safety plan with the adolescent and parent (At Some Risk) to taking adolescent to the Emergency Department (At Very High Risk). This protocol of risk assessment and crisis intervention supports the role of community health worker intervention with high-risk individuals so that they may successfully improve case management, continuity of care, and address provider shortages in Native and other indigenous mental health care systems.

9.3.2 Limitations

Overview

The methodological limitations for this research were: 1) participation by one tribal community, which decreases generalizability; 2) data collection challenges including small sample sizes, absence of a

control group, cross-sectional evaluation, non-probability sampling, use of self-report measures, and a lack of independent evaluators in the randomized trial; and 3) the need for additional randomized controlled trials with longer-term data collection to evaluate the efficacy of the adapted HIV/AIDS prevention intervention. Each potential weakness is discussed below.

9.3.2.1 One Tribal Community

As noted in the introduction, all studies comprising this dissertation were conducted with one tribal community, the White Mountain Apache Tribe. While other tribal communities in the U.S. may face similar behavioural health disparities and challenges, they are by no means homogenous; application of these results to other Native and indigenous populations must be done with care and consideration. This limitation has particular relevance to the study discussed in Chapter 2; the utilization of a community-specific definition for binge substance use limits comparisons to studies using other definitions. Furthermore, tribal stakeholders' hypothesis about binge substance use as potential self-injury may have biased participants during focus group discussion. However as described in our methodological strengths, evaluation conducted with an exclusive sample of Native participants is rare, unique to this line of research, and necessary for pushing the field of behavioural health science forward in the communities most affected (25, 26).

9.3.2.2 Data Collection Challenges

Small Sample Sizes

With the exception of the trial presented in Chapters 7 and 8 and analysis of quantitative surveillance data (Chapter 4), all other studies comprising this dissertation included small sample sizes (<72). However, these sample sizes were appropriate for the qualitative studies (Chapters 2 and 3) whose goal was to understand the context for binge substance use and self-injury and not to generalize findings (33). Small sample sizes were also suitable for the feasibility studies (Chapters 5 & 6) given the stage of the intervention development model in which each respective study was situated. Overall, results should be interpreted within the context of this limitation.

Absence of Control Group

Outside of the randomized trial and the qualitative studies for which it would not be appropriate, our study designs did not include a control group. This decision was based on several factors: 1) budget, resources, and time constraints precluding availability to recruit and retain control participants; 2) community and stakeholder feedback showing reluctance to ask families and adolescents for their time and energy without receipt of a tangible program-related benefit, and 3) lack of a conveniently defined population (i.e. clinic, primary care office, etc.), further challenged in a rural, isolated area with long travel distances and varied living conditions. Together, the limitations of sample size and a control group preclude the generalizability of these findings.

Cross-Sectional Evaluation

In Chapter 3, adolescents provided retrospective accounts of their suicide attempts, which could have been affected by their current mental health status and/or other factors occurring since the time of attempt. Therefore, data was collected close in time to the actual attempt to reduce this type of response bias. In Chapter 4, while surveillance data collection was prospective, the analysis was cross-sectional, such that we could not discern the extent to which substance use preceded or prompted self-harming behaviours. Acknowledging this limitation, study partners agreed that future data collection should be long-term, especially for behaviours such as substance use and self-injury, which occur along a continuum.

Non-Probability Sampling

Non-Probability sampling is appropriate for qualitative studies and feasibility trials (Chapters 2, 3, 5, and 6) however these respective study samples cannot be considered representative of the larger Apache population. In the randomized trial (Chapters 7 and 8), selection bias may have occurred during sampling; some adolescents could view basketball as a deterrent to participation and may differ from those who consented. Similarly, in several of these studies we worked closely with the local schools for participant recruitment (Chapters 2, 7, & 8) which may have biased enrollment towards less at-risk adolescents, given that many Apache adolescents have dropped out or have high truancy rates, and these children are at higher risk. Probability sampling while the gold standard, was further challenged in this community with a small population size (~15,500).

Self-Report Measures

We relied on self-reports for the majority of measures, which are associated with response bias (based on social desirability) and underreporting of sensitive data (34). In Chapter 4 the co-occurrence of substance use with self-injury events may be under-reported due to individual's and families' reluctance to acknowledge binge substance use by their child, social undesirability, stigmatization, or fear of legal consequences. In Chapters 7 and 8, participants in the intervention may have altered their responses based on social desirability; however given the equal amount of contact for both intervention and control groups there is no reason to suspect that this type of response bias would be higher among intervention participants. Future studies could use Audio Computer Assisted Self Interview technology that has been shown to decrease response bias (34) and objective, biological outcome measures (such as self-administered sexually transmitted infection screening) to triangulate self-reported outcomes.

9.3.2.3 More Randomized Trials Needed with Longer Term Follow Up

The randomized trial presented in Chapters 7 and 8 is, to our knowledge, the first of its kind. While evidence was demonstrated for short- and medium-term intervention impact, additional large-scale trials that incorporate booster lessons, parental involvement, and longer term follow-up are needed to evaluate the duration of intervention effects on adolescents over time. Additionally, the Respecting the Circle of Life program differed from the control program in delivery format including repeated social contact and individual attention from trained paraprofessionals, and experiencing the program with peers and close friends. It will be important in the future to determine if differences in the delivery or actual program content resulted in the enhanced intervention impact.

9.4 IMPLICATIONS OF METHODS AND RESULTS

This body of research, both in terms of Methods and Results, has potential to make three significant contributions to behavioural health science:

- 1) The combination of qualitative and quantitative data demonstrates the utility of a staged model of community-based participatory research and helps hone a culturally and contextually based framework of behavioural health risk among American Indian adolescents.

Formative data came directly out of adolescents' own life experiences and a collaborative analysis process that included Native and non-Native researchers and stakeholders from the participating Native community. Findings support the critical role of both quantitative and qualitative data collection, specifically how direct quotes illuminate risk existing at different levels and the large burden of acute behavioural problems converging in adolescence. This research also revealed that self-administered sample collection for sexually transmitted infection screening can be replicated in other Native and indigenous communities through incorporation into existing systems of health care, as well as ideal settings for identifying and intervening with at-risk adolescents (local Emergency Department and recreational sports camps). Finally, this dissertation illustrated how use of a staged model enabled the cultural adaptation and tailoring of an evidence-based intervention to a specific context and Native adolescent community.

2) The randomized controlled trial presented in this research is the first rigorous evaluation of a culturally adapted evidence-based HIV/AIDS prevention intervention (Respecting the Circle of Life) for a Native adolescent population, and provides evidence of impact on adolescents' behavioural outcomes at 6 and 12 months post-intervention. That significant between-group differences were observed on all of the coping-appraisal (positive/protective) but none of the threat-appraisal (negative/risk) theoretical constructs reinforces past research suggesting promotion of protective factors may bear greater importance in Native and perhaps other indigenous populations than a focus on risk (35). Results suggested that this culturally adapted behavioural health intervention can improve condom use self-efficacy. Findings also extended the literature on the use of peer groups in HIV prevention interventions and further support the role of trained Native paraprofessionals in the delivery of sensitive behaviour change information (13-16).

3) This series of studies represents the first application of a staged model of community-based participatory research to the cultural adaptation of an intervention in the behavioural health arena with an exclusively Native adolescent population. The mistreatment of Tribes by the U.S. government and abuse of their trust in past research endeavors create a challenging environment in which to conduct multi-staged investigations of sensitive topic areas including sexually transmitted infection, substance use, and self-injury. This line of research is rooted in values congruent with Native communities and offers a unique perspective on the nature of participatory research. By

exploring behavioural health disparities and possible solutions from the standpoint and language of community members themselves and combining this with rigorous scientific methodologies, the Center has produced a behavioural health research model with relevance and application to other Native and indigenous communities suffering from similar disparities.

These contributions also have social and theoretical relevance. From a social perspective—rural, reservation-based Native communities have several distinctive characteristics that offer a rare opportunity for rigorous scientific investigation and the development of behavioural health interventions, such as sovereignty from the U.S. government (namely their ability to regulate behavioural and mental health programming), and a population that shares an ethnic, socio-demographic, historical, and cultural background. Independence from federal oversight and a shared historical and ethnic background enable greater aptitude among Native communities for uptake and rapid dissemination of promising behavioural health intervention strategies to improve the health and well-being of community members. Successfully conducting behavioural health research in Native communities demands the type of stage-based model described in this dissertation and may sharpen behavioural health intervention development and evaluation in other indigenous communities.

From a theoretical perspective—the majority of evidence-based behavioural health interventions attribute behaviour change mechanisms to theoretical frameworks developed by and for the majority U.S. ethnic group. Our model, which combines qualitative and quantitative methods and a strong emphasis on formative exploration, is an opportunity for Native and other indigenous communities to create theoretical and conceptual frameworks of behaviour change in their own words and language. In Chapter 3, a conceptual framework developed by the Apache was explored qualitatively with Native adolescents who attempted suicide, whereby Apache study partners were able to validate and refine the relevant constructs. Specifically, four levels of suicide risk emerged, detailing individual, family, community, and societal factors that affect youths' pathways to suicide, along with a variety of subthemes and constructs. Some themes paralleled established models of suicide risk, while others were unique to the experience of this sample, including the impact of overtaxed households and family composition, significant grief burden, contagion, and stigma surrounding treatment seeking.

In Chapters 7 and 8, through our community-based participatory process we were able to adapt and enhance Protection Motivation Theory with constructs from the Indigenist Model of Trauma, Coping and Health to create the Respecting the Circle of Life Behaviour Change Framework, based on formative research conducted with the community. We discovered that condom use self-efficacy is low and community- and family-level stigma around obtaining and using condoms is high. Additionally, perceived vulnerability to STIs is lacking and alcohol plays a significant role in sexual risk taking. Further, poor parental monitoring and lack of communication both contributes to and protects against sexual risk taking. Thus theoretical constructs pertaining to family and community influences, stressors, and parent-adolescent relationships from the Indigent Model of Trauma, Coping and Health were incorporated. This line of research exemplifies the advancement of theory development to inform behavioural health intervention with populations most disproportionately affected, Native and indigenous adolescents.

9.5 RECOMMENDATION AND FUTURE DIRECTIONS

The findings from this dissertation suggest several important lines of future research. Study results pertaining to binge substance use and specifically its intersection with intentional self-harm beg many questions regarding the lasting role of alcohol and drugs on collective Native psyche and society. Are alcohol and illicit drugs continuing to function as a direct form of self-destruction; and can this cultural understanding better equip Native communities to address behavioural health problems among adolescents attempting to transition to adulthood (36)? This research demands the use of a stage-based model for developing integrated, culturally competent interventions that target common motivations for engaging in high-risk behaviours while simultaneously promoting culturally-based protective factors (37, 38).

To enhance and replicate the Respecting the Circle of Life intervention, several next steps are warranted: 1) Booster sessions may be needed to sustain short- and medium-term intervention gains. 2) The role of parents and other important adults should be explored in the context of reinforcing HIV risk reduction behaviour change messages; our data support the adaptation and inclusion of ImPACT (Informed Parents and Children Together) into the Respecting the Circle of Life Program package, which has demonstrated sustained and enhanced intervention outcomes at long-term follow-up (39, 40). 3) A larger-scale randomized controlled trial of the Respecting the Circle of Life curriculum conducted with multiple Native communities

and longer-term follow-up is necessary to demonstrate the program's sustained impacts on adolescent behaviour change. 4) If proven effective, study partners could adapt hard-copy train-the-trainer curriculum materials to an interactive training module for other Native and indigenous communities through the eMOCHA platform. eMOCHA (electronic Mobile Open-Source Comprehensive Health Application) is a mobile phone and real-time web-based interface that can deliver multimedia courses, lectures, role-playing, and trainer evaluations and is currently being used to help community workers deliver education and gather process and impact data in over 12 countries worldwide.

Finally, the significant treatment gap in behavioural and mental health systems worldwide, scarcity of indigenous providers, cultural barriers to existing care, and discord between behavioural health etiology and service delivery may be answered by the role of community health workers/paraprofessionals. Current efforts should be concentrated on research to develop and evaluate behavioural health interventions delivered by indigenous community health workers (19). Adding a tier of community health workers to indigenous behavioural health systems of care also holds indirect advantages and opportunities for the originating community. Training and employment of workers increases an indigenous community's ability to deliver culturally relevant care, contributes to local economic development, education, and community leadership, and initiates empowerment from the ground up to overcome leading behavioural health disparities (41, 42).

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Summary
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SUMMARY

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.

SAMENVATTING

De inheems Amerikaanse volkeren (“Indianen”) in de Verenigde Staten vertonen meer dan enige andere etnische groep ongelijkheden op het gebied van gezondheidsgedrag. Vooral onder de adolescenten bij Indiaanse volkeren komen zaken als drugs gebruik, suïcide en seksueel overdraagbare aandoeningen disproportioneel vaak voor. Een verwoestende historische nalatenschap heeft onder Amerikaanse inheemse volkeren een context van armoede en werkloosheid gecreëerd, met een systeem van dienstverlening dat onvoldoende middelen heeft om tegemoet te komen aan de nood aan preventie en behandeling op het vlak van gezondheidsgedrag. Die achterstand wordt verder in stand gehouden door een gebrek aan inheems Amerikanen die zelf opgeleid zijn op het gebied van gezondheidsgedrag .

Onder deze omstandigheden zijn de inheems Amerikaanse gemeenschappen uitzonderlijk veerkrachtig geweest en hebben zij het welzijn van stamleden voor generaties lang gewaarborgd. Inheems Amerikaanse stammen zijn autonoom en worden als onafhankelijke naties gezien door de overheid van de Verenigde Staten. Vanwege hun soevereiniteit in combinatie met een groot aantal individuen die als maatschappelijk werkers getraind kunnen worden om de unieke aspecten van gezondheidsgedragproblemen aan te pakken, zouden inheems Amerikaanse gemeenschappen geschikt zijn om veelbelovende preventie en interventie strategieën over te nemen en te verspreiden.

Ondanks de bestaande achterstanden, is er een tekort aan gedragsinterventies die door middel van een participatieve aanpak in samenwerking met en voor de inheems Amerikaanse adolescenten ontwikkeld zijn. Terwijl er wel dergelijke participatieve benaderingen bestaan, worden deze nog niet vergezeld door een noodzakelijke gefaseerde strategie gebaseerd op wetenschappelijk onderzoek om de noodzakelijke kennis en data te verkrijgen voor het ontwikkelen, invoeren en evalueren van interventies. Community Based Participatory Research (CBPR) is een succesvolle manier die de culturele aanpassingen faciliteert. Deze onderzoeksmethode biedt de mogelijkheid om evidence-based leefstijlinterventies toe te passen in en samen met lokale inheems Amerikaanse gemeenschappen. Daarnaast toont eerder onderzoek in het veld veelbelovende resultaten bij het gebruik van gefaseerde modellen om interventies cultureel aan te passen. Cultureel aangepaste gefaseerde modellen bieden potentieel om ongelijkheden in gezondheidsgedrag aan te pakken, door zowel

elementen van grondig preventieonderzoek als cultureel gebaseerde toenaderingen te incorporeren. Aanpassingen maken gebruik van gegronde theorieën en onderzoeken die aan de basis liggen van de oorspronkelijke interventie en voegen hier kwalitatieve onderzoekselementen aan toe om de inbreng van de gemeenschap te hierbij te betrekken en culturele samenhang te waarborgen.

Tot op heden is er nog nooit een grondige evaluatie geweest van een cultureel aangepaste evidence-based interventie toegepast in een steekproef met enkel inheems Amerikaanse adolescenten. Dit proefschrift behandelt deze leemte in de literatuur door de volgende onderzoeksvraag te beantwoorden: “Kan een gefaseerd onderzoeksmodel gebaseerd op zowel gegronde wetenschappelijke methoden als een uniek cultureel begrip van de inheems Amerikaanse gemeenschappen het ontwerp, de aanpassing, implementatie, en evaluatie van gedragsinterventies gericht op achterstanden onder adolescenten onderbouwen?”

In dit boek worden een serie studies gepresenteerd die zijn uitgevoerd in samenwerking met een rurale, in een reservaat verblijvende inheems Amerikaanse gemeenschap in de Verenigde Staten. De ontwikkelings-, pilot en effectiviteitsstudies laten een beloop zien, lopende van een gefaseerd model ontwikkeld door het ‘John Hopkins Center for American Indian Health’ tot de ontwikkeling en aanpassing van interventies gericht op de grootste leefstijlachterstanden onder de inheems Amerikaanse adolescenten: genotsmiddelenmisbruik, suïcide, en seksueel overdraagbare aandoeningen. Het proefschrift beschrijft de studies in elke fase van het model met een gerichte focus op de evaluatie van een cultureel aangepaste evidence-based interventie om het risico op HIV infectie te verminderen. Het proefschrift sluit af met de implicaties van de methoden en de resultaten en met aanbevelingen voor toekomstig onderzoek.

Hoofdstuk 1 biedt achtergrond informatie over: a) inheems Amerikaanse gemeenschappen, b) achterstanden in gezondheidsgedrag onder inheems Amerikaanse adolescenten, c) het probleem en de mogelijkheden behandeld in dit onderzoek, d) een beschouwing van de relevante literatuur, e) een beschrijving van de ‘Center’ gefaseerde aanpak inclusief theoretisch kader, en f) een omschrijving van de overige hoofdstukken van dit proefschrift.

Hoofdstuk 2 beschrijft de methoden en resultaten van een kwalitatieve studie uitgevoerd met inheems Amerikaanse adolescenten focusgroepen (n=58) waarin het verband tussen middelenmisbruik en

zelfverwonding werd onderzocht. De studie trachtte inzicht te krijgen in hoe ‘binge’ genotsmiddeleengebruik als een potentiële vorm van intentionele zelfverwonding functioneert alsmede in het perspectief van de gemeenschap aangaande duale preventie strategieën. Kwalitatieve data verzameling stelde de onderzoekers in staat om gemeenschappelijke aanleidingen, oorzaken, en sociale invloeden voor middelenmisbruik en zelfverwondingsgedrag en potentiële preventieve benaderingen te identificeren.

Hoofdstuk 3 presenteert de methoden en resultaten van kwalitatieve interviews met n=22 inheems Amerikaanse adolescenten die ooit poging tot suïcide hadden ondernomen. De verzamelde data hielp een inheemse stam-specifiek conceptueel model te specificeren voor inheems Amerikaanse adolescenten met verhoogde risico op zelfmoord. Dit hoofdstuk beschrijft de risico en de beschermende factoren die uniek zijn voor deze groep inheems Amerikaanse adolescenten zowel op het individuele, als het familie-, gemeenschaps-, en samenlevingsniveau. De resultaten tonen praktische implicaties voor onderzoek en ontwikkeling van op zelfmoord gerichte preventie programma’s.

Hoofdstuk 4 rapporteert de kwantitatieve data van op inheemse stammen-gericht surveillancesysteem om het samengaan van genotsmiddelenmisbruik en zelfverwonding onder inheems Amerikaanse jongeren te onderzoeken over een periode van vier jaar (2007-2010). Resultaten laten zien dat bijna de helft van de adolescenten “dronken of high” zijn op het moment van een suïcide gedachte en dat de meerderheid “dronken of high” is ten tijde van een suïcide poging en het slagen hierin. De hoge co-morbiditeit van dit gedrag benadrukt het belang van gedragswetenschappen om de relatie tussen genotsmiddelenmisbruik en zelfverwonding te begrijpen en toegepaste en geïntegreerde interventies te ontwerpen.

Hoofdstuk 5 presenteert de methoden en resultaten van een cross-sectionele studie onder n=71 inheems Amerikaanse adolescenten die een suïcide poging hebben gedaan. We verzamelden kwantitatieve data om het gebruik van medische voorzieningen door de participant in het jaar voorafgaand aan de suïcide poging te exploreren. De resultaten lieten zien dat de meerderheid van de adolescenten gedurende het jaar voor de suïcide poging ten minste één keer hun lokale spoedeisende hulp hadden bezocht, waarvan meer dan een kwart voor een psychiatrische reden. De discussie concludeert dat reseruaat-gebaseerde spoedeisende hulp afdelingen een ideale locatie

zouden zijn om inheems Amerikaanse adolescenten te screenen voor het risico op suïcide en om eventueel interventie aan te bieden.

Hoofdstuk 6 rapporteert de resultaten van een pilot trial uitgevoerd onder n=32 inheems Amerikaanse adolescenten om de haalbaarheid en aanvaardbaarheid te evalueren van zelf-uitgevoerde urine verzameling om te screenen op seksueel overdraagbare aandoeningen. De meerderheid van de adolescenten voelde zich comfortabel met de screening procedures, prefereerde deze methode boven een klinisch-gebaseerde test en zou het aanraden aan vrienden. De resultaten impliceren dat een zelf-uitgevoerde methode om te screenen haalbaar is in een rurale, reservaat-gebaseerde context met bezwaren tegen klinisch-gebaseerde screening, acceptabel is voor een inheems-Amerikaanse adolescentenpopulatie, zelf-gerapporteerde uitkomsten kan integreren in een op gezondheidsgedrag gerichte interventie trial, en mogelijkheden biedt voor het aanpakken en uitbreiden van screening.

Hoofdstuk 7 en 8 presenteren de eerste grondige evaluatie van een cultureel aangepaste evidence-based interventie uitgevoerd met een groep uitsluitend bestaande uit inheems Amerikaanse adolescenten.

Hoofdstuk 7 beschrijft de studie rationale, methoden, theoretische basis en baseline karakteristieken van de randomized controlled trial van “Respecting the Circle of Life:” een cultureel aangepaste evidence-based interventie voor het verminderen van het risico op HIV/aids. Dit hoofdstuk biedt uitgebreide diepte-informatie over het gemeenschapsgebaseerde participatieve onderzoeksproces dat de ‘Respecting the Circle of Life’ interventie aanpassing en trial opzet vorm gaf. Het hoofdstuk specificceert eveneens de ‘Respecting the Circle of Life’ implementatie structuur, inhoud en theoretische onderbouwing. De trial includeerde n-267 inheems Amerikaanse adolescenten die ofwel het ‘Respecting the Circle of Life’ of een controle programma kregen. Participanten werden getoetst tijdens de baseline, 6 maanden en 12 maanden follow-up. Baseline data voor de groep worden gerapporteerd. De discussie beschrijft de noodzaak tot HIV/AIDS preventie interventies als ‘Respecting the Circle of Life’, om de cyclus van achterstanden in gezondheidsgedrag onder inheems Amerikaanse adolescenten te doorbreken.

Hoofdstuk 8 presenteert de uitkomsten na het eerste jaar van de ‘Respecting the Circle of Life’ interventie. We hebben de impact van de interventie beoordeeld op: 1) verbeterde zelfwerkzaamheid bij condoom gebruik, 2) meer HIV preventie kennis, intentie en perceptie,

3) verbeterde partner communicatievaardigheden gerelateerd aan seks en middelenmisbruik, 4) meer condoom gebruik, 5) minder voorkomen van seks samen met genotsmiddelenmisbruik, en 6) uitgestelde initiatie van seks.

De resultaten concluderen dat de ‘Respecting the Circle of Life’ interventie een kort- en medium termijn effect heeft op de gewenste uitkomsten. Het effect van de trial op de belangrijkste uitkomstmaat (zelf-effectiviteit van condoom gebruik) bleef gehandhaafd bij 12-maanden follow up. De studie maakte gebruik van een nieuwe strategie ter behoud van participanten door de trial in een twee weken lang zomerbasketbalkamp op te nemen. Het lage uitvalpercentage (10%) onder deze groep bij de 12 maanden follow-up toont dat de kans op succes bij het implementeren van de ‘Respecting the Circle of Life’ in andere rurale, reservaat-gebaseerde gemeenschappen zeer waarschijnlijk is. De discussie biedt meer detail over de effectiviteit van het bieden van gevoelige gedragsveranderingsinformatie door inheems Amerikaanse basisgezondheidswerkers met de ‘Respecting the Circle of Life’ interventie en de noodzaak voor meer studies over het programma om de impact van interventie te waarborgen.

Het laatste hoofdstuk is Hoofdstuk 9 en vat de bevindingen samen en bespreekt de methodologische sterktepunten en beperkingen van dit onderzoek. De implicatie van de studiemethoden en resultaten worden besproken, met een focus op de replicatie en opschaling van een soortgelijke gefaseerde aanpak van culturele aanpassing, implementatie, en evaluatie van leefstijl interventies in andere inheems (Amerikaanse) adolescente populaties. Aanbevelingen en suggesties voor toekomstig onderzoek worden beschreven.

Er zijn verschillende sterke punten aan het onderzoek beschreven in dit proefschrift, namelijk: 1) getrouwheid aan een gemeenschapsgebaseerde participatieve onderzoek aanpak; 2) interventie toepassing en data collectie uitgevoerd door getrainde inheems Amerikaanse maatschappelijk werkers (‘paraprofessionals’); 3) uitsluitend steekproeven van adolescenten en jong volwassenen van de inheems Amerikaanse etniciteit; 4) gemixte methoden (kwantitatieve en kwalitatieve) evaluatie; en 5) grondige waarborging van zowel kwaliteit als strategieën voor veiligheid van participanten.

De studies in dit proefschrift representeren de eerste gefaseerde modellen van gemeenschap-gebaseerd participatief onderzoek dat zowel aansluit bij het unieke risicoprofiel en de veerkracht in de inheems Amerikaanse gemeenschappen, als bij de aanpassing,

implementatie en evaluatie van een evidence-based interventie voor HIV/AIDS risico reductie onder inheems Amerikaanse adolescenten. De gerandomiseerde gecontroleerde trial beschreven in Hoofdstuk 7 en 8 laat de werkzaamheid zien van de impact van de ‘Respecting the Circle of Life’ interventie onder adolescenten’ gezondheidsgedrags uitkomsten na 6 en 12 maanden na de interventie. Het gezondheidsgedrag onderzoeksmodel geeft het belang aan van de interventie en evaluatie opzet. Het is relevant en heeft toepassingsmogelijkheden in andere inheems (Amerikaanse) gemeenschappen die lijden onder soortgelijke achterstanden.

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My sweet Sage and Ellis, never have I simultaneously felt so challenged and so much joy then when I became a parent. I aspire to be a mom and person of whom you can be proud, and half the parent to you that mine were to me.

Any my darling Patrick, you are my dream and ultimate life partner. In our nearly 20 years together you have always enabled me to self-actualize, to snatch-up opportunities, supported my independence, and brought me strength. Not many husbands two days after their wedding would respond to their wife’s question of: “Should I move to India for my social work field placement?” with: “You have to.” You are my rock and my #1. I don’t know where I would be without you.

ABOUT THE AUTHOR

Lauren LaRue Tingey was born in Evanston, Illinois, USA, on May 30, 1979. After graduating from New Trier High School in Winnetka, IL, she completed a Bachelor's of Science at Cornell University in Ithaca, New York in 2001. After graduation she worked at the Sanford Center for Aging at the University of Nevada, Reno under the mentorship of Dr. Larry Weiss. She conducted research into geriatric medication management issues, specifically finding community-based solutions to reduce over-prescribing, medication interactions, and noncompliance. While working at the University of Nevada she saved for an around the world trip with her now-husband Patrick Smith, which started in October 2002 and lasted fourteen months spanning four continents. During her travels in Sub-Saharan Africa she was introduced first-hand to the HIV/AIDS epidemic and spent time with researchers from Johns Hopkins University in Malawi working on various public health research endeavors, after which she felt an immediate call to action and a special draw to Johns Hopkins. Lauren returned from her world travel and completed a dual-degree Master's in Social Work and Master's in Public Health at the University of Maryland and Johns Hopkins Bloomberg School of Public Health, graduating in 2008. During her graduate study she had the opportunity to volunteer in Nicaragua with an HIV/AIDS nonprofit and the Ministry of Health and live in Kerala, India working with woman and children affected by HIV/AIDS.

Lauren started at the Center for American Indian Health immediately after graduation in 2008 where she joined the Behavioural Health research team. Lauren began her thesis at the University of Amsterdam under the mentorship of Prof. dr. Walter Devillé, in partnership with Dr. Allison Barlow and Dr. Mathuram Santosham, in 2013. Her doctoral thesis highlights a line of research that started in 2010 and focuses on the cultural adaptation and evaluation of evidence-based interventions to address sexual and reproductive health disparities among American Indian adolescents and young adults, specifically risk reduction for sexually transmitted infection and HIV/AIDS. Lauren's research draws on a combination of methodologies including community-based participatory approaches, qualitative research, needs assessments, staged-based adaptation, and biostatistics. Her overarching goal is to develop interventions that are transferable to other American Indian and under-resourced communities which can be incorporated into existing service delivery systems.

Lauren lives in Towson, Maryland with her incredible family: husband Patrick Smith, son Sage age 3, and son Ellis age 1, and her parents Marcia and James Tingey who recently re-located from Winnetka, Illinois and have made her life in Maryland feel truly complete.



