

## **Les inégalités en matière de santé que connaissent les enfants autochtones ayant des troubles respiratoires et leurs parents**

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L'asthme et les allergies sont des affections courantes chez les enfants et les adolescents autochtones. Cette étude a pour objet d'évaluer la santé des enfants touchés ainsi que les inégalités en matière de soins de santé dont ceux-ci et leurs parents font l'objet. Des assistants de recherche autochtones ont mené des entrevues individuelles auprès de 46 enfants et adolescents autochtones qui souffraient d'asthme ou d'allergies (26 des Premières Nations, 19 Métis, 1 Inuit) et auprès de 51 parents ou tuteurs de ces enfants et adolescents. Des entrevues de suivi ont été réalisées en groupe auprès de 16 adolescents et 25 parents/tuteurs. Les participants ont fait état de ressources pédagogiques inadaptées, de vulnérabilité environnementale, de pressions sociales et culturelles, d'exclusion, d'isolement, de stigmatisation, de blâme et de graves lacunes sur le plan du soutien. Ils ont aussi décrit les obstacles à l'accès aux services de santé, les soins de santé inadéquats, le manque de respect et la discrimination dont font preuve les fournisseurs de soins de santé et les carences de l'assurance-maladie. Ces enfants, adolescents et parents ont recommandé que soient instaurés un soutien et des programmes d'éducation culturellement appropriés offerts par des pairs et des professionnels de la santé autochtones.

Mots clés : santé des Autochtones, accès aux soins, maladie chronique, disparités sanitaires, aspects psychosociaux de la maladie, populations vulnérables

# **Health Inequities Experienced by Aboriginal Children With Respiratory Conditions and Their Parents**

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Asthma and allergies are common conditions among Aboriginal children and adolescents. The purpose of this study was to assess the health and health-care inequities experienced by affected children and by their parents. Aboriginal research assistants conducted individual interviews with 46 Aboriginal children and adolescents who had asthma and/or allergies (26 First Nations, 19 Métis, 1 Inuit) and 51 parents or guardians of these children and adolescents. Follow-up group interviews were conducted with 16 adolescents and 25 parents/guardians. Participants reported inadequate educational resources, environmental vulnerability, social and cultural pressures, exclusion, isolation, stigma, blame, and major support deficits. They also described barriers to health-service access, inadequate health care, disrespectful treatment and discrimination by health-care providers, and deficient health insurance. These children, adolescents, and parents recommended the establishment of culturally appropriate support and education programs delivered by Aboriginal peers and health professionals.

**Keywords:** Aboriginal health, access to care, chronic illness, health disparities, psychosocial aspects of illness, vulnerable populations

Disparities between the health outcomes for Aboriginal children and those for children in the general population persist despite advances in health technology and increased global wealth (Letourneau, Hungler, & Fisher, 2005; Victorino & Gauthier, 2009). A recent World Health Organization report contends that investment in children can reduce health inequities in Aboriginal populations (Nettleton, Napolitano, & Stephens, 2007).

In Canada, asthma and allergies are the most common chronic conditions affecting Aboriginal children and adolescents (First Nations Information Governance Centre [FNIGC], 2005; King, Zayas, & Martial, 2004). Thirteen percent of First Nations children under 19 have asthma and treatment levels for First Nations children and adolescents are low (Crighton, Wilson, & Sénécal, 2010; FNIGC, 2005). It has been found that among First Nations adolescents who had an asthma attack in the previous year, only 57.5% were treated for asthma and only 39.1% with

allergies received treatment (FNIGC, 2011). Recent empirical studies reveal that, compared to non-Aboriginal children, Aboriginal children and their parents visit emergency rooms and physicians more frequently for asthma, as their asthma is poorly controlled (Rosychuk et al., 2010; Sin, Svenson, Cowie, & Man, 2003; To, Dell, Tassoudji, & Wang, 2009). First Nations and Métis children are much less likely than non-Aboriginal children to see specialists or receive spirometers (Sin et al, 2003). In spite of higher rates of respiratory illness and associated health-care utilization among Aboriginal children, factors underpinning inequitable health outcomes are poorly understood (Crichton et al., 2010; Rosychuk et al., 2010).

The purpose of this study was to assess the health and health-care inequities experienced by Aboriginal children and adolescents with asthma and severe allergies and by their parents. The research questions were as follows. 1. *What health-equity challenges are experienced by Aboriginal children/adolescents who have asthma and allergies and by their parents?* 2. *What health-service barriers are experienced by Aboriginal children/adolescents with asthma and allergies and by their parents?*

### **Conceptual Foundations**

Social exclusion refers to societal processes whereby certain groups are unable to fully participate in and benefit from societal institutions (Galabuzi, 2005; Labonte, 2004) and experience economic, political, and social deprivations and inequalities (Stevens, Bur, & Young, 2003; Stickle, 2005). Isolation reduces morale and restricts social and economic opportunities (Organization for Economic Cooperation and Development, 2005). Inadequate incomes can prevent people from participating in social activities and can restrict their ability to access and retain social support, leading to social isolation (Hawthorne, 2006). Stigma linked to income and ethnicity can also foster feelings of isolation (Stewart et al., 2009). Social exclusion and social isolation have been associated with poor health outcomes and are intertwined with other social determinants of health, such as ethnicity and income (Labonte, 2004; Marmot, 2007; Raphael, 2007). Indeed some studies have found reciprocal relationships between social determinants of health, such as social support, low income, low education, unemployment, poor housing, and ethnic minority status, and social exclusion (Abbott & Salford, 2005; Davies, 2005). Exclusion from society's structures of opportunity can serve to diminish control and self-esteem (Abbott & Salford, 2005; Campbell & McLean, 2002). Reduction of exclusion and isolation requires attentiveness to structural barriers, multi-sectoral alliances (Crombie, Irvine, Elliott, & Wallace, 2005; Galabuzi, 2005), participation by disadvantaged people in

the design and delivery of services (Davies, 2005; McClure, 2000), and social support (Stewart et al., 2009).

## **The Study**

### ***Design***

This exploratory study employed a participatory research design and qualitative methods to examine sensitive issues and meanings, perceptions, beliefs, values, and behaviours of vulnerable groups (Boffa, King, McMullin, & Long, 2011; Stewart, Makwarimba, Barnfather, Letourneau, & Neufeld, 2008). The research approach was informed by the *CIHR Guidelines for Health Research Involving Aboriginal People* (Canadian Institutes of Health Research, 2007). Extensive time and resources were devoted to developing collaborative relationships with First Nations and Métis communities and agencies that serve Aboriginal people in the province of Alberta and to confirming that this was a priority health issue. A Community Advisory Committee comprising 10 Aboriginal community leaders provided guidance on the development, implementation, and evaluation of the study. To protect the rights of Aboriginal children/adolescents and their parents, the Committee reviewed the process of informed assent/consent (e.g., information letters, consent forms) for cultural and linguistic appropriateness. The study was approved by the university ethics committee, by the participating agencies/organizations, and by Aboriginal community leaders.

### ***Recruitment***

Participants were recruited primarily through snowball sampling, beginning with contacts by Aboriginal research assistants. With the support and permission of the participating First Nations and Métis communities, five Aboriginal research assistants visited schools, community health centres, child-care centres, and community events. They distributed flyers, took part in radio interviews, and advertised in the newsletters of Aboriginal partner organizations. The Aboriginal research assistants represented various backgrounds (i.e., status and non-status, First Nations and Métis) and both urban and rural communities. Recruitment was facilitated by First Nations and Métis community health centres.

### ***Sample***

***Individual face-to-face interviews.*** A total of 46 Aboriginal children and adolescents (23 girls and 23 boys) 6 to 19 years of age took part in individual face-to-face interviews. Of these, 19 identified as Métis, 26 as First Nations, and one as Inuit. A total of 51 parents or guardians (41 women and 10 men) took part in individual interviews. Six of the guardians were

grandparents and two were aunts of the child/adolescent participant. Of the parents/guardians, 33 identified as First Nations, 15 as Métis, and three as Caucasian parents of Aboriginal children.

**Group interviews.** A total of 10 adolescents who participated in the individual interviews and six additional adolescents (First Nations; 3 boys and 3 girls) participated in two group interviews, one conducted in an urban setting and one in a rural setting. A total of 25 parents, 12 selected from among those who participated in individual interviews and 13 additional parents (3 First Nations men, 6 First Nations women, 4 Métis women) participated in two group interviews, one urban and one rural.

### **Data Collection and Analysis**

In-depth *individual interviews* were conducted with children/adolescents who had asthma and/or allergies and their parents/guardians. Two separate semi-structured interview guides were developed to elicit perspectives, challenges, barriers, and needs. Parents responded to 18 questions and children/adolescents to 14 questions. Exemplar questions are as follows: *Tell me what it is like to live with your (child's) asthma and allergies? What are the hardest things about having (dealing with your child's) asthma and allergies? What services/programs are available to help you manage the stresses of dealing asthma and allergies? What was helpful? What was not helpful? Are you using these programs? Please tell me why or why not?* The wording was modified for the younger children for clarity and simplicity. The interview guides were reviewed by the Community Advisory Committee and pilot-tested with two Aboriginal adolescents and their parents. Individual interviews last from 30 to 60 minutes.

During *group interviews*, participants received a synopsis of the results from the individual interviews and were asked if the interpretations were accurate and appropriate. Children and parents responded to 10 questions in the semi-structured interview guides about support intervention preferences and parents were also asked about their children's intervention needs. Exemplar questions are as follows: *How would kids with asthma and allergies (parents) like you like to meet with other kids (parents of children) with asthma? (probes: over the phone, on the Internet, in a talking circle, at an event) Why would that work best for kids (parents)? Who would kids (parents) like to lead the group? When would be the best time to hold the group? How many times would kids (parents) like to meet with other kids (parents) with asthma and allergies? What do you think a group of kids with asthma (parents) would like to know or talk about? What kind of fun things would kids like you want to do with other kids with asthma and allergies?* Group interviews lasted from 1 hour (children) to 2 hours (parents/guardians).

The individual and group interviews were audiorecorded and transcribed verbatim. The data were imported into NVivo (qualitative data

management software) and thematic content analysis was conducted to examine qualitative data elicited from the interviews. To ensure rigour and trustworthiness, two research assistants trained in qualitative inductive and deductive thematic content analysis and NVivo individually coded the transcriptions for common themes and then distilled these into final themes that employed the specific words of participants (Hsieh & Shannon, 2005). Descriptive statistics were used to describe participant demographics.

## **Findings**

### ***Health Inequities Experienced by Children/Adolescents and Parents/Guardians***

**Exclusion.** The children and adolescents reported that they were treated differently from others because of their asthma and allergies. They believed that their peers and the public did not consider breathing problems, exercise limitations, and asthma exacerbations congruent with Aboriginal culture:

*I feel like I was left behind. It was really bad when I was younger because I would get really sick. I had two things. I had my inhaler and I was taking my puffer probably about 12 times a day. I couldn't run when I was younger. I felt left out.* (First Nations adolescent with asthma)

Family gatherings and cultural celebrations are important in Aboriginal culture. However, these children and their parents reported that they were excluded because of asthma and allergies. Participants noted that smoking, pets, animal hides and fur — present at many traditional Aboriginal gatherings — are common triggers for asthma attacks and allergic reactions. Urban Aboriginal children explained that exclusion from school, social events, athletics, and recreational activities made their minority status more visible. School absenteeism was a challenge for adolescents with asthma and allergies:

*I was bullied at school because I couldn't run. The kids kept chasing me. I couldn't go outside in the spring or fall because of the allergens. I was that quirky little Native boy who really didn't know what to do. Missed a lot of school outings and trips. . . . I couldn't do the whole camp thing that the school went on because I couldn't be outside for that long.* (First Nations adolescent with asthma and allergies)

*When I was a little kid, I felt embarrassed because everybody looked at me when I used . . . my inhaler.* (First Nations child with asthma and allergies)

**Isolation.** Children hid their asthma and allergies from others. They indicated that by not disclosing their health problems they averted the stigma of being sick and weak. Many adolescents confirmed that they did not tell anyone about their condition. Some considered it a private health problem and others did not want to be singled out by their peers. They did not use medication or used their medication only when they were alone. Many of the children and adolescents with asthma and allergies lacked self-confidence and felt isolated:

*Usually I don't really tell everyone. Sometimes I'm scared to tell people . . . when I'm having trouble breathing . . . like, when I'm chillin' with some friends or just having a good time and all of a sudden I'll start breathing kind of weird. I'd rather go hide in a corner and deal with it myself than tell . . . the people I'm with, in case something happens. (First Nations adolescent with asthma and severe allergies)*

*She used to go into the bathroom to take her puffer because she didn't want everyone to see her at school. (First Nations parent of adolescent with asthma, allergies, and eczema)*

**Stigma.** The perceived stigma of chronic illness compounded parents' sense of isolation and exclusion. Many parents believed that the stigma of their Aboriginal status impeded access to needed services and supports. Some mothers reported stereotyping, in particular those who were teenagers or in their early twenties when they had their first child or were single mothers. Often, they had to depend on relatives for financial and emotional support. During pregnancy and following the birth of their children, they moved frequently because they lacked financial resources:

*When you have a 6-month-old baby and it's turning blue and you don't know why they can't breathe — because somebody's cat was nearby — it was terrifying. You go to the emergency and you're treated like dirt: "Well, you're just an over-reactive mother, new mother, you don't know anything." And you want to say, "This is my second child. I know lots. What are you doing?" (First Nations mother of two children)*

**Blame.** Many young mothers who did not know much about asthma and believed that asthma did not affect Aboriginal people blamed themselves for their child's condition. Moreover, some young mothers were told by family members that they were responsible for causing their child's asthma. Some children contended that they had asthma because their mother smoked when she was pregnant. One participant blamed her three grandchildren's asthma on her son-in-law's drug use and her daughter's stressful pregnancies.

*As a young mom you of course don't know about chemicals and things like that, but in moving from the old apartment I was using chemicals for cleaning, and not using rubber gloves, and I was nursing, so I believe that the chemicals ingested into my hands and in through my body, absorbed into me and into my milk, and then of course through the vapours. I believe that [son] got poisoned, because he became very lethally ill. (First Nations mother of four children, two with asthma)*

*The hardest thing is them asking how come they got it. . . . I smoked with the older one and I didn't smoke with this one and she still got it. I didn't do anything with the baby and he is fine. I need to blame myself. (First Nations parent of three children with asthma)*

Several mothers reported that health and social service professionals attributed their child's asthma and allergies to poor mothering practices and smoking. Five mothers indicated that they felt threatened with apprehension of their children by child services. Moreover, when children had allergic reactions, some relatives accused parents of abusing their children:

*I put her in the stroller and took her to the park. She sat in that stroller all day, eating that bag of peanuts, at the park. And the next day I got up and went to school. When I went home for lunch, my mom and them started getting mad at me, like, trying to say that I hit her. I said I didn't hit her. But her face was all puffy. They were asking me if she fell off the bed and hit her nose. I said no. And then I thought about the peanuts from the day before. (First Nations parent of child with allergies)*

*How many times a social service was called on me because I'm an Aboriginal woman, you know, to come to make sure I wasn't smoking in my house. (First Nations mother of adolescents with asthma and allergies)*

**Support deficits.** Some parents, particularly younger parents, lacked support outside their family. Identifying triggers for asthma and allergies and preventing exposure was difficult and worrisome for parents. Although some were reassured by friends that they could manage, most did not have sufficient knowledge about the condition or its treatment. They indicated that lack of community awareness of asthma and allergies also contributed to support deficits. These parents wanted support from peers who understood their problems and could help them cope:

*It was just a really, really lonely period for me, to be at the hospital all by myself. Nobody comes to visit because my family's all from the Arctic and I'm doing this by myself. And the truth is that I could have moved up to the Arctic but the cold would have made him even sicker. Like, I was*



*caught . . . I was stuck here. I could deal with the medical stuff fine but I really needed family or somebody to talk to. I really needed to cry to somebody and say, "I'm scared about my baby." (First Nations parent of adolescent with asthma and allergies)*

*I think we need our Elders to give us strength . . . as parents, and we need the older kids so that, you know, if a little boy was going through an asthma attack, would be right there saying, "It's okay, buddy, I'm here . . . It's okay. We'll figure this out. I'll phone the doctor." It would have been nice for [the hospital] to say, "Well, you know, we do have this cultural room if you and your daughter care to use it," or "We do have a visiting Elder," or something like that, you know, just somebody to . . . you never think [about] these things when you're in hospital, or list the numbers of maybe some Elder you could talk to, or maybe you want him to come in and say a prayer or something. (First Nations mother of two adolescents with severe asthma and allergies)*

Some grandparents were guardians or had adopted their grandchildren with asthma and severe allergies. In addition to dealing with family distress, child welfare, and custody issues, they had to learn how to manage asthma and allergies, compounding the complexity of their stressful lives. These grandparents reported significant support deficiencies:

*At about 5 months old she brought him to us, asked us to keep him for a few months. And during that whole time that we've had him, since he was 5 months old, he's been in and out of the hospital 2 to 3 times a month. (First Nations grandmother of child with severe asthma and allergies)*

***Inequities underpinning respiratory problems.*** Parents and children expressed concern about sudden exacerbations, allergy flare-ups, and asthma attacks. For some children ( $n = 8$ ), attacks were triggered by exposure related to cultural practices (e.g., buffalo hide, bearskin, smoke from burning sacred herbs) or traditional practices (e.g., smudge or pipe ceremony). For other children, attacks were triggered by their environment (e.g., incense, fires, dust, animal dander, cigarette smoke) and occurred in work, school, or family contexts. Several parents claimed that the common belief that Aboriginal children do not get severe allergies limited their support from traditional family sources: "I got an allergic reaction to bison, and it was weird that I was Métis and had bison allergies" (Métis child with asthma and allergies).

***Inadequate educational resources and supports.*** The interviews revealed that the majority of parents, adolescents, and children experienced gaps in information about asthma and allergies and how to manage their conditions. Parents did not understand the terminology used by health professionals to describe their children's health conditions, lacked informa-

tion about the short- and long-term effects of inflammation on the lungs, and did not understand what caused asthma and what triggered allergic reactions. Children, adolescents, and parents lacked self-efficacy and believed that their skills for dealing with asthma and allergies were deficient. Many parents and children reported feeling helpless to effect change in their management of asthma and allergies:

*Scared, because I don't really know what it was . . . I wasn't given any idea, and I didn't know. When he gets sick I always make sure he's okay with his breathing, checking up on him all the time, making sure he doesn't need to go on the machine. When he was little he used to get really sick, because sometimes it just seemed like it [medication] didn't work and it would take a while for it to help him. (First Nations grandmother of child with asthma)*

Inadequate information about medication and how to use prescribed medication was a challenge. Participants were very concerned about the side effects of steroid medications and too frequently used rescue inhalers (Ventolin) rather than steroid inhalers. Some participants did not believe in Western medicine and used prescription medication only as a last resort:

*We went through different kinds of medications . . . I didn't know a lot. I didn't know who to ask, and there was really nothing out there that I could see that was handy or helpful. All I knew was [that] asthma . . . was something with breathing. If you did exercise, you'd have problems breathing, but, I mean, I didn't know it was serious. I didn't know much about it. I just knew you always had it. (First Nations adolescent with asthma and allergies)*

**Environmental vulnerability.** Dust, mould, and ground fires are prevalent in rural communities. Mould caused by spring flooding, poor housing design and construction, and inadequate drainage was common. Some parents blamed the petrochemical industry for groundwater contamination and air pollution. One parent attributed increased pollen and mould to climate change:

*I was driving up to [name of reserve] and they have about an hour's stretch of dirt road and it's super, super fine dust. That just went straight into my lungs. I couldn't breathe properly for about a week. (First Nations mother with asthma herself and a son with asthma and allergies)*

*At home when I was a baby it was not the greatest. I had to go on a machine because my asthma was really bad. And my dad got these guys to check my house, and I don't know what was wrong with it but I think*

*there was, like, mould and lots of dust. So he got it renovated and I've been pretty good since then.* (First Nations adolescent with asthma)

*I think living downstream from . . . waste plant. That's had an impact on all of our health overall. There's all these major underground rivers and so when there's seepage and leakage into the ground, it's going directly into our water system. . . . a huge disaster for sure, and they've had many spills there.* (First Nations mother of adolescent with asthma and allergies)

**Health problems attributed to Aboriginal culture.** Some participants indicated that health-related problems, such as missed activities, school absenteeism, fatigue, hyperactivity, and concentration challenges, were attributed by teachers and health professionals to Aboriginal culture. These parents reported that their children were labelled lazy or lacking in ambition. Children with allergic eczema said that they had pain in their feet, but teachers attributed one child's refusal to wear socks and shoes to his Aboriginal culture.

**Lack of culturally appropriate support.** Many participants complained that education and support were not culturally appropriate. They sought emotional and practical support from Elders, but this support was not available through health-care encounters or education:

*Traditional medicines . . . for her eczema, I will soak her . . . hands in tea and that will help. But for asthma, I don't know what the traditional medicine was for asthma.* (First Nations parent of adolescent with asthma and allergies)

*You can only use All Calm [over-the-counter lotion] for a certain amount of time. I do the heat baths for [name] when her skin gets really, really bad . . . I don't know what it does but my grandma used to do that to my sister — she had eczema on her face — and it worked. I know it doesn't work all the time, but it did work for my kids.* (Métis parent of two children with asthma, allergies, and eczema)

**Social and cultural pressures.** Strong social pressures compelled these Aboriginal children and adolescents to take up smoking. In one gathering at a rural First Nations school, 10 of 15 adolescents smoked. One adolescent said that all of his peers smoked and smoking was inexpensive because cigarettes are not taxed for First Nations people:

*I've been smoking since grade 11. I started smoking because I had a job and that was the only way we could get a break — peer pressure, social event type thing.* (First Nations adolescent with asthma and allergies)

Parents and adolescents were aware that smoking aggravated the asthma and that the asthma abated when they stopped smoking or smoked outdoors:

*We used to smoke in the house and she would get a runny nose and ear infections a lot, so we stopped smoking in the house and she doesn't have so many ear infections and runny nose. (First Nations parent of adolescent with allergies and asthma)*

Some found it difficult to ask friends and relatives to smoke outdoors. One participant said that First Nations health policy would pay for nicotine patches but not for smoking-cessation support or counselling.

### ***Health-Care Inequities Experienced by Children/Adolescents and Parents/Guardians***

***Barriers to health-service access.*** Lack of transportation posed major obstacles for both urban and rural participants. In many rural communities, distance from hospitals and delays in ambulance service were significant barriers. Some children reported that their parents or relatives ignored their breathing difficulties and did not seek immediate care. Parents said that they avoided taking children to emergency or calling the ambulance because of anticipated difficulties:

*I know transportation in the past has been a problem, because we lived in really isolated areas, and sometimes if there's not a vehicle, there's no bus or train to catch a ride, and . . . getting an appointment, and getting a ride to the doctor's, is another thing. The costs sometimes — there's a cost to it, because it's not covered by . . . Indian and Northern Affairs health plan. Sometimes what we can get isn't available because they ran out. (First Nations parent of young child with asthma and allergies)*

*We had to wait, like, 5 hours to drive there to a hospital. There was just nothing. There was no clinic either. I didn't have puffers then. (First Nations child with asthma and allergies)*

Conflict between busy work schedules and the time required to manage children's appointments caused problems, as many young parents did not have child care, reliable transportation, a home telephone, or a cell phone. In addition to limited access to computers and unreliable Internet or phone service, many participants described other obstacles to accessing services. Parents commonly reported that cost, work schedules, other commitments, children's activities, inadequate transportation, inaccessible programs, and lack of child care precluded their participation in health education and support programs:

*You restrict your own activities and your own lifestyle because you want to make sure that your kids are going to be okay, and if they're going to get an acute attack and you're outside the home . . . My job involved a lot of travelling. I tried to travel as little as possible because I always wanted to be . . . closer to home or closer to their school to make sure they were going to be fine. (First Nations father of two children with asthma and allergies)*

*It was having to take time off work when she was younger — having to bus to wherever the doctor was — and then you got to the doctor's office and you waited. It didn't matter if [you had an appointment] and you were on time. You still ended up waiting, and then usually after the appointment there was testing and they'd always do blood work. (First Nations mother of adolescent with severe allergies and asthma)*

**Inadequate health care and health education.** Several participants expressed concern about under-diagnosis, reporting that asthma was incorrectly diagnosed as bronchitis or as a short-term condition. Although these Aboriginal parents, children, and adolescents described significant asthma or allergy symptoms, only those who were city-dwellers or had well-educated parents were referred to a specialist for testing:

*There's this one doctor we [went to] and she just [gave us a prescription]. She didn't even know what was wrong or anything. She just, like, okay, what do you need today? And then my mom just told her, and she didn't really help, just kind of just got what we wanted. (First Nations child with asthma and allergies)*

*I was probably about 11 when I [went] through these bouts. The breathing — you're suffocating and you have no idea why you're suffocating and the medical field doesn't know, because they [don't] know much. They kept saying it was bronchitis, and they're giving you medicine for bronchitis. (Métis parent of young child with asthma)*

Parents received conflicting advice from different health professionals. Many said they did not believe the diagnosis or trust that professionals had their child's "best interests at heart." Parents, children, and adolescents claimed that they did not receive instruction on how to use prescribed medication. Parents believed that they lacked support from health professionals. They were frustrated by the casual way in which some professionals treated allergies and by their inability to find solutions:

*One doctor is telling me this and one doctor is telling me that. They are prescribing me medication, this inhaler thing, so we got two of them. One of them hasn't been used. She's had it for about 4 years now. Never, never*

*used it, never had to — never had an idea how it worked. But in terms of ever having to use it in an emergency . . . I can't figure out how to use this.* (First Nations mother of child with asthma)

*It was hard at first because I really didn't know how to treat the hives when he'd get the bug bites or when he'd get a bee sting. But I'd take him to the doctor and the doctor would give me antibiotics because he was scared that they'd get infected, but most of all now we use Benadryl or Reactine.* (Métis mother of adolescents with allergies and asthma)

Many of the children, adolescents, and parents did not understand the basic pathophysiology of asthma and allergies, precipitating factors over which they had control, and treatment options. They contended that they did not receive relevant information. Some used traditional healing methods and others were curious about how traditional medicines would interact with prescribed medications. Many parents and children indicated that asthma and allergies were episodic or seasonal and used medication sporadically. A few participants believed that prednisone administered during an emergency room visit was superior to daily steroid medication:

*He's definitely at the age [when] he doesn't see the importance of traditional medicine, and I don't understand how come they're like this. Because I'm Native . . . my grandmother used to tell me that there's always something that can take care of you. No, you don't have to rely on the medication all the time, you know, and it's a good thing. She used to say . . . there's got to be a way maybe down the road . . . science and natural can come together.* (First Nations mother of adolescent with asthma and allergies)

**Disrespectful treatment.** Several parents described encounters with health-care providers as disrespectful and discriminatory:

*This doctor is just a bitch. I'm sorry, but . . . no bedside manner, you know, not even trying to — it's like it's her fault she's sick and, basically, she didn't say it, but, I mean, in . . . her approach and everything it was just kind of like, "You're Aboriginal."* (First Nations mother of adolescent with asthma and allergies)

*Sitting in a waiting room with four kids is not the most comfortable thing. Also, the way you're treated, especially by doctors, my experience is it has not been too well. Except for the specialists. We were referred to them so they treated us with respect in those cases. But in a regular medi-centre setting, I ran into a lot of difficult issues with doctors.* (First Nations mother of four children)

Many parents believed that they received incomplete information or disrespectful treatment in the health-care system because they were Aboriginal:

*He still has to use that machine, a Ventolin machine. . . . we knew he was allergic to cats and dogs, because when he was around them he reacted, but he's never been tested. So that's something that should have been done early, but the doctors pretty much said, "If he's allergic to anything else we'd know by now." Like, they weren't very helpful. And we just left it at that, and actually just lately, a few weeks ago, he broke out in hives all over and that's never happened before, so we don't know if it was something he ate or what. The doctor, it's like, "Oh, he could be allergic to something." (Métis parent of adolescents with asthma and allergies)*

*She was riding her bike outside [and] a bee was underneath her seat . . . and her leg swelled up . . . like a balloon. We were in the hospital for 5 hours, [in] the waiting room. The nurse said, "Oh, it's not an allergy!" I said, "Excuse me? She's swelling up and it's red!" "Does she have a sore throat?" I said, "No." The doctor [left] and then another doctor [said], "That's an allergy! She's swelling like a balloon!" The doctor ran to the nurse and started screaming at the nurse: "You made this kid wait for 4 hours in our waiting room and she's allergic to bees?" I never take her to clinic no more. (Caucasian parent of Métis child with allergies and asthma)*

**Deficient insurance.** Participants who did not have access to pharmaceutical insurance found it difficult to pay for prescribed medications. Some participants reported that physicians recommended emergency room visits instead of the purchase of medication that might expire because of infrequent use. A few youths rationed their medication because of the cost, using it only when they were unable to breathe. Some parents complained about the cost of over-the-counter medications for asthma, allergies, and eczema:

*It's difficult, especially in Alberta, because it costs a lot to breathe out here. In Ontario your inhalers, your asthma medications are pretty much free, and when you come to Calgary you have to pay about \$150 for a Ventolin inhaler, \$200 for a steroid inhaler, and I'm supposed to be on the new steroid inhaler — that one is about \$375 and I'm on assistance and [they] only take half the price off, so it's too much to afford. So a lot of the time I just go, like, wheezing most of the day . . . It's really quite the struggle. Once you go to the hospital for an asthma attack they give you medication. (First Nations mother with asthma herself and two children with asthma — urban)*

*He's had it since he was a baby. He was diagnosed pretty early. It was very stressful because he was in the hospital a lot. . . . I didn't have a job that had coverage, so his medication was pretty expensive. He still has to use that machine. (Métis parent of adolescents with asthma and allergies — rural)*

Aboriginal participants had different levels of pharmaceutical coverage from employment, provincial plans for people with low income, or federal Aboriginal health-care coverage. First Nations, Bill C31, and Métis status have different health and pharmaceutical coverage. At pharmacies, confusion would arise regarding which plan or which level of government should cover the cost of prescriptions. Some young parents discovered that their infant did not have First Nations medication coverage because the government forms had not been signed or their child's treaty status was not recognized:

*My daughters aren't covered under treaty — I'm the only one, but I'm trying to get their treaty cards — so we're struggling right now. They were covered by social services but they won't cover them because they said that they have to get on treaty before they can get covered by social services. So I basically go months without health coverage for them, and it's a struggle, because they get sick and I don't know where to take them and where to get their medicine. I have to pay [for] their medicine, and that's so hard to do when you're struggling to find money for it and everything. That's why I was referred to the pediatrician, because she would give samples. (First Nations mother of two children with asthma and allergies)*

Government plans covered generic medication and allowed for more expensive, brand-name prescribed medications only when generics were deemed ineffective. This resulted in additional visits to physicians and delays in receiving prescribed medications. Parents believed that medication policy for Aboriginal people should be less complex:

*I know the cost of medication can be quite unreasonable. I know sometimes when she gets a new prescription it may not be covered by our drug plan, or there's a couple of days' wait because they have to get special authorization. (First Nations parent of adolescent with asthma and allergies)*

## **Discussion**

This study has revealed health-care inequalities and underlying societal and systemic barriers. Aboriginal children with asthma or allergies and their families lack a wide range of supports that would help them to manage their health problems. For the participants, lack of education about asthma served to diminish support from traditional family and



community sources. In Aboriginal communities, personal well-being is related to the social, emotional, spiritual, and cultural well-being of the community (Nettleton et al., 2007). Poverty, unemployment, low levels of health literacy, and poor housing quality are experienced by Aboriginal people both on and off reserve (Richmond & Ross, 2008; Richmond, Ross, & Egeland, 2007). Aboriginal children are more likely than Caucasian children to experience race-based discrimination and violence in school (Canadian Council on Child and Youth Advocates, 2011).

Marginalized populations are often expected to access health care without assistance while systemic and structural barriers that impede access are left unaddressed (Van, Herk, Smith, & Andrew, 2011) and responsive and relevant services are not provided (Pauly, MacKinnon, & Varcoe, 2009). Our participants reported negative, discriminatory interactions with health professionals. Studies examining health-service use by Aboriginal women report that poverty, poor health literacy, unemployment, negative encounters with health and social-service systems, discriminatory attitudes on the part of health professionals, and cultural misunderstanding are barriers to timely and appropriate care (Benoit, Carroll, & Chaudhury, 2003; Brown, 2007; Postl, Cook, & Moffatt, 2010; Van Herk et al., 2011). Other recent studies report that health professionals indicate that they are not trained to understand the perspective of Aboriginal people or to provide culturally appropriate care (Larson, Herx, Williamson, & Crowshoe, 2011; Stewart & Nielsen, 2011).

The factors that influence Aboriginal children's and parents' experiences of health and health-care inequalities have not received sufficient research attention (Adelson, 2005; Labonte & Torgerson, 2005; Letourneau et al., 2005; Postl et al., 2010). In Aboriginal populations, health care related to asthma and allergies cannot be separated from myriad influences — social relationships, educational and community institutions, environmental conditions, government policies, culture, and history (Crighton et al., 2010; Nettleton et al., 2007). Previous research reveals that poverty negatively influences the coping abilities of both Aboriginal and non-Aboriginal parents (Letourneau et al., 2005; Reitmanova & Gustafson, 2011). Recent government reports indicate that lack of social support coupled with high rates of poverty creates significant disparities in life chances between Aboriginal and non-Aboriginal children (Canadian Council on Child and Youth Advocates, 2011; Standing Senate Committee on Human Rights, 2007).

The findings of this study have implications for nurses and other health professionals who care for Aboriginal children with asthma or other chronic conditions and their families. Diagnosis and medication are not sufficient to support the day-to-day management of asthma for vulnerable populations, including Aboriginal people living in poverty (King

et al., 2004; Sin et al., 2003). At the level of the individual, culturally appropriate communication can serve to avoid or alleviate problems linked to poor health literacy and cultural misunderstanding. Health professionals should offer Aboriginal children, adolescents, and their parents the time and space to discuss their condition and their cultural beliefs regarding causes and care options (Towle, Godolphin, & Alexander, 2006). Peer support and community education can enhance respiratory health, indoor and outdoor environments, and health behaviours in Aboriginal communities (Bhattacharyya et al., 2011; Richmond, 2007). The research literature also indicates a need for policies that address exclusion and isolation by viewing structural causes as “upstream determinants of health” (Callander, Schofield, & Shrestha, 2011; Marmot, 2007; Stewart et al., 2008).

Our study is the first to examine health and health-care inequities from the perspective of Aboriginal children and adolescents with asthma or allergies and their parents. Our findings indicate that inadequate social support, social exclusion and isolation, income gaps, institutional barriers, and policy limitations influence Aboriginal children’s and parents’ health behaviours and use of health services. While loneliness and social dissatisfaction are common among children with asthma (Protudjer, Kozyrskyj, Becker, & Marchessault, 2009; Stewart, Masuda, Letourneau, Anderson, & McGhan, 2011), social isolation and social exclusion were especially pronounced for the Aboriginal children and adolescents in our study. Moreover, there have been no support interventions addressing the support needs and intervention preferences of Aboriginal children/adolescents with asthma and allergies and their parents. The participants in our study recommended the establishment of culturally appropriate and accessible education programs, delivered by Aboriginal peers and health professionals, to address health inequities and health-service barriers. Consequently, accessible education interventions, based on the needs and preferences identified in the study, were designed and delivered by Aboriginal peers and health professionals for these Aboriginal children and adolescents and their parents.

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