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EDITORIAL

## **Vulnerability, Risk, and Qualitative Methodologies**

A few months ago, the Editor-in-Chief, Sean Clarke, invited me to join *CJNR* as Editor, Qualitative Research. I was quick to accept, and this is my first editorial in that capacity.

*CJNR* has a 44-year history as a forum for issues central to research in nursing, health, and health services in Canada. Moreover, the qualitative scholar Joan Anderson (2013) recently noted that this journal consistently publishes articles across methodologies, which facilitates efforts to track the “state of the art” in Canadian qualitative research in particular. Indeed, well over half the submissions to *CJNR* are qualitative manuscripts.

Various qualitative methodologies are used in Canadian nursing research, and with multiple goals (Anderson, 2013). Within evidence-based environments, qualitative methods can provide detailed evidence on how health-care providers or target populations engage in health interventions (Leeman & Sandelowski, 2012). Qualitative inquiry can tease out the complex causal mechanisms that contribute to the uptake and outcomes of interventions, as well as unplanned adaptations of them, unanticipated effects, and relevant contextual factors for understanding their implementation and impacts (Leeman & Sandelowski, 2012). The growing popularity of mixed methodologies attests to the benefits of “thinking qualitatively.” As Hoff (2011) observes, “many of our deepest understandings about how health care works derive in meaningful part from qualitative research studies” (p. 54).

Beyond its contributions to research in health services, however, “thinking qualitatively” infuses knowledge development in the health-care community with a critical approach — one that is sensitive to how historical context and intersections of social relations organize disparities in health, illness, suffering, and healing (Anderson, 2013). That stream of scholarship is reflected in a number of articles in this issue of *CJNR* that focus on the health of populations typically described as vulnerable.

The use of the word “vulnerability” as an identifier directs attention to individuals or groups whose characteristics place them “at risk” for ill health or for poor access to health services (Mechanic & Tanner, 2007). While policies frequently are focused on individual-level modification of the behavioural- or lifestyle-related characteristics that are purported to

generate risk (Mechanic & Tanner, 2007), the biological and social dimensions of human existence are intertwined, contributing to various health and illness outcomes (Wainwright & Forbes, 2000). As Anderson (2013) reminds us, illness and social suffering are generated within complex social worlds where access to the determinants of health and health care is inequitable. While epidemiologic methods identify those who may be at risk because of their risk-factor exposures or lifestyles, qualitative inquiry contributes much to our understanding of what it is like to be vulnerable or to live with risk (Spiers, 2000). Qualitative inquiry can also take a transformative approach that moves analysis beyond the level of the individual and towards the circumstances that organize suffering and vulnerability, such as dominant social discourses or power relations in the delivery of health-care programs (Bourdieu, 1996). Such inquiries frequently draw on community-based, participatory methods so that multiple worldviews are part of the process.

The articles in this issue of the *Journal* deal with many of the above themes. Miriam Stewart and colleagues explore the health and health-care inequities described by Aboriginal children with asthma and allergies, as well as the concerns of their parents. Their work sheds light on the shortcomings of health services and insurance for these children and they suggest directions for culturally appropriate support and education. Julia Temple Newhook and colleagues seek to understand the social context that shapes the knowledge, experiences, and decision-making of low-income women with respect to infant feeding, revealing the situated logics behind decisions against exclusive or long-term breastfeeding. After discussing feminist postcolonial and Indigenous theoretical frameworks, Janet Kelly describes her application of a decolonizing approach to sexual health nursing with Maori women, using the Aboriginal principles of *Ganma* (two-way sharing of Aboriginal and non-Aboriginal knowledge without losing the integrity of either) and *Dadirri* (deep, respectful listening to each other). Her examples illustrate the tensions that can ensue when not all members of the team understand or follow these principles. Kelly also describes the steps taken by Maori Elder women to help resolve the sources of tension. Wally Joseph Bartfay and colleagues use mixed methods to explore the personal impact of the global economic crisis on the health of unemployed autoworkers. In conducting multi-method research projects as part of a program of study exploring health promotion and health literacy among women who are incarcerated, Sarah Benbow and her team encountered particular challenges and ethical dilemmas at each phase of data collection; the authors share these experiences and the valuable lessons they learned throughout the research process.

The scholars who contribute to this collection of articles explore the worlds of those who could be termed vulnerable or at risk, but they do not stop at examining individual behaviour. They move beyond the individual level to identify the contextualizing influences on health disparities and the relational tensions between the worldviews of health-service providers and the recipients of care. Some question the neutrality of health services by teasing out the silencing of everyday knowledge by powerful discourses that are disseminated in the process of care provision. Others expose relations of discrimination between providers and recipients of health services. All reveal the potential vibrant contribution of critical qualitative thinking to nursing research in Canada and I look forward with enthusiasm to participating in this trend!

**Jan E. Angus**  
**Editor, Qualitative Research**

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

**Miriam Stewart, Malcolm King, Roxanne Blood,  
Nicole Letourneau, Jeffrey R. Masuda,  
Sharon Anderson, Lisa Bourque Bearskin**

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**

**Miriam Stewart, Malcolm King, Roxanne Blood,  
Nicole Letourneau, Jeffrey R. Masuda,  
Sharon Anderson, Lisa Bourque Bearskin**

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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**Alimentation des nourrissons  
chez les femmes à faible revenu :  
le contexte social qui conditionne leur façon  
de voir les choses et leurs expériences**

**Julia Temple Newhook, Valerie Ludlow, Leigh Anne Newhook,  
Kimberly Bonia, Janet Murphy Goodridge, Laurie Twells**

Cet article analyse les points de vue des femmes à faible revenu afin de mieux comprendre le contexte social qui conditionne leur façon de voir les choses et leurs expériences en matière d'alimentation des nourrissons. À partir d'un échantillonnage dirigé, les auteures ont organisé trois groupes de discussion avec 19 femmes qui utilisaient des préparations pour nourrissons pour nourrir leur bébé dans une communauté urbaine et deux communautés rurales dans la région de l'Est de l'île de Terre-Neuve au Canada. Les éléments du contexte social pour l'alimentation comprenaient la prévalence de mythes et de renseignements erronés sur l'allaitement; les attentes culturelles concernant le comportement des nourrissons; l'expérience postnatale, y compris la médicalisation de la naissance et de l'allaitement; le soutien du partenaire et la charge de travail en matière de soins aux enfants; les préjugés culturels sur l'allaitement; et une idéologie moralisante qui associe l'allaitement à un « bon maternage ». Les auteures discutent des implications des constatations dans l'optique des soins infirmiers et de la santé publique en formulant sept recommandations sur la façon dont les infirmières et les professionnels de la santé peuvent mieux soutenir les femmes et leur famille.

Mots clés : allaitement, famille, promotion de la santé, mères, populations vulnérables

# **Infant-Feeding Among Low-Income Women: The Social Context That Shapes Their Perspectives and Experiences**

**Julia Temple Newhook, Valerie Ludlow, Leigh Anne Newhook,  
Kimberly Bonia, Janet Murphy Goodridge, Laurie Twells**

This article explores the perspectives of low-income women in order to better understand the social context that shapes their infant-feeding perspectives and experiences. The authors used purposive sampling to conduct 3 focus groups with 19 women who were formula-feeding their infants in 1 urban and 2 rural communities in the eastern region of the island of Newfoundland in Canada. Elements of the social context for infant-feeding included the prevalence of myths and misinformation about breastfeeding; cultural expectations about infant behaviour; the postnatal experience, including the medicalization of birth and breastfeeding; partner support and child-care workload; cultural stigma of breastfeeding; and a moralizing ideology that equates breastfeeding with “good mothering.” The authors discuss the implications of the findings from a nursing and public health perspective, offering 7 recommendations for how nurses and health professionals might better support women and their families.

Keywords: breastfeeding, family, health promotion, mothers, vulnerable populations

This article discusses the findings of a feminist sociological analysis of a qualitative study with low-income women in the Canadian province of Newfoundland and Labrador who were formula-feeding their infants. We explore the perspectives of these women in order to better understand the social factors that shaped their infant-feeding experiences. We also discuss the implications of the findings from a nursing and public health perspective, offering recommendations for how nurses and other health professionals might better support all new parents as they face the challenges of nurturing and feeding their babies.

## **Literature Review**

Infant-feeding practices vary greatly across the world (Marshall, Godfrey, & Renfrew, 2007; Van Esterik, 2002). Breastfeeding has been the norm throughout history (Small, 1999; Stuart-Macadam & Dettwyler, 1995), but in the 19th and 20th centuries, with the development of an industry

that manufactures and heavily markets infant formula, formula-feeding largely replaced breastfeeding in many parts of the world (Cattaneo, 2012; Van Esterik, 2002). While breastfeeding rates have now generally started to rebound, they remain low in many regions of the world, including Newfoundland and Labrador (Public Health Agency of Canada [PHAC], 2008). The World Health Organization (WHO) recommends that all infants be breastfed for 2 years and beyond, with no additional fluids or solids for the first 6 months (Kramer & Kakuma, 2009; WHO, 2012). In Canada, 90% of new mothers initiate breastfeeding but only a quarter continue to breastfeed their infants to 6 months of age (PHAC, 2008). Newfoundland and Labrador has the lowest breastfeeding rates in Canada (PHAC, 2008). In some of its rural areas breastfeeding initiation rates are as low as 46% (Newfoundland and Labrador Provincial Perinatal Program, 2011). Infant-feeding differences are tied to socio-economic status, with lower incomes and lower educational levels associated with higher levels of formula-feeding (Association of Registered Nurses of Newfoundland and Labrador, 2006; Lee, 2007; MacGregor & Hughes, 2010; Millar & Maclean, 2005).

From a public health perspective, infant-feeding has important consequences for population health. Breastfeeding has been shown to have many health benefits for both mother and child (Alexander, Dowling, & Furman, 2010; Steube, 2009; Wojcicki et al., 2010). Formula-fed infants have higher rates of diarrhea, respiratory tract infection, otitis media, and sudden infant death syndrome (Hanson, 1999; Plagemann & Harder, 2005). There is also evidence to suggest that children who were breastfed are less likely to develop chronic conditions such as types 1 and 2 diabetes (Gerstein, 1994; Rosenbauer, Herzig, & Giani, 2008).

Yet to reduce infant-feeding to a public health concern would be an oversimplification. Infant-feeding is a complex issue — a personal, social, and deeply cultural experience (Callaghan & Lazard, 2011; Choudry & Wallace, 2012; Dykes, 2005; MacGregor & Hughes, 2010; Stuart-Macadam & Dettwyler, 1995). According to Dykes (2005),

breastfeeding practices within a given culture represent the ways in which women negotiate and incorporate dominant ideologies and institutional and cultural norms with the realities of their embodied experiences, personal circumstances and social support systems. (p. 2283)

Infant-feeding is often framed as a “choice” to breastfeed or formula-feed, but there is increasing criticism of this language, particularly by feminist researchers (Callaghan & Lazard, 2011; Hausman, 2008). The notion of choice brings with it individualist assumptions that mask the social inequities that are key to understanding differences in infant-feeding practices. As Hausman (2008) points out, “it is our responsibility, as

feminists, to identify the constraints that reveal the ‘choice’ itself to be not so much a choice but a class privilege, and then to figure out how to challenge the status quo that makes it so” (p. 12).

The notion of choice also takes the focus away from breastfeeding as a women’s rights issue. It opens the door to criticizing women for “choosing” the “wrong” method of feeding. Many have argued that our ideas about infant-feeding have become inextricably linked with morality and that public health promotion of breastfeeding, with its discourse of “breast is best” and use of language such as “successful breastfeeding,” equates breastfeeding with “good mothering” and formula-feeding with “failure” (Burns, Schmied, Sheehan, & Fenwick, 2010; Knaak, 2010; Lee, 2007, 2008; Murphy, 1999; Ryan, Bissell, & Alexander, 2010; Sheehan, Schmied, & Barclay, 2009). Feminist researchers have also argued that messages promoting breastfeeding have contributed to the medicalization of breastfeeding practices, dwelling on fear and on individual mothers’ responsibility for the “risk” associated with formula-feeding (Knaak, 2010; Lee, 2007, 2008; Murphy, 1999, 2000; Sheehan et al., 2009) and undermining women’s trust in and knowledge about their own bodies (Bartlett, 2002; Burns et al., 2010).

As multidisciplinary public health researchers who are concerned with the health and well-being of women, their babies, and their families, we are committed to promoting breastfeeding for its health benefits, but also to profoundly respecting and supporting all new parents and their children. In this article we explore the social factors that shape the infant-feeding perceptions and experiences of low-income women in Newfoundland and Labrador. In the long term, our purpose is to use the knowledge gained to improve supports for these women and their families and to strive towards a society where breastfeeding is a right, not a privilege.

## **The Study**

### ***Method***

This study was carried out as part of a developing body of research on infant-feeding conducted by the Breastfeeding Research Working Group under the Breastfeeding Coalition of Newfoundland and Labrador. This multidisciplinary team includes clinicians, nurses, lactation consultants, faculty, and researchers committed to improving population health in the province. The body of research is focused on understanding the reasons for the province’s low rates of breastfeeding, with the long-term goal of developing interventions to raise the rates.

The initial inquiry for the study was based on the research question *What attitudes, beliefs, and values influence mothers’ decision not to breastfeed?* As explained above, a feminist analysis of the findings made it clear that

there is much more complexity to the issue of infant-feeding. Widening our perspective from a simple decision-making focus to encompass a more complex understanding of women's perspectives and experiences allowed us to examine the subtleties of the social context of infant-feeding.

### ***Participants***

In summer 2010, a purposive sampling of low-income women who were formula-feeding their infants was initiated in the eastern region of the island of Newfoundland. Contact was made with staff of one urban and two rural prenatal nutrition programs. The women were offered a package of material and information about the time and place for the focus group sessions; if they were interested, they could contact the principal interviewer and/or attend the gathering. (The rate of participation is unknown, as staff did not record the number of women approached.) A \$20 gift card was offered to each participant as an honorarium.

A total of 19 women participated, with an average age of 26 years and an infant between 1 month and 2 years of age. Nine were single mothers. Eighty-four percent had a high-school education or less and the median annual household income was \$10,000 to \$20,000, with most participants receiving some form of government support. There were six participants in the urban focus group, 12 in the first rural group, and only 1 in the final rural group. The sessions took place in a room in the local community and lasted between 30 and 50 minutes.

### ***Procedure***

The research question used to guide discussion was *Why did you choose to formula-feed your baby?* An experienced qualitative researcher collected demographic information on a pre-approved form, introduced the study, and requested permission to audiorecord the sessions. She also assured the participants that their identifying information would be removed. Once completed, the interviews were transcribed verbatim. Ethical approval for the study was obtained from the Human Investigation Committee of Memorial University of Newfoundland.

The data were originally analyzed by two researchers (KB and VL) together, and the results of the analysis are published elsewhere (Ludlow et al., 2012). In order to explore the research results in terms of the social context of infant-feeding, a secondary analysis was conducted by a third researcher (JTN), who had not taken part in the focus groups. This secondary analysis, from a feminist sociological perspective, was the basis for this article. Manual coding and qualitative content analysis were conducted from the transcripts. Social factors were identified and categorized using continuous comparison of items within and between the groups.

The validity and reliability of the findings were enhanced by using the participants' own words.

## **Results**

The participants described their own experiences and perspectives regarding the feeding of their baby but in doing so highlighted a number of social and cultural factors that shape the context of infant-feeding in Newfoundland and Labrador. These include the prevalence of breastfeeding myths and misinformation, the postnatal experience and the medicalization of birth and breastfeeding, cultural expectations regarding infant behaviour, partner support and child-care workload, the cultural stigma of breastfeeding, and a moralizing ideology that equates breastfeeding with "good mothering."

### ***Breastfeeding Myths and Misinformation***

The results make it clear that in Newfoundland and Labrador there is a great deal of conflicting and inaccurate information and many myths about breastfeeding. Many of the myths circulate among the public, but research has also documented inconsistency in the messages of health professionals about infant-feeding and has indicated that this may be an important factor in breastfeeding cessation (MacGregor & Hughes, 2010).

Participants confirmed several myths about infant-feeding, including the belief that formula is better for the baby if (1) the mother smokes — "[formula-feeding] is a lot more expensive, but I know she's getting every vitamin . . . and besides, I'm a smoker. It [isn't] fair to feed her from me"; (2) the mother does not have a nutritious diet — "Your diet affects it . . . if you don't eat a lot of what I'll call 'the healthy food.' . . . They're getting more nutrients on the formula"; and, curiously, (3) the infant is lactose intolerant — "My daughter is lactose intolerant anyway, so she wouldn't have been able to be breastfed."

Perhaps the most important aspect of this misinformation is the belief that breastfeeding is an innate and rather rare ability and that many women are simply not physically capable of producing enough breastmilk to meet the needs of their child: "[Breastfeeding] is just not made for some people." Dykes (2005) found that women conceptualized their breasts as "potentially faulty machines" (p. 2285) and expressed a profound distrust of their bodies being able to produce milk for their babies. This distrust has been termed "insufficient milk syndrome" (Dykes, 2002, 2005; Dykes & Williams, 1999; Hillervik-Lindquist, 1991; MacGregor & Hughes, 2010). One of our participants was discouraged from breastfeeding by the experience of her older sister:

*She tried to breastfeed. It never worked out for her. The child was just constantly screaming, screaming, screaming, I guess hungry all the time or not getting enough.*

Another spoke of her early attempts at breastfeeding:

*I was frightened to death. . . . is your child going to get enough to eat? Because, a newborn baby, [you]’re [breast]feeding them and they could drink a little bit and go to sleep and 5 minutes later they want more. . . . At least [with formula-feeding] you can tell [how much] they’re getting.*

One woman was concerned about being able to measure the amount her baby was consuming:

*If you make a two-ounce or a four-ounce or an eight-ounce bottle, you know. If they drink it, they got it. But with breastfeeding you don’t know — you don’t know what they’re getting.*

This concern with insufficient milk, strongly encouraged by the infant-formula industry, is common in Western cultures, where breastmilk is seen as a product (Dykes, 2005; Van Esterik, 2002). The emphasis on particular nutrients in breastmilk also reflects our society’s concentration on the benefits of breastfeeding only in terms of the known physical constituents of breastmilk, as opposed to the mother–infant nursing relationship, skin-to-skin contact, intimacy, and emotional benefits for the infant. Most other cultures throughout the world do not make a distinction between the nutritional and emotional needs of the baby (Dykes, 2005; Van Esterik, 2002) or, for that matter, between the mother’s needs and those of the infant.

Finally, fear of not producing enough breastmilk may be exacerbated by the medicalization of breastfeeding. Researchers have found that health professionals’ focus on the frequency of feeding rather than on the infant’s behavioural cues tends to undermine women’s confidence in their ability to breastfeed (Burns et al., 2010).

### ***Postnatal Experience and the Medicalization of Birth and Breastfeeding***

Learning to breastfeed is part of the postnatal experience, an experience that is difficult for many women (Kelleher, 2006). Many have argued that, like women’s health in general, birth, breastfeeding, and the postpartum period have become overly medicalized in our society (Burns et al., 2010; Gustafson, 2005; Jones & Ste. Croix Rothney, 2001; Mauthner, 1999; Morgan, 1998). In the past, generations of women passed down breastfeeding knowledge within families and communities, but today “there has been a ‘cultural shift in authority’ away from women’s own shared embodied knowledge towards a ‘biomedical narrative’” (Burns

et al., 2010, citing Bartlett, 2002, p. 376). One participant contrasted the nurses' biomedical approach to feeding and infant care with her own trust in her personal, lived experience. She took offence at nurses' attempts to scientifically monitor her breastfeeding:

*[The nurse said], "Oh, have a nap," and by the time you get to sleep they're coming in with the baby again or they're coming in to say, "Oh, did you wake the baby? Did you feed the baby?" No offence, but I've . . . had enough kids to know [that] if the baby is sleeping, let the baby sleep. I'm not going to wake the baby. If I was bottle-feeding in the hospital I'd be left alone. "When was the last time the baby fed? Did it have a pee? Did it have a poo?" Breastfeeding, every hour on the hour.*

Researchers have found that the biomedical discourse of health professionals, with its focus on correct latch position, feeding frequency, weighing the baby, and language of "demand" and "success," can undermine women's confidence in their mothering skills and lead to disillusionment and a sense of failure (Burns et al., 2010; Redshaw & Henderson, 2012).

Some of the women in our study specifically stated that they wanted to formula-feed because they were tired after a long and exhausting labour or a Caesarean section. Caesarean section is associated with low breastfeeding rates (Lin, Lee, Yang, & Gau, 2011). This highlights the need for professional labour support, which has been shown to reduce the length of labour and the rates of Caesarean section (McGrath & Kennell, 2008), as well as to increase breastfeeding rates (Mottl-Santiago et al., 2008; Nommsen-Rivers, Mastergeorge, Hansen, Cullum, & Dewey, 2009).

Many participants spoke about the difficulty of learning to breastfeed in the hospital. Research has documented the negative effect of routine interruptions on maternity wards on breastfeeding (Morrison & Ludington-Hoe, 2012). Some of the women, particularly those who had given birth in an urban centre, described nurses' attempts to help women learn to breastfeed as "intrusive" and "aggressive." One participant claimed that she was not permitted to have visitors while she was learning to breastfeed. She said that she decided to formula-feed because she wanted to leave the hospital and was not permitted to do so until breastfeeding was well established:

*They will not let you leave the hospital until they know that child is getting something to eat. That was one of the main reasons why I [formula-fed]. [When I was breastfeeding], it was just me and him and there was nobody allowed to come visit me. They said, "Well, we're going to keep you here now another couple of days." I said, "No, you're not. I'm going home now. I'm giving him a bottle."*

Such findings have led many researchers to question whether the “chaotic nature of hospital-based post-natal care in many countries may not be conducive to women taking on their roles as new mothers and learning to breastfeed” (Sheehan et al., 2009, p. 378).

In contrast, women who had given birth in a rural centre described an assumption of formula-feeding on the part of health professionals:

*I don't think there [are] enough people encouraging [women] to breastfeed. I went to the doctor and he never once asked me if I was going to breast-feed. When I had the baby that morning, you're usually asked if you're going to breastfeed or are you formula-feeding. They just brought in formula: "Here, this is what your baby is getting."*

Clearly, in regions where the majority of women formula-feed their baby from birth, there may be a particular need to educate health professionals on the importance of supporting breastfeeding.

Once women return home from hospital with their infant, there is an immediate reduction in professional support. Many participants described feeling overwhelmed with breastfeeding once they were discharged:

*You get home from the hospital and that baby is not latching on. Well, everybody is getting frustrated. The baby is screeching because it's starving to death and you don't know what to do. So, here's the bottle, you know. Obviously you got to feed him.*

Several participants said that they had to formula-feed because they found engorgement too painful and did not realize that this was temporary or know how to alleviate their discomfort. These experiences, and particularly the decision to discontinue breastfeeding in response to difficulties encountered early on, illustrate the lack of information and support for women once they are discharged from hospital. They also point very clearly to the need for high-quality postnatal care and breastfeeding support in the first days and weeks after delivery.

### ***Cultural Expectations Regarding Infant Behaviour***

Cultural expectations about infant-feeding are inseparable from cultural beliefs about infant behaviour and parenting. Researchers have noted that when women believe that their baby is “unsettled” they are less confident about breastfeeding and come under more pressure from family members to formula-feed (Marshall et al., 2007). This idea of a “settled” baby is part of Western society’s focus on “civilizing” babies, a concept that is rare in other societies (Dykes, 2005; Marshall et al., 2007; Small, 1999; Van Esterik, 2002; Vincent, 1999). Women in our study spoke of the importance of getting their baby onto a schedule of feeding and napping and

felt that formula-feeding was much more suited than breastfeeding to establishing a routine:

*Feeding off of me, it was non-stop. She was constantly attached to a boob. Now . . . she drinks her four bottles a day, sometimes five. . . . She's set to her times, set to her schedules.*

The infant behaviour described may represent normal behaviour for a breastfeeding baby, yet there clearly is considerable pressure for women to produce a “good” baby who fits into a particular schedule and does not make too many demands (Dykes, 2005; Van Esterik, 2002). For health professionals working with new parents, it may be important to acknowledge this pressure and to contextualize infant-feeding as part of a holistic approach to infant care, including an emphasis on the normal range of infant behaviour, and supports to draw on for the challenges of infant care.

We need more research on how differences in parenting behaviour, such as that around sleeping arrangements and infant-carrying, might shape infant-feeding in various cultural settings such as Newfoundland and Labrador.

### ***Partner Support and Child-Care Workload***

Research has shown that partner support is a key factor in whether or not a woman initiates and continues with breastfeeding (Rempel & Rempel, 2004, 2011). However, research in the United States has found that expectant parents emphasize the father's support for the new infant but rarely his support for the mother (Avery & Magnus, 2011). The partner of one of our participants was quite willing to give his infant daughter a bottle of formula but was not inclined to help out with less pleasant tasks:

*He doesn't like diapers. I can count on two hands how many times he's changed the diapers in 4 and a half months.*

Many of the participants reported that their partner preferred that they formula-feed, sometimes simply because they purportedly did not want to be “left out of the nighttime feedings.” Although some of the women tried to pump breastmilk, they all agreed that this was too time-consuming to be feasible on a regular basis. Unfortunately, we have no more details on the women's pumping experiences, such as whether they had access to hospital-grade pumps.

A strongly gendered imbalance in parenting expectations and child-care workload was a key social element of the participants' infant-feeding experiences. This is an important finding, since research has shown that domestic workload can have consequences for mental and physical health

(Messing, 1998; Temple, 2009). Several women who had initially attempted breastfeeding felt that it had created an enormous imbalance in child-care responsibilities between themselves and their partner and that formula-feeding was a way to force their partner to take on some of the workload:

*I breastfed my other children but . . . after 3 months of lying on my couch and being the only one that bathed and changed her . . . [I said to my partner], “You know what? I grew [the baby], I gave birth to [her], for 3 months I had [her] attached to my boobs 24/7. Guess what. It’s your turn.”*

Many participants described feeling overwhelmed by their child-care and domestic responsibilities after the birth of a new baby. Even though some of these women began breastfeeding and would have liked to continue, formula-feeding allowed them to better manage their heavy workload:

*With the formula-fed baby . . . I could feed her her bottle at nighttime and lie down and sleep through the night. Breastfeeding, I couldn’t do it. I’ve got other kids in the house. It’s too much.*

*With three kids at home, I can say, “Guys, can somebody give me a hand feeding the baby?” Because supper could be half-cooked and that’s when she decides she wants to be fed. . . . When you got two other kids at home and a little baby and you’re trying to do homework, do the pick-ups from school and the drop-offs to school . . . it’s not easy.*

Participants described being exhausted, finding themselves getting angry with their partners and children, and being unable to cope with day-to-day infant care. They struggled to balance their own needs with those of their baby, sometimes challenging the ideology of “intensive mothering” (Hays, 1996), whereby the mother’s needs are always subordinated to those of the infant (Marshall et al., 2007). For these women, the decision to discontinue breastfeeding was a matter of coming to terms with their own limits for the sake of the whole family and their own mental and physical health: “You’re no good to your child if you’re not fit yourself.” The words of these women echo those in a serial-interview study in the United Kingdom, which found that women and their families experienced pivotal moments when it seemed that the only way to improve the well-being of the immediate family was to discontinue breastfeeding (Hoddinott, Craig, Britten, & McInnes, 2012).

Like most women in Canada (Duxbury & Higgins, 2003), the majority of women in this study had primary responsibility for child care

within their household. If lack of child-care support is an important factor in women's decision to formula-feed, then it is crucial that those promoting breastfeeding acknowledge that increased child-care assistance is an essential part of supporting women who want to breastfeed.

### ***The Cultural Stigma of Breastfeeding***

In Newfoundland and Labrador, as in most Western cultures, there is a powerful stigma around the public exposure of breasts and discomfort with reconciling the sexual and nurturing aspects of women's bodies. Consequently, there is a strong tendency to see breastfeeding in public as embarrassing (MacGregor & Hughes, 2010; Matthews, Webber, McKim, Banoub-Baddour, & Laryea, 1998) and as risking predatory male attention (Henderson, McMillan, Green, & Renfrew, 2011). For example, Henderson and colleagues (2011) found that men tend to see formula-feeding as convenient and safe and breastfeeding as "natural" but problematic because they believe it involves excessive public exposure.

The participants were very concerned about exposing their breasts while feeding their baby. They talked about their own discomfort with breasts and breastfeeding and the social pressure not to breastfeed openly in public areas:

*Lots of people . . . give the look as if to say, "How dare you do that in public!" . . . If I breastfed I don't think I'd leave the house, because I'm really private. The public health nurse had to come to my house to see what problems I was having . . . I was really happy that she had called and offered that. I was lucky because I needed her and I wasn't going to go up [to the clinic] and say, "Gee, can you take a look?"*

Many participants indicated that they were pressured not to breastfeed by partners or family members because of the public exposure of breasts. One woman admitted that she would not feel comfortable breastfeeding even in her own home. Others reported that family members were embarrassed or even "horrified" that they intended to try breastfeeding. One participant recalled being discouraged from even discussing breastfeeding as soon as she announced her pregnancy: "My mom said, 'Now, we're not even going to talk about that. You're not going at it!'"

Ironically, lack of exposure to breastfeeding has also been identified as an important factor in the low breastfeeding rates among low-income women, and increased public exposure to breastfeeding has been recommended in order to develop a supportive breastfeeding culture (MacGregor & Hughes, 2010).

### ***Breastfeeding Equated With “Good Mothering”***

The association of breastfeeding with “good mothering” (Marshall et al., 2007) was painfully clear in the words of our participants. Almost every participant admitted feeling guilty about not breastfeeding. One woman said that health professionals “make you feel guilty and improper as a mother if you’re not doing it.” Another admitted that she felt so guilty about deciding to use formula that when the public health nurse asked if she was still breastfeeding she said yes even though she had discontinued several months before. Also, many women clearly had internalized the “risk” discourse surrounding formula (Knaak, 2010; Lee, 2007, 2008), worrying that they were harming their children by feeding them formula. One participant put it in terms of feeling she had betrayed herself and her daughter by switching to formula:

*There’s so much pressure put on you about the breastfeeding that, even though that’s what I wanted to do, when I knew that . . . I couldn’t do it any more I felt guilty . . . I knew I gave her what I could give her and it was better than nothing at all, but I still felt that guilt because of the pressure that was put on me about breastfeeding. I didn’t want to admit to caregivers or doctors or the health nurses that I wasn’t doing it any more, because that made me feel inadequate — that made me feel like I was a failure.*

Perhaps the most telling comment to come out of the study emerged in a discussion of how the women would feed any future children they might have. Although every woman in the group was currently using formula, some were determined to try breastfeeding again should they have another child:

*If I were to find out I was pregnant tomorrow, you know what the sad thing is? I’d breastfeed again. I’d do it. I’d put myself through it, knowing full well . . . within 3 months I’d be right back to the formula-feeding for my own sanity. I know that.*

For nurses and other health professionals, these words are a reminder of how committed many women are to breastfeeding, how difficult breastfeeding can be in many circumstances, and, most importantly, how pressing is the need for formal and informal supports for women and their families.

## **Discussion**

In Newfoundland and Labrador, as in Canada generally and much of the Western world, society is structured in a way that makes breastfeeding challenging, particularly for women with low levels of resources, educa-

tion, and life experience (Hausman, 2008). Under such conditions, breastfeeding becomes not a right or a choice but a privilege of class. From our perspective, this is very much an issue of health equity, since it means that breastfeeding disproportionately benefits more affluent mothers and children. The insights of the women in this study have helped us to develop seven recommendations for raising breastfeeding rates as well as for supporting new families, no matter how they feed their babies. These recommendations concern *research, resources, maternity care, child care, partner support, public education, and empowerment and respect.*

### **Research**

From a research perspective, we need more detailed information on infant-feeding, particularly on breastfeeding initiation and duration rates in areas such as Newfoundland and Labrador. To this end, in order to design evidence-based interventions, we need quantitative and qualitative research specifically with women who intend to and attempt to breast-feed but later switch to formula. In terms of public health, we also need research on how best to deliver positive breastfeeding messages to different target groups. Hoddinott and colleagues (2012) suggest that a family-centred, narrative approach to breastfeeding support would be more effective than our current feeding education programs. They also indicate that the current recommendation of 6 months exclusive breastfeeding may be unrealistic and overwhelming for many families and that it might be more helpful to set achievable incremental goals. More research is needed on this issue and on the effectiveness of these approaches.

### **Resources**

There is a pressing need for increased resources to improve breastfeeding support. All nurses working with mothers and infants should have core knowledge of breastfeeding (Centers for Disease Control and Prevention [CDC], 2012). We recommend that frontline hospital and community health nurses avail themselves of comprehensive breastfeeding-education programs such as the World Health Organization/United Nations Children's Fund 24-hour course, including 3 hours of supervised clinical work (WHO & UNICEF, 2009). This would help to ensure that new mothers have access to high-quality breastfeeding advice. We need more lactation consultants, so that all women experiencing difficulty with breastfeeding have access to professional advice. Physicians, particularly family doctors, obstetricians, and pediatricians, also need high-quality breastfeeding education. In addition, we need to increase the number of Canadian hospitals certified by the WHO/UNICEF Baby-Friendly Hospital Initiative, which recommends specific ways to improve breastfeeding support in the hospital setting (WHO & UNICEF, 2009). In

addition to hospital support, women need more prenatal and postnatal support, “pro-actively offered to women who want to breastfeed” (Renfrew et al., 2005, p. 63; see also Health Canada, 2011; WHO & UNICEF, 2009), including peer-support groups, high-quality breastfeeding programs as part of prenatal classes, and 24/7 support via telephone, text, and Internet, and, where possible, face-to-face. With a publicly funded health-care system, this inevitably would mean an increase in public funding for breastfeeding. However, we believe that such funding would more than pay for itself, considering the long-term health benefits associated with breastfeeding.

### ***Maternity Care***

Infant-feeding decisions need to be understood within the context of women’s other postnatal experiences and needs. We recommend a holistic, evidence-based approach to maternal and postnatal care (Baker, Choi, Henshaw, & Tree, 2005) that integrates breastfeeding as a core part of the postnatal experience and builds women’s trust and confidence in their own bodies and mothering abilities. We echo the call of Burns et al. (2010) for a more holistic language around infant-feeding and infant care that better articulates the “embodied reality of breastfeeding” (p. 212). Considering the high rate of Caesarean section in Canada, which is steadily rising and is at its highest in Newfoundland and Labrador (Canadian Institute for Health Information, 2012), we must also increase women’s options for care during labour and delivery. This means regulating the midwifery profession and incorporating it into the provincial medicare system in jurisdictions (such as Newfoundland and Labrador) where midwifery legislation has yet to be enacted. It also means encouraging labour professionals, such as doulas, since a growing body of research (including a randomized controlled trial) shows that labour support improves women’s birth and breastfeeding experiences (McGrath & Kennell, 2008; Mottl-Santiago et al., 2008; Nommsen-Rivers et al., 2009).

### ***Child Care***

If we are serious about supporting women who are learning to breastfeed, we will challenge current gender dynamics and child-care expectations that place primary responsibility for care on the mother and will press for political change that includes high-quality affordable child care. In terms of the immediate postpartum period, we also need to support and promote a cultural shift towards respecting a new mother’s need for a period of rest and recuperation following the birth of her child, freed from other domestic responsibilities.

### ***Partner Support***

Research has shown that the support of a woman's partner is vitally important in breastfeeding (Rempel & Rempel, 2011). We recommend that a new mother's partner (whether or not he or she is a co-parent) become involved by developing a nurturing relationship with the infant, "by becoming breastfeeding savvy, by using their knowledge to encourage and assist mothers in breastfeeding, by valuing the breastfeeding mothers, and by sharing housework and child care" (Rempel & Rempel, 2011, p. 115). We also recommend a sharper focus on the role of the entire family, educating fathers, partners, grandmothers, and other family members about breastfeeding (CDC, 2012).

### ***Public Education***

We recommend public education campaigns that promote breastfeeding based on knowledge and empowerment rather than risk and fear (Lee, 2007). We also recommend a realistic approach that addresses the lived experiences and physical and emotional challenges associated with early breastfeeding (Kelleher, 2006; Sheehan et al., 2009).

### ***Empowerment and Respect***

We need a change in focus, from a scientific-bureaucratic, medicalized approach to breastfeeding (Sheehan et al., 2009) that is centred on "measuring" an infant's breastmilk intake to an empowering approach (Kang, Choi, & Ryu, 2008) that respects individual needs and diversity while bolstering a woman's trust and confidence in herself, her body's ability to produce milk for her baby, and her baby's nursing and satiation cues (Dykes, 2005). In their metasynthesis of research on women's experiences of breastfeeding support, Schmied, Beake, Sheehan, McCourt, and Dykes (2011) found that continuity of caregiver facilitated "an authentic presence, involving supportive care and a trusting relationship with professionals" (p. 58). In addition, for nurses and other health-care providers, as well as for researchers and for society, it is important to show respect for all families and to avoid language that frames infant-feeding in moral terms such as "right" or "wrong." For nurses working with parents and newborns, it also means providing high-quality support and information to all families, no matter how they feed their babies (Lee, 2007).

### **Limitations**

One limitation of this study was its small number of participants. One group became an individual interview since there was only one participant, though the information was mirrored by the stories of the other rural group, comprising 12 individuals. The findings cannot be statistically

generalized to larger populations; however, the purpose of qualitative research is not to make statistical generalizations but to provide rich detail about participants' perceptions and experiences (Denzin & Lincoln, 2005).

A second limitation is that the study was restricted to mothers. This focus was chosen because, in our society, it is most often women who make the infant-feeding decision. In many families there are two parents who both contribute (equally or not) to this decision, and it would be valuable to do a study that focuses on both parents. (There are also cases where grandparents or other individuals take part in the decision. We are currently conducting a study of grandmothers' contribution to the infant-feeding decision.) Our focus on mothers excludes families in which infants are raised by single fathers, gay male couples, or grandparents or other caregivers and also omits the experiences of transgendered fathers who may be breastfeeding. It would be worthwhile to conduct research that specifically addresses infant-feeding experiences and support needs in diverse family settings.

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*The Infant-Feeding Experiences of Low-Income Women*

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## **Décolonisation des soins infirmiers en santé sexuelle pour les femmes autochtones**

**Janet Kelly**

Les infirmières et infirmiers qui s'efforcent d'offrir des soins de santé de qualité aux personnes et aux communautés autochtones d'Australie, de même que de travailler avec celles-ci, sont confrontés à des difficultés particulières. En raison de politiques et de pratiques de soin de santé passées ou présentes à caractère discriminatoire ou ne répondant pas à leurs besoins, de nombreuses femmes autochtones et leur famille se méfient des professionnels de la santé et du travail qu'ils effectuent. Il est par conséquent essentiel pour les infirmières et infirmiers d'élaborer en collaboration avec leurs collègues et leur clientèle autochtones des méthodes de travail respectueuses et adaptées sur le plan culturel. L'auteure du présent article traite de la façon dont les infirmières et infirmiers du Canada et d'Australie se sont inspirés des théories féministes postcoloniales, des épistémologies et méthodologies autochtones, ainsi que des modèles de la sécurité culturelle pour mettre au point une approche décolonisatrice et mieux adaptée des soins de santé et de la formation. Deux exemples pratiques issus du contexte australien permettent à l'auteure de mettre en évidence les difficultés et les avantages de l'intégration d'approches décolonisatrices à la pratique. Les similitudes et les différences entre les deux cas indiquent clairement la nécessité d'approches décolonisatrices souples et adaptées.

Mots-clés : Australie, Autochtones, soins infirmiers, santé

# **Decolonizing Sexual Health Nursing With Aboriginal Women**

**Janet Kelly**

Nurses striving to provide quality health care for and with Indigenous individuals and communities in Australia face particular challenges. Past and present discriminatory or non-responsive health-care practices and policies have caused many Aboriginal women and their families to mistrust health-care professionals and practices. It is vital that nurses develop culturally safe and respectful ways of working in partnership with Aboriginal colleagues and clients. The author discusses how nurses in both Canada and Australia have drawn on critical and postcolonial feminist theories, Indigenous epistemologies and methodologies, and models of cultural safety to develop a more responsive, decolonizing approach to health care and training. Two practice examples from the Australian context highlight both the challenges and the benefits of incorporating decolonizing approaches into practice. The similarities in and differences between situations reveal a clear need for responsive and flexible decolonizing approaches.

Keywords: Australia, Aboriginal, Indigenous, nursing, health

## **Introduction**

The need for quality, effective, and responsive health care for Indigenous people in Australia<sup>1</sup> cannot be overstated. Like most Western countries, Australia has colonized and marginalized Indigenous people in health care and society (Taylor & Geurin, 2010). A complex interaction of poor access to the social determinants of health, including poor access to responsive health care, has led to a disproportionately high incidence of ill health among Aboriginal compared to non-Aboriginal Australians (Taylor & Guerin, 2010). The startling reality is that although Australia has a world-class health service, there is a life expectancy gap of 10 to 12

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<sup>1</sup> In Australia, Indigenous people may refer to themselves as Aboriginal, Torres Strait Islander, or Indigenous. They may also go by their local community/cultural name — for example, Kaurna (people of Adelaide City) or Yolngu (people of Arnhem Land in the Northern Territory of Australia). In this article I use the term “Aboriginal,” the preference of the majority of people involved in the study, and “Indigenous,” to refer more broadly to Indigenous people in Australia. Both the Aboriginal cultural group and individual authors of each Indigenous methodology are included. The words “Aboriginal” and “Indigenous” and cultural group names are capitalized, which is the usual practice in Australia and is considered respectful.

years between Indigenous and non-Indigenous people (Australian Bureau of Statistics, 2010).

While there have been many improvements over the last 30 years, unacceptable health inequalities remain. Successive governments and health services have attempted to improve the health status of Aboriginal and Torres Strait Islander people through a variety of approaches, but these have largely involved ad hoc, unsustainable programs, developed and implemented without the partnership or support of local communities. In response to ongoing concerns, the National Strategic Framework of the National Aboriginal and Torres Strait Islander Health Committee (2003) advocated for a partnership approach involving Aboriginal and Torres Strait Islander individuals, communities, and organizations. This approach was to be underpinned by concepts of shared responsibility, full collaboration, cultural respect, teamwork, localized decision-making, capacity-building, holistic practices, and comprehensive primary health care. The challenge for nurses was working out how best to put it into action.

This article considers how postcolonial feminist theories and Indigenous methodologies may help nurses to develop new ways of understanding and enacting partnerships and active decolonization. Examples are given to illustrate how Western theories and Indigenous methodologies can be respectfully combined to inform nurses in culturally safe practice.

### **The Australian Context**

Australia's colonization of Aboriginal and Torres Strait Islander peoples, past and present, mirrors colonization in many parts of Canada, New Zealand, and the United States (Australian Health Ministers' Advisory Council, 2004). In Australia, initial violent clashes were followed by denial of personal, cultural, and land rights and discrimination and marginalization in society generally. Until 1967, Indigenous people were not formally recognized as citizens of Australia (Human Rights and Equal Opportunities Commission, 1991). Unlike in New Zealand and parts of Canada, in Australia there are no treaties to enforce standards of care and inclusion. For the last 200 years, the lives of Aboriginal and Torres Strait Islander people have been highly regulated, with many experiencing misguided and racist government policies and practices, such as having their children removed on the basis of race (Hampton & Mattingley, 1998). This denial of basic human rights led to a profound mistrust of health and support services, which continues for many Indigenous people today (Taylor & Guerin, 2010). Complicating the situation is the fact that most nurses currently practising in Australia have received little or no cultural

training in health care and education beyond basic “cultural awareness” sessions (Downing & Kowal, 2011). With such limited knowledge and training with regard to colonization effects, and with few strategies in place to counter the negative portrayal of Aboriginal people in the media, intercultural relationships in health-care settings often involve miscommunication and misunderstanding (Dwyer et al., 2011).

Let us now turn to two cultural models in use.

### ***Cultural Awareness***

In Australia, cultural training has predominantly drawn on a “cultural awareness” framework for educating workers about an “Other” Indigenous culture. This “recipe” approach has been limiting, for a number of reasons. First, the emphasis on teaching *about* Indigenous people and their health-care needs in a particular social-cultural context has fed into colonizing beliefs and stereotypes and has positioned Aboriginal peoples as having fixed and static cultures that are entirely knowable and visible to the observer. It has reinforced cultural difference and created a cultural chasm, leaving some nurses so confused and so hesitant about interacting with specific cultural groups that they avoid interactions with Indigenous patients (Downing & Kowal, 2011). Second, cultural awareness training avoids a critical gaze on the culture of health professionals and the health-care system itself, reinforcing the dominant ideology as the norm (Taylor, 2003). This can result in nurses having a false sense of “cultural knowledge” based on assumptions and misunderstandings, which they then incorporate into their practice (Browne & Varcoe, 2006). For example, a nurse may confuse the cultures of Indigenous peoples with the culture of poverty into which they have been driven (Ramsden, 2003, p. 6). Finally, cultural awareness without a critical reflective component enables racist and discriminatory practices to go unchallenged (Downing & Kowal, 2011). Also of concern in Australia is the heavy reliance on cultural awareness training for individual nurses and other health professionals as the main method for developing responsive cultural care, with little emphasis on organizational and structural change. This places unreasonable emphasis on individuals, when the underlying issues for access and equity are often of a systemic nature (Downing & Kowal, 2011).

### ***Cultural Safety***

Slowly, the emphasis of cultural training in Australia is changing to more critical and decolonizing approaches, with cultural safety being the model that has gained most traction in nursing. Cultural safety, a nursing model developed by Maori nurses in Aotearoa/New Zealand, promotes respectful partnership between a client and a nurse/midwife underpinned by social justice, critical, feminist, and postcolonial (neocolonial)

theories and treaty rights (Ramsden, 2002). Cultural safety focuses on the “knowledge and understanding of the individual nurse or midwife rather than on attempts to learn accessible aspects of different groups. It is based on the belief that a nurse or midwife who can understand their own culture and theory of power relations can be culturally safe in any context” (Nursing Council of New Zealand – Te Kaunihera Tapuhi o Aotearoa, 2002, p. 8). Thus, cultural safety is positioned beyond cultural awareness and cultural sensitivity. Instead of focusing on the learning rituals, customs, and practices of a group in a “checklist” approach, it alerts practitioners to the complexity of human, social, and political behaviours and interactions.

Maori nurses (particularly Ramsden, 2002) describe how many Pakeha (non-Maori) nurses and other health-care providers brought with them (often unconsciously) their assumptions, stereotypes, and prejudices from the dominant society, leading to unsafe care for Indigenous people, many of whom already viewed the health-care system with distrust. Ramsden encouraged Pakeha nurses to not blame the victims of historical processes for their plight but to question the issues impacting on their ill health and to be open-minded, flexible, and self-aware. Rather than caring for people *regardless* of their differences, she encouraged nurses to provide care *regardful* and in recognition of their differences and life circumstances (Ramsden, 2002). She sought ways to engage nurses and other health professionals and alert them to the colonial past and present but not lose them in historical guilt.

Many aspects of cultural safety are relevant to the Australian context, even though Australia, like many parts of Canada, is a multicultural rather than a bicultural society, with no treaties in place on which to measure commitment to improved health and social services for Indigenous people (Taylor & Guerin, 2010). The principles of social justice and decolonization embedded in cultural safety make it applicable and transferable to both countries. Recently in Canada, nurse researchers have explored cultural safety as a means to draw attention to power imbalances and inequitable social relationships in health care, promoting both systemic change and individual and practitioner change (Browne et al., 2009). In doing so, they have provided new perspectives on the complexities, ambiguities, and tensions inherent in transferring the concept of cultural safety to practice and have developed a knowledge translation process and strategy to enable nursing staff and administrators to critically reflect on the structures, discourses, and assumptions within their health-care system. This work and the theoretical frameworks being developed offer new understandings with respect to decolonizing approaches. In both countries, nurses have found a combination of postcolonial and

feminist theory and Indigenous methodologies most responsive to their needs.

## **Building a Decolonizing Theoretical Framework**

### ***Postcolonial and Feminist Theories***

When nurses and other health professionals combine concepts of post-colonial theory and feminism, they create a powerful critical framework that enables a consideration of gender, class, socio-economic, and power differences in many forms, as well as in relation to colonization. Postcolonialism describes “issues of domination and colonization, race, racialization, culture and ‘Othering’ in Indigenous health and other settings” (Browne, Smye, & Varcoe, 2005, p. 21). When combined with feminism it leads to a broader humanistic approach that enables health professionals to work respectfully within the complex and multiple aspects of health care and equity.

However, a balance is needed between using social categories such as colonization, gender, age, skin colour, occupation, and class to explore and explain shared experiences of people experiencing similar social and historical events and stereotyping people as marginalized, disadvantaged, and/or victims by virtue of their social or racial standing (McConaghy, 2000). It is critical that we seek to understand the nature of specific oppressions at specific sites. By widening the theoretical possibilities, from *postcolonial* with an emphasis only on colonization, to *postcolonial feminism*, we run less risk of making assumptions about what is happening in any given health-care encounter. In presuming that there is a shared experience of colonization among Aboriginal women, health providers could overlook important differences, unique experiences, and personal agency.

In addition, both Aboriginal and non-Aboriginal and both health professional and community women are situated in complex and ambiguous positions, experiencing differing levels of capacity, resistance, and agency at different times and in different situations (Browne et al., 2005; McConaghy, 2000). Complex relationships and changing dynamics lead to intercultural health-care encounters that are rarely predictable or the same. Health-care interactions involve the coming together of two or more people, each with his or her own culture, history, priorities, and concepts of knowledge and power, either consciously or unconsciously. In order to understand this more fully, non-Indigenous nurses may benefit from shared Indigenous knowledge and methodologies.

### ***Indigenous Methodologies***

Indigenous methodologies offer non-Indigenous nurses new ways of understanding expectations and behaviours within intercultural health-

care interactions. In postcolonial Australia and Canada, Western and Indigenous epistemologies (ways of thinking) can be used together or in parallel in respectful and mutually beneficial ways. However, a distinction must be made between the two and how they interact in relation to the history of Western dominance (Browne et al., 2005). Postcolonial Indigenous discourse not only stems from Indigenous knowledge but also challenges non-Aboriginal people to re-evaluate their own colonial frameworks of interpretation, portrayals, and inclusion or exclusion of Indigenous knowledge (Smith, 2003). I will discuss two Aboriginal Indigenous methodologies that have been shared with a non-Aboriginal audience for the purpose of improving relationships in Australia and beyond (Ungunmerr, 1993; Yunggirringa & Garnngulkpuy, 2007). These methodologies provide nurses with pragmatic and decolonizing ways of levelling the playing field and sharing knowledge in intercultural interactions. The first is Ganma, or genuine knowledge-sharing, and the second is Dadirri, which involves deep, reflective, compassionate listening.

**Ganma — knowledge-sharing.** Ganma is a concept of genuine two-way sharing of knowledge between Aboriginal and non-Aboriginal people described by the Yolngu people of Arnhem Land in the Northern Territory of Australia (Pyrch & Castillo, 2001). It is a way for people from different cultures and backgrounds to share deeply without losing their integrity. Using a phenomenon that occurs naturally on their lands as a metaphor, the Yolngu people describe what happens when two different kinds of water or knowledges meet and mix together: A river of water from the sea (Western knowledge) and a river of water from the land (Aboriginal knowledge) engulf each other upon flowing into a common lagoon and becoming one. In coming together, the streams of water mix across the interface of the two currents and “foam” is created. This foam represents a new kind of knowledge that can be shared (Yunggirringa & Garnngulkpuy, 2007). “Essentially, Ganma is a place where knowledge is (re) created” (Pyrch & Castillo, 2001, p. 380). This imagery provides a conceptual framework for how Aboriginal people and non-Aboriginal nurses can work collaboratively in postcolonial Australia, mindful and in respect of their separate and combined experiences, backgrounds, and knowledges. Water, like knowledge, has memory, and “when two different waters meet to create Ganma, they diffuse into each other, but they do not forget who they are, or where they came from” (Pyrch & Castillo, 2001, p. 380). To give up or ignore one’s history is to risk losing one’s integrity; strength comes from understanding where we have been. Ganma describes ways that people can connect and work with each other “deeply” and respectfully, creating new knowledge that is not *yours* or *mine* but *ours*. Creating foam requires more than a joining of intellect

and egos; in order to hear the quiet sounds of foam, one needs to listen with one's heart, *to be aware of the experiencing, not just the experiences* (Yunggirringa & Garnggulkpuy, 2007). It involves a deep understanding of who we are, what we have to offer, and how we can engage with others in respectful relationships in postcolonial Australia. The first step involves listening deeply to each other.

**Dadirri — listening to one another.** Many Aboriginal people discuss the importance of deep, respectful listening and building connections with each other. Atkinson (2002) highlights the role of deep listening in healing and positive change in postcolonial Australia. She refers to the concept of Dadirri, an inner deep listening shared by the Ngangikurungkurr people of the Northern Territory. Dadirri is a quiet, still awareness, similar to contemplation (Ungunmerr, 1993). It is non-obtrusive observation, quietly aware watching, where people are recognized as being unique, diverse, complex, and interconnected, part of a community where all people matter and all people belong.

Dadirri is an inward as much as an outward journey, an awareness of one's own *beliefs, influences, assumptions, intrusions, decisions, and choices* and how these impact on health-care interactions. Dadirri can lead health professionals to "act with fidelity in relationship to what has been heard, observed and learnt" (Atkinson, 2002, p. 18), to understand the pain beneath anger, what a body says when a tongue cannot, and to listen with one's heart as well as one's ear. Using Dadirri, practitioners can acknowledge and support the courage and hope of people, to move beyond common (and often misguided) understandings, to add another layer of healing and responsiveness to health care. Both Ganma and Dadirri provide guidance for nurses on how to interact respectfully in intercultural situations.

### **Putting Theories Into Practice**

I will now share my experiences of bringing together the concepts of Ganma and Dadirri, cultural safety, and postcolonial feminism in nursing practice, made possible through master's and doctoral studies in nursing from 2000 to 2011 and through clinical practice. These studies received ethical approval from the Aboriginal Health Council of South Australia, the South Australian Department of Health, and Flinders University. All stages were guided by an Aboriginal women's reference group comprising Elder and younger community women and Aboriginal health and research professionals. I will share two situations and challenges as well as my responses and reflections. The first involves working with a young Aboriginal woman in a remote location and the second involves supporting the attempts of an Aboriginal colleague to preserve her own cultural

safety and that of Aboriginal trainees during a time of organizational change.

### ***Knowledge-Sharing in Clinical Practice***

I have had the privilege of flying to a remote area of South Australia to provide nursing care at the same women's health clinic two to four times a year over 15 years. Relationships of trust developed over time between the local Aboriginal Elder women, Aboriginal health workers (health professionals who provide primary health care), and me. After a while, the women began to share stories of past colonization and negative health-care practices, including children being removed from their families, young women being given injectable contraception without their consent, and Aboriginal people being denied access to equitable health care and treatment options. These stories were told with the understanding that I would listen deeply (Dadirri), reflect, and conduct my clinical practice accordingly (using Ganma).

During one clinic, a young Aboriginal woman came requesting contraception. Being mindful of past negative practices, I began a two-way discussion regarding her level of understanding about her contraception options, her priorities and preferences, and whether she had any known medical issues. She indicated a general knowledge and no particular preferences and reported seeing a doctor recently after having fainted. I wondered aloud if the fainting event could indicate an underlying health concern that might impact on the contraception method she should choose and asked if she knew the reason for the fainting. She looked at me intently and paused. I could sense her weighing up the situation and I waited patiently (reminding myself of the importance of taking my time and listening to what is spoken and unspoken). After a while, she said, "Well, actually, it ended up that it was a cultural and spiritual thing, not a medical thing." She explained that the doctor at the local hospital had declared her medically fit and healthy but her family had determined that the fainting was spiritually linked and arranged for appropriate ceremonies to be held.

As she awaited my reply, I realized that what I said and did next would be a turning point in the consultation. Three options came to mind. I could ignore the spiritual aspect as not clinically relevant. I could ask curious questions about her spiritual experiences, which might not be appropriate for a non-Aboriginal person to ask. Or I could respectfully incorporate the information she was sharing into the discussion. With Ganma in mind, I chose the third option and inquired whether these cultural and spiritual aspects would impact on her choice of contraception method. I explained that if, for example, she took the contraceptive pill, her periods would come at set times rather than moon

times. She was not sure whether this would impact on her spiritual journey and said that she would need to speak with the Aunties (Elder women) about it.

Being also mindful of her immediate contraceptive needs, I then asked if she would like some condoms to provide immediate contraceptive cover until she was able to make a fully informed decision. She replied that her partner was a “Traditional man.” Again, I was unsure what the significance of this was, so I asked if her partner was okay with wearing condoms. She said she wasn’t sure but would take some and see. We discussed condom technique and the importance generally of women protecting against sexually transmitted infections as well as pregnancy. I told her about the high rates of chlamydia for all young people, regardless of cultural background and location. At the end of the consultation, the young woman left with contraception-option pamphlets and a supply of condoms.

On reflection, I felt that this consultation had provided opportunities for my clinical nursing knowledge and the client’s personal and cultural knowledge to swirl together in an intercultural knowledge exchange (Ganma). We had preserved and respected the integrity of our own and each other’s knowledges while creating new mutual knowledge, or foam — in this case, the contraceptive options most suited to her physical, economic, cultural, and spiritual needs. The concept of Dadirri had instilled in me the importance of taking the time to listen deeply and react carefully and respectfully to the information shared. Critical awareness of colonization and marginalization practices generally, and those involving the women of this community specifically, as well as knowledge about teenage pregnancy and infection rates, alerted me to the spoken and unspoken nuances of providing quality contraception options for this young Aboriginal woman. Supporting her wish to be fully informed, both clinically and culturally, while meeting her immediate and long-term needs was of great importance. There were also specific structural supports to ensure that the consultation was conducted in a culturally safe manner. The clinics were held within an Aboriginal Community Controlled Health Service, allowance was made for longer appointments, and a well-respected Aboriginal health professional was available for further discussion and contraception provision.

### ***Between a Rock and a Hard Place: Cultural (Un)safety in the Workplace***

The second example involves a culturally unsafe situation for an Aboriginal nurse colleague and trainees and my partially successful attempt to address it. Before beginning, I should provide contextual and background information, particularly for a Canadian audience. In Australia, many Aboriginal community groups and individuals hold

specific cultural values regarding single-gender gatherings. Multi-generational, single-gender meetings were traditionally, and in many places are still, held at designated times and locations. Single-gender camps held in more remote areas may stipulate that no person of the other gender be allowed within a certain distance of the campsite. The preference for single gender may or may not extend to health-education and health-care encounters, depending on the nature of the discussion or situation, the people present, and their relationship with each other. For example, in a recent study Aboriginal women from a remote area indicated that they would attend women's health screening or education sessions only if female practitioners were available and there were no men in the vicinity, whereas if the situation was life-threatening, or if there was only one specialist available, the need for care might take priority over gender — the specialist is then placed in a *genderless specialist role*; other women indicated that their relationship with a practitioner was more important than their gender (Dwyer et al., 2011).

The Aboriginal nurse colleague and I were in the early stages of organizing an Aboriginal women's reproductive and sexual health course for Aboriginal primary health care workers. My role as a non-Aboriginal nurse was co-writer and co-facilitator of the sessions on female anatomy and physiology. The Aboriginal nurse served as project coordinator. She worked closely with Aboriginal Elders, health professionals, and community women across the state of South Australia, designing a course that would meet their individual and collective training and cultural needs. In return, the Elder women invited her to take part in their women's ceremonies and gatherings. With this involvement came the expectation that she would uphold cultural values related to Aboriginal-specific discussions about sexual and women's health, both personally and in the workplace, which she did. The first two training sessions were well attended and were evaluated by the participants, some of whom were senior Elder women, as being culturally safe and respectful (Kelly, 2004).

Following this success, our health service employed an Aboriginal male health professional and began planning for an Aboriginal men's sexual health course. My colleague was asked to assist him with the planning. Being mindful of her cultural obligations, she determined that she could provide advice about the structure, process, and content of the course within the office environment without compromising her personal or cultural values. Some time later, however, a new team leader determined that the Aboriginal nurse should be present during the men's sexual health course to support the male worker, as this was common practice in the other (non-Aboriginal) sexual health courses. My colleague explained that it would be culturally unsafe for her to publicly position herself, as an Aboriginal woman, in an Aboriginal men's sexual

health course covering anatomy and physiology, sexual concerns, and infections. She had “danced with the Elders” and participated in specific ceremonies, and so could not be publicly involved in “men’s business.” The team leader disputed this, arguing that such strict gender rules were necessary only “out bush,” where men’s and women’s camps were held separately, and not in an urban location. The Aboriginal nurse and I put forward the argument that our statewide courses should meet the deepest cultural needs of all Aboriginal people attending from across the state, rather than follow the business-as-usual practices of our organization. In addition, we argued, Aboriginal employees should be encouraged to work in culturally safe ways, with their relationships and responsibilities to communities acknowledged and respected. These arguments fell on deaf ears and my colleague became more and more distressed as the date for the men’s course drew near, to the point where she contemplated resigning.

As a last resort, my colleague and I arranged for me to take her place in the men’s course. This would meet the organizational expectation that the male professional be supported, but because I was a non-Aboriginal woman the impact on cultural safety would not be as great. While neither of us was comfortable having any female health professional present during the Aboriginal men’s course, we felt powerless as employees and this seemed the best solution.

Our actions were not without repercussions. The next time I met local, city-based Elder women, they questioned my involvement in the men’s course and reprimanded me, saying that I should not have been involved (Kelly, 2009). I explained that we felt there were no other options, that it came down to either the Aboriginal nurse or I becoming involved. If it was the Aboriginal nurse, she would lose the support of her community and the Elders. If it was I, I might no longer be able to work in the area but I would not be losing the respect of my own community. The Elder women accepted my reasoning, saying, “Okay, but don’t do it again.” Then one of them said, “You’ve come a little bit over to where I am, for you to understand what we do and how we feel about things a bit. It’s not fair for someone to say, ‘You go back over the line and you don’t do what these people here tell you. You do what I tell you — I’m your boss’” (Kelly, 2009).

At that moment I was reminded that while the Elders understood and embraced the principles of Ganma and decolonization, our team leader did not. Following this meeting, the Elder women contacted our employers and met with them to discuss their concerns. A positive outcome was that a culturally safe approach for both staff and future participants was developed, largely due to the initiative of these Elder women.

As an employee, colleague, and nurse researcher collaborating with Aboriginal women, I was caught between a rock and a hard place. The act of Dadirri, deep listening, had enabled me to grasp the devastating impact of this situation for my colleague, her communities, and the course participants. As described by Atkinson (2002), once I had heard and understood, once I listened with my heart as well as my ear, I had an informed responsibility to act. The series of actions I took, however, were limited in their overall effectiveness. While they helped my colleague specifically, my involvement in the men's course threatened the very concepts of cultural safety that I meant to uphold. While in the end the Elder women intervened, with a good outcome, there was no mechanism in place for them to become involved earlier or for us to seek their assistance earlier. This example highlights the need for organizations and systems to embed the principles of community engagement and cultural safety into their employment, training, and everyday practice. Workers and nurses alone cannot uphold cultural safety; there has to be structural and policy support as well.

### **Discussion: Embedding Decolonizing Practices**

Nurses in Canada and Australia face similar challenges in providing quality, responsive, and safe health care and access for Indigenous people. Past and present colonization policies and practices in both countries have significantly impacted on the health and well-being of Indigenous people and their willingness to engage with health-care professionals and systems. Many of the culturalist models currently in use in nursing education and health care focus on the perceived cultural beliefs and values of the "Other" instead of critically reflecting on health-care structures and approaches and the ideologies of health professionals and administrators. This has led to a continuation of inflexible and at times misguided health-care practices and policies (Browne et al., 2009; Downing & Kowal, 2011). Also, in Australia particularly, there is a reliance on narrowly focused cultural awareness training of individuals to resolve issues of access and inequity, without significant system and operational changes and without strategies to combat racism (Downing & Kowal, 2011).

In contrast, cultural safety is a cultural model specifically developed to address the social, structural, and power inequities that underpin health inequalities/disparities (Smye, Josewski, & Kendall, 2010). Although the model originated in New Zealand and is closely linked to treaty rights and biculturalism, its underlying principles of social justice and critical inquiry make cultural safety transferable and applicable to other settings and countries. Nurses in both Australia and Canada have begun drawing on cultural safety to develop new ways of addressing inequities and bar-

riers to quality health care for Indigenous people. However, structural and ideological barriers in both countries have impacted on the introduction of cultural safety into health-care education and practice. In Canada, Browne and colleagues (2009) found a need for a social justice curriculum for practice and a philosophical stance of critical inquiry at both the individual and the institutional level. In Australia, similarly, philosophical and fixed ideologies have at times curtailed the cultural safety potential of nurses and programs (Taylor & Guerin, 2010). Nurses in both countries are striving to overcome the barriers to putting cultural safety into practice, and there is great value in sharing knowledge and strategies between the two countries.

Bringing postcolonial and feminist theories and Indigenous methodologies together creates a theoretical framework to address ongoing oppression and complex intercultural interactions. An awareness of the differing levels of capacity, resistance, and agency among both staff and community members, and of new and shifting levels of access, offers insights into barriers and possible ways forward. Indigenous methodologies such as Ganma knowledge-sharing and Dadirri deep listening offer nurses and health services insights and strategies for enacting effective health care across cultures. These involve both interpersonal aspects of providing clinical care and training programs and the management and organizational structures and support needed to ensure that adequate time, space, policies, and training are provided. The importance of including Aboriginal people in true partnership and decision-making is clear.

### **Conclusion**

This article has discussed the need for health care to be both flexible and responsive in order to meet the needs of Aboriginal individuals and communities in postcolonial Australia and Canada. Non-Aboriginal nurses who are mindful of past and present inequities, who adopt a theoretical framework such as postcolonial feminism informed by Indigenous methodologies, and who embed cultural safety strategies into their practice are well placed to move towards the decolonization and increased equitability and accessibility of health care.

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*Résumé*

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## **Répercussions de la crise économique mondiale sur la santé des travailleurs de l'automobile sans emploi**

**Wally Joseph Bartfay, Emma Bartfay, Terry Wu**

Une étude phénoménologique a été réalisée dans le but d'examiner les effets de la récession économique mondiale de 2008-2009 sur la santé des cols bleus sans emploi de l'industrie automobile de la province canadienne de l'Ontario, entre septembre et novembre 2009. Un total de 22 hommes et 12 femmes ont participé à l'étude. Les participants ont répondu à un questionnaire visant à recueillir des données quantitatives de nature démographique et financière. La part qualitative de l'étude consiste en une analyse phénoménologique de séances de discussions de groupe semi-structurées ayant duré entre 2 et 2,5 heures. Le nombre d'années d'expérience des travailleurs se situait entre 2 et 31,7 ans, pour une moyenne de 15,8 ans. Les participants ont dit souffrir d'un degré élevé de stress, d'anxiété et de dépression, ressentir des douleurs et des inconforts physiques accrus, avoir observé une transformation de leur poids et de leurs fonctions sexuelles, et éprouver des difficultés financières, y compris une incapacité de payer pour des médicaments prescrits. Les auteurs concluent de leur étude que les pertes d'emplois provoquées par la récession mondiale ont eu des effets négatifs sur la santé des travailleurs de l'automobile en Ontario.

Mots-clés : perte d'emploi, santé, travailleurs de l'automobile, récession mondiale

# **Impact of the Global Economic Crisis on the Health of Unemployed Autoworkers**

**Wally Joseph Bartfay, Emma Bartfay, Terry Wu**

A phenomenological investigation was undertaken to examine the effects of the 2008–09 global economic recession on the health of unemployed blue-collar autoworkers in the Canadian province of Ontario between September and November 2009. A total of 22 men and 12 women took part. Participants completed a quantitative demographic and financial questionnaire. The qualitative aspect of the study consisted of a phenomenological component comprising semi-structured focus group sessions lasting 2 to 2.5 hours. The number of years employed ranged from 2 to 31.7 with a mean of  $15 \pm 8$ . Participants reported high levels of stress, anxiety, and depression; increased physical pain and discomfort; changes in weight and sexual function; and financial hardships, including inability to purchase prescribed medications. The authors conclude that unemployment associated with the global recession has negative health effects on autoworkers in Ontario.

Keywords: unemployment, health, autoworkers, global recession

Unemployment is regarded as one of the greatest single stressors that an individual or family can face (Bezrucka, 2009; D'Arcy & Siddique, 1985; Jin, Shah, & Svoboda, 1995; Stuckler, Basu, Suhrcke, Coutts, & McKee, 2011). During the 2008–09 global economic crisis, the General Motors (GM) truck plant in Oshawa, Ontario, Canada, closed after 44 years of production, resulting in 2,600 jobs lost. Similarly, in June 2008 the Forment plant in St. Thomas and Magna in Aurora, which make frames for GM trucks, announced that they were cutting their workforce by 800 employees (CBC News, 2008). The Durham Region of Ontario has lost over 6,700 auto-manufacturing jobs during the past few years due to plant restructuring, downsizing, and/or closures by GM and associated auto-parts plants (<http://www.cawlocal.ca/222/>).

## **Description of Problem**

The worst global economic recession since the Great Depression (1929–39) occurred in the period 2008–09 and affected both developing countries (e.g., Brazil, India, Mexico, Thailand) and developed countries (e.g., Canada, France, Germany, the United Kingdom, the United States). Strully (2009) used a panel study to examine the impact of employment

on health in the United States. The study found that losing one's job was associated with a 54% chance of reporting fair or poor health and, for an individual with no pre-existing health conditions, the chances of reporting a new state of ill health increased by 83%.

Stuckler and colleagues (2011) examined negative public health effects associated with the recent global recession and government expenditures for 26 countries in the European Union. They found that every 1% increase in unemployment in the European Union was associated with a 0.79% rise in the rates of suicide and homicide. Similarly, unemployment attributed to the global recession in Greece (Giotakos, Karabelas, & Kafkas, 2011), Hungary (Duleba, Gonda, Rihmer, & Dome, 2012), Iceland (Hauksdottir, McClure, Jonsson, Olafsson, & Valdimarsdottir, in press), and Italy (de Belvis et al., 2012) are associated with increased rates of stress, suicide, depression, and psychiatric disorders. There is a dearth of research examining the impact of the global economic crisis on the health and well-being of unemployed Canadian workers. Furthermore, to our knowledge no previous investigations have examined the effects of the recent global recession on workers in the highly vulnerable automotive manufacturing sector in Canada. This study was intended to fill the gap in the literature by examining the health effects experienced by autoworkers in the Durham Region of Ontario, an automotive manufacturing region. The study sought to answer three primary research questions: 1. *How has unemployment affected the health and well-being of blue-collar autoworkers?* 2. *What is the lived experience of an unemployed blue-collar autoworker?* 3. *What are the current health-service needs of unemployed blue-collar autoworkers?*

### **Purpose**

Public health nurses and allied health professionals need a better understanding of perceived health-care needs and required services during economic downturns in order to effectively plan and implement primary health care services in their communities. It has been found that unemployment and poverty have negative effects on the health and well-being of individuals, families, and entire communities (e.g., Bezrucka, 2009; Brenner, 1987; D'Arcy & Siddique, 1985; Morris & Cook, 1991). In their quest for knowledge, nursing and allied health disciplines have historically relied heavily on a positivist as opposed to a humanistic approach to scientific inquiry (Cruickshank, 2012; Rose, Beeby, & Parker, 1995). The deductive positivist approach assumes that nature is basically ordered, regular, and largely predictable and that an objective reality exists independent of human observations. By contrast, humanistic approaches involve inductive processes that value the subjective and holistic compo-

nents of the quest for knowledge. Phenomenological methods are congruent with nursing ideals, which value humanistic knowledge and considers that the true meaning of phenomena can be explored and understood only through the described experiences of those affected (Beck, 1994; Jasper, 1994; Kleiman, 2004; van Manen, 1990). To our knowledge, this is the first qualitative study to examine the lived experiences of unemployed workers in the automotive manufacturing sector in Canada or abroad.

## **Methods**

### ***Design and Sample***

We chose a principally qualitative research approach based on phenomenological inquiry, which identifies the essence of a phenomenon and describes it through the lived experiences of those undergoing the condition or state of existence (Balls, 2009; Rose et al., 1995; Sorrell & Redmond, 1995). All participants were blue-collar workers who had been employed full-time or part-time in automotive assembly or parts manufacturing in the Durham Region of Ontario. Our sample comprised 22 male and 12 female ( $N = 34$ ) laid-off autoworkers from Durham Region. The investigation had institutional ethical approval from the University of Ontario Institute of Technology and conformed to Tri-Council Standards. Informed written consent was obtained from all participants. The study received support from the Canadian Autoworkers Union (CAW) Local 222 Community Action Centre in Oshawa, Ontario, where participants were recruited by means of purposive sampling. Purposive sampling is the most common sampling approach used in phenomenological research (Streubert Speziale & Rinaldi Carpenter, 2007). This method was chosen because we specifically targeted participants based on their particular knowledge of a phenomenon (i.e., being a laid-off autoworker). Recruitment posters were placed on community bulletin boards and in the CAW Local 222 Community Action Centre. Network (snowball) sampling techniques were also used (Polit & Tatano Beck, 2004).

### ***Measures and Analytic Strategies***

Those who consented to participate were asked to complete a short demographic and financial questionnaire and to take part in a focus group discussion related to their lived experiences of being unemployed and how it affected their overall health and well-being. Demographic and financial information related to gender, age, highest level of formal education completed, monthly household income, number of dependants, number of years employed in the automotive sector, and number of

	<b>Male n = 22</b>	<b>Female n = 12</b>	<b>Total N = 34</b>
<i>Age</i> (years)	42.9 ± 7.3 (20–52)	44.5 ± 10.3 (40–56)	44.3 ± 6.9 (20–56)
<i>Highest level of education completed</i> (high school)	10.2 ± 2.0 (9–12)	11.4 ± 1.8 (10–12)	(11.3 ± 1.7) (9–12)
<i>Monthly household income when employed</i>	3879 ± 142.3 (\$2,450–\$7,750)	3897.6 ± 1332 (\$3,200–\$8,000)	4026.9 ± 1407.2 (\$2,450–\$8,000)
<i>Monthly household income currently</i>	1532.3 ± 1285.5 (\$0–\$4,200)	1372.3 ± 1104.1 (0–\$3,676)	1596.6 ± 1550.8 (\$0–\$4,200)
<i>Number of dependants</i>	1.9 ± 1.4 (0–5)	1.3 ± 1.5 (0–4)	1.6 ± 1.5 (0–5)
<i>Number of years employed in automotive sector</i>	15.7 ± 7.3 (5.4–24.9)	14.2 ± 8.7 (2–31.7)	15 ± 8 (2–7)
<i>Number of months laid off at time of interview</i>	13.7 ± 9.4 (1–36)	11.9 ± 6.8 (1–29)	13.9 ± 10.1 (1–36)
Notes: All values shown are mean ± standard deviation. Ranges are shown in parentheses. All values have been rounded off to the first decimal place.			

months laid off at the time of the interview. Descriptive statistics, including means, standard deviations, and ranges, were computed from the demographic and financial information and are summarized in Table 1. Inferential statistics consisted of paired *T* tests to determine statistical significance between groups or conditions (e.g., unemployed vs. employed income levels) and a *P* value of  $\leq 0.05$  was deemed significant *a priori*.

The lived experiences of laid-off blue-collar automotive workers were examined qualitatively employing a phenomenological approach in a focus group setting. Phenomenology is defined as an approach to human inquiry that emphasizes the complexity of human experience and the need to study that experience holistically as it is actually lived (Balls, 2009; Rose et al., 1995; Sorrell & Redmond, 1995). Because phenomenological inquiry requires that the integrated whole be explored, it is a suitable method for the investigation of phenomena important to the profession of nursing (Streubert Speziale & Rinaldi Carpenter, 2007).

The focus groups consisted of between four and six participants and lasted from 2 to 2.5 hours. Light refreshments were provided. For standardization and consistency of approach, all focus groups were facilitated by the same member of the research team, who employed a semi-structured interview format consisting of three open-ended questions: *How has being laid-off affected your health and well-being? What health-care services are you currently utilizing? What health-care services are you currently in need of?*

The narrative responses were recorded and transcribed verbatim, categorized, and thematically analyzed. Quality assurance checks for data completeness and accuracy were performed on 40% of the raw data transcribed. Giorgi's (1985) seven-step process was used as the methodological guide for the interpretation of the qualitative data, which can be summarized as follows:

1. Read the entire description of the experience to get a sense of the whole.
2. Reread the description.
3. Identify the transition units of the experience.
4. Clarify and elaborate the meaning by relating constituents to each other and to the whole.
5. Reflect on the constituents in the concrete language of the subject.
6. Transform concrete language into the language or concepts of science.
7. Integrate and synthesize the insights into a descriptive structure of the meaning of the experience of being a laid-off autoworker.

## **Results**

Data were collected between September and November 2009 and a total of 22 men and 12 women ( $N = 34$ ) took part (see Table 1). The participants ranged in age from 20 to 56 years with a mean age of 44.3 years ( $\pm 6.9$ ). The highest level of high school completed was  $10.2 \pm 2.0$  for men and  $11.4 \pm 1.8$  for women. No participants had postsecondary training or education (e.g., community college or university).

Reported monthly household income while employed ranged from \$2,450 to \$8,000 with a mean of \$4,026.9 ( $\pm 1550.8$ ). As anticipated, we found that the reported monthly household income while unemployed had decreased, ranging from \$0 to \$4,200 with a mean of \$1,596.6 ( $\pm 1,550.8$ ). Moreover, a statistically significant difference was noted between employed and unemployed household monthly income ( $P < 0.001$ ). The number of dependants ranged from 0 to 5 with a mean of 1.6 ( $\pm 1.5$ ). The total number of years employed in the automotive sector ranged from 2 to 31.7 with a mean of  $15 \pm 8$ , and no significant differences were noted between unemployed men and women ( $P > 0.05$ ).

**Table 2 Major Health Issues Directly Attributed to Being Laid Off**

	<b>Male n = 22 (%)</b>	<b>Female n = 12 (%)</b>	<b>Total N = 34 (%)</b>
<b>Mental Health Issues</b>			
Stress/anxiety and depression	22 (100)	12 (100)	12 (100)
Lack of mental health resources to access services in the community	12 (54.5)	7 (58.3)	19 (55.9)
Altered sexual function and intimacy with partner	7 (31.8)	3 (25)	10 (29.4)
<b>Physical Health Issues</b>			
Occupational-related chronic pain and discomfort	16 (72.7)	8 (66.7)	24 (70.6)
Inability to access or afford health professionals, whether traditional (e.g., dentist) or alternative (e.g., chiropractor)	15 (68.2)	6 (50)	21 (61.8)
<b>Health Related to Financial and Social Issues</b>			
Inability to afford prescription medications	6 (27.3)	5 (41.7)	11 (32.4)
Need for alternative housing arrangements	4 (18.2)	3 (25)	7 (20.6)
Hardships experienced by family members	9 (40.9)	4 (33.3)	13 (38.2)

The total number of months laid off during the data-collection period ranged from 1 to 39 with a mean of  $13.9 \pm 10.1$ . No statistically significant differences were noted between unemployed male and female autoworkers ( $P > 0.05$ ).

Table 2 presents the number and percentage of participants experiencing selected health issues due to being laid off. These issues are summarized under three broad categories: mental health, physical health, and financial and social health. Each of these is described below.

### **Mental Health Issues**

The first theme that emerged from the qualitative data was the high degree of stress, anxiety, and/or depression expressed by all participants (100%). For example, one male respondent stated, "I'm so stressed out. I look for work every day but there's nothing out there for me, with no

university degree or trade.” Another man said, “It’s so stressful being in limbo, not knowing what the future holds. I can understand why some people go postal. I’m so stressed I’m going to develop an ulcer or die of a heart attack or something, I swear.”

Several respondents ( $n = 19$ ; 55.9%) expressed concern about the lack of resources in their community to help them manage their depression and other mental health issues after being laid off. A female respondent reported, “I can’t go to EAP [Employee Assistance Program] to get help with my depression and anxiety because I’m not a worker any more at GM . . . I have to suffer alone now.” A male respondent said, “There’s a long waiting list to access specialists in Durham who can help you work through these tough times . . . so you just have to [grit] you teeth and try to move forward solo.”

A third mental health theme that emerged from the focus groups was altered sexual function and intimacy due to emotional stress and problems sleeping ( $n = 10$ ; 29.4%). A male respondent said, “My manhood and ego hurt a lot since [I was] laid off at the factory. I hate being dependent on my girlfriend for food and rent. I can’t perform for my girlfriend because I’m really not in the mood, worrying all the time, and stress.” Similarly, a female respondent said, “Being laid off has been a big stress on my marriage. It’s taken away my identity and purpose in life . . . I can’t get to sleep because of all the worry and stress.”

### ***Physical Health Issues***

Another prominent theme was inability to effectively manage occupation-related chronic pain and discomfort ( $n = 24$ ; 70.6%). In fact, approximately three quarters of the respondents indicated that they suffered from chronic neck, knee, shoulder, and/or back pain attributable to the repetitive nature of assembly-line work. One male respondent stated, “Line jobs are really hard . . . the typical person doesn’t realize just how hard [the work] really is . . . The repetitive nature of the job really messes you up day after day after day. There’s no break or downtime on your body. Your shoulders, back, knees all hurt and you don’t feel like getting up to go to work in the morning. That’s why line workers are hooked on painkillers . . . 95% of the people I know took something to get through their shift.”

Respondents also reported that since being laid off they had ceased going to dentists, physical therapists, massage therapists, acupuncturists, and chiropractors to help manage their work-related pain and discomfort ( $n = 21$ ; 61.8%). This was attributed to the financial costs of these traditional (e.g., dentists) and alternative health-care professionals (e.g., chiropractors, registered massage therapists), whose services were not covered by the participants’ public health insurance plans and were no longer

covered by their former employers. A female respondent explained: “When I was working for GM, I used to go to a chiropractor and massage therapists regularly for my neck and back pain. It really made a difference . . . Now that my benefits have been cut, I can’t afford these guys any more and the pain has been a living hell.” Seven participants (20.6%) reported that they could not afford to visit a dentist despite the fact that they were in pain with suspected gum disease or dental caries that needed filling. A male respondent said, “I couldn’t afford a dentist, so I pulled out my own infected tooth with a pair of pliers.”

### ***Financial and Social Health Issues***

Another health concern was the cost of prescription medications ( $n = 11, 32.4\%$ ). A male respondent stated, “The costs of meds are too high, especially since they cut off all my drug benefits . . . I can’t afford all the pills I have to take for my heart, Crohn’s disease, and stuff. So I cut the pills in half or take them every other day.” A female respondent reported, “My husband had prostate cancer and it was really hard to pay for all the meds he needed to fight his cancer. We had to pay over \$500 every month to keep him alive . . . This is Canada . . . where is medicare when you really need it?” The following statement by another woman was a typical response by focus group members ( $n = 13; 43.8\%$ ): “What’s the point of seeing a doctor or going to a walk-in clinic anyway? . . . If they write you a prescription for a problem you have, you can’t afford to fill it . . . so what’s the point?”

The second financial and social theme was the need to make alternative housing arrangements due to inability to meet rent or mortgage obligations ( $n = 7; 21.9\%$ ). One respondent stated, “I lost my wife, then my home, after being laid off at GM. I couldn’t keep up with the payments.” Another said, “The severance package they gave me at GM is long gone . . . Now I live in my pickup truck and go to the food bank to feed myself. The cops come by and knock on my window to see if I’m okay.” Six participants (18.8%) indicated that they sold their home, downsized their apartment, broke their lease, were evicted, or moved in with relatives because they were unable to pay the rent: “I couldn’t afford to pay for a two-[bedroom] apartment for my wife and my daughter, who’s only 6 now, so I basically got evicted and thrown out on the street. I had to move in with my parents, which is pretty embarrassing given that I’m 32 years old now and can’t afford a place on my own.”

The third financial and social theme was the notable hardships and ripple effects for family members of the laid-off workers ( $n = 13; 38.2\%$ ). Seven participants (21.9%) indicated that their children were experiencing stress and anxiety and/or problems in school. A female respondent reported, “My daughter used to be an A student. This has hit

her hard . . . her marks have been dropping like a bomb.” Eleven respondents (32.4%) stated that since being laid off they could not afford new clothes for their children or memberships in clubs or sports programs (e.g., hockey, gymnastics). A male participant stated, “My two boys love to play hockey. We’re a hockey family and it’s what we do to bond with our kids. Since being laid off, I can’t afford to pay for new hockey equipment and membership in the league. To tell you the truth, I can’t even afford to pay for gas to drive them to hockey practice. So this has hit us all very hard indeed.”

### **Discussion**

Taken together, our findings suggest that unemployed autoworkers and their families experience negative effects on their health and well-being due to financial constraints and the termination of employee-based health benefits. These findings appear to be consistent with previous findings with respect to laid-off autoworkers (Adams, 1981; Browman, Hamilton, Hoffinan, & Marodlot, 1995; Hamilton, Browne, Hoffman, & Renner, 1990; Jin et al., 1995).

It is notable that all respondents in our focus group sessions reported high degrees of stress, anxiety, depression, and/or sleep disturbance following lay-off. This finding is consistent with those of Browman and colleagues (1995) and Hamilton and colleagues (1990), who found that automotive plant closures resulted in altered mental health, increased stress, and somatization disorder. It is important to note that these mental health issues (e.g., depression, high levels of anxiety) had not been apparent when our respondents were employed; although laid-off autoworkers reported increased levels of psychological stress, anxiety, and somatization disorder, there was little evidence that they sought more mental health services or counselling than previously. In contrast to our findings, Browman and colleagues (1995) found increased use of mental health services among unemployed blue-collar GM autoworkers in the United States, which was positively correlated with increased levels of psychological distress and self-blame. Nonetheless, our findings are consistent with those of other investigations that have reported increased incidence of mental health issues following lay-off in European Union countries due to the global recession of 2008–09 (de Belvis et al., 2012; Duleba et al., 2012; Giotakos et al., 2011; Hauksdottir et al., in press; Stuckler et al., 2011). To our knowledge, however, ours is the first qualitative investigation to examine the lived experiences of laid-off workers following the global recession and the first to examine its impact on blue-collar workers in Canada’s large automotive sector. The long-term health effects of unemployment for individuals and their families and dependants have

not been addressed in the empirical literature (Bezrucka, 2009; Leach-Kemon et al., 2012; Stuckler et al., 2011). Prospective studies examining health issues that arise as a consequence of unemployment would address this gap.

Our findings also suggest that unemployed autoworkers are reluctant to access private or public health services due to financial constraints. For example, our respondents were reluctant to seek out publicly funded health providers such as physicians to write prescriptions, due to termination of employee-based health benefits. Similarly, they were reluctant to seek the services of other traditional or alternative health professionals, including dentists, chiropractors, massage therapists, and acupuncturists. Our findings are not consistent with those of Jin and colleagues (1995), who report that unemployed factory workers in the United States had increased use of prescription medications and visits to physicians in comparison to employed workers. One of the limitations of our study is that we did not determine the total number or type of pre-existing medical conditions (e.g., heart disease, hypertension, diabetes, repetitive strain injuries) requiring prescription medications. Nonetheless, we can deduce that any pre-existing diagnosed condition requiring a prescription for its clinical management would be exacerbated by the inability to afford prescription drugs. Follow-up investigations are warranted to examine the impact of unemployment on pre-existing medical conditions and how these might be worsened by the inability to afford prescription medications.

Our findings indicate that the lived experiences of unemployed autoworkers have negative health ripple effects for their family members and dependants. Given that the family members of our participants were not interviewed and were not the target population for the study, we acknowledge this limitation with respect to the true impact on families and dependants. Hence, future investigations examining the impact on family members (e.g., spouse, partner, parent) of an unemployed person would provide more accurate and holistic insights into the negative ripple effects experienced by family members and dependants. Nonetheless, our findings are consistent with those reported in the literature related to unemployment and its effect on families and dependants (e.g., Brenner, 1987; Browman et al., 1995; D'Arcy, 1986; Hamilton et al., 1990; Jin et al., 1995).

To better understand how major economic recessions and associated unemployment affect the health of various regional populations requires an examination of the social determinants of health, including how communities share various resources among their members (Bezrucka, 2009; de Belvis et al., 2012). Fishback, Haines, and Kantor (2007) examined the negative health impacts associated with the Great Depression of the

1930s in 114 cities in the United States. They found that infant mortality rates in those cities actually declined during the period 1929 to 1940, linked to increased relief spending under the federal New Deal program. This program consisted of a series of job-creation measures to counter the effects of the Great Depression through enormous public works projects (e.g., roads and infrastructure). More recently, data from 23 nations collected by the Organization for Economic Cooperation and Development show that negative health effects associated with economic downturns are significantly less in nations with strong social safety nets (e.g., unemployment security benefits, housing supports, food security, early-life support, retraining programs) (Bezrucka, 2009; Gerdtham & Ruhm, 2006; Leach-Kemon et al., 2012).

We conclude that unemployment associated with the 2008–09 global economic recession had negative health effects for blue-collar workers in the auto-manufacturing sector located in the Durham Region of Ontario. Our findings suggest the need to embrace and implement various public health strategies to dampen the impact during economic downturns in Canada. Such strategies could include (1) identification of high-risk individuals affected by unemployment (e.g., autoworkers); (2) decreased wait times for community-based health and social services; (3) integration of social and health services for the most vulnerable groups identified; and (4) public health surveillance and tracking of disease and states of health (Bambra & Eilemo, 2009; Bauer & Thant, 2010; Stuckler et al., 2011). Public health nurses in Durham Region should seek to empower families by building partnerships with local, provincial, and national agencies, organizations, and governments to plan for and implement primary health care interventions that promote the health and well-being of all family members during economic downturns. Lastly, additional studies are warranted to examine the benefits and impact factor of these community-based health services for unemployed workers and their families during economic downturns.

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## Meilleures pratiques en matière de recherche

### **Effectuer une étude auprès des femmes criminalisées en milieu carcéral : le point de vue des chercheurs**

**Sarah Benbow, Jodi Hall, Kristin Heard, Lorie Donelle**

Bien que d'importantes menaces pèsent sur la santé des femmes incarcérées par le système de justice pénale, il n'existe que très peu de travaux de recherche qui portent sur leur hygiène de vie. Afin d'apporter leur contribution aux projets de recherche sur la condition de santé des femmes criminalisées, les auteures ont mené une recherche multiméthode dans le cadre d'un programme de recherche visant à étudier la promotion de la santé et les compétences des femmes ayant des démêlés avec la justice sur le plan de la santé. Les travaux de recherche effectués en milieu carcéral présentent des difficultés uniques et soulèvent des dilemmes éthiques qui ont problématisé chaque phase de la collecte de données. Les auteures font part de leur expérience en tant que chercheuses en santé menant une recherche en milieu carcéral auprès des femmes criminalisées. Elles décrivent certaines des difficultés, des réussites et des précieuses leçons apprises durant le processus de recherche dans l'espoir qu'en transmettant leurs connaissances à d'autres chercheurs en santé, elles inspireront de futures études auprès de femmes criminalisées.

Mots clés : méthodes de recherche en collaboration, promotion de la santé, populations mal desservies, santé des femmes

## *Best Practices for Research*

# **Conducting Research With Criminalized Women in an Incarcerated Setting: The Researcher's Perspective**

**Sarah Benbow, Jodi Hall, Kristin Heard, Lorie Donelle**

Although women incarcerated by the criminal justice system encounter significant challenges to their health, there has been little research focusing on their health practices. To contribute to the research literature on the health experiences of criminalized women, the authors conducted a multi-method study as part of a program of research exploring the health promotion and health-literacy skills of women in conflict with the law. Conducting research in an incarcerated setting posed unique challenges and ethical dilemmas that problematized each phase of data collection. The authors share their experiences as health researchers conducting research in an incarcerated setting and with criminalized women. They document some of the challenges, successes, and valuable lessons learned during the research process in the hope that by sharing their knowledge with other health researchers they will support future studies with criminalized women.

Keywords: collaborative research methods, health promotion, under-served populations, women's health

### **Introduction**

Conducting research in incarcerated settings entails special and specific considerations for researchers (Pollack, 2004; Quina et al., 2011; Roberts, 2011; Woods-Bryne, 2005). While researchers in the United States and the United Kingdom have begun to share their unique experiences of data collection in incarcerated settings, relatively little attention has been paid to research conducted in incarcerated settings overall, and particularly amongst health researchers in Canada (Hall & Donelle, 2009). The purpose of this article is to share our experiences as health researchers that were unique to conducting research in a detention centre and to consider the personal and professional implications of research with criminalized women.

Researchers' experiences were documented during a multi-method program of research to examine perceived strengths and deficits in health knowledge, access to information, services, social support, and advocacy skills related to participant-identified health promotion issues for criminalized women. Throughout the 2 years of data collection and analysis, members of the research team took field notes, met both formally and informally to debrief, and dialogued in person and via e-mail around emerging findings. During these team meetings, reflections by researchers revealed the theme that conducting research in an incarcerated setting poses unique challenges and ethical dilemmas that problematize each phase of data collection for both participants and researchers. In this article we report on some of the challenges, successes, and valuable lessons we documented in field notes, minutes of meetings, and e-mail dialogue throughout the research process. Our hope is that by sharing our knowledge with other health researchers we will support future studies in incarcerated settings generally and with incarcerated women in particular.

### **Background**

The impact of women's incarceration reverberates beyond the individual; it also impacts their children (O'Brien & Bates, 2003). In addition to the unique realities of women's lives, women's experiences of reproductive health, menstruation, and gynecological conditions demonstrate that their biological health-care needs are different from those of incarcerated men (Acoca, 1998; Flanagan, 1995). While for some women the health care received during incarceration may provide an avenue of access that would not exist otherwise (Peternej-Taylor, 2008), health-care access is generally limited and inconsistent for incarcerated individuals (Stoller, 2003). Although research has shown that experiences tend to vary based on gender (Ammar & Weaver, 2005), "the needs and challenges of these women [female offenders] have been overlooked in favour of those of men, who far outnumber women in the criminal justice system" (O'Brien & Bates, 2003, p. 210). Consequently, nationally there is limited knowledge regarding health promotion issues and services at Canadian correctional facilities (Moloughney, 2004), particularly as related to women (Hall & Donelle, 2009).

The five-member research team was made up of a principal investigator and four graduate students with combined expertise in the areas of community-based nursing, women's health, trauma, and mental health. Our multi-method program of research was intended to address a gap in the literature related to health promotion, specifically issues of health literacy among criminalized women. Our approach focused on exploring

political, social, and economic inequities that construct women's "choices" related to surviving as criminalized behaviour (Pollack, 2004).

The projects within this program of research incorporated diverse data-collection strategies, including arts-based body-mapping (Soloman, 2007), individual semi-structured interviews, social network analysis (Vera & Schupp, 2006), structured survey assessments (health literacy survey assessment), and content analysis of institutional medical charts. The research team spent approximately 2 years and 200 collective research hours inside the detention centre. While the purpose of the research program was to investigate health promotion and health literacy among incarcerated women, what emerged throughout data collection and analysis was the significance of the experience of conducting research in an incarcerated setting. Thematic analysis of field notes, minutes of meetings, and e-mail dialogue was conducted to document and report on our experiences. Trustworthiness of the data was attended to through the reflective memoing that researchers engaged in throughout data collection and analysis, data confirmability by members of the research team, and researcher consensus on similarities and differences of data coding through open dialogue (Graneheim & Lundman, 2004).

### **Challenges**

Through our review process, we identified three overarching themes related to the challenges of conducting research in the incarcerated setting: *the process of (re)gaining entry, conducting research within the space of an incarcerated setting, and leaving the space behind.*

#### ***The Process of (Re)gaining Entry***

Gaining entry to the detention centre required the approval of two separate ethics review boards, the principal investigator's university ethics review board and the provincial Ministry of Community Safety and Correctional Services. As with conducting research in other institutional settings, gaining approval from more than one review board delayed initiation of the project. While the ethics forms for the two boards were not substantially different in focus, reconciling discrepant recommendations from each board extended the preparatory period of the study. For instance, offering participants an honorarium, a common practice in research, is forbidden in most incarcerated settings (Brewer-Smyth, 2008) and was authorized by one ethics review board but not the other. A compromise was reached by offering refreshments (juice or coffee and muffins). While an honorarium is always a moral and ethical issue, no matter the setting, there were additional considerations and regulations, and the potential for coercion was heightened due to the restrictive envi-

ronment unique to an incarcerated setting (Woods–Bryne, 2005). Safety is also a consideration in this setting, such that any honorarium had to meet institutional standards of what the women could have access to.

***Fostering relationships.*** Similar to research in many institutional health-care settings, research in the incarcerated setting was outside of normative institutional practices. Therefore, fostering trusting and professional relationships within the institution was integral to the successful initiation and completion of the study, although this strategy never fully eradicated barriers to accessing the women. With the support of health-services administration, a registered nurse working at the facility was assigned to partner with the research team and acted as a liaison between staff and researchers during our time there. This RN helped us to understand the cultural norms, brokered a relationship between the research team and correctional staff, and facilitated participant recruitment. Data collection was predicated on the RN's scheduled shifts. Day-to-day data-collection plans remained tentative until we confirmed with the RN by telephone and/or text whether we would be allowed to collect data on any given day. Our alliance with the health-care staff, particularly the RN assigned to our study, and our own identities as health professionals and nursing researchers seemed to facilitate relationship development with the participants.

### ***Conducting Research Within the Space of an Incarcerated Setting***

Unlike in other institutional settings, in this setting it was not uncommon for women to be in “lock down” because cells were being searched or because of staff shortages. Inmates were not permitted to take part in research, or any other activity, during lock down. Additionally, scheduled programming during the data-collection “window” competed with recruitment and data collection. At times women had to choose between participating in our study and attending a group program that was running simultaneously. Some days we were permitted to enter the facility and the female unit, while other days we would be questioned, left waiting, and/or refused access/entry, despite having adhered to the conditions for entry. Conducting research in an incarcerated setting also resulted in a lack of (safe) spaces to meet with the women, which resulted in our meeting in locked rooms without monitoring, or at times not being able to meet at all. Therefore, despite our established relationships and the approval of the research, each time we entered the detention centre we were faced with new and unique challenges.

As we were not employees of the detention centre, we were fully dependent on the generosity, flexibility, and regulation of the staff to gain entry to the institution and access to potential participants each time we arrived for data collection. The willingness of staff to support our project,

and therefore our entry, fluctuated and was reflective of a number of complex contextual situations. As a consequence, data collection took considerably longer and was more tenuous than anticipated. While women readily volunteered to take part in our study, most days a wait list of potential participants was drawn up because of the 1-to-2-hour hour restriction placed on our data-collection window. The high rate of turnover at the centre meant that many of the women were released or transferred to another facility before they could take part in our study.

***Enacting contradictory alliances.*** Within the incarcerated space we had to continuously negotiate our roles. This system of control and power created contradictory alliances, regardless of intent, with the participants and correctional staff. Engaging in such polarizing alliances was not something we had anticipated prior to entering the detention centre, and it is not a topic widely discussed in the health literature. In enacting an alliance with the correctional staff, we were expected to support the power differential between us as “outsiders” and the inmates while simultaneously holding a position of less power than the staff. There was an expectation on the part of correctional staff that we would be vigilant in monitoring and regulating women’s access to such items as drinking straws and writing devices. A comment by a research assistant captures the challenge of attempting to ensure safety while conducting an interview:

*The first [part of working within the space] is in relation to negotiating my own abilities to be vigilant and give the attention required to maintain “control,” “safety,” “order,” while at the same time trying to be present with the women in the interview.*

This was a difficult balancing act, since we sought to be authentically present with the women during each interview. The level of vigilance that was required of us during our time with the women became a focus of the data-collection process; we were constantly counting the number of pens being distributed and returned and ensuring that the women’s drinking straws were handed in to us after interviews. This was an aspect of the research that we had not considered in advance.

In alliance with the participants, we were locked in a small room and our mutual ability to exit was controlled and authorized by the correctional staff, as “order” within the facility was maintained through restricted movement. Like our participants, we were perpetually locked in or out and needed permission to exit each room, hallway, and the building itself. At times the women observed how the staff used their power and control over the researchers. For instance, there was a delay between the time when we notified staff that we were ready to leave a room and the time when they arrived to let us out. Further, in building

relationships with the participants we were cognizant of the privilege that we held and made decisions that were mindful of their lack of access to many commodities. While privilege is acknowledged in the research literature mainly in terms of the socio-economic differences between researcher and participant (McCorkel & Mayers, 2003), in the case of incarcerated women privilege needs to be further conceptualized in terms of access — what is available to those outside versus those inside. For example, participants commented on the soap and shampoo we had access to “on the outside” when they smelled a particular soap that they were denied “on the inside.” While we were able to adjust our presentation in this regard, there were many aspects of our privilege that we could not minimize. For instance, our clothing stood out from the ministry jumpsuit and footwear that incarcerated women are required to wear.

Given our alliance with the women, we were conflicted when acting as “situational correctional officers” while trying to build a collaborative research environment. We were neither insiders nor outsiders. This suggests the broader issue of the unavoidable ways in which incarcerated settings enforce and reproduce hierarchical systems of power, control, and compliance. Conducting research in an institution designed to “punish, regulate, control, and produce law-abiding citizens” (Pollack, 2004, p. 701) challenged our role as “health researcher,” which is guided by the values of respect, empowerment, and social justice.

***Different worldviews.*** While differences in worldviews in conducting research in incarcerated settings have been explored (Arditti, Joest, Lambert-Shute, & Walker, 2010; O’Brien & Bates, 2003), ideological differences related to health-professional identities are not thoroughly discussed in the literature. Our personal and professional understandings of health as an asset contrasted with the focus on physical and psychiatric dysfunction that predominates in the incarcerated setting. The disconnect between the health promotion perspectives of the researchers and the medical care offered at the institution created ethical and professional turmoil for the researchers, as the services being provided were less than comprehensive and did little to address the multifaceted and complicated influences on health. Although the facility had a health-services department, we observed and perceived limited ability to promote health in an institution whose mandate is punishment.

***Personal safety.*** Ensuring the safety of participants and the environment was emphasized in the conduct of all our work; however, safety considerations were a distinctive element of conducting research in this setting. During the interviews we were locked in a room with anywhere from one to nine women, some of whom had a record of violent behaviour. A research assistant recounts her personal feelings about safety:

*After banging on the door a few times [to be let out, as instructed by staff], and realizing no one was coming, the potential safety risk of being locked in a room came to mind. I felt safe, especially with this particular woman, but the process did not feel safe. At one point the woman stated, "It's a good thing I'm not trying to kill you," and I responded, "I appreciate that." We were both laughing but there was truth to her statement . . . Correctional officers did pass [by] but did not open the door . . . Finally, someone came.*

Learning to feel safe in situations of inherent instability and constant flux required us to adopt both personal and professional ways of negotiating. It was exhausting to constantly shift our way of being within the setting in order to form an alliance with whoever was present. Tensions mounted as we learned to perform roles with the participants that were neither familiar nor comfortable to us. This exacted a toll on our emotional well-being.

***Anonymity and confidentiality.*** There were limits to maintaining participant confidentiality and anonymity as a direct result of the incarcerated environment, particularly during the recruitment process. Because of the limited space and restricted movement, we were able to recruit women only during specific times of the day — primarily when they were “on the range,” a locked common room. Through a barred “cage,” we proceeded to collect the names of women interested in participating, and had to give these names to the correctional staff so they could unlock the cage and escort the women to another locked room that would serve as the interview space. Since the only way to access the women was through correctional staff, the staff were aware of who had chosen to participate in the study. However, once the women were in the “research room” the correctional officers were not privy to any information being shared.

### ***Leaving the Space Behind***

We had to not only learn ways of negotiating the space while collecting data, but also grapple with the feelings that lingered each time we left the correctional facility. For us, feeling was a way of knowing (Ferrell, 2005), as we believed that the research process was strengthened by the emotions that emerged (e.g., sorrow, powerlessness, guilt, anger, and frustration) (Arditti et al., 2010; Brewer-Smyth, 2008). The emotions grounded us and were sources of insight into the experience of conducting research with criminalized women. The culture of power and compliance deeply impacted us, particularly in relation to the attitudes displayed towards the women and ourselves (as outsiders and researchers) by certain correctional officers. It was difficult to make sense of this in terms of our role

as health researchers without the authority to intervene. Witnessing such behaviour and mistreatment did not negatively influence our ability to collect data, but, rather, reified our commitment to conduct research with criminalized women and to use our relative position of power to leverage their voices, issues, and health needs.

The professional backgrounds of the research team influenced the emotional toll on us:

*One would think that being locked in a room with someone convicted of murder would be terrifying, that it would feel unsafe. I thought it would. I was wrong. What is terrifying and leaves me feeling empty is the feeling that I should be able to help. We should all be able to help. These lives, these stories, these women — they are not safe. They have never been safe. Do I play a role in that? That is what hurts.*

Our experiences as community health nurses, mental health nurse, and trauma counsellor made us sensitive to the unique health needs of this population, which were simply not being met.

***Grappling with the privilege of freedom.*** In the physical and emotional transition out of the incarcerated setting, there was often a sad silence as we moved from cell bars, locked doors, and bulletproof glass into the fresh air, bright sunshine, and occasional snowy day — a pleasure denied the women we had just interviewed. This invoked a bittersweet feeling of freedom while at the same time causing us to grapple with our position of privilege. In reflecting on the experience of collecting data in a detention setting, one research assistant used poetry to capture the tensions:

these cinderblock walls that steal my words  
swallow them whole . . . leave sentences incomplete  
I talk louder so she can hear me  
so much noise — not decipherable noise, but noise  
but there is no breeze because we're sealed in tight  
the smooth feel of a pen gliding on paper  
“oh, a pen . . .” (she exclaims) compared to the resistance of a pencil  
clanging guards' keys that mark time . . . the only marker of time.  
“they don't care because we're inmates — just because I'm in here  
doesn't mean I shouldn't get health care”  
“they treat us better because you are here,” she says to me  
they gotta catch the woman having a seizure  
“ah, she's fine, she's already on the floor,” says the women's keepers  
'cuz according to them they're: fakers, manipulators, track marks/  
markers.

Recognizing the potential and purpose of this research as a vehicle for change was foundational in our ability to overcome feelings of privilege, frustration, anger, sorrow, powerlessness, guilt, and hopelessness.

### **Recommendations and Conclusions**

It is important to acknowledge outright that there are significant and numerous challenges and barriers to initiating and completing research in incarcerated settings. These are inevitable, and expectations, preparation, and timelines need to be adjusted accordingly. However, in spite of all the challenges, data collection with the women provided insightful lessons regarding the research process, and was rewarding, meaningful, and important.

Based on our research experiences, we have developed four recommendations for health researchers as to the challenges and opportunities of conducting research in incarcerated settings in general and with criminalized women in particular: (1) develop strong research relationships, (2) draw up a thorough safety and debriefing plan, (3) place oneself external to the system, and (4) use data-collection methods that provide opportunities for participants' voices to be heard.

Developing strong relationships and liaisons is critical to conducting research in any institutional environment. It takes on special significance in an incarcerated setting, as the researcher is unable to enter and move about the building without making prior arrangements. It is important to partner with insiders and include their insights about which research methods might be appropriate and likely to be approved. We found that taking the time to repeatedly explain ourselves to staff and describe the purpose of the research was particularly important when conducting research in a space where policing the whereabouts and activities of outsiders is an integral aspect of correctional officers' role. Helping staff to understand how the processes of recruitment and data collection were challenged by the incarcerated setting enhanced their willingness to continue supporting our study when deadlines for data collection were exceeded.

To process the challenging circumstances we witnessed, we found it necessary to have a thorough debriefing process in place for the research team. Our team meetings served several functions. They became a formal dialogic space to make sense out of what we were engaged and implicated in. Debriefing, with the aid of field notes that captured the immediate thoughts and feelings of a researcher after a data-collection session, was useful for contextualizing and giving deeper meaning to research findings, processes, and experiences (Arditti et al., 2010).

In addition to a debriefing process, there is a need to place oneself as the researcher, external to the correctional system (Roberts, 2011). This strategy meant emphasizing to the participants (and to ourselves) our connection to the university rather than to the detention centre. Because we foregrounded our identities as female health professionals and university-based researchers during the recruitment and consent process, the incarcerated women appeared eager to participate. We expressed genuine interest in what they had to say and conveyed an unwavering belief in the value of their opinions — a position that stood in direct contrast to their experience within the correctional system.

Lastly, the data-collection methods adopted should provide opportunities for participants' voices to be heard. We learned that the data-collection method mattered to both the participants and ourselves. The methods that required longer periods of engagement both enhanced the research-participant relationship and fostered a type of reciprocity unique to the incarcerated population. The demographic questionnaire and the quantitative assessment tool required much less time (20 minutes) than the individual semi-structured interviews (60 minutes) and were completed in a group setting (at the request of the correctional officers, due to time and space limitations) rather than in a one-on-one scenario. Participants' comments suggest that the time spent taking part in an individual semi-structured interview versus the briefer group health assessment served as an honorarium in and of itself.

Conducting research with criminalized women has, in retrospect, proved to be enriching, moving, and deeply impactful. We feel honoured and privileged to have worked with these participants. We hope that by sharing our challenges and successes with other health researchers, we will continue to carry the women's stories forward.

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### **Acknowledgements**

This work was supported by the Social Sciences and Humanities Research Council.

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Résumé

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## **Une évaluation de l'utilisation du RSAIS par le personnel infirmier en soins à domicile**

**Lynn M. Nagle, Peggy White**

Résultats dans le domaine de la santé pour l'amélioration de l'information et des soins (RSAIS) [Health Outcomes for Better Information and Care (HOBIC)], un programme financé par le ministère de la Santé et des Soins de longue durée de l'Ontario, introduit un ensemble de mesures de résultats cliniques fondés sur des données probantes et reflétant les réalités vécues dans le domaine des soins infirmiers. Les auteures font état d'une évaluation des expériences vécues par le personnel infirmier ayant participé au programme RSAIS dès ses débuts, en contexte de soins à domicile. Les résultats ont révélé la présence de nuances et de défis associés à l'introduction du RSAIS et l'utilisation de technologies d'appui dans le cadre de la prestation de soins infirmiers à domicile. Les futurs efforts de mise en œuvre doivent chercher à optimiser la convivialité de la technologie et l'utilité du RSAIS dans la pratique infirmière. D'autres efforts doivent être déployés pour soutenir la pleine intégration et l'utilisation maximale des données de résultats par le personnel infirmier et les gestionnaires en vue d'étayer les orientations en matière de pratique.

Mots clés : résultats, soins à domicile, RSAIS [HOBIC], technologies d'appui

# **Evaluating Nurses' Use of HOBIC in Home Care**

**Lynn M. Nagle, Peggy White**

Health Outcomes for Better Information and Care (HOBIC), a program funded by the Ontario Ministry of Health and Long-Term Care, introduces a collection of evidence-based clinical outcome measures reflective of nursing care. The authors report on an evaluation of the experiences of nurse early adopters of HOBIC in home care. The findings reveal challenges and nuances associated with the introduction of HOBIC and the use of supporting technologies in the delivery of home nursing care. Future implementation efforts should focus on optimizing the usability of technology and the usefulness of HOBIC in nursing practice. In addition, efforts need to be directed at supporting the full integration and use of HOBIC outcome data by nurses and management personnel to inform practice directions.

Keywords: outcomes, home care, HOBIC, C-HOBIC

## **Introduction**

In the Canadian province of Ontario a unique program is leading the way in introducing data standards across the health-care continuum. While the program's initial focus was the electronic collection of standardized clinical outcomes in acute care, complex continuing care, and long-term care, it has been extended to the home care sector. The long-term goal for Health Outcomes for Better Information and Care (HOBIC) information is that it will accompany patients and be updated and reviewed by nurses and other clinicians during transitions in care. It has been designed as the foundation for a common set of outcomes, to enable consistent monitoring and measurement throughout care trajectories and allow nurses to detect positive or negative changes in patients/clients over time. Given the increasing emphasis on reducing hospital readmissions, alternate level of care (ALC) days, and lengths of stay, and given the increasing incidence of functional decline in seniors in acute care, the use of HOBIC is worthy of consideration.

The implementation of information technology and electronic health records is critical to health-system integration; however, uptake in the home care sector has lagged behind that in other sectors (Canadian Home Care Association, 2008). Until recent years, a majority of if not all home care providers in Ontario were largely reliant on paper records and faxed referrals and schedules. The extent of ICT (information and com-

munication technology) use by home care providers in other jurisdictions is unknown. In Ontario, recognizing the need to move to electronic record management, a number of large home care agencies have begun to invest in applications and devices to support the work of nurses in the community (Bayshore Home Health, 2010; CellTrak Canada, 2010, 2012; ParaMed, 2013; Victorian Order of Nurses, 2008). Applications being deployed are access to online documentation, including the HOBIC tools, and productivity tools such as client and staff scheduling and Global Positioning System (GPS) mapping functions. Notwithstanding these efforts, the increasing emphasis on providing health services closer to home and in the home indicates a need for continued implementation of ICT in the home care sector.

On March 31, 2010, nurses working for a select group of home care organizations in Ontario began collecting the HOBIC standardized clinical outcomes. In this article, we report the findings of an evaluation of the home care early adopter experiences of collecting and using HOBIC. The evaluation was framed with consideration given to the experience and perceptions of the nurse users, impact on clinical processes, and usability and practicality of the technologies employed in the initial home care implementations of HOBIC.

### **Background**

The HOBIC program is funded by the Ontario Ministry of Health and Long-Term Care and managed by the Institute for Clinical Evaluative Sciences (ICES). It introduces a collection of evidence-based clinical outcome measures reflective of nursing care. The standardized clinical outcomes are as follows:

- functional status/activities of daily living (e.g., eating, bathing, personal hygiene, walking, transfer to toilet, toilet use, bed mobility, bladder continence)
- symptom status (e.g., pain, fatigue, dyspnea, nausea)
- safety outcomes (e.g., falls, pressure ulcers)
- therapeutic self-care/readiness for discharge (e.g., ability to manage medications, understanding of symptoms and how to treat them, general self-care ability, awareness of whom to contact for help, ability to handle or adjust activities of daily living)

The HOBIC program originated with the recommendations of an Ontario Nursing Task Force that identified the need for health information systems to provide comprehensive and reliable data on the impact of nursing services (Ontario Ministry of Health and Long-Term Care, 1999). Originally designated the Nursing and Health Outcomes Project, the initiative evolved into HOBIC in recognition of the efforts of other

health professionals contributing to the selected outcome measures. Nevertheless, from the outset HOBIC has been focused on the collection of standardized clinical outcomes in acute care, long-term care, complex continuing care, and home care.

Each HOBIC clinical outcome has a conceptual definition, has a valid and reliable measurement scale, and is based on empirical evidence linked to specific nursing functions (inputs and/or interventions) (Doran, 2003). Furthermore, each clinical outcome can be collected via standardized questions by nurses or other providers with applicability across the health-care system. Some of the measures are already part of other assessments, such as the interRAI™ (<http://www.interrai.org/index.php?id=3>) suite of tools. These instruments are also built on a core set of standardized assessment items and are already being used in complex continuing care, long-term care, and Community Care Access Centres (CCACs), the agencies that coordinate access to home care services throughout the province. In settings where some of the HOBIC measures exist as components of interRAI™ instruments already in use (e.g., functional status, symptoms of fatigue and dyspnea, falls, and pressure ulcers), outcomes are extracted from the documentation associated with these pre-existing tools and duplication is not required.

Table 1 lists the scales used to assess the HOBIC clinical outcomes by sector and frequency of assessment. Regardless of sector, nurses may opt to complete the assessments more frequently should a change in the client's circumstances warrant it.

The HOBIC concepts represent dimensions of patients' health status that all clinicians assess every day in their practice. The primary difference from traditional documentation is that information is gathered in a standardized way across sectors of care, supporting comparison at selected points in time within and across settings. In acute care and home care, the questions are asked upon admission and discharge. In long-term care and complex continuing care, clients are assessed on admission and quarterly bases, or if there is a significant change in health status. While not comprehensive of all nursing care, the measures have been demonstrated to be robust and sensitive to changes in status (Doran et al., 2006). Perhaps most foreign to clinicians is the evaluation of *therapeutic self-care* (i.e., a patient's self-care ability related to the disease/medical condition and its treatment) or readiness for discharge, which is assessed using an instrument developed by Sidani and Doran (Doran, Sidani, Keatings, & Doidge, 2002). While clinicians informally assess therapeutic self-care in acute care and home care, the HOBIC program introduces standardization to this component of the assessment, thereby providing information on clients' ability to manage their care when they are discharged from acute care or from the home care program.

**Table 1 Sources of HOBIC Information, by Sector**

<b>Concept</b>	<b>Acute Care</b>	<b>Complex Continuing Care</b>	<b>Long-Term Care</b>	<b>Home Care</b>
<i>Frequency</i>	<i>Admission/ Discharge</i>	<i>Admission/ Quarterly</i>	<i>Admission/ Quarterly</i>	<i>Admission/ Discharge</i>
Functional status	interRAI <sup>a</sup>	interRAI	interRAI	interRAI
Continence	interRAI	interRAI	interRAI	interRAI
Therapeutic self-care	Doran & Sidani tool	N/A	N/A	Doran & Sidani tool
Pain – frequency	interRAI	interRAI	interRAI	interRAI
Pain – intensity	0–10 numeric	interRAI	interRAI	ESAS <sup>b</sup>
Fatigue	interRAI	interRAI	interRAI	interRAI
Dyspnea	interRAI	interRAI	interRAI	interRAI
Nausea	MOH scale	MOH scale	MOH scale	MOH scale
Falls	interRAI	interRAI	interRAI	interRAI
Pressure ulcers	interRAI	interRAI	interRAI	interRAI
<sup>a</sup> <a href="http://www.interrai.org/">http://www.interrai.org/</a> <sup>b</sup> Edmonton Symptom Assessment System				

When feasible, HOBIC measures are embedded in existing admission and discharge assessments within organizational clinical information systems. The HOBIC data can therefore be collected at the point of care and then abstracted with admission, discharge, and transfer information to the central HOBIC database housed at ICES. For organizations that do not have an online clinical documentation system, a Web-based application has been developed to support electronic capture of the HOBIC data. Since two of the home care providers participating in our evaluation had not yet implemented a clinical information system, they were provided access to the HOBIC Web application. Using any Web browser, nurses were able to log into the HOBIC database, complete the HOBIC assessments, and print the information for inclusion in the client's paper health record. While it is not ideal to have both computerized and paper-based documentation tools, the two organizations saw this as an opportunity to introduce computerized functions to their providers and set the stage for the future acquisition of a clinical system.

In April 2012 the HOBIC data set received approval from the Ontario Health Informatics Standards Council (OHISC), the authority for recommending and endorsing health information standards in the province. OHISC approval acknowledges HOBIC as a standard that has been accepted, tested, and widely used by the nursing profession throughout the province. At the end of June 2012, approximately 186 provider sites across Ontario were participating in the HOBIC program. The HOBIC database included more than 900,000 assessments at that time and continues to grow daily. With direct access to the database, authorized clinicians have real-time access to information concerning individual clients, to use in planning and evaluating care. In addition, management personnel have real-time access to a variety of reports at the unit/program level to support quality improvements and to link with other data for performance reporting and benchmarking.

Early experiences with HOBIC in acute care are described elsewhere. In general, they highlight the merits of using standardized assessments in care planning, risk management, quality improvement, and accreditation (Nagle, White, & Pringle, 2007, 2010). McGillis-Hall and colleagues (2012) conducted an online survey with 37 nurse leaders in acute-care and long-term-care settings to derive strategies for future implementation and identify potential uses of the HOBIC data. Respondents reported numerous benefits of HOBIC, including data comparability, more effective care planning, and enhanced understanding of particular patient groups (e.g., the elderly). They also reported a benefit related to the use of technology and nurses' increasing comfort with electronic documentation. A study conducted in 2011 focused on the perspectives of 15 staff nurses in three clinical units of an academic health-care organization (Jeffs, Wilson, et al., 2012). The nurses described how the HOBIC measures "trigger" and "prompt" what to look for when one is completing patient assessments and also how they inform care planning. Another important finding of the study was the need for nurses to appreciate the overall value and benefits of HOBIC for patient care. This finding is consistent with the authors' anecdotal findings in discussions at HOBIC early adopter sites in all settings.

More recently, researchers have found evidence for the predictive use of HOBIC in conjunction with other measures, such as length of stay, ALC days, and readmission rates (Jeffs, Jiang, et al., 2012; McGillis-Hall, Wodchis, Ma, & Johnson, 2013; Wodchis, McGillis-Hall, & Quigley, 2012). Although preliminary, these findings offer direction and possibilities for research across the care continuum. In this article, we describe and discuss the findings from an evaluation of early adopter experiences in the home care sector.

### **Supporting Standardization in Home Care**

One of the lessons learned from HOBIC implementation in acute-care organizations is that clinicians collect a large amount of information at the time of admission, much of which is never used during the client's hospital stay. Therefore, one of the key tasks in working with the home care providers was to ensure that the information being collected was supportive of practice. In Ontario, although CCACs are responsible for the initial assessment of client needs to determine home care requirements, the delivery of services is contracted out to provider organizations (e.g., Bayshore Home Health, Victorian Order of Nurses, St. Elizabeth Health Care). Hence, in order to advance standardization of documentation in the sector, five large not-for-profit and for-profit providers in Ontario collaborated to delineate the data elements required for admission and discharge assessments in home care. A review of current paper-based assessments and mandated reporting for the sector resulted in a "letting go" of some information that had been historically documented, as it was deemed to not bring value to practice. The review process led to the development of a consensus-based standardized admission and discharge assessment for the sector. The use of common assessment tools set the stage for the comparability of outcomes among different providers of home care services.

### **Evaluation of HOBIC in the Home Care Sector**

Following the creation of the common assessment tools, three home care organizations volunteered to become early adopters of the HOBIC program. This allowed for an evaluation of the initiative in the sector prior to its implementation by other home care agencies. With the theoretical underpinnings from diffusion of innovations theory (Rogers, 2003) and the Technology Acceptance Model (TAM) (Davis, 1989, 1993), the evaluation was designed to derive learnings from the early adopters of HOBIC in the home care sector. According to Rogers (2003), early adopters are not necessarily the first to adopt an innovation once its benefits have been demonstrated, but typically are among the second group of adopters. Among the factors described as intrinsic to adoption is the perception of relative advantage, compatibility, and complexity or simplicity of the innovation. As these home care agencies were largely new to HOBIC and the use of computing devices in service delivery, this was seen as an opportunity to test the solutions and obtain feedback with a view to making enhancements and improvements. In addition to these concepts, Rogers's notions of the importance of trialability and observability of the tools allowed for the capture of reactions by clients and peers. Similarly, in Davis's (1989, 1993) TAM framework,

users' perceptions of the usability and usefulness of a technology are germane to their intention to adopt and use it. Because some challenges in the home care setting are not paralleled in institutions, the HOBIC provincial program leaders were interested in the overall perception and experience of the users (nurses, managers, educators, and clients) in collecting HOBIC data in people's homes and with the use of point-of-care technology to support same. As in other sectors, they were also interested in whether communications, documentation, and/or practice were impacted by the introduction of HOBIC. In sum, the evaluation was focused on the perceived usefulness and usability of HOBIC and the technologies employed in its collection as well as the impact on users and clinical processes.

### **Sample**

The implementation of HOBIC was initiated in select home care organizations in April 2010 and the evaluation was conducted 6 months post-implementation. The evaluation focused on the early adopters' initial experiences with collecting and using the HOBIC information. The sample of HOBIC users for the evaluation came from three home care organizations. These provider organizations varied in size but together employed approximately 160 registered nurses and registered practical nurses (agency A,  $n = 30$ ; agency B,  $n = 50$ ; agency C,  $n = 80$ ). While neither the CCAC nor clients were a focus of the evaluation, some client views were derived from the experiences of the nurse participants. The largest provider organization had already incorporated the standardized HOBIC admission and discharge assessments into its online clinical record. For the other organizations, however, these were new documentation tools; hence the training for the nurses in these organizations included orientation to the HOBIC elements of the admission and discharge tools.

### **Methodology**

Using a mixed-method approach, a single evaluator gathered information on users' perceptions and experiences using (a) an online survey; (b) focus groups to further explicate the survey results; and (c) interviews with senior leaders from each home care organization, to obtain their feedback and review the overall findings and recommendations from the evaluation.

**Survey.** The survey items were intended to determine the users' perceptions of usefulness and usability of the HOBIC tools and supporting technologies and whether completion and use of the HOBIC measures were deemed to be of value in home care nursing. Given the unique nature of this evaluation, no suitable existing questionnaire was found. A

short survey (23 questions) was developed using Survey Monkey<sup>®</sup> and was expected to take no more than 5 to 10 minutes to complete. A draft was circulated to three members of the HOBIC leadership team and the three senior home care leaders for their review in advance of distribution to the nurse users. Each was asked to vet the survey for readability and clarity. A number of frontline nursing personnel were also asked for their feedback on the survey. With the recommended changes incorporated, a revised survey was circulated for final review. The survey was deemed to have face validity but no other psychometric properties.

Completion of the survey was deemed to be consent for participation. The survey comprised three sections, focused on (a) the collection and use of the HOBIC measures (6 items), (b) perceived effectiveness of the computing device in use (6 items), and (c) extent to which the HOBIC information was perceived to have influenced practice (5 items). Respondents were asked to indicate, on a five-point Likert scale, the extent of their agreement with 17 statements (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree). They were also asked about their home computer use, comfort with computing, gender, years of nursing experience, years of home care nursing experience, and primary home care employer. All users of the HOBIC outcome measures were invited by their employers to complete the online survey. The survey was made available to potential respondents for a period of 6 weeks, from mid-September to the end of October 2010. The names of those who completed the survey were entered into a draw for an iPod, which was held when the survey closed.

**Focus groups.** Three focus groups were scheduled for October and November 2010. They were led by the evaluator and held in a meeting room on the premises of each home care organization. At the beginning of each session, the facilitator briefly described the background and current status of the HOBIC initiative, the rationale for the evaluation, and the purpose of the specific session. The discussions were guided by questions pertaining to the user experience in completing and using the HOBIC data, the applications, and the devices in use. These sessions also provided an opportunity for validation of the findings from the online survey. The evaluator documented key comments, questions, and suggestions for future consideration.

**Follow-up interviews with senior leaders.** Upon completion of the survey and focus group sessions, the senior leader from each home care organization was invited to meet with the evaluator. During these interviews, the senior leaders were given an opportunity to share their perceptions and feedback about the HOBIC experience and offer their recommendations for future implementations in the home care sector.

## **Findings**

Despite the differences in size of the early adopter organizations, there were no significant variations in terms of the users and the clinical documentation applications and devices in use. One of the provider organizations had already adopted an online clinical documentation system incorporating the standardized admission and discharge assessments. It intended to deploy this system across Canada for use by all of its visiting nurse employees. From this system, HOBIC data are being extracted and submitted to the HOBIC database on a daily basis. The other two organizations were using a Web-based application, HOBIC@HOME, developed specifically for home care to support their online documentation of admission and discharge assessments. This application includes store-forward capability so that in the event of lost Internet connectivity, nurses can still enter information and the data automatically uploads to the HOBIC database when connectivity is restored. This is an important feature for the home care sector, as many nurses work in rural and remote areas where wireless connectivity is unreliable or limited. HOBIC data collected via the HOBIC@HOME tool are also extracted and submitted to the HOBIC database on a daily basis. The types of computing device used to capture HOBIC data also differed. They comprised tablets, laptops, and netbooks, with some providers offering nurses the option of trying more than one type of device.

The home care providers varied in the type and number of users collecting HOBIC data (e.g., registered nurses, registered practical nurses, professional practice leaders). Nonetheless, all users received comparable education and training in the HOBIC tools and ongoing support provided internally by designated “super users” or clinical practice leaders. The senior leaders at all three organizations were supportive of the HOBIC implementation and eager to participate in the evaluation.

### ***Survey Results***

There were 69 responses to the survey, for a response rate of 43%. Although two respondents did not complete the entire survey, their answers were included when available. A majority of respondents were female (95.5%) and 92.5% reported having more than 6 years' nursing experience and 52.3% more than 16. In terms of home care nursing, 71.2% had more than 6 years' experience and 21.3% more than 16. Overall, 95.5% of the respondents reported having access to a computer outside of work and only 6% reported being uncomfortable using a computer. A majority, 56.7%, reported being “very comfortable” and 37.3% “somewhat comfortable” using a computer. There may well be a

degree of response bias associated with this question, as those completing the survey were more at ease than others with doing so online.

A majority of the responses (61.2%) came from providers working for the largest home care organization (agency C), suggesting that the responses might not have been entirely representative of all three participating organizations. Nonetheless, the findings from the focus groups subsequently lent support and validation to the survey results, indicating that the prevailing views were shared within all three.

**Perceived ease of collection and use of HOBIC.** Overall, a majority of respondents agreed or strongly agreed that the HOBIC measures are easy to use (65.2%), are relevant to care (53.6%), inform clinical practice (62.3%), support clinical decision-making (62.3%), are not reviewed at each visit (60.9%), and are perceived to increase workload (79.7%). This finding is illuminated by the perspectives and experiences shared in the focus group discussions.

<b>Table 2 Frequency Distribution of Responses: Collection and Use of HOBIC</b>						
<b>The following question relates to the collection and use of the HOBIC outcome measures (e.g., functional status, continence, symptoms, falls, skin breakdown, and therapeutic self-care). The HOBIC outcome measures:</b>						
<b>N = 69</b>	<b>Strongly disagree % (n)</b>	<b>Disagree % (n)</b>	<b>Neither disagree nor agree % (n)</b>	<b>Agree % (n)</b>	<b>Strongly agree % (n)</b>	<b>Mean</b>
Are easy to use	8.7 (6)	10.1 (7)	15.9 (11)	<b>60.9 (42)</b>	4.3 (3)	3.42
Are reviewed at each client visit	20.3 (14)	<b>40.6 (28)</b>	17.4 (12)	20.3 (14)	1.4 (1)	2.42
Are relevant to the care of my clients	1.4 (1)	11.6 (8)	33.3 (23)	<b>50.7 (35)</b>	2.9 (2)	3.42
Inform my clinical practice	2.9 (2)	10.1 (7)	24.6 (17)	<b>58.0 (40)</b>	4.3 (3)	3.51
Support clinical decision-making	2.9 (2)	11.6 (8)	23.2 (16)	<b>58.0 (40)</b>	4.3 (3)	3.49
Create additional workload	1.4 (1)	5.8 (4)	13.0 (9)	<b>43.5 (30)</b>	36.2 (25)	4.07

Table 3 <i>Frequency Distribution of Responses: Perceptions of Computing Device</i>						
The following question is intended to understand the extent to which the computer (e.g., laptop, tablet, netbook) you are using is an effective tool. The computer that has been provided to me:						
N = 69	Strongly disagree % (n)	Disagree % (n)	Neither disagree nor agree % (n)	Agree % (n)	Strongly agree % (n)	Mean
Is easy to use	14.5 (10)	13.0 (9)	21.7 (15)	<b>42.0 (29)</b>	8.7 (6)	3.17
Is reliable	26.5 (18)	16.2 (11)	26.5 (18)	27.9 (19)	2.9 (2)	2.65
Is sufficiently portable for my clinical work	4.4 (3)	20.6 (14)	17.6 (12)	<b>50.0 (34)</b>	7.4 (5)	3.35
Makes access to client information more efficient	5.8 (4)	10.1 (7)	36.2 (25)	<b>40.6 (28)</b>	7.2 (5)	3.33
Makes documentation of clinical visits more efficient	11.6 (8)	27.5 (8)	<b>31.9 (22)</b>	24.6 (17)	4.3 (3)	2.83
Has added value to my clinical practice	8.7 (6)	18.8 (13)	29.0 (20)	<b>37.7 (26)</b>	5.8 (4)	3.13

**Perceived ease of use of computing devices.** These items were intended to elicit a sense of the user's satisfaction with the computing device that was provided. The three early adopter organizations deployed three devices: the Motion C5™ tablet, the Lenovo™ notebook, and the HP™ netbook. Two of the organizations offered their nursing personnel more than one option, to determine which design was preferable.

Although the responses regarding the portability (57.4%) and access (47.8%) features of the computing devices were largely positive, the issues of perceived reliability, efficiency, and value added to practice varied among respondents. While some of the comments offered insights as to why this might be so, more discussion of device issues ensued within the focus groups. The comments indicated that laptops were the preferred device. Tablets were considered too heavy and more difficult to use. The users liked having a keyboard rather than a touch screen.

Table 4 <i>Distribution of Responses:</i> <i>Perceptions of HOBIC Impact on Practice</i>						
The following question addresses the extent to which the use of the HOBIC outcome measures has influenced your practice. Using the HOBIC outcome measures has:						
N = 67	Strongly disagree % (n)	Disagree % (n)	Neither disagree nor agree % (n)	Agree % (n)	Strongly agree % (n)	Mean
Improved the consistency of clinical documentation	9.0 (6)	16.4 (11)	25.4 (17)	<b>47.8 (32)</b>	1.5 (1)	3.16
Made the completion of clinical documentation more efficient	9.0 (6)	20.9 (14)	25.4 (17)	<b>41.8 (28)</b>	3.0 (2)	3.09
Been easy for me to integrate into my practice	7.5 (5)	16.4 (11)	35.8 (24)	<b>37.3 (25)</b>	3.0 (2)	3.12
Improved the timeliness of communication with other care providers	13.4 (9)	34.3 (23)	<b>41.8 (28)</b>	7.5 (5)	3.0 (2)	2.52
Improved the timeliness of completing client documentation	20.9 (14)	<b>40.3 (27)</b>	22.4 (15)	13.4 (9)	3.0 (2)	2.37

**Perceived influence of HOBIC on practice.** Responses to the use of the HOBIC measures were weighed in terms of pros and cons (e.g., the time needed to complete the HOBIC assessments was offset by the value derived from identifying other client issues that needed to be addressed).

The findings of improved consistency and efficiency of clinical documentation are promising, while the timeliness of communication with other care providers appears to have had less impact. The timeliness of client documentation was not improved, with a majority of respondents (61.2%) disagreeing or strongly disagreeing with this statement. We spec-

ulated that this finding was related to the perception of increased workload associated with HOBIC, which the focus group discussions subsequently confirmed.

### **Focus Groups**

A focus group was conducted with representatives from each of the home care organizations to further validate the survey findings and solicit additional perspectives on the early adopter experience with HOBIC for both managers and nurse users. A total of 26 registered nurses, registered practical nurses, professional practice leaders, and team leader/supervisory/management personnel participated in one of the focus groups (agency A,  $n = 10$ ; agency B,  $n = 6$ ; agency C,  $n = 10$ ). A consistent set of questions was posed to each group to further explore the survey responses and to focus on the perceived usefulness and usability of HOBIC and the collection technologies employed, as well as the impact on users and clinical processes.

A number of consistent themes emerged from the collective reflections of the focus group participants.

**Perceived effectiveness of education and training.** Peer-to-peer training was identified as the most effective way to engage nurses in the adoption of the technology. However, participants felt that the training sessions provided too much information at one time. Further, some found it frustrating to have novice and expert computer users mixed together in a training session, believing that sessions should be scheduled to keep those with similar levels of computer literacy together. Participants suggested that education to do with HOBIC and training in the use of the application and device be addressed separately, to ensure that nurses appreciate the significance of the HOBIC outcome measures. In addition, it was suggested that once users have reached a level of comfort with the technology the rationale for HOBIC be revisited so that, over the long term, nurses do not see this simply as yet another data-collection exercise. Overall, participants felt that cycling back to users monthly for about 6 months after go-live would be helpful for identifying and resolving any application, device, or HOBIC issue in a timely manner. Further, both managers and nurse providers expressed an interest in and a need for follow-up education and support with respect to the effective use of HOBIC data and reports.

**Perceived applicability of HOBIC measures to clients.** Participants questioned the applicability of the activities of daily living assessment to many of their clients. In particular, a significant number of individuals being seen for follow-up home care are young and able-bodied. Participants believed that this assessment would, in many instances, be a waste of their time or inapt. Others commented on the length of the

assessment and said that some of the items seemed redundant. This perception of redundancy, although not validated, may have arisen from requirements to duplicate documentation due to other requisite components of organizational and sector reporting.

Participants also offered design suggestions, most notably a decision-support function that would generate an age-, diagnosis-, or visit-appropriate (short or long stay), quasi-customized assessment.

**Review of HOBIC assessments.** In discussing their use of HOBIC assessments, participants indicated that assessments were rarely reviewed during actual visits, as providers often lacked the time. Nurses also indicated that, because of the large number of short-stay clients, in many instances discharge assessments are never completed (an estimated 40% of the time). In addition, due to environmental conditions, nurses do not always take their computing device into the home, so the HOBIC data are not always available at the time of a visit. Moreover, a single client's nurse providers may not be constant. Hence, printing and leaving a copy of the HOBIC assessment for others to review was suggested as a way of encouraging them to do so.

**Client perceptions of computer use.** An interesting discussion arose regarding clients' perceptions of computer use in the home. Some nurses reported that clients had commented that it was encouraging to see the home care sector catching up with the rest of the health-care system in computer adoption. Nurses also reported that some clients expressed concern if the nurse did not have a computing device during the visit. They commented that computing devices seemed to boost the clients' confidence; some clients were under the illusion that the nurse also had connectivity with their family physician and the hospital. Other nurses indicated that clients were not pleased with having a device present, claiming that it interfered with their interactions. It was suggested that, in the transition to computerized clinical documentation, client education should be an important consideration at the outset of any implementation. Anecdotally, the inclusion of clients and families in the HOBIC review process has been found to be beneficial in garnering their interest and support regarding the use of computing devices in other sectors.

**Duplication of documentation.** There is a significant degree of redundant documentation in the home care sector, which nurses viewed as compounded with the introduction of HOBIC. Nurses who used a computing device only to complete the admission and discharge assessments found that they had to duplicate the documentation of several data elements on other forms, including those required by the referring agency (e.g., CCAC). Having their documentation tools auto-populate some of the CCAC tools, or at least link to the CCAC, was deemed a

useful functionality worthy of consideration. Completing paper forms is a workload burden consistently experienced by home care nurses, a burden that is only worsened by the need to record visit notes and findings on paper for later electronic input.

The numerous forms that must be completed by home care nurses make it obvious that computing devices represent an opportunity to streamline documentation. In view of the volume of forms they are required to complete, it is not surprising that some nurses viewed the introduction of HOBIC as yet another data-gathering exercise rather than as a useful tool for their practice. The participants validated the survey findings, with the majority indicating that HOBIC had increased their workload and time spent on documentation. In general, they did not find that using an online tool was necessarily more efficient.

**Communication with other providers.** Users of the complete online system expressed frustration that the outputs of their assessments were not available to other providers (e.g., physicians, dietitians). They were required to leave a paper note, the chart being no longer available in the home for any other provider seeing the client. Further, they indicated that it would be useful to have access to HOBIC data from other care sectors (e.g., acute-care discharge HOBIC available upon admission to home care) to support the planning and management of care across the continuum. At the time of writing, another HOBIC initiative is underway, focused specifically on providing and evaluating the impact of HOBIC access across care settings and among a broader group of providers involved in an individual's care.

**Perceived usefulness and practicality of computing device.** Overall, nurses indicated that the computing devices they were using did not consistently meet their needs. They found the touch screen on the tablet difficult to use, while those using laptops or netbooks preferred the full keyboard. Tablet users reported the devices as heavy but found the stylus good for tick-box applications. Tablet users also tried making narrative notes, but the handwriting recognition was deemed too slow and the transformation to type not very accurate.

Several participants raised the issue of not wanting to take the device into the homes of certain clients. Issues of infection control and cleanliness were raised; in some situations, nurses were concerned about finding a place to lay the device. In several instances, the nurses left their device at home and made their online assessment later. Others were concerned about leaving the device in their car for fear of theft and damage to the vehicle. Several participants said that they would much prefer a BlackBerry™ type of device that could also serve other purposes. Some nurses cited the lack of continuous wireless capability as another barrier to ease of use.

Comments were made about unreliable network connectivity, log-on and printing difficulties, the frustration of different password expiry timeframes (HOBIC@HOME password expiration different from provider's network password), the need for password resets (request for HOBIC password lists), and trying to get help from someone who lacks an understanding of one's practice.

***Perceived usability of HOBIC application.*** A number of the application issues identified were directly linked to the need for additional training or to users' level of computer literacy. But there were extreme responses with respect to the value and acceptance of HOBIC. One participant described the HOBIC@HOME application as "like a hot stove," while another stated, "I love it!" The participants expressed an interest in having other measures (wound type and outcome, mental status) incorporated into the HOBIC assessment; this finding is consistent with the views expressed by early adopters in other sectors and provides direction for future expansion of the HOBIC suite of measures.

Some issues were clearly related to the design of the application and had little to do with the HOBIC measures directly. Users described a preference for specific features, such as scrolling capability versus point-and-click and the value of embedded drop-down menus such as HOBIC help screens. The existing HOBIC report functionality was also deemed to need review, revision, and enhancements to meet the needs of the home care sector. Managers indicated that they would like to be able to monitor outcomes longitudinally for specific client populations in support of ongoing improvements to service delivery.

There was variability within and between focus groups, depending on the device in use and whether the participant needed to use it for other tasks. For users of the HOBIC@HOME application, the need to continue providing all other documentation on paper made computerized access to HOBIC more of a burden. Nurses from the home care organization that had migrated entirely to an online documentation system found the transition from a paper chart that also included the HOBIC measures to be an easy process.

### ***Senior Leadership Feedback***

A total of seven leadership interviews were conducted (agency A,  $n = 3$ ; agency B,  $n = 1$ ; agency C,  $n = 3$ ). The senior leaders vetted the findings with others on their respective leadership teams; with few exceptions their commentaries indicated that the evaluation had aptly captured the home care experience of nurses using HOBIC in their organization. There was agreement among the leaders from all three organizations regarding the following priorities:

- Revisit the purpose of HOBIC with all nurse users following implementation.
- Continue to review emerging technology options, particularly design improvements to applications and devices of choice to support data capture.
- Examine possibilities for streamlining and consolidating clinical documentation within the home care sector.
- Review the applicability of the HOBIC measures to all home care clients and determine the most appropriate target populations.
- Continue to advance the longer-term vision for wholly integrated clinical documentation that is accessible to other disciplines and provider organizations across the care continuum.

Overall, the senior leaders saw the value of participating in the early adoption process and expressed appreciation for the opportunity to learn from one another's experiences.

### ***Limitations of the Evaluation***

The data analysis did not control for differences in approaches to implementation, user experience with technology, or access to resources such as super users or supplementary support personnel. Also, the evaluation did not delve into specific usability issues of either the applications or the technologies used to support the collection of HOBIC data. Future evaluations might focus more intensively on specific design issues and explore the contextual supports provided within organizations to facilitate adoption of technological solutions.

Further, there could be response bias due to nurses' varying levels of comfort with online surveys (e.g., those with greater comfort may have been more inclined to participate). Since the majority of responses came from nurses working for the largest home care organization, the results may well have been skewed. But even though these nurses had been using all of the HOBIC measures several months longer than the others, on paper and electronically, the substantive issues raised in the focus groups were notably consistent across all organizations.

During discussions with HOBIC senior leaders, the issue came up of whether the evaluation was conducted too soon to capture the degree of HOBIC integration and use in practice. Follow-up evaluation at 12, 18, and 24 months, as each organization advances in its adoption of electronic clinical record solutions, could reap valuable insights.

## **Discussion**

The collection of standardized clinical information benefits clients, nurses, and the health-care system. As patients move from one sector of

the health-care system to another, it is important that information follow them in order to ensure coordination and continuity of care. The HOBIC suite of measures provides valuable information to support care transitions. These standardized measures also support nurses' accountability by providing information that enables comparison and benchmarking and an understanding of what practices lead to improved health outcomes. Furthermore, they can provide administrators with valuable information on the performance of their organizations in terms of outcomes management (i.e., how well staff are preparing patients for discharge).

Studies focused on nurses' perceptions of the usability of technological solutions and the clinical usefulness of a suite of measures such as HOBIC are limited in number (Jeffs, Jiang, et al., 2012; Jeffs, Wilson, et al., 2012; McGillis-Hall et al, 2012, 2013). Those focused on the home care sector are particularly scarce and consist largely of vendor-driven testimonials to the success of a specific solution (CellTrak Canada, 2010, 2012). Now more than ever before, there is an opportunity and a need for nurses to provide input and evaluate emerging technology to ascertain fit with practice in different settings.

The early adopters in this evaluation underscored the importance of obtaining nurses' views on the usefulness and usability of the HOBIC measures and the supporting software and hardware. Technological issues clearly impact nurses' intention to use these tools and integrate them into their practice. Nurses' perception of the limited usefulness of HOBIC for certain clinical populations in the community has led to a rethinking of the circumstances appropriate for its deployment. Issues around the usability and practicality of the technologies have also led to further evaluation of devices and modifications to the HOBIC@HOME application, in particular the redesign of reports to ensure their relevance for home care nursing.

Although many of the issues identified in this evaluation relate to the introduction of new technology in home care nursing, the implications for the collection and use of HOBIC data are clear. Many of the issues raised by the participants could be rectified with education and support directed at both clients and providers. As for the technology, it is obvious that ideal application and hardware solutions have yet to be identified.

While not necessarily a direct result of the introduction of HOBIC, the perception of additional workload related to documentation has nonetheless been associated with HOBIC. The prevalence of duplicate documentation and the multiplicity of forms to be completed by home care nurses will be a challenge in the face of any new documentation requirements. In sum, the long-term success of initiatives such as HOBIC depends on the use of a clinical information system that integrates all aspects of clinical documentation and interfaces with relevant down-

stream systems. Future user evaluations should continue to consider Rogers's (2003) concepts of relative advantage, compatibility, and complexity of use.

Nurses in all settings need to be given opportunities to trial technological solutions and to provide feedback and recommendations to ensure that they are equipped with tools and technologies that support rather than impede their practice. Equally important is educating nurses in the importance of using outcomes information such as HOBIC to inform their practice. The use of outcomes information in the management and monitoring of care must be made a cornerstone of entry-to-practice nursing competencies. With the increasing integration of clinical information systems between care settings, the use of standardized measures such as HOBIC promises to improve continuity of care and communication among providers.

### **Implications for the Future**

Researchers have traditionally used historical data. Electronic documentation based on standardization enables them to use real-time data. These data are readily accessible and retrievable, whereas the traditional method involves the time-consuming task of sifting through stacks of charts for information (Rutherford, 2008). Timely access to measures such as HOBIC will not only support clinical decision-making but also increase the ability to evaluate clinical practice, make improvements to the health-care system, and enable benchmarking practices.

The HOBIC database can potentially be linked to other databases, such as the Canadian Institute for Health Information's Discharge Abstract Database. The importance of this type of linkage is reflected in recent studies using the HOBIC database in conjunction with other data sources. Specifically, researchers have begun to examine the relationship between HOBIC acute-care discharge measures and the likelihood of acute-care readmission within 3, 30, 60, and 90 days; changes in clinical health outcomes between admission and discharge in acute care; and the ability of this suite of standardized clinical information to predict the need for ALC status and length of stay for patients admitted to acute care (Jeffs, Jiang, et al., 2012; McGillis-Hall et al., 2013; Wodchis et al., 2011). The findings of studies such as these are only beginning to emerge but show great promise for the use of standardized clinical data, demonstrating nurses' contributions to care and serving as a starting point for linking clinical interventions to care outcomes. Future nursing research could also focus on the relationship between HOBIC and the use of best practice guidelines, the impact of HOBIC on transitions between sectors of care, and the impact of structural variables such as staffing and staff mix

on outcomes. Health-system research should further examine the relationship between outcomes and factors such as length of stay, emergency room visits, hospital readmission rates, and population-based needs.

Future HOBIC implementations should attend to the findings of this informative albeit limited evaluation, not least of which is the need to emphasize the use of HOBIC data to inform practice rather than having it viewed as a means of data collection. To this end, in any implementation, HOBIC should be deployed as a management and practice tool for nurses at all levels. Technology acquisitions to support the capture of clinical data should focus on features and functions that optimize usability and adoption. Based on the views of the participants in this study, the ideal application and device have yet to be realized, particularly in the context of the unique issues encountered in the home care sector.

Consideration must also be given to extending the HOBIC suite of measures to include other outcomes important to nursing practice. In particular, a measure of mental health has been repeatedly identified as a critical domain needing consistent capture and monitoring by nurses in all sectors. The participants in this evaluation also posed questions about the applicability of the current set of HOBIC reports to the home care sector. These should be reviewed and discussed with a view to modifications that are meaningful for provider organizations.

In sum, this evaluation has produced a number of important insights to inform future implementations of HOBIC in any setting, as well as several that are unique to the experience of home care nurses. Subsequent deployments of HOBIC and associated technologies should continue to be evaluated, as our understanding of nurse perceptions of usability, usefulness, and benefits to be derived is as yet very limited.

### **Conclusion**

The results of this evaluation show clearly that there are some unique challenges and nuances in the implementation of online documentation to support the delivery of home nursing. Nonetheless, a finding consistent with the experience of other sectors (e.g., acute care, long-term care) is the need to cycle back to nurses and managers to ensure that HOBIC data are used to inform and review practice outcomes. Overall, the nurses and management personnel who took part in the focus groups expressed overwhelming enthusiasm and support for this work and a commitment to seeing it continue into the future. The collection of HOBIC data in the home provides an important understanding of client needs and abilities beyond acute episodes of care. In the future, the transmission of HOBIC and other clinical data between care settings and providers will

further enhance the continuity of information and care delivered throughout the province of Ontario and beyond.

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*Résumé*

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**La prévention du tabagisme chez les jeunes :  
une démarche concertée mobilisant les parents,  
le milieu scolaire et la société**

**Sandra P. Small, Kaysi Eastlick Kushner,  
Anne Neufeld**

L'objectif de la présente recherche était d'étudier les points de vue de différents professionnels sur la prévention du tabagisme chez les jeunes. Les chercheurs ont utilisé un modèle d'étude qualitatif et descriptif reposant sur un échantillon par choix raisonné qui consistait en un groupe de neuf professionnels composé d'enseignantes ou enseignants du niveau primaire, d'infirmières ou infirmiers de la santé publique et de spécialistes de la lutte contre l'usage du tabac provenant d'organisations non gouvernementales. Les données de l'étude ont été recueillies au moyen d'entrevues semi-dirigées et analysées de manière à en dégager les thèmes. Selon l'opinion des participants, bien que la responsabilité d'éduquer les enfants à propos du tabagisme incombe principalement aux parents, seule une démarche concertée mobilisant également le milieu scolaire et la société de façon plus générale permettra d'obtenir les meilleurs résultats. La nécessité d'une démarche globale présentant de multiples facettes et usant de plusieurs moyens de communication pourrait expliquer pourquoi les interventions isolées de prévention du tabagisme sont généralement inefficaces. Les infirmières et infirmiers de la santé publique occupent une position de premier plan pour encourager et soutenir les efforts de prévention du tabagisme déployés par les parents auprès de leurs enfants ainsi que pour promouvoir l'adoption de politiques sociales rigoureuses en matière de lutte contre l'usage du tabac ainsi que de pratiques exemplaires relativement à l'élaboration des programmes de prévention du tabagisme dans les écoles.

Mots clés : enfants, infirmières et infirmiers, tabac et santé, tabagisme, écoles, recherche qualitative

# **Smoking Prevention Among Youth: A Multipronged Approach Involving Parents, Schools, and Society**

**Sandra P. Small, Kaysi Eastlick Kushner,  
Anne Neufeld**

The purpose of this research was to examine the perspectives of professionals on youth smoking prevention. The researchers used a qualitative descriptive design with a purposive sample of 9 professionals consisting of elementary school teachers, public health nurses, and tobacco control experts from non-governmental organizations. Data were collected through semi-structured interviews and were analyzed for themes. The view of the participants was that although parents have the main responsibility for educating their children about smoking, a multipronged approach, which also includes school and society more generally, will have the greatest effect. The need for a comprehensive, multifaceted, multi-channel approach might explain why single smoking prevention interventions are often ineffective. Public health nurses are in a prime position to foster and support parents' smoking prevention interventions with their children and to advocate for strong tobacco control social policy and best practice for smoking prevention curricula in schools.

Keywords: children, nurses, tobacco and health, smoking, schools, qualitative research

Tobacco use is a leading cause of preventable illness and death worldwide and has been described as a global epidemic (World Health Organization [WHO], 2011b). One half of all long-term smokers die prematurely from tobacco-related diseases (US Department of Health and Human Services [USDHHS], 2010). Tobacco use causes personal suffering and family burden due to resulting chronic illness and disability and socio-economic burden because of health-care costs and lost productivity (USDHHS, 2010; WHO, 2008). The financial costs to nations are enormous, consuming significant proportions of the gross domestic product (WHO, 2011a). In Canada the annual economic cost of tobacco abuse has been estimated at \$17 billion (Rehm et al., 2006).

Smoking initiation typically happens in adolescence (USDHHS, 2012). Tobacco dependence occurs rapidly, even at low levels of cigarette use (Di Franza et al., 2002, 2007), and is considered a childhood condition (Hu, Muthen, Schaffran, Griesler, & Kandel, 2008). Initiation at a

young age is associated with heavy smoking (USDHHS, 2010). Tobacco use is also associated with subsequent alcohol and illicit drug use among youth and has been described as a gateway drug (National Center on Addiction and Substance Abuse at Columbia University, 2007).

Although youth smoking has declined in some economically advantaged countries in recent years, rates are high in many countries worldwide and smoking remains a major public health concern (USDHHS, 2012). In Canada 14% of adolescents aged 15 to 19 are current smokers (Health Canada, 2011) and 22% of children aged 11 to 14 have at least tried smoking (Health Canada, 2010b). However, cigarette smoking is only one part of the story, as many youths globally smoke tobacco in other forms, such as little cigars and pipes (Health Canada, 2010a, 2010b; Warren, Asma, Lee, Lea, & Mackay, 2009). Clearly, smoking prevention among youth is needed to end the epidemic, suffering, and costs to society (USDHHS, 2012).

Traditionally, smoking prevention efforts have largely been directed at adolescents. However, primary prevention should include younger children before they are at the vulnerable adolescent stage. Little is known about the perspectives of professionals in the field with respect to smoking prevention efforts for younger children. Therefore, the following question was addressed in this research: *What are the perceptions of professionals whose work involves smoking prevention concerning youth smoking, social influences on youth smoking, and smoking prevention, especially among pre-adolescents?* Insight obtained from professionals in the field could inform smoking prevention interventions for that cohort of children. This research was part of a larger study (Small, Eastlick, Kushner, & Neufeld, 2012) on parents' communication with their children about smoking.

## **Method**

The study was approved by the two affiliated ethics review boards and informed written consent was obtained from the participants. The research took place in a city in eastern Canada. A qualitative descriptive design was used.

### ***Sample***

Participants were recruited through administrators in elementary schools (kindergarten through grade 6), a community health authority, and non-governmental organizations (NGOs) with a smoking prevention mandate. The administrators were given information about the study and the need for a sample of professionals who had expertise in the area of youth smoking or had experience working with youth, including

smoking prevention. The administrators were asked to inform suitable employees about the study. Nine employees expressed an interest and were selected to participate. Data analysis was begun concurrent with data collection and revealed sufficient data from these participants to capture their perspectives on the subject. Hence, the purposive sample consisted of two teachers from a public elementary school in a middle-class neighbourhood, two public health nurses (PHNs), and five employees of three NGOs. The teachers had a number of years' experience teaching children in elementary schools, teaching different grades and subject matter, including health. The PHNs had extensive public health experience. They had been involved in providing smoking education and cessation programs for youths and others. The NGO employees had academic backgrounds in education, arts, or health promotion. They had varied experience in such areas as smoking prevention education, anti-smoking advocacy, antismoking social marketing, and smoking cessation counselling.

### ***Data Collection and Analysis***

Data were collected through semi-structured interviews. An interview guide was used to elicit the perceptions of participants. Broad open-ended questions were used, such as *What social factors influence children to smoke (not to smoke)? What programs are currently in place to prevent children from smoking? What can be done to prevent smoking in children? What factors are helpful for an effective approach (barriers to an effective approach)?* The responses were probed for detail. The interviews were conducted in person and in private by the first author. They were audiorecorded and transcribed verbatim to form the text for data analysis.

The analysis was carried out principally by the first author, with team meetings to discuss the findings and finalize the results. The approach used was "conceptual ordering" as proposed by Strauss and Corbin (1998), whereby data are organized into distinct categories, called themes, based on their characteristics. Description was used to delineate these themes and associated relationships. The procedures for data analysis were also based on the work of Strauss and Corbin (1998) and involved coding, comparison, memo-writing, and diagramming. Open coding with a sentence-by-sentence approach was used to identify concepts and their properties. Incidents in the data were compared for similarities and differences both within and across interviews. Those that were conceptually similar were combined to form themes. Memos were written to help derive the concepts, themes, and relationships. Diagrams were drawn and refined to illustrate the themes and how they were connected.

## Findings

The view of the participants was that smoking prevention among youth requires strong and sustained effort by three key players: parents, schools, and society. Although each player can make a contribution, it is the link among them and the combined effort that have the greatest effect. Parents have the main responsibility for educating their children about smoking. Schools have a responsibility to reinforce the antismoking message. Ideally, the efforts of parents and schools are mutually supportive. Society has a responsibility to support both parents and schools through social policy. Provision of resources for parents is important. One participant concluded, “Parents work together with teachers, and I think society is responsible as well.” The perspectives of the participants are represented by the theme *smoking prevention requires a multipronged approach involving parents, schools, and society*.

### ***Parents Have the Main Responsibility for Educating Their Children About Smoking***

The participants thought that parents are a young child’s greatest “influence” and that smoking prevention education should come from them first and foremost. Although they did not have direct knowledge, the PHNs and NGO professionals thought that many parents might not address smoking with their young children. They surmised that parents fail to address smoking early for any number of reasons: They do not know the facts about youth smoking; they do not view smoking as a relevant issue for young children; they think that it is being dealt with in school; they simply do not “feel equipped” to address smoking or do not know what approach to take — this could especially be the case for parents who smoke.

*Parents aren’t sure . . . when, at what age, to [broach] the subject . . . Lack of communication is a big barrier [to smoking prevention]. A lot of . . . parents don’t necessarily know how to talk to their kids [about smoking] . . . they don’t know how to tell their kids how [to] say no to a peer group.*

Those professionals had made the observation that although their organizations had services and resources concerning smoking, rarely had parents sought help to proactively talk with their children. That observation supported their view that parents might not be dealing with the issue:

*In 18 years, I don’t remember ever having been contacted by a parent to say . . . “I have young children and what resources are available for me to educate them on the risks of smoking.” I’ve never had those questions.*

When parents sought help, it usually was because they had discovered that their children already were smoking and they wanted to know what they could “do to help their kids,” which is a late point for intervention. The view of the participants was that parents could have an effect, and a long-lasting one, by using an approach that entails both proactively talking with their children about smoking and displaying behaviour that is consistent with an antismoking message, such as having non-smoking homes and vehicles.

**Talking with children about smoking.** Participants contended that parents should start speaking about it as soon as the children are old enough to understand. “Even a toddler can get some message around it”; “The earlier the intervention the better . . . like preschoolers . . . [if] they’re taught . . . the negative things about smoking . . . [they] just grow up knowing that.” Parents should continue to talk about smoking “often” throughout childhood using a “casual” approach. Such an approach involves taking advantage of everyday “opportunities” — for example, using an antismoking advertisement on television to raise the topic and convey key messages. It is not necessary to have a scheduled or formal discussion, and it is important not to overdo it. Talk about it “without smothering the child”; “Bring it up a lot in casual conversation. . . . It’s okay to talk about it a lot if it’s in casual conversation.”

*I think using the teachable moments with children all along, integrating it into their everyday life, not sitting down and having a special session: “Now we’re going to talk about why you shouldn’t smoke.” Just . . . using all the times that parents . . . have to put in the key messages about not smoking. . . . And then of course [it] needs to be constantly reinforced at those teachable moments.*

The participants thought that parents should use “open dialogue” and engage their children in discussion. Telling children not to smoke or using an authoritarian approach might not work and could backfire if children choose to rebel against parental authority as they get older. “I think keeping that open dialogue, because . . . when you get into those teenage years you want to rebel and you want to do your own thing and you want to discover who you are.”

*Not attacking them about the negatives of it . . . some of the kids will want to rebel against that: “You said it’s no good, but, really, is it?” So just try and get their opinions on it. . . . If they see people smoking, they’re obviously going to be curious and want to know what that is . . . maybe the smell from a smoker is enough to kind of turn them off. . . . Work with them to get them to see the true effects of smoking and the danger of smoking. I don’t know if you need to . . . preach to them. . . . If you make*

*a child, even a 5-year-old, feel important and feel that they're contributing to a conversation . . . they learn better or they learn to react the right way. . . . just going at it positively and not taking a lecture style, a scolding type approach.*

The participants thought that the message should be age-appropriate, “depending on their developmental level.” Young children need only a simple message about the health “benefits of not smoking. . . . ‘If you don’t smoke, then you can be more healthy and do more fun activities . . . you can run and play longer’ . . . Put kind of a positive spin on it.” Older children, pre-adolescents and adolescents, need more detail about the health consequences. They are better able to cope with “candid” messages about health effects or messages with “shock value” than younger children, who could become “scared.” Older children need to know about the factors that influence children to begin smoking, especially peer pressure, and be given guidance on how to resist it. They need to understand about addiction and how difficult it is to quit smoking once a person begins. Parents who smoke should talk in an “open” and “honest” way about their smoking and addiction. They should make it clear to their children that they are aware of the “contradiction” they are living and that they would like to quit smoking:

*It's really important . . . for the smoking parent to be saying, “I'm addicted to this” . . . “This is a drug” . . . “This is something that I'm desperate to stop” . . . “I'm addicted and I'm having trouble, and that's why I'm doing it away from you, because I really don't want you to be influenced by that” . . . rather than “It's my choice” and “I just want to” and “I really like it” and . . . “I need a cigarette because I need to relax” and all of those other little messages that parents can send to children about why they're smoking.*

**Having non-smoking homes and vehicles.** Participants asserted that parents should also show that smoking is unhealthy and unacceptable by having non-smoking homes and vehicles. This is especially important in homes where there is a parent who smokes: “You can say all you want, but the practice is really what sends the message.”

*It's all in how it's handled. If a parent is . . . allowed to smoke in the house wherever they want, while doing whatever they want, that's a totally different message that you're giving your kids [from] you have a parent that's smoking but they have to go outdoors . . . they have to make sure that there are no cigarettes around the house . . . even if it's a blizzard outside they're still not allowed to smoke in the house . . . they're banished, sort of thing. That's a totally different message . . . [from] Here we are in the house. You're in the smoke. I'm in the smoke. It's fine. It's*

*okay. . . . Designating a smoke-free home and a smoke-free car . . . sends a message to kids that, yeah, Dad does this but it's not a good thing . . . Mom doesn't like it and he's not allowed to do it around me and he's not allowed to do it around Mom. . . . It's that whole impression that you're giving. . . . It's how you place it. You can either place it as normal or . . . as abhorrent and away from us and not near us.*

***Schools Have a Responsibility to Reinforce the Antismoking Message***

The participants thought that schools have an important “role to play” in prevention education but that without parental support a school’s efforts might be less successful. They thought that the relationship between parents and the school should be a two-way one, with parents setting the foundation for smoking prevention and schools bolstering it:

*I think it should come from both . . . it needs to come from home first and for the school to reinforce it. Like with everything . . . you teach your child their letters before they [go] to school and of course [teachers] reinforce that. Most parents do. . . . I think it needs to come from home. [Teachers] can only play the role so far.*

In turn, parents need to be tuned in to what their children are learning in school and strengthen the message at home. “Parents need to be on side . . . parents and teachers should be working together . . . which is ideal.”

*[Parents should] be aware of what [their children] are actually being taught within the school system . . . speak to them about that. Talk to them about those particular things they're learning and again ask them, “What's your understanding?” Because it's not always about you telling them . . . [It's also] them telling you.*

Although participants thought that smoking prevention education should come primarily from the home, they acknowledged that this may not necessarily be the case and that for children who do not receive it at home, education at school is essential. However, their sense was that prevention education is not as strong in schools as it could be. The teachers confirmed that, in their jurisdiction, smoking prevention education was a component of the curriculum in elementary school (grades 4 to 6) but not primary school (kindergarten to grade 3). They believed that, for grades 4 to 6, it was limited to a topic in the health curriculum. Their impression was that smoking was not a priority for instruction and therefore might not receive much attention. They explained that pressure to meet objectives in core subjects and teacher preference often determine the extent to which smoking is covered in elementary school.

Participants thought that, although more emphasis might be placed on prevention education in junior high and high school, this might be too late, as some children start smoking early. They believed that the earlier smoking prevention is introduced the better. It needs to start from day one and be “integrated” into the curriculum, throughout the grades. It should not be isolated, occasional, random presentations on the topic: “It needs to be repeated . . . start at a very early age . . . the message needs to be throughout the entire school process, kindergarten right through grade 12.” However, the teachers raised concerns about causing emotional reactions, such as anxiety or fear, in children who have family members, especially parents, who smoke. For those children smoking can be a “sensitive topic” and educators need to be “delicate” in their approach:

*As an educator I have to be very careful how I approach it, because the students who have parents that smoke can be easily hurt or offended or even scared for the parents' safety and health. I have to be cautious about that . . . so that's a factor for an educator to consider.*

They agreed that, to avoid undue concern among children, the focus of education in the lower grades should be on “health in general,” not the serious illnesses. They thought that the best approach is to emphasize overall healthy living, with non-smoking being one thing among many that make people more healthy:

*The main thing . . . is focusing on the health, making it a part of a healthy lifestyle. . . . It becomes a way of life. It becomes a part of being healthy. Physical activity is a part of being healthy. Non-smoking is a part of being healthy . . . if it's kind of taken under that umbrella it's not going to be as frightening. But also I think we have an opportunity with children to say some factual things like about the . . . coughs and about the bad smell and about the dirty teeth and all that . . . those are the kinds of things that I don't think [are] frightening . . . they're observations.*

### ***Society Needs to Provide a Supportive Environment***

The participants thought that, while interventions by parents and schools are vital, a “supportive environment” at the societal level is also essential. Smoking prevention requires a “community effort,” a “coordinated voice” involving all three players, so that the message conveyed is prominent and consistent across sources. One participant declared, “If [anti-smoking] messages are everywhere, then that helps to instil those messages they have at home.”

Considerable attention has been paid to smoking prevention in Canada in recent years through measures such as legislation (e.g., raising

the legal age for the purchase of tobacco products to 19 years, restricting promotion and advertising of tobacco products, and requiring graphic warnings on tobacco products), public policy (e.g., smoke-free school premises), and public education (e.g., mass-media campaigns directed at youth smoking and the health effects of smoking). However, the participants said that youth smoking is still too prevalent: “It isn’t as normal as it used to be but . . . is still very prevalent when you look at . . . how many kids are actually still smoking.” The NGO professionals specified that more needs to be done, as youths are still accessing cigarettes and still being exposed to pro-smoking messages in society. They singled out movies as an important source of these messages. Stricter social policies to curb such influences would validate and strengthen the messages of parents and teachers. Participants also indicated that parents need direct support. The nursing and NGO professionals noted that there are few if any resources targeting parents. They believed that parents would benefit from information about youth smoking that they could use to educate their children: “I really think educating parents is where we have to go, and then that will transfer to the children.”

*If they know more about it, they’re more inclined to tell their children about it. So I think maybe an education process . . . [to] help them to help their children . . . the facts about children and smoking . . . there’s still the risk and . . . most concerned parents will want to know more about how they can help their children.*

Participants suggested that resources in the form of lay print and electronic information could be made available through health-care providers such as PHNs and various agencies. Some thought that because parents tend not to seek help for smoking prevention, providers could promote the resources through a “widespread campaign” — for example, through “schools, maybe at curriculum night” — since schools are “the biggest link to parents.”

*Maybe there can be something done through public health or in the schools [to] get the ball rolling with parents to discuss this, something that can be sent home through the school that the kids can give to their [parents] . . . That might be a way to open up the door . . . It’s almost like they have to be pushed.*

## **Discussion**

The perspective of the professionals who participated in this study, that parents are a young child’s most important influence with respect to smoking, corresponds with the position of authorities on smoking prevention, that parents can be a powerful influence on children’s decision

to smoke and should take preventive measures (Centers for Disease Control and Prevention [CDC], 2010; Health Canada, 2008). Indeed, in the literature on parenting it is generally accepted that parents can make a difference in children's behavioural outcomes (Baumrind, 1993; Duncan, Coatsworth, & Greenberg, 2009; Galambos, Barker, & Almeida, 2003). Although our participants believed that parents have the main responsibility for educating their children about smoking, they believed that many parents might not address it with their young children. Little is known about parental smoking-specific communication in the period prior to adolescence. In our study with parents of school-age children (5–12 years), however, we found that most parents had addressed the topic often with their children, some had done so periodically, and a few had done so only minimally (Small et al., 2012). In studies concerning pre-adolescent and adolescent children, there is evidence that many parents at least raise the topic with their children (e.g., Baxter, Bylund, Imes, & Routsong, 2009; Bush et al., 2005; Muilenburg & Legge, 2009; Wyman, Price, Jordan, Dake, & Telljohann, 2006). It is difficult to tell, from most of those studies, the degree to which parents talk with their children.

Whether or not parents are involved in smoking prevention, the following approaches suggested by the professionals who took part in our study are consistent with recommendations in the literature (e.g., American Academy of Pediatrics, 2009; Health Canada, 2008; USDHHS, 2009). Parents should start speaking with their children about smoking at an early age; bring up the topic often; use an open communication style and engage children in a discussion about smoking; take a casual approach; use age-appropriate messaging; talk about health effects and factors that encourage children to smoke, especially peer pressure and addiction; provide guidance on how to resist peer pressure; and, if the parents smoke themselves, speak about their experience with smoking and their addiction. Much of the research conducted on the effectiveness of parental discussion for smoking prevention has involved adolescents. Inconsistency of findings across studies and differences in study methods make it difficult to draw conclusions, but there is some evidence that parental discussion about smoking is effective (den Exter Blokland, Engels, Harakeh, Hale, & Meeus, 2009; Otten, Engels, & van den Eijnden, 2007).

Our participants also believed that parents should take action to reduce their children's exposure to smoking. In addition to the harmful health effects of smoking, it has been established that exposure to smoking is a risk factor for youth because of modelling and the acceptability that exposure suggests. Young people who are exposed to smoking receive messages that contradict the prevention messages about smoking

norms that they receive from other sources (Alesci, Forster, & Blaine, 2003; CDC, 2000; Corbett, 2001). To reduce exposure to smoke and smoking, it is recommended that homes and vehicles be smoke-free and that parents who smoke not do so in the presence of their children (American Academy of Pediatrics, 2009; Health Canada, 2008). There is some research evidence to support the importance of not exposing children to smoking. In a number of studies, home restrictions on smoking were found to be protective against youth smoking (e.g., Bernat, Erickson, Widome, Perry, & Forster, 2008; Ditre, Coraggio, & Herzog, 2008; Rainio & Rimpela, 2007).

In addition to the parental role, the view of our participants was that schools have an important role to play in smoking prevention; they believed that prevention education should be integrated into the curriculum from kindergarten through grade 12. There is evidence that parents hold a similar view (Small et al., 2012; Wyman et al., 2006). The teachers' concern about the possibility of prevention education causing emotional upset in young children is similar to the concern voiced by teachers in another study (Spratt & Shucksmith, 2006). Those teachers thought that working in a meaningful way with children from homes where there are adults who smoke is problematic and calls for sensitivity; most reported treading carefully when presenting information on long-term health effects and being cautious about saying anything that could be construed as critical of parental behaviour. The professionals in our study thought that the issue could be reconciled by focusing on health rather than illness when providing prevention education in the lower grades.

That smoking prevention education should be carried out in schools has been the recommendation of health authorities for many years. For instance, the CDC recommends that developmentally appropriate, comprehensive prevention education be provided in kindergarten through grade 12. Smoking prevention should be reinforced in all grades to ensure that it does not dissipate over time. Further, it can be delivered as a single focus or embedded in broader health curricula as long as it meets the recommended standard (CDC, 1994, 2008). The latter is consistent with what the professionals in the present study suggested for the lower grades — that is, an integrated health approach.

Despite the recommendation that smoking prevention education be implemented in schools, the participants in the present study believed that it might not receive much attention in curricula. The literature indicates that getting schools to adopt effective prevention programs is not easy due to competing pressures and the demands placed on schools for academic achievement (Flay, 2009; Reid, 1999). Although we lack information on the extent to which recommended smoking prevention education is being adopted by schools, it is thought that implementation

is not widespread and that curricula are less than complete (CDC, 2000; Flay, 2009).

Numerous studies have been conducted to test various school-based interventions, including such approaches as information-giving, affective education, social influence education, and social skills training, and several systematic reviews and meta-analyses have been carried out to examine their effectiveness. It has been proposed that effective school-based prevention programs could accrue substantial cost-benefits in terms of economic returns and health-related quality of life (Flay, 2009). However, although some studies, mainly for social influences intervention, report short-term positive effects of school intervention on children's smoking behaviour, we lack strong evidence of smoking prevention among youth in the long term (e.g., Dobbins, DeCorby, Manske, & Goldblatt, 2008; Thomas & Perera, 2006). This speaks to the need for interventions that are complementary and effective over the long term.

The professionals in our study expressed satisfaction with societal initiatives taken in recent years to deter youths from taking up smoking. However, they said that more could be done and identified youth access to tobacco products, exposure to smoking in film, and educational resources for parents as areas needing attention. Access is an issue (Warren et al., 2009), even in countries such as Canada that have legislation prohibiting the sale of tobacco products to minors. In a recent Canadian survey, 64% of adolescents aged 15 to 19 who were underage in their jurisdictions purchased tobacco products from a retail source (e.g., a corner store). The others obtained their cigarettes from social sources (e.g., friends, relatives, individual sellers) (Health Canada, 2010a). Social sources were more prevalent among younger children — 85% of children in grades 6 to 9 who smoked obtained their cigarettes in this way (Health Canada, 2010b). Access is a function not only of legislation forbidding sale to minors but also of enforcement of the legislation and availability through social sources. Interventions are needed to address all of these factors.

The prevalence of positive images of smoking in movies is supported in the literature (Dalton et al., 2002; Sargent, 2005). In many instances smoking is modelled by movie stars (Sargent, Dalton, Heatherton, & Beach, 2003). Motivational factors for smoking by screen characters, such as agitation, sadness, happiness, and relaxation, and situations in which smoking occurs, such as while socializing or engaging in risky behaviour, are consistent with those for tobacco use in society generally. Negative reactions to and negative consequences of tobacco use are rare in film (Dalton et al., 2002). It is agreed that pro-smoking messages in media to which children are exposed are an important influence (Dalton et al., 2009; Sargent, 2005; Wellman, Sugarman, DiFranza, & Winickoff, 2006).

A ban on depiction of smoking in movies is warranted (Wellman et al., 2006).

Consistent with the view held by the professionals in our study, there is evidence in the literature that at least some parents think they would benefit from having resources to use in their smoking prevention efforts. Parents report that it would be helpful to have information on youth smoking, prevention strategies, and effective communication with children about smoking (King, Wagner, & Hedrick, 2002; Small et al., 2012). However, the participants in our study noted that parents rarely requested help in talking with their children about smoking. This finding is consistent with parents' own reports that they do not seek resources for intervening with their children about smoking (Small et al., 2012). This suggests that despite parents' desire for resources, they might not seek them out on their own initiative or look to professionals for assistance. Our participants believed that parents could be reached with resources dispensed by community agencies, public health nurses, or schools. Although we found no studies examining the effect on parents of simple provision of resources, there is some evidence that parents prefer resources that can be mailed home or brought home from school (Tilson, McBride, Albright, & Sargent, 2001) as well as parent-directed interventions that they are able to access at home (Beatty & Cross, 2006). Interventions with parents to promote their participation in prevention efforts have been found to result in more smoking-related discussions with their children (Beatty, Cross, & Shaw, 2008; Jackson & Dickinson, 2003; Mahabee-Gittens, Huang, Slap, & Gordon, 2007).

Taken together, the perspectives of professionals on the role of parents, schools, and society represent a multipronged approach to smoking prevention. This is consistent with the socio-ecological approach to health promotion, wherein a combination of strategies is used to target multiple levels of a system (Edwards, Mill, & Kothari, 2004). Specific to smoking prevention, the view of authorities is that a comprehensive, multi-message, multichannel approach that is sustained over time is more effective than single-component interventions. It is argued that a combination of strategies is synergistic and should include school-based education, community-based activities, interventions that engage parental influence, youth-oriented mass-media campaigns, regulations for product promotion and sale to minors, policies for smoke-free environments, and price inflation (American Academy of Pediatrics, 2009; CDC, 2007; National Cancer Policy Board, Institute of Medicine, & National Research Council, 2000). Even though one strategy might not produce an effect independently, a combination might do so through interaction. The need for a comprehensive, multifaceted, sustained approach might help to explain why single strategies have been shown to yield disap-

pointing results. In recent years the trend in many countries has been to implement a comprehensive strategy for smoking prevention, and the decline in smoking in these countries is attributed to this strategy (Health Canada, 2006; National Cancer Policy Board et al., 2000).

### **Implications for Practice and Research**

The findings of this study are based on a small, select sample of professionals and therefore are not generalizable. However, the perspectives of the participants are consistent with the views of smoking prevention authorities and with recommendations in the literature. The findings have implications for health education practice, advocacy, and future research.

Although health professionals should encourage parents to proactively talk with their children about smoking according to recommendations in the literature, little is known about the effectiveness of such communication. Research is needed to establish the effectiveness of parental communication for smoking prevention. Parents might not seek resources for smoking prevention measures with their children. Therefore, resources to guide them should be readily available and offered to them as a matter of course. However, research is needed to determine what resources would be the most useful to parents in their smoking prevention efforts and how best to reach parents with those resources.

Because school smoking prevention curricula might not be sufficiently strong and comprehensive, professionals should be aware of what is offered in their jurisdictions and advocate for best practice. School PHNs are in a prime position to exert influence. Research to document the extent to which schools comply with guidelines would be helpful for advocacy. We also need research to determine which school programs have a long-term effect (beyond high school). Although considerable efforts have been made in many countries in recent years, in terms of social policy to prevent smoking, youth smoking is still prevalent and continues to be cause for concern. PHNs are encouraged to work with other professionals and to advocate for strong social policies. In particular, regulations restricting access to tobacco products and exposure to pro-smoking messages need to be strengthened and enforced.

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### **Acknowledgements**

The authors acknowledge financial support for this research from Canadian Respiratory Health Professionals through the Canadian Lung Association and the Association of Registered Nurses of Newfoundland and Labrador.

Conflict of interest: The authors declare no conflict of interest with respect to this article.

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*Résumé*

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**L'intention du personnel infirmier de favoriser la prise de décision éclairée en matière de dépistage du cancer du sein par mammographie**

**Lawrence Ndoh Kiyang, Michel Labrecque,  
Florence Doualla-Bell, Stéphane Turcotte, Geneviève Roch,  
Céline Farley, Myrtha Cionti Bas, France Légaré**

La prise de décision éclairée en matière de dépistage du cancer du sein par mammographie suscite un intérêt croissant et le mouvement pour la diffusion d'une information équilibrée sur les bienfaits et les méfaits potentiels de cette technologie prend de l'ampleur. Les auteurs font rapport d'une enquête évaluant l'intention du personnel infirmier à fournir un soutien aux femmes ciblées par le programme de dépistage du cancer du sein du Québec dans une prise de décision éclairée en matière de dépistage du cancer du sein par mammographie. Des 840 questionnaires remplis, 618 ont été utilisés pour l'analyse de données. La moyenne + et l'écart type quant à l'intention était de 1,7 + 1,2 sur une échelle de Likert de 6 points, allant de -3 à +3, indiquant la présence d'une forte intention d'apporter un soutien aux femmes ciblées. Le contrôle comportemental perçu constituait la variable théorique la plus étroitement associée à l'intention, suivi de l'attitude et de la norme sociale. Ces résultats peuvent être utilisés pour élaborer des interventions pédagogiques qui amèneront les infirmières et les infirmiers à intégrer des interventions favorisant la prise de décision éclairée en matière de dépistage du cancer du sein par mammographie à leur pratique, et pour concevoir des outils d'aide à la prise de décision pertinents.

Mots clés : dépistage du cancer du sein, prise de décision éclairée, intention, attitude, contrôle, norme

# **Nurses' Intention to Support Informed Decision-Making About Breast Cancer Screening With Mammography: A Survey**

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There is growing interest in informed decision-making about breast cancer screening with mammography and growing advocacy for the provision of balanced information about potential benefits and harms. The authors report on a survey evaluating nurses' intention to support women targeted by the Quebec Breast Cancer Screening Program in making informed decisions about breast cancer screening with mammography. Of the 840 questionnaires completed, 618 were included in the data analysis. The mean  $\pm$  standard deviation score for intention was  $1.7 \pm 1.2$  on a 6-point Likert scale ranging from -3 to +3, indicating strong intention to support the targeted women. Perceived behavioural control was the theory-based variable most strongly associated with intention, followed by attitude and social norm. These results can be used to develop interventions to train nurses in integrating informed decision-making about breast cancer screening with mammography into their practice and to design relevant decision support tools.

Keywords: breast cancer screening, informed decision-making, nurses' intention, attitude, control, norm

## **Background**

In 1998 the Quebec Ministry of Health and Social Services (MHSS) began recommending that all women aged 50 to 69 participate in the Quebec Breast Cancer Screening Program (QBCSP). Its slogan was "Breast cancer screening saves lives." However, since controversies arose about the net benefit of breast cancer screening with mammography (Götzsche & Nielsen, 2011; Green & Steph, 2003; Gummersbach et al., 2009; Jørgensen & Götzsche, 2009; Jørgensen, Klahn, & Götzsche, 2007) and the emergence of scientific evidence about the benefits of informed decision-making for cancer screening (Briss et al., 2004; Joosten et al., 2008; Rimer, Briss, Zeller, Chan, & Woolf, 2004; Stacey et al., 2012; Stefanek, 2011), in 2008 the MHSS revised its policy and the QBCSP

replaced its slogan with “Screening for breast cancer: A choice that belongs to you.” This new approach is aimed at informed decision-making. Informed decision-making is said to occur when an individual understands the disease or condition being addressed and comprehends what the clinical service involves, including its benefits, risks, limitations, alternatives, and uncertainties; has considered his or her preferences and makes a decision consistent with them; and believes he or she has participated in decision-making at the desired level (Rimer et al., 2004). This significant paradigm shift encourages women to choose the option they feel most comfortable with.

The MHSS believes that women will wish to consult health professionals for assistance with the decision and that nurses will be called upon to play this role. In addition to being a trusted source of health-related information (Koutsopoulou, Papathanassoglou, Katapodi, & Patiraki, 2010), an increasing number of nurses are the first point of direct contact with patients in primary care (Marleau, 2012; Swiadek, 2009) as well as first to assume an advocacy role and promote informed decision-making (Bu & Jezewski, 2007; Stacey et al., 2008).

While the new QBCSP approach is not yet (as of March 2013) fully operational, the new slogan has appeared on the MHSS Web site, along with a discussion of advantages and disadvantages, and new leaflets have been produced. In addition, the MHSS is making plans to develop interventions, including training programs, to better equip health professionals in contact with women targeted by the QBCSP, mainly primary care physicians and nurses, to play a decision support role. As intention has been repeatedly shown to predict behaviour (Eccles et al., 2006; Godin, Bélanger-Gravel, Eccles, & Grimshaw, 2008), it is worth investigating whether nurses intend to play this supporting role and what might facilitate or hinder their assuming the role along with its associated behaviour.

The Theory of Planned Behaviour (TPB) (Ajzen, 1991) has proved an adequate model for predicting health professionals’ intention to adopt new behaviour (Armitage & Conner, 2001; Conner & Norman, 2005; Eccles et al., 2006; Godin et al., 2008). According to the TPB, behaviour is directly determined by intention to engage in the behaviour, but also by perceived control over the behaviour. Intention, in turn, is determined by attitude towards the behaviour, social norms, and perceived behavioural control (Ajzen, 1991; Conner & Norman, 2005). The primary objective of this study was to measure nurses’ intention to support women targeted by the QBCSP to make informed decisions about breast cancer screening with mammography and to identify determinants of this intention. The secondary objective was to identify barriers and facilitators that nurses perceive in adopting this behaviour.

## **Methods**

### ***Participants and Recruitment Strategy***

In order to identify primary care nurses in the province of Quebec who might be in contact with women targeted by the QBCSP, we used the 2010–11 registry of the Quebec Order of Nurses. A total of 10,447 nurses, including nurse practitioners, reported working in primary care domains (Marleau, Lapointe, Saint-Georges, & Lord, 2011). Of these, we identified 7,199 nurses who might be in contact with women targeted by the QBCSP (women aged 50–69), excluding those working exclusively in maternal, child, and adolescent health care, and selected 2,267 who had given authorization to be contacted for research purposes and provided a valid e-mail address to the Order of Nurses at the time of their annual registration. During December 2010 and January 2011 we contacted these nurses, as well as all 92 nurses working with the QBCSP, by e-mail and invited them to complete an online questionnaire hosted on the Survey Monkey Web site (<http://www.surveymonkey.com/>). Duplicate e-mail addresses were deleted. Two reminder e-mails were sent at 3-week intervals. Each respondent could complete the questionnaire only once, in order to avoid duplicate responses.

### ***Data Collection***

The questionnaire, consisting of 17 questions in French, was divided into four parts and was preceded by a brief description of the QBCSP, including its old and new slogans (Appendix 1). The first part (question 1) was aimed at identifying nurses who might be in contact with women targeted by the QBCSP (our eligibility criterion). The second part (questions 2 to 10 — 12 TPB-based items) measured respondents' intention to support women targeted by the QBCSP in making informed decisions about breast cancer screening and assessed the determinants of this intention (attitude, social norm, and perceived behavioural control) (Ajzen, 1991). Each of four socio-cognitive variables (intention, perceived behavioural control, attitude, and social norm) was assessed by means of three items using a six-point Likert scale ranging from -3 to +3. Chomeya (2010) and Preston and Colman (2000) have demonstrated that the six-point Likert scale is reliable and one of the easiest and quickest scales to use. The internal consistency of the socio-cognitive variables was acceptable as measured in our study by their respective Cronbach's alphas: intention (0.71), attitude (0.67), social norm (0.78), perceived behavioural control (0.72).

The third part of the questionnaire consisted of two questions about factors that might hinder (question 11) or facilitate (question 12) nurses in supporting women targeted by the QBCSP in making informed deci-

sions about breast cancer screening. The fourth part (questions 13 to 17) was aimed at collecting sociodemographic data.

### **Data Analysis**

Data from the questionnaires were independently entered into a Microsoft Access database and validated by two trained assistants. We excluded from the analysis nurses who reported not being in contact with women targeted by the QBCSP as well as those who either did not answer any of the 12 items used in assessing intention (three items) and its three determinants (attitude, social norm, and perceived behavioural control, with three items per determinant) or who answered only one of the three items assessing each of the socio-cognitive variables. We imputed missing values using the Monte Carlo method (Roth, Switzer, & Switzer, 1999) for all respondents who provided answers to two out of the three items assessing each socio-cognitive variable. The proportion of missing values was 135/7415 (1.8%).

Nurses' reported level of contact with the targeted women was dichotomized into high contact (often in contact) and low contact (sometimes or rarely in contact). We computed descriptive statistics for all variables collected. The proportion of nurses with a strong or very strong intention (score of 2 or more) and its 95% confidence interval (CI) was calculated. Means were presented with their standard deviation (SD). In order to identify which of the TPB determinants of intention (attitude, social norm, and perceived behavioural control) might best explain the variation in nurses' intention, we first calculated the Spearman's rank correlation coefficients between intention and each of the variables. Then, in order to evaluate the adjusted effect of each variable on the intention, we performed a multivariate analysis. We could not use multiple linear regressions for data analysis due to violation of the normality and linearity assumptions that persisted even after attempting to transform the data. We therefore used multinomial logistic regression, specifically the partial proportional odds model. We could not use the proportional odds model (multinomial ordinal logistic regression) because the data violated the proportional odds assumption due to lack of proportionality in the attitude variable (Kleinbaum & Klein, 2010; Stokes, Davis, & Koch, 2003). We categorized socio-cognitive variable scores into either two (attitude) or three (all other variables) categories, according to the distribution of scores for each variable.

We also computed the proportion of nurses who selected or mentioned each of the facilitating or hindering factors vis-à-vis supporting women targeted by the QBCSP in making an informed decision about breast cancer screening. All analyses were done using the Statistical Analysis System software, Version 9.2 (SAS Institute, Cary, NC, USA).

**Results**

Of the 2,359 nurses invited by e-mail to participate in the study, 840 (36%) completed the questionnaire. Of this number, 716 (85%) reported being in contact with women targeted by the QBCSP. The number of nurses eligible for data analysis was 618 (86%) after the exclusion of 89 who did not answer any of the 12 items assessing the socio-cognitive variables as well as nine who answered only one of the three items assessing each socio-cognitive variable. Table 1 shows the sociodemographic characteristics of participants. As expected, there was a strong gender imbalance, with most participants being female. Most had a bachelor's degree (58%) or a college diploma (30%) and many years' experience. They were most likely to be working in a local community service centre or in a private primary care clinic. More than half of the participants reported being "rarely" or "sometimes" in contact with the women targeted by the QBCSP.

<b>Table 1 Sociodemographic Characteristics of Nurses (N = 618)</b>	
<b>Characteristic</b>	<b>n (%)</b>
<b>Gender</b>	
Male	38 (6.3)
Female	565 (93.7)
Mean ± SD years in practice (n = 589): 20.7 ± 11.9	
<b>Frequency of Contact With Targeted Women</b>	
Often	248 (40.1)
Sometimes	234 (37.9)
Rarely	136 (22)
<b>Education</b>	
Master's or PhD degree	40 (6.6)
Postgraduate diploma (specialized studies)	33 (5.5)
Bachelor's degree	349 (57.7)
College diploma	183 (30.2)
<b>Practice Domain</b>	
Primary care private clinic	187 (30.9)
Local community service centre (home care, frontline care)	347 (57.3)
Public health service	35 (5.7)
Other (community pharmacy, nurse manager)	37 (6.1)
<i>Note: The denominators for some characteristics differ from the sample size due to missing values.</i>	

Participants had a strong intention to support women in making informed decisions about screening for breast cancer, with a mean  $\pm$  SD and median intention score of  $1.7 \pm 1.2$  and 2.0, respectively. The proportion of nurses who had strong or very strong intention (score = 2.0 or more) was 53% (95% CI 49% to 57%). The distribution of the scores for all socio-cognitive variables was skewed to the left, with scores for attitude and social norm even more so than those for intention and perceived behavioural control. The distribution of scores for intention to support women in making an informed decision about breast cancer screening was significantly different between high-contact nurses ( $2.0 \pm 0.9$ ) and their low-contact counterparts ( $1.4 \pm 1.2$ ) (Student's t-test,  $p < 0.001$ ).

<b>Table 2 Association Between Intention and Its Theory of Planned Behaviour Determinants: Multinomial Logistic Regression (Partial Proportional Odds Models)</b>			
<b>Determinants of Intention</b>	<b>Low-Contact Nurses OR (95% CI)<sup>a</sup></b>	<b>High-Contact Nurses OR (95% CI)</b>	<b>All Nurses OR (95% CI)</b>
<b>Attitude</b>			
Higher score (low/medium vs. high intention score)	7.3 <sup>b</sup>	9.4 <sup>b</sup>	7.9 <sup>b</sup>
Higher score (low vs. medium/high intention score)	1.7 (1.0–3.1)	4.0 (1.8–9.1)	2.2 (1.4–3.4)
Lower score <sup>c</sup>	1	1	1
<b>Social Norm</b>			
Higher score	2.4 (1.3–4.6)	1.1 (0.4–2.9)	1.6 (1.0–2.6)
Medium score	1.7 (0.9–2.9)	1.0 (0.5–2.2)	1.2 (0.8–1.8)
Lower score	1	1	1
<b>Perceived Behavioural Control</b>			
Higher score	2.7 (1.6–4.6)	7.0 (3.0–16.3)	3.9 (2.5–6.0)
Medium score	1.9 (1.1–3.2)	3.7 (1.8–7.8)	2.4 (1.5–3.7)
Lower score	1	1	1
<sup>a</sup> OR = odds ratio; CI = confidence interval <sup>b</sup> CI could not be calculated. <sup>c</sup> Lower score: reference category			

There was moderate correlation between intention and attitude (0.47,  $p < 0.001$ ), social norm (0.43,  $p < 0.001$ ), and perceived behavioural control (0.56,  $p < 0.001$ ). The results of the multinomial ordinal (partial proportional odds model) logistic regression analysis of the association between intention and its determinants are shown in Table 2. Only results from the model without missing values imputed are reported, as results with and without them were similar. The odds ratio between low/medium and high intention scores and between low and medium/high intention scores were assumed to be similar for social norm and perceived behavioural control. Attitude did not meet the proportionality of odds assumption. Therefore, odds ratios are presented for low/medium versus high intention scores and for low versus medium/high intention scores. These analyses confirmed that, overall, all three determinants were associated with the nurses' intention.

The nurses' level of contact with women targeted by the QBCSP had a modifying effect on the association between intention and its socio-cognitive determinants (Table 2). The association between intention and two of its determinants, perceived behavioural control and attitude, was stronger for high-contact nurses than for their low-contact counterparts. In contrast, the association between social norm and intention was stronger for low-contact nurses. The association between intention and social norm was neither statistically nor clinically significant for high-contact nurses. None of the sociodemographic factors (number of years in practice, gender, education level, and domain of practice) was associated with nurses' intention to support the targeted women.

**Table 3** *Barriers to and Facilitators of Supporting Women in Making Informed Decisions About Breast Cancer Screening (N = 618)*

Factor	Barrier		Facilitator	
	<i>n</i>	(%) <sup>a</sup>	<i>n</i>	(%) <sup>a</sup>
Time constraints	240	39	–	–
Training	430	70	545	65
Relevant tools <sup>b</sup>	336	45	551	66
Other <sup>c</sup>	26	4	21	3

<sup>a</sup> % of nurses who selected or cited the factor  
<sup>b</sup> Information and decision support tools for both nurses and patients  
<sup>c</sup> Other barriers: state of scientific knowledge,  $n = 3$ ; self-efficacy,  $n = 2$ ; motivation,  $n = 1$ ; public awareness,  $n = 3$ ; preferences of targeted women,  $n = 4$ ; organizational factors,  $n = 13$ . Other facilitators: state of scientific knowledge,  $n = 1$ ; self-efficacy,  $n = 6$ ; motivation,  $n = 3$ ; public awareness,  $n = 2$ ; awareness of targeted women,  $n = 2$ ; organizational factors,  $n = 7$

Barriers and facilitators vis-à-vis supporting women targeted by the QBCSP in making informed decisions about breast cancer screening are presented in Table 3. The most frequently cited or selected factors were time constraints (barrier) and availability of relevant information and decision support tools both for nurses and for patients (facilitators). Other relevant factors were the state of scientific knowledge, self-efficacy, motivation, general public awareness, preferences of targeted women, organizational factors (e.g., organization structure, preferences of managers or supervisors, remuneration, availability of other human resources), and awareness among targeted women of benefits and risks of breast cancer screening with mammography. When asked about the preferred mode of training in informed decision-making, more participants preferred online training (57%) to classroom training (43%).

### **Discussion**

Our findings show that nurses who participated in the study had strong intentions to support women in making informed decisions about breast cancer screening. As expected, the mean intention of nurses who reported being often in contact with women targeted by the QBCSP was significantly higher than that of their low-contact counterparts. Perceived behavioural control was the strongest determinant of this intention, followed by attitude, no matter what the nurses' level of contact. Social norm was associated only with intention of low-contact nurses.

Perceived behavioural control has been identified as the strongest determinant predicting nurses' intention in other clinical contexts. Edwards et al. (2001) found that perceived behavioural control was the strongest predictor of nurses' intention to administer opioids for pain relief. In the same vein, Nash, Edwards, and Nebauer (1993) found that perceived behavioural control was the strongest predictor of nurses' intention to assess patients' pain. In another study, Coté, Gagnon, Kouffé-Houme, Ben-Abdeljelil, and Gagnon (2012) used the TPB to show that nurses' intention to integrate research evidence into clinical practice was explained by perceived behavioural control, normative beliefs, and past behaviour. The trend of results in these studies and ours concurs with the results of a systematic review by Armitage and Conner (2001) to assess the efficacy of the TPB in predicting intention and behaviour. They documented that health professionals' perceived behavioural control was the strongest predictor of intention, followed by attitude, while social norm was the weakest. While these findings are congruent with ours, they are not directly comparable because, to the best of our knowledge, ours is the

first study based on a theoretical model to assess nurses' intention to support women in making informed decisions about screening for cancer. These other findings, however, reinforce our results and indicate the need for interventions to make nurses believe they are capable of supporting women in making informed decisions about breast cancer screening. This can be achieved by overcoming barriers relating to perceived control and attitude.

While some studies have pointed out the difficulties of informed/shared decision-making in clinical practice (Sinding et al., 2010; Sinding, Miller, Hudak, Keller-Olaman, & Sussman, 2012), many research findings have illustrated its numerous potential benefits (Adamsen, Larsen, Bjerregaard, & Madsen, 2003; Joosten et al., 2008; Légaré, Shemilt, & Stacey, 2011; Rimer et al., 2004; Stacey et al., 2012). However, health professionals still perceive many barriers to its implementation. Hutchinson and Johnston (2004) document time constraints, lack of awareness of the research literature, and difficulty understanding statistical analyses as the chief factors influencing uptake of research findings by nurses. In the same vein, Carlson and Plonczynski (2008) report that insufficient time for nurses to implement new ideas was the most frequently mentioned barrier in 73% of the studies included in their review. Adamsen et al. (2003) found that 90% of the participants in their study saw the overwhelming amount of research findings as a barrier, while 75% complained of difficulty understanding them. Carlson and Plonczynski (2008) also found that 29% of studies included in their review reported mostly on the difficulty of understanding research findings. The barriers and facilitators reported by these researchers are closely related to those encountered by other health professionals in the implementation of informed decision-making or shared decision-making (Charles, Gafni, & Whelan, 2004; Légaré, Ratté, Gravel, & Graham, 2008).

These findings are similar to our own, in which the most widely reported barriers to supporting women in making informed decisions about breast cancer screening were as follows: lack of relevant decision aids; lack of training (in helping women make informed decisions about breast cancer screening and in using evidence-based decision aids); and lack of time, including organizational constraints. Interventions that target the barriers and facilitators identified in our study are likely to be successful in helping nurses, and possibly other health professionals, support women targeted by the QBCSP. According to the TPB, the barriers and facilitators identified by nurses in this study represent external factors that collectively are mainly associated with perceived behavioural control and attitude.

The TPB suggests that optimal intention and subsequent behavioural change are possible if interventions address issues that our study found to be related to the principal determinants of intention: (1) perceived behavioural control — nurses feel they could easily adopt this behaviour, do not perceive obstacles (such as lack of training or organizational barriers related to the health-care system), and feel they would be provided with relevant support tools; and (2) attitude — nurses consider this behaviour useful and responsible and see more advantages than disadvantages to adopting it. Interventions targeting nurses who are seldom in contact with targeted women may add components reinforcing the fact that this behaviour is the socio-professional norm.

### ***Strengths and Limitations***

This study has a number of strengths. Firstly, as intention has been shown repeatedly to predict behaviour (Eccles et al., 2006), our questionnaire was based on the TPB, a theoretical model validated and used in many international research projects to predict intention and its determinants regarding the adoption of health-care behaviours (Godin et al., 2008). Secondly, we complemented the assessment of intention and its determinants by asking nurses to identify barriers to and facilitators of adoption of the behaviour, allowing us to make concrete suggestions for designing interventions and techniques targeting behavioural change. Thirdly, the list of studies included in a systematic review by Godin et al. (2008) indicates that ours is one of the largest studies based on a socio-cognitive theory to assess the intentions of health professionals.

This study also has limitations. Of the total population of 7,291 nurses assumed to be in contact with women targeted by the QBCSP and potentially eligible to participate, our sample was restricted to the 2,359 (32%) who had given authorization to be contacted for research purposes and had provided a valid e-mail address. In addition, the response rate among these was only 36%. However, this rate is very close to the expected mean e-mail survey response rate of 37%, based on a review of 31 studies (Sheehan, 2001). Furthermore, the mean number of years in practice for the 618 nurses eligible for data analysis ( $21 \pm 12$ ) did not differ widely from that of the 7,291 nurses potentially eligible for our study, whose mean number of years in practice was 20. In addition, the distribution of the 618 participants by gender (6% male, 94% female) and education level (58% bachelor's degree, 30% college diploma) is comparable to that observed in the total population of 7,291 potential eligible nurses (7% male, 93% female; 44% bachelor's degree, 38% college diploma). Another limitation is that the intention of participants may have been overestimated due to a socio-professional desirability bias towards informed decision-making.

## Conclusions

Nurses will likely play an increasingly important role in supporting women in making informed decisions about breast cancer screening with mammography. The results of this study could be used to develop interventions aimed at helping nurses play this role. Using the components of perceived behavioural control and attitude to train nurses in how to integrate informed decision-making into their practice and providing both nurses and targeted women with decision support tools could foster the targeted behaviour. Interventions may also consider the importance of socio-professional norm for nurses who are not often in contact with the targeted women. The feasibility and effectiveness of these interventions should be further evaluated.

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### **Acknowledgements**

We thank Jacques Rivard and Sun Makosso-Kallyth for their contributions to the data analysis.

We are also grateful to the Institut National de Santé Publique du Québec for its financial support.

Competing interests: The authors report none.

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**Appendix 1 Questionnaire<sup>1</sup>**

For the past 10 years the Quebec Ministry of Health and Social Services (MHSS) has sent a letter to all women aged 50 to 69 inviting them to participate in the Quebec Breast Cancer Screening Program (QBCSP). Until recently the QBCSP encouraged all women in this age group to participate. The MHSS will now be changing this approach.

In line with its current slogan, “Screening for breast cancer: A decision that belongs to you,” the QBCSP will put in place mechanisms to inform women about the potential disadvantages as well as the benefits of breast cancer screening, based on the best scientific evidence. These will consist of awareness campaigns targeting the general public and health professionals, leaflets, a Web site for women invited to participate in the program, and training for health professionals in informed decision-making about breast cancer screening.

The goal is to ensure that every woman contacted by the QBCSP is able to make an informed decision whether to undergo breast cancer screening. According to this approach, there is no best decision (to screen) or worst decision (not to screen). Both options are acceptable. Each woman has to choose the option she feels most comfortable with after having reviewed the information provided. Please imagine that this approach has already been adopted and then respond to the following questions.

<sup>1</sup> Translated from the original French. Only questions 1 to 11 are included here. The full version (17 questions) may be obtained by contacting Michel Labrecque at [michel.labrecque@fmed.ulaval.ca](mailto:michel.labrecque@fmed.ulaval.ca).

*Informed Decision-Making About Mammography*

1. In my current practice, I meet women targeted by the QBCSP:  
 OFTEN  SOMETIMES  RARELY  NEVER

2. I intend to help women targeted by the QBCSP in making informed decisions about screening for breast cancer:  
STRONGLY DISAGREE STRONGLY AGREE  
 -3  -2  -1  1  2  3

3. The likelihood that I will help women targeted by the QBCSP in making informed decisions about screening for breast cancer is:  
VERY WEAK VERY STRONG  
 -3  -2  -1  1  2  3

4. I feel that helping women targeted by the QBCSP in making informed decisions about breast cancer screening is:  
USELESS VERY USEFUL  
 -3  -2  -1  1  2  3  
VERY DIFFICULT VERY EASY  
 -3  -2  -1  1  2  3  
VERY UNLIKELY VERY LIKELY  
 -3  -2  -1  1  2  3  
VERY IRRESPONSIBLE VERY RESPONSIBLE  
 -3  -2  -1  1  2  3

5. Most people in my work environment would approve/disapprove of my helping women targeted by the QBCSP in making informed decisions about screening for breast cancer:  
STRONGLY DISAPPROVE OF STRONGLY APPROVE OF  
 -3  -2  -1  1  2  3

6. I don't see any obstacles in helping women targeted by the QBCSP in making informed decisions about screening for breast cancer:  
STRONGLY DISAGREE STRONGLY AGREE  
 -3  -2  -1  1  2  3

7. I believe that there are more advantages than disadvantages for women targeted by the QBCSP if I help them in making informed decisions about screening for breast cancer:  
STRONGLY DISAGREE STRONGLY AGREE  
 -3  -2  -1  1  2  3

8. Most people who are important to me would approve/disapprove of my helping women targeted by the QBCSP in making informed decisions about screening for breast cancer:

STRONGLY DISAPPROVE OF

STRONGLY APPROVE OF

-3       -2       -1       1       2       3

9. I am able to help women targeted by the QBCSP in making informed decisions about screening for breast cancer:

STRONGLY DISAGREE

STRONGLY AGREE

-3       -2       -1       1       2       3

10. Most of my patients targeted by the QBCSP would approve/disapprove of my helping them in making informed decisions about screening for breast cancer:

STRONGLY DISAPPROVE OF

STRONGLY APPROVE OF

-3       -2       -1       1       2       3

11. Factors that could hinder me from supporting women targeted by the QBCSP in making informed decisions:

LACK OF TIME

LACK OF TRAINING (TRAINING IN INFORMED DECISION-MAKING)

LACK OF RELEVANT DECISION SUPPORT TOOLS

LACK OF TIME

OTHER (PLEASE SPECIFY) \_\_\_\_\_