Quality in practice

Building community involvement in cross-cultural Indigenous health programs

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Abstract

Objectives. To gain preliminary knowledge about issues identified by Native health investigators who would encourage greater community involvement in Indigenous health programs and research in Canada, Pacific Rim, and the United States.


Setting. Indigenous health agencies and institutions in New Zealand, Australia, Canada, and the United States.

Participants. Thirty-six health professionals from rural and urban health centers participated, which resulted in 10 group and four individual interviews. Subjects included program managers, clinical physicians, and health researchers. Approximately 58% of the subjects self-identified as Indigenous.

Results. Three overarching themes emerged from the interview data: (i) integration of cultural values of family and community into health provision; (ii) emphasis on health education and prevention programs for Indigenous youth; and (iii) indigenous recognition and self-determination in health delivery and research.

Conclusions. To improve and promote community involvement in primary health programs and services for Indigenous people involves a long-term social and political commitment to health protection on a national and an international level, as well as the understanding that research methodologies and health interventions must explicitly involve culturally appropriate values and behaviors that are implemented by Indigenous people.

Keywords: community involvement, cross-cultural health, Indigenous health, qualitative research

Despite cultural differences and a diversity of local living conditions, Indigenous people of the Pacific Rim, Canada, and the United States share many factors in common. Although their languages, traditional beliefs, and cultural ways of life remain distinct, the dominating impact of the eighteenth-century European colonialism continues to have profound and disparate effects on their autonomy, access to resources, and community health status. Numerous reports have documented the high prevalence of diabetes, obesity, smoking, violence, and substance abuse in Indigenous societies compared with other non-Native groups inhabiting the same geographic regions [1–5].

Although many Indigenous health outcomes may be attributable to genetic factors or routine lifestyle, they are also influenced by broader external social and political factors requiring immediate reform and social action. Because there are so few Indigenous health researchers and providers, there has been little information emanating directly from Native populations about strategies for promoting community involvement and participation in primary health programs within their respective communities [6–8]. Consequently, the cultural and medical framework that has defined Indigenous health and delivery in many countries continues to be fraught with misrepresentations of Native people by Eurocentric scholars [9,10].

The current article examines insights and concerns that were identified by Indigenous health investigators as suggestions to improve community involvement and participation in Indigenous health programs. In view of the fact that many Western health providers possess only a vague understanding of the diversity, complexity, and richness of Indigenous cultures, the intent of this exploratory study was to gather knowledge of salient cultural, community, and ethical issues that are believed to have an impact on the efficacy of health delivery for Native people throughout the Pacific Rim, Canada, and the United States.

Methods

The present study was designed as a multi-site pilot/feasibility project. Our primary objective was to gain preliminary

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knowledge about levels of community involvement and participation in Indigenous health programs. For this study, we focused our attention on the opinions and concerns held by practicing health professionals. We began by conducting informal group interviews with health investigators, who either maintained close working relationships with or were themselves members of Indigenous cultures working in the United States, Canada, New Zealand, and Australia. With the assistance of colleagues known in each of the countries selected, a series of regional site visits were organized and scheduled from August 2001 to April 2002. Using a non-random expert sampling strategy [11], the participants were recruited from each site among health researchers, clinical physicians, and health program administrators. All participants were employed in ongoing regional Indigenous health and research programs and involved in clinical or research work that included studies of diabetes, obesity, substance abuse, domestic violence, or maternal–child health.

A total of 14 Indigenous health institutions or clinics were visited (Table 1). Participants at each of the locations were recruited into informal group interviews based on availability and willingness to meet and talk with the authors during the date and time of our scheduled visit to each site. This resulted in a total of 10 group interviews with two to four participants and an additional four individual interviews that were conducted for health professionals unable to participate with scheduled agency discussions. A total of 36 individuals took part in the study, resulting in approximately 58% of the participants who self-identified as Indigenous (n = 21), which included Maori, Pacific Islander, Aboriginal and Torres Strait Islander, Samoan, American Indian, Alaska Native, First Nations, and Inuit communities.

The authors created a short interview guide composed of 10 open-ended questions. Questions 1–7 were used to facilitate an exchange of information about different health agencies’ objectives, program core values, and the use of traditional knowledge and language. Questions 8–10 were designed to elicit comments focusing on the relevance of cultural responsiveness and community empowerment (Table 2) and were intended to engage health professionals to speak freely about specific indigenous health issues for which they had an opinion or had previous experience within their own programs and projects. Before initiating the study, the interview guide was previewed by a small group of colleagues working in Indigenous health care, who aided in assessing the questions for clarity and cultural appropriateness. One or both of the authors conducted each of the group or individual interviews. Audiotaping was permitted during only four of the group interviews; so all the remaining interviews (both group and individual) were documented through rigorous field notes.

Owing to the lack of uniform sampling techniques maintained in the study, the authors were unable to perform a standardized comparison of the individual responses collected from each interview location. As an alternative, we elected to make use of the field notes and transcripts by collectively summarizing these texts using what Glasser and Strauss [12] call the ‘constant comparison method’. Firstly, the authors independently conducted multiple readings of all interview materials, comparing each set of field notes and transcripts to the previous set read. Secondly, we began searching for repeating ideas on the basis of a priori (i.e., questions in the interview guide) or independent themes found to emerge with high frequency of mention and connected to other categories emerging from the texts [13]. Lastly, all concepts and themes

| Table 1 | Number of study participants by location and self-reported Indigenous affiliation |
|-----------------|---------------------------------|-----------------|
| Country    | Location          | Total number of participants | Number of indigenous participants |
| New Zealand | Auckland         | 3                             | 3                             |
|            | Rotorua           | 3                             | 3                             |
|            | Wellington        | 1                             | 1                             |
| Australia  | Darwin            | 4                             | 0                             |
|            | Melbourne         | 1                             | 0                             |
|            | Sydney            | 1                             | 1                             |
|            | Queensland        | 1                             | 0                             |
| Manitoba  | Winnipeg          | 4                             | 1                             |
| Alaska     | Anchorage         | 3                             | 0                             |
|            |                   | 3                             | 2                             |
| California | San Diego         | 3                             | 3                             |
| Total      |                   | 36                            | 21                            |

Table 2 | Interview guide questions

1. Overview of staff roles for the health agency/institution
2. Brief description of agency/institution (including length of time operational)
3. Description of the history of how the agency/institution was established (community initiated, government initiated, and charitable trust)
4. Objectives or mission statement of the agency/institution
5. Core values of the agency/institution
6. Describe ways in which the agency/institution incorporates the use of traditional knowledge or cultural activities in the development of program design (model) and curriculum
7. Describe ways in which the health agency/institution incorporates the use of indigenous language in the development of curriculum and education
8. In what ways do the objectives of the health agency/institution specifically empower clients as members of a cultural community?
9. What goals must agency/institution meet to be considered ‘successful’ by the granting funding agency?
10. What goals must agency/institution meet to be considered ‘successful’ by participants?
identified were then named using the interview participants’ own terminology where possible. Concepts and themes were then compared between authors. Any disagreement in the assignment of themes was resolved through discussion; however, the initial analysis generated nearly identical sets of themes for both authors. These findings were then reviewed with four independent research participants to strengthen the validity of the initial theme categories and interpretations. After further consideration, the authors ultimately agreed on a final selection of three dominant thematic domains to represent the interview findings.

**Results**

Evaluation and analysis of the study field notes and audio transcripts revealed three overarching themes relating to concerns for building community involvement in Indigenous health programs. These themes included (i) integration of cultural values of family and community into health provision; (ii) emphasis on health education and promotion programs for Indigenous youth; and (iii) indigenous recognition and self-determination in health delivery and research. Direct quotes from the four audiotaped group interviews are included to enhance the conceptual understanding of ideas expressed in all four of the thematic domains.

**Integration of cultural values of family and community into health provision**

All cultures practice traditions that support their beliefs, customs, and values for family and community. In determining the effectiveness of health care programs serving Indigenous communities, explanations were offered that linked sustainability to the Indigenous philosophy of good health as a ‘holistic’ perspective. A physician from Alaska commented, ‘our program has been providing care to the whole person as opposed to just their diabetes . . . our goal is to enable people to live well with diabetes on all levels . . . physically, spiritually and socially’.

Also, many Native families believe that the problems faced by Indigenous people today are a direct result of their historical experiences with European colonialism. Differences in cultural values, knowledge, and communication also help to explain Indigenous behaviors of relevance to health. A Samoan program staffer explained, ‘there is a Pacific way of communicating . . . it is more than just communicating the language, it’s also the rules . . . there is a Pacific way of doing things and taking care of one’s self’. This dynamic was often viewed as being compromised by non-Indigenous medical practitioners, who rarely seem aware even of the impact that their own culture and training have on the therapeutic relationship with Indigenous clients. Indeed, most measures of process and health outcome are largely based on Eurocentric perspectives that often fail to address issues that matter most to people of a different cultural origin. ‘We give instruction through the medium of waananga instruction’, offers a Maori clinic administrator. ‘It’s like very intensive sitting around comfortably and working long into the night and talking . . . it’s quite different than you would ordinarily design a [Western] program but it’s what our families understand [traditionally] and respond to in taking greater responsibility for their health’.

Considering that many families make choices about health practice based on their cultural backgrounds and beliefs, it was suggested that health care models incorporate the different expectations that people may have about the way services are offered. ‘You cannot just walk in and say I am here to do this . . . and do this . . . because they do not want to listen when you start raving on like that’, advised a Pacific Island program coordinator. ‘A period of social conversation may be necessary before each contact . . . or sharing a meal may be an important feature of home-based health services’, a Canadian physician recommended. Indeed, westernized health care and research are not the only set of perspectives and practices from which Indigenous professionals have to choose from for their communities. A Maori clinic director offered, ‘when we initiated our “Family Start Project”, we began completely outside of the Western model by using trained community members to spread the message of health. From the medical community we received a huge amount of criticism that we were placing our families at risk but we knew that communication was the key to getting access and building trust with our people’.

**Emphasis on health education and prevention programs for Indigenous youth**

Another important theme emerging from the data focused on the physical, emotional, and social needs of Indigenous youth. General concerns highlighted the increasing number of young Indigenous people, complicated by rural isolation, poor nutrition and exercise, high teen pregnancy, substance abuse, family violence, and suicide. One Alaska Native therapist voiced the following concerns about adolescent behaviors in his community. ‘Our clients often mirror the painful periods that occurred in our own lives. You can’t help someone if you haven’t helped yourself, and for many of us . . . we haven’t really dealt with the trauma of our own histories of abuse’. For many discussants, these issues pose critical challenges not only regarding the provision of adequate health care for youth but also to future cultural safety of Native populations of the Pacific Rim. A medical health advisor in the Pacific Islands commented, ‘I call it the Coca-colonization. Junk food not only tastes better it is often cheaper . . . we’re seeing 10-year-olds with Type 2 diabetes now’. In response, community-based primary prevention diabetes programs have emerged as an important strategy because they are well suited to small communities where interventions not only target individuals but work synergistically to enhance community knowledge and behaviors. This approach is also fitting in with Indigenous beliefs that wellness depends on extended family involvement and community support. In this regard, even Western physical activities have been successfully incorporated as both prevention and intervention into even the most traditional communities. ‘What’s big in the villages’, remarks...
an Alaskan physician ‘is basketball. Everyone plays basketball in rural Alaska . . . kids, teens, young mothers and middle-aged adults. It has become a social focal point for intervention with our families and communities. We try to promote these programs for physical activity and support these events with diet and nutrition education by involving native foods. Traditional recipes are modified rather than abandoned to achieve nutritional goals with accessible resources'.

Indigenous language revitalization programs have also played a significant role in communicating culture and health to the young. The continued success of these programs will depend, at least in part, on the attitudes and commitment of Indigenous speakers as a whole to maintaining and revitalizing the language in the home, in the community, and beyond. ‘Because children learn by doing actions and singing, I bring my ukulele along’, said a Maori nurse. ‘That is what we do after the teaching session . . . we sing about our health. We have songs for the ear . . . the chest and smoking . . . we have a song about road safety for injury prevention. So when the kids go home . . . the whole family hears the message’.

Indigenous recognition and self-determination in health delivery and research

Distrust of mainstream health systems was also considered a major barrier to seeking and maintaining health care for many Indigenous people. The most valuable resource for promoting participation in Indigenous health programs comes from the people already living in those communities. ‘The first people we employed were all the grandmothers of our community’, revealed a Maori program manager, ‘so education flowed very naturally from that generation through to the young mothers and their families’. Community health worker functions often resemble those of other professionals, including nurses, social workers, case managers, and health educators. A nurse practitioner offered, ‘because many Alaskan villages are geographically isolated from hospitals and doctors, Native community health aides [CHA] are the best resource possible for integrating health delivery and medical knowledge about diabetes and health prevention into the traditional activities of village life’.

Although there was general agreement for the usefulness of Western medical practices, the majority of discussants clearly insisted that non-Indigenous health care practitioners and researchers must now co-create with Indigenous people to mandate and promote sustainable standards of ‘best practice’ through community and culturally identified needs. Solutions toward self-determination involved establishing and maintaining a strong staff representation (preferably ≥50%) on every health or community project that directly affects Indigenous people.

Expanding on the theme of Indigenous self-determination were other concerns specific to ethical and protocol matters for non-Indigenous researchers. Primary issues identified included the misappropriation of culturally and spiritually sensitive information by non-Indigenous researchers, an ethnocentric attitude amongst many non-Indigenous researchers, and the philosophical differences between Indigenous and non-Indigenous people regarding the ‘ownership of knowledge’. From the European invasion to the present day, Indigenous communities have often been merely the objects of research, whereas the health researchers who are overwhelmingly non-Indigenous, have benefited greatly in their personal academic careers. ‘For a lot of Native people, “research” is a dirty word. Many of us have been victims of research that’s been done wrong. We have policies placed on our communities today that are the result of bad research or the misinterpretation of what is actually going on in our communities’, stated an American Indian program manager. In fact, many Indigenous communities have become highly critical and cynical about research activities. They describe the experience as paternalistic, self-serving and question how non-Indigenous researchers have the appropriate knowledge of their cultures to become ‘experts’ about them.

Perhaps one of the most important aspects to understand about Indigenous cultures is their need for extended time frames in which decisions are made and the collective nature of how those decisions evolve. Individualistic approaches to Western research methodologies run nearly counter to Indigenous community values and expected ways of behaving.

Discussion

Our pilot/feasibility study has several limitations. One of the advantages of conducting this type of study, however, is that we have become alert to some of the obvious research vulnerabilities where future research projects could potentially fail. Firstly, the authors acknowledge using only a small and highly select sample of health professionals. Although slightly more than half of our sample self-identified as Indigenous, we believe that future studies on this topic would be greatly strengthened by listening and learning from cultural voices of the communities, such as tribal lineage members, Indigenous leaders, and venerated elders. Additionally, generating a larger and more representative sample framework would have greatly enhanced the impression of ‘the truth’ in our study findings. Secondly, given our inability to standardize sample size for each group or in each location, future considerations might be to conduct only individual interviews that could be more easily structured and standardized among every participant. There is also always the possibility in group interviews that participants may mimic the opinions of others already expressed or simply fail to speak up so as not to disrespect the feelings of others. Lastly, the challenge of working with a multi-site international sample of participants is a daunting task under any circumstances. As pointed out by Linda Tuhiwai Smith in her book ‘Decolonizing Methodologies’, what we have learned foremost from this study is that to gain access to knowledge about social and health issues faced by Indigenous communities, it is essential to include Indigenous people in the design of research protocols and proposals at the very conception of the study project [14].

Although the results of our study must be viewed within the context of exploratory research, the authors suggest these findings are, in fact, valid cross-cultural concerns (integration of cultural values of family and community into health provision, health education and prevention programs for Indigenous
youth, and indigenous recognition and self-determination in health delivery and research) and provide a noteworthy starting point for advanced investigation. A current publication by Stephen Buetow [15] draws upon similar insights as a measure for quality improvement in health care, which he has paralleled alongside principles from the New Zealand Maori culture. Using the Maori 'ideal type', Buetow outlines 'six lessons' (encourage cultural governance, foster spiritual health, manage health care operations as a family, and respect everything for itself) that he believes can be used to inform and improve health care delivery for Indigenous communities. We agree that culturally based models such as Buetow’s are essential to understanding the significance of the relationship that links health, culture, family, and community values as integral parts within the Indigenous worldview.

Furthermore, the authors assert that what is critically necessary for building community involvement and improving the health status of Indigenous people involves not only a long-term social and political commitment to health protection on a national and an international level but the understanding that research methodologies and health interventions must explicitly involve culturally appropriate values and behaviors that are implemented by Indigenous people [16–18]. This does not suggest that we believe Western medicine has no place in Indigenous health care programs. But rather than continuing to straddle both sides of the division between Western medicine and Indigenous knowledge, we agree with Maori scholar Mason Durie [19] that future health programs and research must shift the momentum of their interests to incorporate aspects of both approaches and in so doing create new and shared opportunities for advanced knowledge and sustainable quality health care.

Acknowledgements

The terms Indigenous and Native are used interchangeably in this article to refer to people who have retained either partially or totally their traditional languages, lifestyles, and spiritual beliefs that distinguish them from the dominant society and who occupied particular geographical areas before other population groups arrived on the same land. The use of the term Pacific Rim includes those countries bordering on or located in the Pacific Ocean. This study was approved by the Internal Review Board Committee of the University of California, San Diego, and was funded by the University of California, Office of the President, Pacific Rim Research Program.

References


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