Engaging Aboriginal Families Affected by Allergies and Asthma: Identifying Gaps in Social Support and Developing Culturally Relevant Interventions for Educational Programming
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**Manitoba:** Assembly of Manitoba Chiefs, Dakota Tipi First Nation

**Nova Scotia:** Tui’kn Partnership (Eskasoni First Nation, Membertou First Nation, Potlotek First Nation, Wagmatcook First Nation, Waycobah First Nation)

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Introduction

This report provides an overview of a participatory, multi-site study that has been conducted in Alberta, Manitoba, and Nova Scotia with support from the participating First Nations and Métis communities and guidance from three local Community Advisory Committees. The goal of this community-based participatory research was to develop geographically accessible, culturally safe and appropriate, and innovative peer support programs for Aboriginal children with asthma and allergies and their families. The objectives of this three phase study were to: 1) assess the support resources, support needs, and support intervention preferences of Aboriginal children/youth with asthma and allergies and their parents; 2) develop and pilot-test an accessible and appropriate support education intervention, based on their identified preferences and in partnership with Aboriginal communities; and 3) identify implications for improved practice, programs, and policies.

Background

Asthma and allergies are the most common chronic conditions affecting Aboriginal youth. Aboriginal children are high users of emergency services and more likely to be admitted to the hospital for their asthma. Recent studies reveal significant gaps in social support for children with asthma and allergies and their parents. Social isolation and loneliness are commonly reported among children/youth with asthma and allergies. Given the fact that very little is known about what Aboriginal families need to cope with allergies and asthma, it is important to understand how to provide support and services for Aboriginal children and their caregivers, affected by these conditions, in order to improve their overall health and wellbeing.
Phase 1: Assessment of Support Needs and Intervention Preferences

In Alberta, 46 Aboriginal children and adolescents with asthma and allergies, and 51 parents/guardians, completed individual interviews with Aboriginal research assistants about their asthma and allergy experiences, support needs, and intervention preferences. Four in-depth group interviews (with two older children/youth, and with two parents/guardians) were subsequently conducted (two rural, two urban) to further explore their support needs and intervention preferences. Sixteen adolescents and 25 parents participated in these group interviews.

In Nova Scotia, 21 Aboriginal children who have asthma and 17 parents took part in individual interviews administered by Aboriginal community researchers, to identify their asthma support needs and intervention preferences.

Phase 2: Design and Pilot Testing of Culturally Appropriate Support Interventions for Aboriginal Children and Youth and Their Parents

All support interventions were designed to provide support and education for Aboriginal children with asthma and allergies and their parents. In each site, interventions for children and/or parents were determined by preferences expressed in pre-intervention interviews regarding mode (e.g., telephone, internet, face-to-face), supporters/helpers (e.g., peers, professionals), timing, frequency, duration, and discussion topics.

In Alberta, four health interventions were pilot tested. Twelve rural Aboriginal parents participated in eight support sessions delivered by professionals through a Telehealth initiative (oneHealth). Following each session, an Aboriginal peer facilitator and health centre professional provided face-
to-face support in the First Nations Health Centre. Fifteen rural Aboriginal children and youth attended a three-day asthma support camp with face-to-face support provided by five trained young adult Aboriginal peers and professionals. Seven urban Aboriginal parents took part in eight face-to-face support group sessions delivered by a trained Aboriginal peer facilitator and professionals (held at a community school). Nine urban Aboriginal children and youth participated in eight face-to-face support group sessions delivered by two trained Aboriginal peer mentors and professionals (held at a community school).

In Nova Scotia, 17 Aboriginal parents and 21 asthmatic youth attended a two-day asthma camp with face-to-face support provided by Aboriginal peers and professionals. In addition to cultural and educational activities related to asthma, parents took part in one focus group and one sharing circle to assess their asthma support needs, and participating youth drew what it is like to have asthma and discussed these drawings with a research team member.

In Manitoba, nine urban youth and three parents met for five support group sessions at a local community centre. The program included asthma/allergy education, traditional dance, addictions and health mentorship, learning about traditional medicine, drawing, and games.
Phase 3: Implications of Phase 1 and 2 Results for Programs, Policies, and Practices

In Phase 3, each site consulted with program planners, practitioners, service providers, service managers, and policy influencers working with Aboriginal communities to identify appropriate knowledge translation strategies and to stimulate new or changed policies and programs that promote financially and culturally accessible programs on respiratory health for Aboriginal populations.

In Alberta, 30 Aboriginal youth and parent community leaders, community health representatives, band council members, policy influencers, and health leaders attended a symposium/focus group. In Manitoba, a half-day symposium was held with 150 asthma specialists, asthma educators, nurses, and community representatives. In Nova Scotia, 22 Aboriginal and non-Indigenous community health care professionals and school staff (nurses, doctors, community health representatives, school teachers, and coaches) participated in five focus groups.

The doctor, all she ever did was give him inhalers. That’s it. No information. I really don’t know anything about asthma right now

~ Aboriginal Mother, Nova Scotia
Findings and Recommendations

Phase 1

Parents perceived that they lacked support to manage their children’s asthma and allergies because they did not understand: asthma or the health implications of asthma, prescribed and traditional medication use, and trigger avoidance. They were concerned about mold in their homes and environmental conditions (dust, smoking, ground fires).

Parents wanted support to understand and manage asthma, information on use of prescribed, over the counter, and traditional medicine, advice on how to talk to health professionals, and to know how other Aboriginal parents managed their children’s condition. In addition, they thought people in their Aboriginal communities were unaware that many Aboriginal children had asthma, and of respiratory health conditions. They wanted advice from a variety of health related professionals (e.g. housing), along with face-to-face support from Aboriginal peers and professionals.

My biggest wish is... if every health centre in [our region] would take one person and really seriously train them on this topic. So then they could pass on the information to the parents. Because a lot of the parents don’t have the proper information or they are not sure how to give the medication.

That’s all I wish for
~ Aboriginal Mother, Nova Scotia
Aboriginal children and youth said their biggest challenges were: difficulty breathing during exercise, avoiding asthma triggers, asking for permission to use puffers at school, and feeling left out of activities. Children/youth preferred face-to-face support from Aboriginal peers and professionals. The majority of Aboriginal children/youth said they received little support from anyone other than their immediate families. Most didn’t tell others about their condition. They felt isolated, and commented on being less popular than their school peers, picked last for sports, and even bullied because of asthma and allergies.

Aboriginal children and youth intervention preferences were: 1) feeling normal, like their peers; 2) receiving information support on asthma and asthma management; 3) reducing isolation by building a supportive network of peers with asthma and allergies; 4) improving support seeking coping and other coping skills. Their reported needs included information, emotional, and affirmation support. Parents wanted: 1) support for their children, 2) support and education for themselves, 3) culturally appropriate support, 4) increased community awareness, and 5) child care.

Because at the beginning...he wouldn’t really talk to people. He was a lot more introverted and he didn’t see the value in it. He was a lot harder to get involved, and to get him to doing things. So, by the end of the camp, I think he really liked the camp environment...where he could just like socialize, you know...I think he loved it and like the arch [of learning] in particular he really grew

~ Peer Mentor, Alberta
**Phase 2**

In Alberta, parents reported that as a result of the pilot interventions, they were more prepared to seek support, but that resources were still only minimally available in the community. They believed the support intervention had raised awareness of asthma and smoking in the rural community. Parents were particularly appreciative of the increased capacity of staff members at the Health Centre, because of the intervention, who became champions for asthma and allergy support in the community. Rural parents enjoyed meeting on oneHealth, but would have preferred to meet in the evening whereas oneHealth is only available 9 AM to 5 PM. Urban parents enjoyed sharing a meal with Elders and the information they received on asthma and allergies. In the interviews, urban parents said that after experiencing this support, they needed similar resources and support in other challenges in their lives (e.g. with their other children).

In Manitoba, through the intervention, youth were engaged in active, cross-cultural, community based approaches to building pride, resiliency, and sense of capacity to address respiratory and other health conditions. Parents and community members perceived the intervention was interactive, engaging, culturally relevant, and community led. The activity and games-based approach to the program was considered a welcome alternative to the more formal methods that youth were accustomed to at school.

> [At first] I assumed it was going to be more of an information session, based on the lungs, how the lungs operate, the deterrents, the pros and the cons, but ultimately it became a lot more than that... That was the good thing about it ... we had the dance, we had the games, we had our culture, all those components, condensed into one

~ Community Elder, Manitoba
In Nova Scotia, virtually all caregivers commented on the value of the asthma camp (intervention) as a way of connecting with peers, specifically other Aboriginal parents, dealing with asthma-related issues. The camp helped reduce loneliness, improve asthma support and education, enabled social learning and friendships, family communication, and taught strategies for dealing with and informing other community members.

Phase 3
In Alberta, a symposium/focus group was held in Edmonton for Aboriginal youth and parent community leaders, community health representatives, band council members, policy influencers, and health leaders, to discuss implications for programs, practice and policies, and appropriate audiences and vehicles for dissemination.

In Manitoba, participants reflected on the ability of the youth to engage with the program (intervention) content. In addition, health professionals expressed satisfaction at the opportunity to present their education program in the youth-and-caregiver intervention.

In Nova Scotia, as a result of the new information provided by the study, opportunities for improving asthma support in Aboriginal communities were identified, including school-based educational initiatives that engage students and school staff. Participants recommended developing an asthma education and training program for community health centre staff. Health professionals and school staff recommended implementing an annual asthma camp to reduce existing support barriers facing Mi’kmaw families managing the condition. Other recommended strategies were asthma seminars and ‘lunch and learns’. Participants identified appropriate dissemination audiences, including Chief and Council, school staff, and community members, as well as knowledge translation strategies (e.g. lay summaries, social media, and community newsletters).
Conclusions

Across the three sites, participants of this study uncovered a lack of asthma support available to Aboriginal families managing the condition. Parents were challenged by: sudden and severe asthma attacks, lack of knowledge, poverty, blame on parents, under-diagnosis, uncoordinated health care, disrespectful treatment, environmental challenges (dust, mould, ground fires), and lack of culturally appropriate support. Children and youth reported that their greatest challenges were many triggers for asthma, being left out, school attendance, feeling different, isolation, and barriers to physical activities. Generally speaking, the intervention strategies were well received by families who reported increased support and education as a result of their participation. Ongoing, community-level supports that make use of the findings brought forward through this study were identified as an ideal way of addressing existing asthma support gaps in the participating communities.

The way we do things may be a little different than the way the university does things; we start off with a prayer, a smudge, and the children understood that. And it showed them that the university was just as interested in learning and taking part in that... it was important for them to bring in the cultural side of it so that the kids can experience both.

~Community program facilitator, Manitoba