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EDITORIAL

**The Slaying of Facts by Dubious  
Hypotheses and Ugly Misrepresentations<sup>1</sup>:  
The Musings of a Canadian Editor  
on the 2009 Health-Care Debate  
in the United States**

It has been a cool summer in eastern Canada, but as we move into August it is warming up. This change in temperature can be attributed not just to climatic conditions but also to the heat that is being generated by the health-care debate south of the border. We Canadians find ourselves in the uncomfortable position of being pawns in this debate — bandied about by the different interest groups in the United States. Canada is portrayed as having either the world's best health-care system — warts and all — or the worst. Canadians are either the healthiest and luckiest people on earth or the poorest of saps just a heartbeat away from death because of an inadequate health-care system. The groups who condemn the Canadian system are the most vitriolic and are the ones most responsible for the hot air blowing our way. When these opponents of health-care reform use the word “Canadian,” it is with disdain, pity, and fear. It is as if we were a country infected with a deadly virus — ready to bring ruin to the United States.

While there are arguments to be made on both sides of the debate, the opponents of a partially government-funded system seem to be the more vocal. Their positions and the arguments they put forth are designed to incite fear within a climate where emotion trumps facts. Many people genuinely fear that they will lose their rights — their right to choose their doctor, health-care plan, and health-care facility (if these are available), their right to have access to the finest health-care system in the world, with the best doctors and the most sophisticated technologies (if they can afford to pay for it), their right to affordable and accessible health care (if it does not affect their taxes). Yet apparently these Americans who are so concerned about rights do not necessarily subscribe to the idea that health is a right — a right of everyone, not just those few who can afford to pay for it. In Canada, on the other hand,

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<sup>1</sup> A twist on the saying “the slaying of a beautiful hypothesis by an ugly fact.”

health is considered a basic human right — one that people at all socio-economic levels believe in and value and are willing to pay for.

As the debate rages in the United States, I have never felt prouder to be a Canadian and to be one of those poor saps who willingly pay taxes to finance our government-funded, universal health-care system — first, because I believe it to be the right way, and second, because a healthy society is the best way to protect and benefit individual citizens.

Two personal incidents this past summer illustrate just how fortunate we Canadians are to have the health-care system we do.

This past year I have been on sabbatical and have travelled extensively. My final destination was Hawaii, joined by my children and grandchildren. On the second day of our vacation, my adult son, unbeknownst to him, stepped on a sea urchin while snorkelling. At first he was unsure about the nature of his injury, but he did know he required medical care. I watched his anxiety mount, not over the injury but over how much a visit to a doctor would cost him: Should I see a doctor? How much will it cost? Can I afford it? Will the clinic accept my insurance plan? (My son is a Canadian living and working in the United States.) When the pain intensified and the swelling increased, I convinced him that he was in need of immediate attention. The first round of questions from the secretary at the medical clinic concerned payment. As it was Friday afternoon and the offices in the east had long since closed for the weekend, my son could not find out if his insurance plan would reimburse him. The answer would not be forthcoming until Monday, and by then his minor wound could potentially be major! The nearest facility that might possibly accept his insurance plan was more than 100 kilometres away. He hemmed and hawed, and after much coaxing agreed to see the doctor at the medical clinic. Five minutes later he was \$350 poorer, and the figure would have been \$750 had we not had the broad-spectrum antibiotic that my husband and I always carry with us when we travel. (The doctor told us that this particular antibiotic would have cost my son \$400.) The bill included a charge of \$85 for “medical supply,” which was an ordinary 20¢ Band-Aid! So much for choice. So much for affordability.

The second incident occurred two weeks later. My husband and I attended a medical seminar at the University of Hawaii. The first speaker, a physician, spoke on his idea on how to leverage resources differently to provide health-care services. In building his case he recited the usual litany of shortcomings in the Canadian system: long waiting lists, lack of choice, and so on. His talk was followed by a slide presentation based on a new book by Richard Wilkinson and Kate Pickett, *The Spirit Level: Why More Equal Societies Always Do Better* (Penguin, 2009). The authors make the case that people living in societies where there is more equal distribution of wealth (where the wealthy pay higher taxes) are healthier

and better off.<sup>2</sup> The United States, with its wide disparity between rich and poor, ranks low on almost all health indices compared to those countries, including Canada, where the wealth is more evenly distributed. These statistics were hardly new and came as no surprise. What did surprise us was the fact that no one in the audience of health professionals asked about the relationship between more equitable distribution of wealth and health outcomes, and the missing link — access to affordable care. That is, until we spoke up. Although we had been introduced as a professor in nursing and a researcher in genetics at McGill University, few at the seminar realized that McGill University was in Canada. We corrected some of the misconceptions about the Canadian health-care system and confirmed some of the truths, providing context and giving concrete examples from our own experience and from the research literature. I'm not sure we changed any minds, but at least we dared to question what has been widely accepted as fact.

Nurses, and all Canadians, should take heed of what is transpiring in the American health-care debate. We need to correct misperceptions and factual errors and produce research that addresses the link between health and the quality of health services. If we fail to do so we risk buying into the misrepresentation of the Canadian health-care system by the American media, politicians, and interest groups. Many Canadians may come to believe the propaganda and to doubt the premises and values upon which our health-care system is built. Fear knows no borders. It can infiltrate our national psyche. We cannot let this happen.

That is not to say we should be complacent about our health-care system. One lesson to be learned from the American debate is that our own system merits close monitoring. It is imperative that researchers describe, both qualitatively and quantitatively, the shortcomings of the system as well as its strengths, and to always ask *why*, *how*, and *what*: Why is this occurring? How can we make things better? What else needs to be done? The fruits of such research will help us to maintain, sustain, and improve a system that is built on sound values and principles as outlined in the *Canada Health Act*.<sup>3</sup> Only by taking notice of the winds that are blowing across our southern border will we be able to protect what we have and prevent erosion from within as well as from without. Nurses, other health professionals, and all citizens need to become the sentinels

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<sup>2</sup> The slides are available at [www.equalitytrust.org.uk/resources/slides](http://www.equalitytrust.org.uk/resources/slides).

<sup>3</sup> The *Canada Health Act* was passed in 1984 when Monique Bégin was minister of health. It is a great honour to have the former minister contribute to this issue of *CJNR*. Monique Bégin's vision, principled actions, and tenacity shaped our health-care system. We need to remind ourselves on a regular basis why these principles are important and why they are worth fighting for.

*Editorial*

of our health-care system. For, flawed as it may be, our system is among the best in the world. And it has the potential to be even better, because it is built on the bedrock of cherished Canadian values.

**Laurie N. Gottlieb**  
**Editor-in-Chief**

**GUEST EDITORIAL**

# **Social Network, Social Support, and Health**

**Miriam Stewart**

The World Health Organization's Commission on Social Determinants of Health called for research on strategies that alter health inequity (Commission on Social Determinants of Health, 2008). Monique Bégin's thoughtful reflection on the important and timely work of the Commission and the significance of social support as a health determinant sets the stage for this exciting issue of *CJNR*. This groundbreaking international contribution and the Chief Public Health Officer's 2008 *Report on the State of Public Health in Canada* (Butler-Jones, 2008) reinforce the salient role of social support and social networks as a key social determinant of health, a health promotion mechanism, and a protective factor in resilience. Indeed this recently released national document contends that "loving, being loved and having family, friends and other social connections that give us a sense of being part of something larger than ourselves . . . matter because health is more than physical" (p. ii). Chua, Madej, and Wellman's Discourse on innovative social networks challenges readers to reframe traditional views of the mechanisms through which connections with others meet social and health needs in the current context in Canada and the global community.

Interactions and relationships with members of social networks can be supportive or non-supportive and can exert salutary or detrimental effects on physical, psychological, and spiritual health and well-being. Gantert and colleagues examine challenges inherent in interactions between family caregivers (informal sources of support) and service providers (formal sources) and point to the need for collaborative and collegial relationships. The authors would likely concur that such partnerships could capitalize on the experiential knowledge of citizens and caregivers and the professional knowledge of nurses and members of other health and health-related disciplines.

Social support influences physical and psychological health status, health-services use, and health behaviours. Collins-McNeil and colleagues investigate links among social support, mental health, and physical activity. They report the finding that social support was inversely

related to depressive symptoms and directly related to social support. Moreover, they note that social support seemed to be a protective factor for African-American women with type 2 diabetes. Guruge and Humphreys focus on the potential role of social support in reducing health disparities and enhancing resilience of another vulnerable population — immigrants. Specifically, they examine the barriers faced by Sri Lankan Tamil women in accessing formal supports to deal with interpersonal violence. Both of these articles assess multicultural meanings of social support and investigate links between social support and other social determinants of health — in this case, ethnicity, race, and culture.

Gender as another significant social determinant is a prominent theme in Letourneau, Duffett-Leger, and Salmani's study investigating the impact of social support available from fathers on children's behavioural development in families affected by maternal postpartum depression. The authors propose a theoretical model of resilience that profiles social support as a protective factor for vulnerable families. They also employ sophisticated quantitative techniques for analyzing pertinent data from the National Longitudinal Survey of Children and Youth. The previous articles primarily use qualitative methods. Multi-methods and mixed methods are timely and transformative for studies of the mechanisms by which social support and other social, as well as biological, determinants interact and exert their effect on health.

The call for papers for this issue of *CJNR* invited manuscripts that describe research examining the measurement properties of social support indicators or instruments at the individual or population level. Ward-Griffin and colleagues delineate the development and psychometric validation of the Double Duty Caregiving Scale, which encompasses factors germane to social support and social networks, such as familial expectations, making connections, and negotiating, as well as two factors that emphasize personal and professional supports.

The articles included in this issue of the Journal shed some light on implications for practice, programs, and policies in health and health-related sectors. However, there is a pressing need for more multi-level and multi-method intervention studies that test theories and use innovative mechanisms and modalities to mobilize knowledge translation. Chua, Madej, and Wellman point to the transformative promise of technology in fostering social networks and social support, which in turn can enhance the health of people in Canada and worldwide. Assessment and intervention investigations should be informed by participatory strategies that engage diverse stakeholders, including affected people, members of the public, practitioners, program planners, and policy influencers. As the Senate Subcommittee on Population Health declares in its 2009 report, *A Healthy, Productive Canada: A Determinant of Health Approach*, "Because



the determinants of health play out at the local level, governments must draw upon the expertise and capacity of citizens to build the strong and inclusive communities that are required for a healthy and productive population” (Keon & Pépin, 2009, p. 3).

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## Discourse

# Personal Communities as Sources of Social Support

Vincent Chua, Julia Madej, and Barry Wellman

There are at least two ways of looking at community: (a) as a traditional spatially bounded community rooted in neighbourhoods, and (b) as the new type of community we discuss here: *personal communities* defined as connected to the individuals at their centres. From this standpoint, friends, neighbours, kin, acquaintances, co-workers, and fellow members of organizations are personal community members, connected to the individual at the centre and often connected to each other. Personal communities are the subset of those members of personal networks whom people care about and with whom they are in frequent contact and exchange resources.

While personal communities have always been with us, they have become more palpable and visible since the advent of the Internet. E-mail lists of friends and social networking Web sites such as Facebook and MySpace (which we collectively call MyFace) organize people's social worlds in terms of lists of their friends and acquaintances — large chunks of their personal communities.

Whereas some scholars continue to study community in terms of spatially bounded units such as groups, neighbourhoods, and villages, the current state of the art focuses on community as an interpenetrating combination of online and offline worlds managed by autonomous individuals at their respective centres (Boase & Wellman, 2006). To be sure, personal communities have always existed, but their form has changed drastically with time. In an earlier period, personal communities were mostly geographically bound, densely knit, and broad-based — organized around discrete social units such as bars and taverns, steel towns, and neighbourhoods. Today, many personal communities are unmistakably far-flung, loosely knit, and specialized. The growth of social affordances such as mobile phones and e-mail has facilitated this transformation. Where landline phones link “households to households,” mobile phones and e-mail sustain communication directly between “person and person,” giving rise to a contemporary form of community called “networked individualism” (Wellman, 1979, 2001).

A pressing concern with respect to contemporary communities is their alleged decline over the past hundred years. In the mid-1990s the political scientist Robert Putnam (2000) argued that Americans were “bowling alone” and that civic activities such as voting, social club membership, and family dinners were on the decline. Recently McPherson, Smith-Lovin, and Brashears (2006) repeated the caution, showing that the discussion networks of Americans decreased from three to about two members in the space of two decades, from the mid-1980s to the mid-2000s. A second and related concern has been the possible decline of community in the so-called Internet Age. Some commentators have expressed the belief that the Internet will beset individuals with online addictions and deprive them of face-to-face communication as they focus their attention on online interactions (Boase & Wellman, 2006).

Yet most personal network studies show that community has rarely disappeared from societies but is embedded in personal networks. A number of studies conducted in Asia, Europe, and North and South America have demonstrated that communities persist in the form of personal networks and flourish as a central part of people’s lives (Chua, Madej, & Wellman, forthcoming; Wellman, 2007). Although formal leisure organizations (such as the Lions Club) have declined in membership, they have been supplanted by more informal means of communicating and socializing. Large networks of specialized ties are compensating for the shrinkage of very strong ties. Moreover, with social affordances such as the Internet and e-mail, distance has become less of a hindrance as communication has increasingly become defined by social rather than spatial accessibility (Hogan, 2008). Also, while contemporary communities may have gone indoors, to cafés and living rooms and computer screens, community has not disappeared (Fischer, 2005; Wellman, 1999). From indoors, people continue to be social: They chat with friends online, meet them offline to round out discussions, and meet online again to talk about other things.

The Internet has not destroyed or even weakened community, but, rather, has enhanced it. Online and offline interactions are becoming seamlessly integrated (Boase, Horrigan, Wellman, & Rainie, 2006). In everyday life, people use the Internet to achieve what they have always been achieving — social interaction. The Internet is a technological marvel, to be sure, but the technology is marvellous precisely because it allows people to be especially social.

### **Communities as Personal Networks**

One way to understand the personal network approach is to think about a person’s Friends on the Facebook social networking Web site. The sub-

scriber of the account is “ego.” His/her personal community comprises all the other Facebook users personally linked to him/her as Friends. A Friend can be anyone — from an acquaintance living miles away, to a neighbour living next door, to a sibling living in the same house. With Internet-based social affordances such as Facebook, modern-day personal communities typically comprise a combination of local and global ties, reflecting the social trend towards “glocalization” (Hampton & Wellman, 2003).

Recently, concerns have been raised about the lack of privacy on MyFace, but such is the world we live in today: Communities have become personal and private and yet in some ways significantly public, with Friends being shared and recommended across networks. For example, it has become quite common for Friends to peruse one another’s personal networks in their free time. This is done by simply clicking on the name of a particular network member and pointing the cursor to that person’s network. One hypothesis is that MyFace facilitates transitive relations — that is, if Bob knows both Ted and Alice, then over time Ted and Alice are likely to get to know each other. In short, personal communities are personal, but they are also shared across personal networks. As this sharing is multiplied, different parts of the social structure overlap and intersect. Such intertwining may break down barriers between groups and unite individuals through the sharing of new information and friendship. MyFace creates opportunities for the development of diverse personal communities: To have diverse friends is to have diverse experiences, and all these experiences add up to a culturally enriched life.

### **Personal Community and Social Support**

A personal community typically comprises a network of arrangements differentiated roughly by an inner and an outer core. The inner core tends to comprise networks that are densely knit and multiplex, while the outer core tends to comprise networks that are sparse and segmented (Hogan, 2008; Wellman & Wortley, 1990). As modern societies have become differentiated, the functions of personal communities have likewise become specialized and diverse.

Reflecting modern trends in marketing, individuals now shop for support at specialized interpersonal boutiques rather than at general stores. Diverse ties fulfil diverse functions. Strong ties in the form of immediate kin are typically associated with long-term care and small services. Friends, siblings, and organizational members, especially those with strong ties, are likely to be social companions. Physically accessible relations are more likely to provide large and small services and women are more likely to provide emotional aid. As personal managers of their

personal communities, individuals come to learn about what kinds of networks work for what purposes, and thereby “invest” in unique and diverse combinations of relationships in accordance with their needs and life goals.

Personal communities are important to the routine functioning of households, are crucial to the management of crises, and are sometimes instrumental in effecting change. They provide havens: a sense of belonging and of being helped. Family and close friends are often counted on to provide routine emotional aid and small services that help one cope with the stresses and strains of various circumstances. When faced with a medical crisis, people typically consult close friends and family. These network members constitute a “therapy managing group” (Pescosolido, 1992, p. 1124) and are partners in the health-management process.

Personal communities are also instrumental in changing situations. As conduits for the exchange of resources, personal communities can often lead to enhanced life chances such as getting advice on important matters (Fischer, 1982), gaining diverse knowledge (Erickson, 1996), and securing a paid job (Granovetter, 1995). They are useful for negotiating barriers, such as formal bureaucratic structures, in everyday life. For example, in pre-market China, close connections with influential friends and family were often invoked to expedite illegal job changes amid tight governmental control (Bian, 1997). Network-led changes in situations often bring about significant improvements in individuals’ mental health, strengthening the overall well-being of the help-seeker (Pescosolido, 1992).

### **Personal Community and Inequality**

While personal communities are channels for the transmission of many benefits, they are also conduits for social control and the reproduction of social inequalities. Ironically, personal communities can themselves be stressors. For example, in some tightly knit ethnic communities, in-group pressures may often aggregate to suppress individual achievement, so that anyone who succeeds beyond the norm may be accused of exchanging his/her ethnic roots for mainstream values (Portes & Sensenbrenner, 1993).

Personal networks also contribute to the transmission of inequalities within labour markets. With many employers choosing to use insider networks in addition to formal hiring methods, the personal recommendation has become a popular hiring tool for both high-end and low-end jobs (Burt, 1997; Erickson, 2001). From the employer’s point of view, networks reduce screening costs and ensure good-quality candidates, but they may disadvantage those candidates who lack connections (Fernández, Castilla, & Moore, 2000).

The best connections tend to be those that reach up to influential people (Lin, 2001). Influential people are often gatekeepers of useful job information (Marin, 2008) and other forms of knowledge, ranging from sports to literature (Erickson, 1996). Unfortunately, opportunities to reach up are seldom equally distributed in the population. As friendship networks are often stratified by class (Ferrand, Mounier, & Degenne, 1999; Wright & Cho, 1992), people in lower ranks seldom get to add influential contacts to their networks. In the rare event that they do, they reap substantial labour-market benefits (Ooka & Wellman, 2006). Further, it cannot be assumed that job-seekers and information-holders are always willing to cooperate. Studies indicate that the nature of seeker-helper relations is often highly contingent upon the more powerful person being willing to help the less powerful person (Marin, 2008; Smith, 2005).

### **Conclusions**

Personal communities are personal. And yet they are intensively social, spanning social boundaries such as physical continents, social divisions, and other networks. In reality, personal communities are not like the thousands of isolated islands in the Indonesian archipelago but overlap with other social networks to create a system of social interactions resembling a loosely coupled but unmistakably linked social whole (Wellman, 1988). The birth and development of communication technologies such as the Internet, e-mail, mobile phones, and “smartphones” are social affordances that allow people to build communities in new and exciting ways. Because these technologies enable people to talk over large distances as well as to keep short-distance ties, distance has become less of a barrier to the cultivation and maintenance of personal communities.

With the explosive growth of technologies and social affordances, the contemporary world can be said to be undergoing a *triple revolution*: an Internet revolution, a mobile revolution, and a network revolution (Rainie & Wellman, in press). The *Internet revolution* has opened up renewed ways of communicating and finding information. The power of knowledge is no longer the monopoly of professionals, since common folk can now engage the Internet and compare “research notes” with health-care and financial experts.

This Internet revolution is bound up with the *mobile revolution*, which allows individuals to communicate and gather information while on the move. With greater connectivity all around, people can engage their networks and access information regardless of their physical location. Home bases are still important as sources of ideas and inspiration, but the mobile

revolution ensures that we never lose touch with either home base or other important social worlds.

Together, the mobile and Internet revolutions intersect with the *social network revolution*. Although bound up with technology, this third revolution is focused on the intensely social worlds of care and support that they afford to those who have communication access.

The social network revolution is, at its heart, a revolution aimed at sustaining worlds of resource provision, including the social support, comfort, and informality of personal community networks. While networks and social resources remain unevenly distributed within populations, giving rise to inequalities, they continue to be deployed and harnessed by individuals in pursuit of the care and well-being they desire in a sometimes unkind world.

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## Reflections

# Social Determinants of Health

**Monique Bégin**

In February 2005, when I was contacted by telephone by Sir Michael Marmot to discuss the possibility of my serving on the still to be announced Commission on Social Determinants of Health of the World Health Organization, I had no idea who he was. I was familiar with the 1980 Black Report as well as Margaret Whitehead's 1987 follow-up report, *The Great Divide*, which I used in my courses. I knew a bit about the Whitehall Studies I and II but did not follow their scientific publications. However, as far back as 1993, in speeches on women's health, I had referred to and discussed the social determinants of women's health. Gender, poverty, violence. I knew the words. I did not know the science behind them nor the research evidence.

So I Googled Sir Michael Marmot to get to know him and his work. One of the very first texts I accessed was a long interview with Marmot, conducted in March 2002 by Professor Harry Kreisler of the Institute of International Studies at the University of California at Berkeley. I was fascinated. An internationally known scientist, a physician with impeccable credentials in epidemiology who had been a clinician in a cardiac clinic and a chest clinic — a “British empiricist,” as Marmot calls himself — addressing the societal role in health, discussing individual versus societal causation of disease? I could not believe what I was reading. And right then, before we had met as a Commission and before I had met Sir Michael, what surprised me most was his observation that, besides the classical factors leading to pathologies, much had to do with the degree to which people are able to participate fully in society. “We found clear social gradients in people's participation in social networks,” he added. That was a very surprising observation, as the first Whitehall study was set up as a rather conventional study of risk factors for cardiovascular and respiratory disease in male British civil servants.

In a recent interview for the excellent PBS series *Unnatural Causes*, Marmot said:

We have strong evidence that there are two important influences on health in explaining the hierarchy in health. The first is autonomy,

control, empowerment. . . . The second is what I loosely call social participation. It's being able to take your place in society as a fully paid-up member of society, as it were, to benefit from all that society has to offer. Now, in part that's social supports and social networks, but it also functions at a psychological level. It's self-esteem; it's the esteem of others. It's saying that I can benefit from the fruits that society has to offer.

So it is not surprising that the Commission, having decided from the start to have eight so-called knowledge networks — international research teams, each working on a specific determinant of health — had one on Social Exclusion. We could have easily identified a dozen different determinants, but we focused on those eight. Jennie Popay, Professor of Sociology and Public Health at Lancaster University, chaired the knowledge network on Social Exclusion, which released a report titled *Understanding and Tackling Social Exclusion (A Person Is a Person Because of Other People)*. The report discussed country case studies both of situations and of processes of social exclusion as well as good practices in different parts of the world, and it offered recommendations to the Commission for our own final report.

As pointed out by the research team, the concept of social exclusion/inclusion overlaps with related concepts such as social cohesion, social capital, social justice, and social/human rights, as well as constituent elements of these concepts such as empowerment, emancipation, disaffiliation, and marginalization. The concept of social exclusion/inclusion speaks directly to the theme of this journal issue: social support, social networks, and health.

A proverb of the Nguni people (parts of eastern and southern Africa), “A person is a person because of other people,” which is used as the subtitle of the knowledge network report, captures the most fundamental piece of wisdom. Like the report itself, it focuses “on the central role of relational interdependence in the working of any social system.” It also makes explicit the individual and collective self-interest inherent in pursuing actions to promote inclusion. Here is the summary of the conceptual approach taken by the knowledge network research team as it appears in their report (p. 8):

- The concept of social exclusion is not equally salient around the world: alternative discourses may have greater relevance for policy and action.
- A relational understanding of social exclusion has advantages:
  - Providing a wider lens to understand the causes and consequences of unequal power relationships
  - Making explicit the links between exclusion and a “rights” approach to the social determinants of health

- Directing analytical attention to interactions between relationships and outcomes at different levels e.g. community, nation state and global regions
- Highlighting both active and passive exclusionary processes
- Recognising that exclusionary processes will impact in different ways to differing degrees on different groups and/or societies at different times
- Avoiding the stigma of labelling particular groups as “excluded”
- Allowing for the possibility of inequitable inclusion and extreme exclusion
- Acknowledging the potential for groups and/or nations to actively resist exclusionary processes and ensuing negative consequences
- Recognising diversity and hence providing for global relevance
- Both constitutive and instrumental pathways link SE to health inequities:
  - Constitutively: restricted participation in economic, social, political and cultural relationships will negatively impact on health and well-being.
  - Instrumentally, these restrictions result in other deprivations, for example, poor working conditions or complete exclusion from the labour market leading to low income, poor nutrition, etc which contribute to ill health.

A few additional observations. Social exclusion is often equated with, and reduced to, poverty. In fact it is much more than poverty, although poverty is often a part of it. How has the Commission on Social Determinants of Health dealt with these interrelated issues? We stated from the start our three principles of action embodied in our three overarching recommendations:

- Improve the conditions of daily life — the circumstances in which people are born, grow, live, work, and age.
- Tackle the inequitable distribution of power, money, and resources — the structural drivers of those conditions of daily life — globally, nationally, and locally.
- Measure the problem, evaluate action, expand the knowledge base, develop a workforce that is trained in the social determinants of health, and raise public awareness about the social determinants of health.

At first glance, the importance for health of social support networks made up of friends, family members, and peers (not to diminish the key role of support groups, which are usually structured around a single issue) appears to pertain to daily living conditions. In fact social support networks have both an individual and — even more important — a societal dimension. Consequently, in its final report the Commission points to

the need to develop political empowerment, inclusion, and voice as overall structural changes — a societal responsibility as opposed to a daily living condition. It should be kept in mind that the report, being international, is addressing vastly different situations. In some countries the ability to develop social support networks requires, first and foremost, a basic respect for human rights. Inequity being at the root of our work, the chapter on social exclusion discusses issues of power imbalance, identity, and fairness in political representation and in decision-making generally. It also points to the importance of the growth of civil society organizations, networks, and movements “and their progressive ability to challenge inequity and push for the installation of equity — in general and in relation to health — in the centre of all existing and emerging political debates.” Above all, it takes a bottom-up approach to health equity and speaks to the power of the local community.

We do know that solidarity between neighbours, friends, family members, and colleagues has an effect on health status and outcome. It nurtures a sense of belonging. Spending time with people helps ward off loneliness. It also increases one’s sense of self-worth. Finally, it enhances one’s feeling of security. By reaching out and sharing with others, people have the added security of knowing that if they start to show signs of depression or an unhealthy lifestyle, their friends will alert them to the problem.

We have enough evidence to initiate action. This is not to say that additional monitoring, research, and capacity development are not needed.

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## **L'activité physique, les symptômes de la dépression et le soutien social chez les Afro-Américaines atteintes de diabète de type II**

**Janice C. McNeil, Ezra C. Holston, Christopher L. Edwards,  
Debra Benbow et Yvonne Ford**

Cette étude de nature descriptive et corrélationnelle visait à analyser les rapports entre l'activité physique, les symptômes de la dépression et les perceptions en matière de soutien social au sein d'un échantillon constitué de 45 Afro-Américaines d'âge moyen et avancé souffrant de diabète de type II, et qui reçoivent des soins dans l'un de trois centres de soins primaires situés dans le sud-ouest des États-Unis. Sur l'ensemble, 82 % des participantes ont indiqué qu'elles s'adonnaient à une activité physique et 88 % qu'elles jouissaient d'un degré élevé de soutien social. La prévalence des symptômes de dépression était élevée au sein de l'échantillon ( $n = 15$ ; 30 %); on a relevé un lien entre les symptômes de dépression, le fait d'être jeune et un soutien social moindre. Ces conclusions confirment la nécessité de mener d'autres recherches sur les caractéristiques de l'activité physique, les symptômes de la dépression et le soutien social chez les Afro-Américaines atteintes de diabète de type II.

Mots clés : activité physique, dépression, soutien social, diabète, femmes



# **Physical Activity, Depressive Symptoms, and Social Support Among African-American Women With Type 2 Diabetes**

**Janice C. Collins-McNeil, Ezra C. Holston,  
Christopher L. Edwards, Debra Benbow, and Yvonne Ford**

This descriptive–correlational study examined the associations among physical activity, depressive symptoms, and perceived social support in 45 middle-aged and older African-American women with type 2 diabetes receiving care in 1 of 3 community-based primary care centres in the southeastern United States. Of the participants, 82% reported weekly physical activity and 88% reported a high degree of social support. The prevalence of depressive symptoms was also high in the sample ( $n = 15$ ; 30%), and depressive symptoms were associated with younger age and less social support. Further investigation of physical activity characteristics, depressive symptoms, and social support in African-American women with type 2 diabetes is warranted.

Keywords: physical activity, depression, social support, diabetes, women

## **Introduction**

Type 2 diabetes mellitus (T2DM), with its associated morbidities, is one of the leading causes of disability and death in the United States (Borrell, Dallo, & White, 2006). Among the multiple behaviours that affect quality of life in those with diabetes, physical inactivity appears to account for a significant number of the negative outcomes associated with the disease (Morrato, Hill, Wyatt, Ghushchyan, & Sullivan, 2003). The study reported here looked at factors, including depressive symptoms and social support, associated with physical activity in African-American women with diabetes.

African-American women bear a disproportionate burden of T2DM and its complications and mortality (Liburd, 2003; Mokdad et al., 2003). Despite this disproportionate burden, little attention has been paid to the determinants of physical activity in this high-risk population. Further, physical activity is reported to be one of the most neglected aspects of the T2DM treatment regimen (Dutton, Johnson, Whitehead, Bodenlos, & Brantley, 2005) and research has found that low-income African-

American women with T2DM have lower levels of physical activity than their Caucasian counterparts (Dutton et al., 2005).

### ***Effects of Depression on Physical Activity***

Depression, which is one of the most common mental disorders among individuals with diabetes (Gavard, Lustman, & Clouse, 1993; Peyrot & Rubbin, 1997), may exacerbate the propensity towards physical inactivity and reduce other self-care behaviours (Sacco & Yanover, 2006). Few studies have examined the prevalence of depression in African Americans with T2DM (Carrington, 2006; de Groot & Lustman, 2001). Yet among patients with diabetes, the prevalence of depression is significantly greater in women (28%) than in men (18%) (Anderson, Freedland, Clouse, & Lustman, 2001) and African-American women with diabetes are reported to have more depressive symptoms than their Caucasian counterparts (Blazer, Moody-Ayers, Craft-Morgan, & Burchett, 2002; National Institute of Mental Health, 2000; Shea & Owens-Gary, 2009; Wagner, Tsimikas, Heapy, de Groot, & Abbott, 2007). Further, Gary, Crum, Cooper-Patrick, Ford, and Brancati (2000) report that 45% of African-American participants with T2DM had moderate depression (Center for Epidemiological Studies–Depression [CES-D] scores above 16) and 30% had moderately severe depression (CES-D scores above 22). In a recent study, Wagner, Abbott, Heapy, and Yong (2009) found that African Americans with diabetes had depressive symptoms that were associated with higher glucose levels, more long-term diabetes complications, and more diabetes medications; further, African-American women with diabetes reported more depressive symptoms than African-American men with diabetes.

### ***Effects of Social Support***

Research has documented that social support has a significant influence on health outcomes. A recent study found that social support plays a role in diabetes-specific quality of life and self-management practices (Tang, Brown, Funnell, & Anderson, 2008). High levels of social support have also been associated with improved physical health and more positive health behaviours in African-American women (Belgrave & Lewis, 1994; Martin, 1996). Social support may increase the probability of adherence to self-care regimens, including physical activity, and decrease the risk for depression (Chlebowsky & Garvin, 2006; Devlin, Roberts, Okaya, & Xiong, 2006; Ford, Tilley, & McDonald, 1998a, 1998b; McDonald, Wykle, Misra, Suwonnaroop, & Burant, 2002). For instance, Tang et al. (2008) found that social support was associated with multiple self-care practices pertaining to diet and physical activity. Further, inadequate social support has been reported to adversely affect the motivation of patients and

reduce their efforts to stay actively involved in diabetes management (Nouwen, Gringras, Talbot, & Bouchard, 1997; Wallhagen, 1999).

The findings of recent research indicate that social undermining and low social support are related to depression in African-American women (Gant et al., 1993; Myers et al., 2002). Thus, although social support is recognized as a resource that may assist with effective stress management, we do not fully understand the role of social support in promoting physical activity and positive mental health outcomes in African-American women with T2DM.

In summary, the mechanisms by which physical activity is related to depression are unclear and there are no data on the dose effects of physical activity (Faulkner, 2009). In particular, little is known about the relationships among physical activity, depressive symptoms, and perceived social support in African-American women with T2DM. Therefore, this study examined physical activity, depressive symptoms, and perceived social support in African-American women with T2DM and explored the relationships among these variables.

## **Methods**

### ***Setting and Sample***

This secondary data analysis examined the physical activity characteristics, depressive symptoms, and perceived social support of 45 African-American women with T2DM residing in the southeastern United States. Data were derived from a study with 57 African Americans with T2DM (Collins-McNeil, 2006) and have been reported elsewhere (Collins-McNeil, Holston, Edwards, Martin, & Benbow, 2007). Participants in that study were outpatients at three urban primary care centres in the southeastern United States. All participants were required to demonstrate written or verbal comprehension by signing or making a witnessed mark indicating consent. Individuals were excluded if they were legally blind, profoundly deaf, or cognitively impaired (confirmed by medical records) to a degree that would prevent comprehension of verbal instructions or completion of an interview. In addition, individuals were excluded if they had a history of coronary heart disease (myocardial infarction, angina pectoris) or cerebrovascular disease (stroke). The study was approved by the university institutional review board.

### ***Procedures***

Potential participants were approached by their health-care providers about taking part in the study. After these individuals volunteered and signed a consent form, face-to-face interviews were conducted by the first author and trained nurse research assistants. At the end of their inter-

view, participants received a Walmart gift card valued at \$25 as a token of appreciation.

### **Instruments**

Four instruments were used to measure the study variables.

The Personal Health and Sociodemographic Form was used to collect date of birth, marital status, years of education, annual income, race/ethnicity, personal/family medical history, mental health history, medications, and physical activity.

The 20-item Center for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977) was used to assess depressive symptoms. The CES-D has been shown to be a reliable measure for assessing the number, types, and duration of depressive symptoms across racial, gender, and age categories (Knight, Williams, McGee, & Olaman, 1997; Radloff, 1977). Good internal consistency has been reported, with Cronbach's alpha coefficients ranging from .85 to .90 across studies (Radloff, 1977). Concurrent validity by clinical and self-report criteria has been demonstrated, as has substantial evidence of construct validity (Radloff, 1977). Scores can range from 0 to 60, with a cut-off of 16 indicating clinical depression (Jiang et al., 2003). In the present study, Cronbach's alpha was an acceptable .74.

The Medical Outcomes Survey Social Support Questionnaire (MOS-SSQ) (Sherbourne & Stewart, 1991) was used to assess social support. This widely used brief measure of perceived social support assesses the contributions of network size and four categories of support (instrumental, emotional, informational, and companionship). The instrument's 20 items are scored on a five-point Likert scale; subscale scores and total scores range from 0 to 100, with higher scores representing greater perceived social support. Criterion-related validity of the MOS-SSQ has been established through convergent correlations with loneliness ( $r = -.53$  to  $.69$ ), marital and family functioning ( $r = .38$  to  $.57$ ), and mental health ( $r = .36$  to  $.45$ ) (McDowell & Newell, 1996; Sherbourne & Stewart, 1991). In the present study, Cronbach's alpha was .88.

The Diabetes Self-Care Practices Measure (DSCPM) (Skelly, Marshall, Haughey, Davis, & Dunford, 1995) was used to assess physical activity. The DSCPM assesses self-care practices such as diet, insulin and medication administration, physical activity (exercise), home glucose monitoring, and foot care. Respondents are asked how frequently they follow these self-care practices using five responses, from *all of the time* (100%) to *never* (0%). Scoring yields an adherence score in each of the regimen areas. Physical activity (defined as *moving large muscle groups for at least 20 minutes in the last week*) was measured by self-reported frequency of the activity/week, duration of activity/week, type of activity, and

intensity (slow or brisk). The DSCPM has a test-retest reliability of 95% measured at a 2-week interval (Skelly et al., 1995).

Medical records were reviewed to obtain data on medical history or family history of coronary heart disease or cerebrovascular disease, age, and anthropometric measures: total cholesterol (TC), low-density lipids (LDL-C), high-density lipids (HDL-C), hemoglobin A1c (HbA1c), body mass index (BMI), systolic blood pressure (SBP), diastolic blood pressure (DBP), smoking status, and diabetes diagnosis.

### **Data Analysis**

Statistical analyses were performed using SPSS version 12.0. Descriptive statistics were used to analyze means, standard deviations, medians, ranges, and proportions. The distribution of the data was determined using the Kolmogorov-Smirnov test and skewness ratio. Nonparametric statistics were used because the distribution of the data was not normal since the skewness ratio was less than  $-2$  or greater than  $2$  and the Kolmogorov-Smirnov test was significant ( $p \leq .05$ ) (Portney & Watkins, 2000). The variables selected for analysis were age, education, CES-D total score, MOS-SSQ total score, self-reported physical activity (frequency/week), age, and physiometrics: BMI, HbA1c, TC, LDL-C, HDL-C, SBP, and DBP. The variable DEPGRP was computed to categorize participants into two groups by CES-D total score — non-depressed (CES-D  $< 16$ ) and depressed (CES-D  $\geq 16$ ). The Mann-Whitney U test was used to examine differences between the two groups based on total CES-D, BMI, age, education, HbA1c, and physical activity. Level of significance was set at  $.05$ . A post-hoc power analysis was conducted using G\*Power 3.0.5 (Faul, Erdfelder, Lang, & Buchner, 2007). The power for this descriptive, correlational study ( $n = 45$ ) was  $.79$  with a moderate effect size of  $0.4$ . Effect size was determined by computing the coefficient of determination ( $r^2 = .16$ ) and was based on the average correlation ( $r = .4$ ) for the targeted variables. Although the power was less than  $.80$ , for a descriptive study a power of  $.70$  is adequate for analyses (Pedhazur & Schmelkin, 1991).

### **Results**

The study participants were African-American women aged 35 to 73 years ( $\bar{x} = 55.94 \pm 11.95$ ); 88% ( $n = 36$ ) were high-school graduates and 22.2% ( $n = 10$ ) were college graduates; 76% ( $n = 34$ ) were unmarried; and the majority (76%) reported annual household income less than \$25,000. The mean duration of T2DM was  $8 \pm 10$  years and the mean HbA1c level was  $8.5\% \pm 2.65$ , indicative of poor glycemic control; 48% of participants ( $n = 22$ ) had HbA1c levels above 7% (Table 1).

<b>Variable</b>	<b><i>M</i> ± <i>SD</i></b>	<b><i>Range</i></b>
Duration of T2DM (months)	96.62 ± 117.93	1–636
HbA1c (%)	8.5 ± 2.65	5.3–15.9
Total cholesterol (mg/dl)	191.00 ± 39.06	118–303
HDL-C (mg/dl)	47.2 ± 11.54	26–80
LDL-C (mg/dl)	116.07 ± 33.18	59–210
SBP (mm Hg)	134.35 ± 20.93	100–198
DBP (mm Hg)	77.00 ± 14.19	49–100
BMI (kg/m <sup>2</sup> )	33.2 ± 6.9	23–50
Physical activity (days)	3.07 ± 2.06	0–7
CES-D score	9.51 ± 9.45	0–35
MOS-SQ total	85.62 ± 15.28	49–100

Approximately 60% of participants ( $n = 27$ ) had TC levels at the upper limits of normal ( $\bar{x} = 191.7 \pm 39.06$  mg/dL), with HDL-C levels ( $\bar{x} = 47.20 \pm 11.54$  mg/dL) within the recommended range and LDL-C ( $\bar{x} = 116.07 \pm 33.18$  mg/dL) levels exceeding the recommended goal of under 100 mg/dL. Mean BMI ( $\bar{x} = 33.2 \pm 6.9$  kg/m<sup>2</sup>) met the national diagnostic criterion for Class 1 Obesity (BMI  $\geq 30$ –34.9 kg/m<sup>2</sup>) (National Heart Lung Blood Institute, National Institutes of Health, 2000). Approximately 29% ( $n = 13$ ) of participants reported smoking currently (Table 1).

For social support, 68% of participants ( $n = 31$ ) had high scores ( $> 80$ ), 20% ( $n = 9$ ) moderately high scores (60–80), and 10% ( $n = 5$ ) moderate scores (40–60). Overall, the mean MOS-SSQ score was 85.8 + 15.3, with a median of 92.0 and a range of 60 (Table 1).

Approximately 66% ( $n = 30$ ) of participants reported engaging in regular physical activity (moving large muscle groups for at least 20 minutes 3 or more days a week), while 16% ( $n = 7$ ) reported physical activity only 1 to 2 days a week and 16% ( $n = 7$ ) reported no physical activity. Approximately 76% ( $n = 32$ ) reported doing walking exercises, 5.3% ( $n = 2$ ) reported doing biking exercises, 5.3% ( $n = 2$ ) reported doing sitting exercises and stretching, and 2.6% ( $n = 1$ ) reported performing housework as a physical activity. Approximately 46% ( $n = 17$ ) of participants described their exercise intensity as slow, while 54% ( $n = 20$ ) reported it as brisk. For duration of physical activity, 88% of participants ( $n = 37$ ) reported an average of  $51 \pm 76.75$  minutes per week; for two

participants, duration of physical activity values exceeded the 75th percentile of data points.

Based on the CES-D, 67% ( $n = 30$ ) of participants did not meet the clinical criteria for clinical depression ( $CES-D < 16$ ;  $\bar{x} = 9.5 \pm 9.5$ ) (Table 2). Depressive symptom scores were inversely related to age ( $\rho = -.44, p = .002$ ) and MOS-SSQ ( $\rho = -.44, p = .003$ ) and positively related to BMI ( $\rho = .47, p = .001$ ) (Table 2). Participants scoring in the depressive range tended to be younger ( $\bar{x} = 50 \pm 9.6$ ) than their non-depressed counterparts ( $\bar{x} = 58 \pm 12.13$ ). Also, those with higher levels of MOS-SSQ tended to engage in more physical activity ( $\rho = .32, p = .038$ ) (Table 2). There were no significant relationships noted among depressive symptoms, education, and HbA1c (Table 2).

**Table 2** *Associations Among Physical Activity, Depressive Symptoms, Social Support, and Selected Sociodemographic Variables (N = 45)*

<b>Variables</b>	<b>HbA1c</b>	<b>BMI</b>	<b>Depressive Symptoms</b>	<b>Social Support</b>	<b>Age</b>	<b>Education</b>
Physical Activity	.026	-.086	-.179	.310*	-.086	.104
HbA1c		.007	.168	-.215	.007	-.020
BMI			.466**	-.056	-.435**	.015
Depressive Symptoms				-.438**	-.441**	.03
Social Support					.140	0.17
Age						0.06

\*  $p \leq 0.05$  \*\*  $p < 0.01$

There were significant differences when participants were categorized into groups. The women with T2DM and CES-D scores under 16 (non-depressed) differed significantly from those with scores over 16 (depressed) in terms of age ( $p = .0008$ ) and BMI ( $p = .007$ ). Participants with CES-D scores over 16 were younger ( $\bar{x} = 50 \pm 9.6$ ) than those with CES-D scores under 16 ( $\bar{x} = 58 \pm 12$ ), and participants with CES-D scores over 16 had higher BMIs ( $\bar{x} = 36.6 \pm 5.2$ ) than those with CES-D scores under 16 ( $\bar{x} = 31.2 \pm 7.0$ ) (Table 3). The two groups did not differ significantly in education ( $p = .60$ ), HbA1c ( $p = .91$ ), or physical activity (.28).

<b>Table 3 Descriptives by Depressive Symptom Group Scores (Mean)</b>		
	<b>Non-depressed (n = 30)</b>	<b>Depressed (n = 15)</b>
Age	58 ± 12	49.8 ± 9.6
Years of education	13 ± 3.3	12.7 ± 2
HbA1c	8.5 ± 3	8.4 ± 2.3
Total cholesterol	194.7 ± 32	185.8 ± 50.6
HDL-C	48.3 ± 11.9	45.0 ± 10.8
LDL-C	119.9 ± 28.7	108.4 ± 40.7
BMI	31.2 ± 7	36.6 ± 5
MOS-SQ	88.6 ± 14	80.2 ± 16
Physical activity (frequency)	3.3 ± 1.8	2.6 ± 2

### Discussion

This study examined the relationships among physical activity, depressive symptoms, perceived social support, and selected anthropometric measures in African-American women with T2DM. We found that the women with depressive symptom scores consistent with clinical depression were more likely to be younger, heavier, and less physically active and to have lower levels of perceived social support than the other women. The women with higher levels of perceived social support tended to be more physically active and have fewer depressive symptoms. However, depressed and non-depressed women did not differ significantly in education level or HbA1c level.

Since this was a correlational study, it is unclear whether African-American women who are heavier or have less social support also tend to be depressed, or whether clinical depression leads to changes in health behaviours such as physical inactivity and withdrawal from social support. The clinical literature, as summarized in the DSM-IV-TR criteria for major depression (American Psychiatric Association [APA], 1994), would favour the latter scenario. Clinical depression is associated with hypervegetation, psychomotor retardation, reduced physical activity, and sleep disturbances, all of which result in substantial weight gain (APA, 1994). Weight gain and depressive symptoms in African Americans with chronic illness can in turn exacerbate low self-esteem, low self-worth, and self-devaluation, even to the point of increased risk for suicide (Edwards et al., submitted). Further, negative reactions to the symptoms and conse-



quences of chronic disease can increase the likelihood of a depressive episode (Edwards et al., in press) and, ultimately, poorer glycemic control (van Tilburg et al., 2001). However, prospective studies with African-American women who have T2DM are needed, to dissect this complicated set of relationships.

Many of the participants in the present study had BMIs indicative of obesity, and the prevalence of obesity is reported to be higher among African-American women (49.7%) than among Caucasian women (30.1%) (Flegal, Carroll, Ogden, & Johnson, 2002). However, the significance of obesity among African-American women with T2DM is poorly understood. Being overweight or obese clearly increases the risk for T2DM and may increase the risk for depression in these women (Blazer et al., 2002).

The participants reported that their average engagement in physical activity was less than 150 minutes per week; 44% ( $n = 20$ ) reported brisk walking, while the majority (55%,  $n = 25$ ) reported walking at a slow pace or no physical activity. Thus the majority of these African-American women with T2DM did not meet the American Diabetes Association (ADA) clinical recommendation of at least 150 minutes per week of *moderate-intensity aerobic physical activity* or at least 90 minutes per week of *vigorous aerobic exercise* to improve glycemic control, assist with weight maintenance, and reduce the risk for cardiovascular disease (Morrato et al., 2003). According to Banks-Wallace and Conn (2002), the lack of physical activity among African-American women may result in part from limited knowledge of ways to increase physical activity. Previous research has focused on the role of physical activity in preventing T2DM (Ekelund et al., 2005). There has been little attention given to the role of physical activity in African-American women with T2DM or at high risk for T2DM. Agurs-Collins, Kumanyika, and Adams-Campbell (1997) tested a 6-month supervised weight-loss and exercise program designed to improve diabetes management in overweight older African-Americans (predominantly women). Increased physical activity was reported at 3 months. However, at 6 months the physical activity scores did not significantly differ from baseline values. Pearte, Gary, and Brancati (2004) found that African-American women with T2DM walked significantly less than African-American men with T2DM, and that the independent predictors of a low level of physical activity were obesity, low household income, and the perception of being more active than one's counterparts. In a recent study, Misra and Lager (2008) found that physical activity was perceived as a more difficult self-management behaviour by African Americans with diabetes than by their Hispanic, Asian-Indian, and non-Hispanic Caucasian counterparts.

The present findings suggest that African-American women with T2DM should be encouraged to follow clinical recommendations for physical activity in order to improve insulin sensitivity, promote weight loss, and reduce the risk for depressive symptoms (ADA, 2008). The sample showed a relatively high rate of depressive symptoms. One third of the women reported symptoms equal to or exceeding the threshold for depression commonly accepted as clinically significant. The rate was nearly twice the reported rate of major depression (17%) among African-American and Caucasian-American primary care patients (Brown, Schulberg, Sacco, Perel, & Houck, 1999). Gary et al. (2000) report a high prevalence of depressive symptoms (30–45%) in a predominantly female (76%) sample of African-American adults with T2DM, low socio-economic status, and suboptimal metabolic control. Blazer et al., (2002) report several factors associated with comorbid depression/diabetes in a community-based sample that included African-American race, female gender, low level of education, high BMI, functional impairment, and cognitive impairment. Thus the high prevalence of depressive symptoms in the present study may be partially explained by the illness burden carried by the sample. It could also be related to the fact that the investigative team and health-care providers in the study were African American and predominantly female; the women may have been more willing to disclose their symptoms to these providers (Mahoney, Sterkenburg, Thom, & Goldschmidt, 2008; Malat & van Ryn, 2005; Somnath, Taggart, Komaromy, & Bindman, 2000; Stinson & Thurston, 2002). In a randomized controlled clinical trial, Gary, Hill-Briggs, Batts-Turner, and Brancati (2005) were successful in recruiting and retaining 542 urban African Americans with T2DM. This success may reflect the fact that the investigative team had extensive experience in recruiting African Americans and included African-American investigators and racially concordant research staff. However, the effects of using racially concordant research investigators and research staff have not been well documented in the literature and warrant further study.

According to the ADA (2008), women with significant depressive symptoms and poor self-management should be referred for mental health services. However, African-American women may have different cultural perceptions and beliefs with respect to depression and mental illness, given the pervasive stigma of mental illness in many ethnic minority communities (Bolden & Wicks, 2005; Corrigan, 2004; Gary, 2005). For example, Waite and Killian (2008) report that barriers to seeking mental health services identified by African-American women include stigma associated with mental illness, certain fervent religious beliefs, images of being strong, perceived discrimination, distrust of the medical profession, and factors such as language and literacy. Further, African-

American women may have different perceptions of overweight and obesity that are related to their culture and traditions (Beauboeuf-Lafont, 2005; Carrington, 2006; Corrigan, 2004; Gary, 2005; Jones & Ford, 2008; Waite & Killian, 2008). Thus cultural competence and the interactions of health-care providers may be pivotal in treating African-American women with T2DM who present with depressive symptoms and obesity (Wagner & Abbott, 2007).

Social support has been associated with better clinical outcomes in a number of disease states, including diabetes (Bowman, 2008; Murphy et al., 2008; Rasmussen, Dunning, & O'Connell, 2007). In the present sample, social support was inversely related to depressive symptoms and directly related to physical activity. This suggests that African-American women with T2DM who perceive greater social support may also report fewer depressive symptoms and more physical activity. In a national sample of African-American men and women (Brown & Gary, 1987; Lincoln, Chatters, & Taylor, 2005), a greater degree of social support was associated with fewer depressive symptoms. Also, Keyserling et al. (2002) found an association between social support and modestly enhanced physical activity in African-American women with T2DM. It is possible that women with more social support have lower levels of depression and consequently more energy to engage in physical activity.

Social support is a salient protective factor for African-American families (Black, Cook, Murry, & Cutrona, 2005) and is particularly important for African-American women with diabetes, since stress reduction may enhance self-regulation by increasing time for self-care (McBride et al., 2003). Irritability often accompanies depression and anxiety and may lead to a decrease in emotional and tangible support from support networks (Beach, Martin, Blum, & Roman, 1993; McBride et al., 2003) — that is, family members and friends tend to disengage from a person who demonstrates negative affect, depriving the person of social support when he or she needs it most (McBride et al., 2003). Further, Chelbowy and Garvin (2006) found that African Americans with diabetes reported less satisfaction with social support than Caucasians. Thus middle-aged African-American women with many depressive symptoms may need additional social support to make the lifestyle changes necessary for successful diabetes self-management.

Research has shown a link between physical activity and depression (Lane & Lovejoy, 2001; Mitra, Wilber, Allen, & Walker, 2005; Pollock, 2001; Stephens, 1988). Paradoxically, depressive symptoms and a low degree of physical activity have both been identified as risk factors for the development of T2DM but are also complications of T2DM. Depressive symptoms may contribute to unhealthy behaviours (e.g., physical inactivity, smoking, overeating), and unhealthy behaviours may contribute to

depressive symptoms and physical inactivity (Mitra et al., 2005). Reducing or minimizing these risk factors may decrease the risk for comorbidity and mortality in African-American women with T2DM.

### **Limitations**

The cross-sectional nature of this analysis does not permit inferences of causality. Other limitations include the small size of the convenience sample and the limited range of demographics of the sample. Finally, self-report measures of physical activity and depressive symptoms may not be sufficiently sensitive to detect culturally defined perceptions and differences in perceived physical activity and to detect depressive symptoms among middle-aged and older African-American women.

### **Conclusions**

Nevertheless, the low physical activity levels, prevalence of depressive symptoms, and obesity, hyperglycemia, and elevated LDL levels in this sample of middle-aged and older African-American women with T2DM are worrisome, particularly since these modifiable lifestyle factors are associated with *cardiovascular* complications of T2DM (Diabetes Control and Complications Trial Research Group, 1993; UK Prospective Diabetes Study Group, 1998). The prevalence of depressive symptoms found in this sample is a major concern, suggesting a substantial unmet need for mental health services for these women.

We recognize that African Americans tend to depend on mental health services provided in primary care settings (Das, Olfson, McCurtis, & Weissman, 2006), but in primary care settings symptoms may be less identifiable among African-Americans than among their Caucasian counterparts (Das et al., 2006; Gary et al., 2000). Middle-aged and older African-American women with T2DM and obesity may need routine depressive-symptom screening during primary care visits so that clinical and subclinical symptoms can be detected. Also, based on the recent finding of differences in the clinical presentation of depression in African-American women, clinicians may need to explore symptoms of anxiety, anger, and hostility in these women (Myers et al., 2002). Further, when seeing African-American women, clinicians may need to allow more time, inquire directly about physical activity, and have the women describe their physical activities and social support resources on their "own terms" (Cagle, Appel, Skelly, & Carter-Edwards, 2002; Jacobson, Strohecker, Compton, & Katz, 2005; Wallhagen, 1999). Clinical and prescriptive physical activity recommendations should take into account cultural preferences and the availability and quality of social support, and patients should be monitored for adherence. Qualitative descriptions of

depressive symptoms, physical activity, and perceived social support provided by patients may facilitate treatment, education, and interventions, thus helping to prevent complications of diabetes, delay morbidity, and improve quality of life.

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## **Négocié un terrain d'entente : les perceptions des soignants membres de la famille sur la dynamique des relations avec les prestataires de services de santé à domicile**

**Thomas W. Gantert, Carol L. McWilliam,  
Catherine Ward-Griffin et Natalie Allen**

La prestation de services de santé à domicile aux personnes âgées exige la participation de nombreux professionnels et auxiliaires, mais elle dépend aussi largement de l'implication d'un réseau de soignants formé d'amis et de membres de la famille. Par conséquent, les relations entre prestataires à domicile et soignants membres de la famille constituent désormais un aspect essentiel de la prestation des soins. Les observations, toutefois, mettent en lumière des lacunes, des ambiguïtés, des tensions et des luttes de pouvoir. La présente étude avait pour but d'analyser les perceptions des soignants membres de la famille sur leurs rapports avec les prestataires de soins à domicile. Prenant appui sur la phénoménologie interprétative, les auteurs ont d'abord mené des entrevues en profondeur auprès d'un échantillon choisi à dessein constitué de soignants membres de la famille, puis employé une méthode d'analyse par immersion-cristallisation pour obtenir des données. On constate que ceux-ci conçoivent la construction du rapport avec les prestataires à domicile comme un processus dynamique, qui comporte des facteurs facilitants et des obstacles à caractère individuel et systémique. Ces facteurs d'explication permettent de mieux saisir comment se construisent les rapports entre prestataires et soignants membres de la famille dans le cadre des soins à domicile.

Mots clés : prestation des soins, famille

# **Working It Out Together: Family Caregivers' Perceptions of Relationship-Building With In-Home Service Providers**

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Provision of in-home services to seniors involves the contributions of numerous professional and paraprofessional health-care providers but is largely dependent upon the involvement of caregiver networks consisting of friends and family members. Therefore, in-home provider/family caregiver relationships have become an essential component of care provision. However, evidence suggests that provider/family caregiver interactions often are lacking or are ambiguous and characterized by tension and power struggles. The purpose of this study was to explore family caregivers' perceptions of their relationships with in-home care providers. Applying interpretive phenomenology, the authors conducted in-depth interviews with a purposive sample of family caregivers and used an immersion/crystallization analysis strategy to elicit the findings. The findings reveal that family caregivers perceive their relationship-building with in-home providers as a dynamic process with facilitators and barriers encountered at both individual and system levels. The interpretive findings afford several insights into building provider/family caregiver relationships within the in-home context.

Keywords: caregiving, community health nursing, family, gerontology, nurse relationships/professional issues, therapeutic relationships

Over the past several decades, health-care delivery has shifted from institutions to community settings (Coyte & McKeever, 2001). The origins of this shift can be traced back to the deinstitutionalization of persons suffering from mental illness in the 1950s along with amendments to Canada's *Mental Health Act* providing for those who are not acutely ill to be cared for in the community rather than in hospital (Bibbings, 1994). Concern over the costs of institutionalization has also prompted the adoption of a health-care philosophy favouring community-based over institutionalized care (Weissert, Cready, & Pawelak, 1988). Hence, home care has grown exponentially across Canada.

As the population ages and life expectancy increases, seniors over the age of 65 presenting with multiple chronic conditions are expected to constitute the majority of those receiving in-home services. Provision of in-home services to seniors involves the contributions of numerous pro-

fessional and paraprofessional health-care providers but is largely dependent on the involvement of caregiver networks consisting of friends and family members. In fact, evidence suggests that these networks provide 75 to 85% of the personal care delivered to seniors (Fast & Keating, 2000), a role considered by family members as both essential and expected (Stajduhar, 2003).

Nevertheless, demographic and social changes raise concerns about the ability of family members to continue providing the bulk of care to seniors in the future. As families shrink in size (National Family Caregivers Association, 2003) and as increasing numbers of women enter the workforce (Wisensale, 2001), there may be fewer family caregivers available to provide the ever-growing amount of intensive unpaid care required. In-home provider/family caregiver relationships have become an essential component of care provision as health-care providers and family caregivers are required to coordinate their efforts to ensure that seniors' care needs are met on an ongoing basis (Ward-Griffin, 2001).

Accordingly, models of care provision have shifted away from the more individualistic "person-centred" or "client-centred" approaches that tend to focus on the client (Post, 2001) and towards models such as the "partnership approach" (Adams & Clarke, 1999) and "relationship-centred care" (Nolan et al., 2004), which extend care relationships to include clients, family caregivers, and others involved in the client's care management. In responding to this shift, providers have had to relinquish their traditional expert approach (Qureshi, Bamford, Nicholas, Patmore, & Harris, 2000) and adopt a more relational orientation based upon mutual respect, equity, and shared understanding (Clarke, 1999). In keeping with this paradigmatic shift and the contention that relationships are foundational to nursing practice (Gastmans, 2002), best practice guidelines have been developed to promote and facilitate provider/family caregiver relationships for the purpose of enhancing nurses' knowledge and skills in order to meet the needs of families (Registered Nurses Association of Ontario, 2002).

The evidence to date, however, suggests that there remains a gap between theory and application. Often, provider/family caregiver interactions are non-existent (Fischer & Eustis, 1994) or are ambiguous and characterized by tension and power struggles (McWilliam, Ward-Griffin, Sweetland, Sutherland, & O'Halloran, 2001; Ward-Griffin, 2001; Ward-Griffin, Bol, Hay, & Dashnay, 2003; Ward-Griffin & McKeever, 2000). The successful implementation of partnering and relationship-centred approaches calls for a greater understanding of family caregivers' perceptions of their relationships with in-home providers. Much of the literature addressing relationships between family caregivers and health-care providers is conceptualized in terms of a division of labour between the

two roles (Duncan & Morgan, 1994). Few studies (Clark, Corcoran, & Gitlin, 1995; Scharer, 1999; Ward-Griffin et al., 2003) have explicitly examined relationship-building amongst health-care providers and family caregivers, and virtually nothing is known about how family caregivers perceive relationship-building with providers during the delivery of home care.

The purpose of this study was to explore family caregivers' perceptions of relationship-building with health-care providers, including the barriers to and facilitators of this experience. The research question was *How do family caregivers perceive relationship-building with providers in the context of in-home service delivery?* It was our belief that the findings would have the potential to inform relationship-centred approaches to health-care delivery for seniors and have significance for practice, education, and in-home service delivery.

## **Literature Review**

### ***Provider/Family Caregiver Relationships***

Research suggests that family caregivers prefer having close, personal rather than distant, professional relationships with nurses (Smyer & Chang, 1999) and that the type of relationship has an influence on the delivery of health care to senior clients. For example, Duncan and Morgan (1994) found that the formation of relationships with health-care providers enabled family caregivers to communicate their knowledge about the needs of senior clients and the most effective care strategies. Additionally, family caregivers have reported that forming relationships with providers allowed them to gain information about their relative's care, improved care coordination, made care delivery easier for providers, and ensured that clients' needs were met (Gladstone & Wexler, 2002). Family caregivers who develop relationships with health-care providers feel more comfortable accepting respite care provided in-hospital (Gilmour, 2002). Also, the formation of provider/family caregiver relationships has been shown to be instrumental in the ability of family members to let providers do the caregiving (Smyer & Chang, 1999).

However, family caregivers and providers are not always successful in establishing a positive relationship. Ward-Griffin et al. (2003) found the provider/family caregiver relationship to be characterized by an imbalance of power and status, with providers taking "power over" and limiting the input of family caregivers. Similarly, McWilliam et al. (2001) found that provider/family caregiver relationships based on the expert medical model of service delivery undermine care partnerships and contribute to family caregivers' sense of empowerment. Research findings also suggest that conflicting roles and expectations strain provider/family caregiver

relationships and contribute to the exploitation of family caregivers (Ward-Griffin, 2001; Ward-Griffin & McKeever, 2000).

### ***Facilitators of Provider/Family Caregiver Relationship-Building***

Numerous facilitators of relationship-building among providers and family caregivers are described in the literature. For example, providers can build relationships with family caregivers by offering emotional and cognitive support, being friendly and caring, communicating effectively, and establishing trust (Clark et al., 1995). Research indicates that provider/family caregiver relationships may be facilitated by providers who are empathetic, supportive, encouraging (Laitinen & Isola, 1996), non-judgemental, positive in their expectations, and willing to spend time with and engage with family caregivers (Scharer, 1999). It has also been found that provider/family caregiver relationships are facilitated by providers who are concerned, appreciative, compassionate, and welcoming and who take family caregivers' opinions seriously and regularly provide feedback (Hertzberg & Ekman, 2000; Ward-Griffin et al., 2003). For their part, family caregivers' positive expectations as well as readiness and willingness to engage with providers also serve to promote relationship-building (Scharer, 1999).

### ***Barriers to Provider/Family Caregiver Relationship-Building***

Researchers have also examined the barriers to provider/family caregiver relationships. Such barriers include a disregard by providers for family caregivers' knowledge and expertise (Duncan & Morgan, 1994; Gilmour, 2002; Hertzberg & Ekman, 2000; Ward-Griffin et al., 2003), lack of contact with family caregivers (Hertzberg & Ekman, 2000), and strict adherence to a division of labour (Duncan & Morgan, 1994; Ward-Griffin et al., 2003). Relationship-building is also hindered by ineffective communication (Gilmour, 2002) and by providers' negative and incongruent expectations of family caregivers (Scharer, 1999). Other impediments are absence of family caregivers when health-care providers are present in the home and family caregivers' lack of respect for or unrealistic expectations of health-care providers.

In summary, evidence suggests that provider/family caregiver relationships are highly valued by family caregivers. While researchers have identified facilitators of and barriers to relationship-building, much of the research has been conducted in institutions and has focused on the actions and perspectives of health-care providers. Greater understanding of family caregivers' perceptions of relationship-building in a community context could serve to optimize positive provider/family caregiver relationships during the provision of in-home care to seniors.



## **Methodology**

Interpretive phenomenology is a methodological approach for the study and interpretation of everyday life. Using this methodology, the researcher is able to examine the “present and living reality” of perception and the complexities of human relations (Merleau-Ponty, 1964, p. 25). Interpretive phenomenology lends itself well to interpreting family caregivers' perceptions of their relationships with providers, particularly the facilitators and barriers encountered in this human experience.

The study was conducted within one home care program for seniors in southwestern Ontario, Canada. The program provides in-home services delivered by a multiplicity of professional and paraprofessional providers (case managers, registered nurses, registered practical nurses, social workers, speech-language pathologists, occupational and physical therapists, home support workers, and, on occasion, physicians). Characteristic of in-home service delivery in general, family caregivers were exposed to whatever categories of provider the client's care required, through visits scheduled only as frequently and regularly as needed. For this reason, the more general term “provider” is used to refer to those individuals who delivered paid in-home services.

The study was approved by and implemented in accordance with the guidelines of the University of Western Ontario's Ethics Review Board. Case managers employed by the home care program served as key informants, identifying potential family caregivers for the study. To be eligible for recruitment, family caregivers had to have provided care to a person 65 years of age or older who was or had been receiving in-home services. From among those eligible, participants were purposively selected to achieve maximal variation (Patton, 2002) of sex (nine females; two males); age (range = 35–94 years; mean = 67.4 years); relationship to the client (one woman caring for her mother; six women caring for their husbands; two men caring for their wives; one woman functioning as a power of attorney for an unrelated senior; one woman whose ill husband had recently died but who still wished to be interviewed); duration of relationship with in-home provider (range = 1.5–6 years; mean = 2.78 years); type of in-home service received (home support; registered nursing; registered practical nursing; occupational therapy; physical therapy); type of living arrangement (nine lived with the client; two lived away from the client); and types of care provided (personal care; banking and finances; shopping; housekeeping; preparation of meals; transportation; wound care; physical, spiritual, and emotional support; household maintenance), thereby promoting a holistic interpretation of the diversity of perspectives that might be found amongst family caregivers of community-dwelling seniors. Recruitment and sampling ceased when the

researchers encountered theme saturation (Patton, 2002) — that is, when the data were sufficient to answer the research question. The final sample consisted of 11 family caregivers.

Data were collected using face-to-face semi-structured, in-depth interviews (range = 60–150 minutes; mean = 83 minutes). All interviews were audiotaped and transcribed verbatim. Field notes of observations made during interviews captured non-verbal nuances and subtleties.

The immersion and crystallization strategy for interpretive analysis (Spiegelberg, 1982) was used to elicit the findings. This reflective process entails reading and rereading interview transcripts while simultaneously listening to the audiotaped interviews with the aim of achieving sensitization to nuances in the text. As themes and their connections to patterns became apparent, they were crystallized into an integrated, holistic interpretive analysis that was subsequently subjected to member-checking and peer review (Kuzel & Like, 1991) to ensure authenticity and credibility.

## Findings

### ***Family Caregivers' Experience of Relationship-Building With In-Home Providers***

Family caregivers perceived their relationship-building with in-home providers as a holistic, interconnected, and dynamic process consisting of three components. From their perspective, relationship-building with the in-home providers began with *reluctantly making essential connections*. These relationships developed through two other relational components: *getting to know each other* and *finding ways to work together*. There was movement from one component of the relationship-building process to another, with facilitators and barriers encountered at both contextual and individual levels, as described in the following sections.

#### ***The Context of Care***

Participants identified two contextual barriers and facilitators arising from the home care context. They perceived the barriers and facilitators of *not having/making time* and *not having/having continuity of provider* as vital to the relationship-building process as a whole.

***Not having/making time.*** The participants perceived that their ability to build relationships was contextually impeded or facilitated by time. Family caregivers perceived that the time limitations of in-home providers undermined their relationship-building efforts:

*[The provider] is so busy and has so little time when she's here, we often don't get the chance to talk much.*

They also perceived that their own ongoing caregiving responsibilities put severe limits on the amount of time they were able to spend with in-home providers. The arrival of in-home providers afforded family caregivers the opportunity to obtain necessary respite or to attend to the necessities of daily living. One participant reported:

*[The in-home provider] is here for 45 minutes. While she's with [the client] I have to do the grocery shopping and things like that. . . . It's not much time. I can't leave her [the client] any other time, you know. I'm afraid she'll fall again. . . . [The in-home provider] comes, I go.*

Conversely, family caregivers perceived that their opportunity to build relationships with in-home providers was facilitated when they made the time to relate to one another:

*The first day that she came, she was here quite a while . . . and we talked. That helped [build the relationship].*

**Not having/having continuity of provider.** The family caregivers perceived that relationship-building with in-home providers was contextually impeded or facilitated by the assignment of in-home providers. They desired contact with the same in-home provider over time. They saw lack of continuity as a barrier to relationship-building and were frustrated by it:

*I didn't get the same ones. Every time, someone different comes. I didn't really get to have a real relationship with any of them. They [provider agencies] switched to a new batch of people and I wasn't quite as pleased with that. . . . I find I have to show them where everything is and that kind of thing. It's frustrating. I find I keep repeating the same things over and over.*

When participants were afforded continuity of in-home provider over the course of the client's care, they perceived that their ability to build relationships was improved:

*I've had the same [in-home provider] for the last 3 years. That's made it much easier to have a relationship, I'd say.*

Thus, family caregivers believed that the relationship-building process was facilitated by having time and by continuity of assignment of in-home provider. Not having time or continuity of provider often undermined their relationship-building efforts.

### ***Reluctantly Making Essential Connections***

Participants struggled with having to enter into a relationship with an in-home provider. For some, difficulties initiating such a relationship

stemmed from a perceived societal stigma against requesting outside assistance for an ill family member:

*You have your pride. In our generation you didn't ask for help. Both of us came through the Depression, and in those days only those who really needed it got help, and you didn't dare take anything. Asking for help was a stigma in our minds. I guess it still is.*

However, when the care demands of the ill senior became too great to be met by friends and family members, family caregivers had to confront the reality that outside assistance was required if institutionalization of the ill senior was to be avoided:

*I'd like to keep doing it [providing care] myself if I could, but I can't. . . . It's either this [having in-home provider assistance with care] or [placing the client in] a home. I certainly don't want that.*

**Resenting/appreciating each other.** Commencement of in-home health care presented an opportunity for family caregivers and in-home providers to form a relationship. However, some family caregivers resented having to accept outside assistance:

*I'm sure they can sense that I'm not thrilled with having them here. . . . I'm short with them.*

Others, however, saw the arrival of in-home providers in a positive light and expressed their appreciation:

*I'll thank them and say, "Oh, gee, that made him [the client] feel so good" and "It's nice that you take time with him." Well, I think that it makes them [in-home providers] happy if they know that you're happy. It gets things off on the right foot.*

Family caregivers also wanted in-home providers to appreciate them and their struggle to care for the senior:

*I think the main thing is [for in-home providers to] just let people [family caregivers] know that they're going through a hard time and that you have feelings for them, not just the patient but also the caregiver.*

**Perceiving no need/need to connect.** In addition to mutual expressions of appreciation, family caregivers perceived that relationship-building was facilitated by connections between in-home providers and themselves. However, even though in-home providers were in the home on a regular basis, some family caregivers saw no need to connect with them and were absent during their visits. According to one participant, there simply was no reason to be present while a provider was in the home:

*There's no reason for me to be there when the providers are in the house.*

Some family caregivers also believed that care relationships should exist primarily between in-home providers and the senior client and therefore chose not to attempt to make a connection. One participant elaborated:

*She [the in-home provider] asked me at first or early on [to be involved], but I said, "Oh, no, this is between you and [the client]. . . ." After all, they were looking after him, not looking after me . . . we never talked.*

Relationship-building was facilitated when in-home providers and family caregivers perceived a need to connect with each other. For instance, some family caregivers expressed a desire to connect with in-home providers by requesting inclusion:

*I have a relationship with them [in-home providers] because I've asked for inclusion.*

Several in-home providers also perceived a need to connect with family caregivers and expressed a desire to form relationships by inviting family caregivers to become involved. One participant explained:

*She [the in-home provider] offered me [the opportunity] to come in [and be involved] . . . so I did.*

**Distancing/spending time.** Although family caregivers and in-home providers were often in the home together during home care visits, some chose to distance themselves from each other, thus impeding relationship-building:

*I really don't like having to have them here. . . . It's a bit of an intrusion. I don't get involved with the nurse.*

Others, in contrast, perceived in-home providers as creating distance during the provision of care:

*She [the provider] really didn't talk to me. She came in, did her thing, and then left.*

Conversely, family caregivers and in-home providers facilitated relationship-building by spending time with one another. One participant reported:

*I have a relationship with them because I've made a point of spending more time and talking with them when they're here with him [the client].*

Family caregivers perceived that in-home providers made similar efforts to spend time with them:

*They're here to help [the client], you know, but on their way to the bedroom or if they're preparing a bath they . . . come out here just to chat [with me].*

On occasion, however, the nature of in-home service provision made it problematic for family caregivers and in-home providers to spend time together. As illustrated by the comments of one participant, in such instances providers arranged to meet with family caregivers outside the home:

*You have to remember that when you're dealing with a husband and wife there are times when you won't say things in front of your spouse for fear of hurting them. . . . She [the provider] said, "Well, I'm working a lot up near [your area], so I'll give you a call some day and we'll have coffee." And that's how it [the relationship] started.*

In summary, relationship-building within *reluctantly making essential connections* was impeded by those family caregivers who resented the involvement of in-home providers or by members of both groups who saw no need to connect. Additionally, when family caregivers and/or in-home providers maintained a distance, relationship-building was undermined. Conversely, family caregivers and in-home providers who expressed appreciation for each other, perceived a need to connect, and spent time together facilitated the building of what they viewed as an essential relationship.

### **Getting to Know Each Other**

Participants described a "feeling out" process that involved mutual self-disclosure:

*Well, I mean, when somebody comes in [to the home] they're a complete stranger. You sort of feel them out a little bit, to know whether you're comfortable with them. . . . You share things about yourself, and they do the same. You have to make the effort, I think. It's like that with anything . . . it makes it easier [to build the relationship] when you know a bit about them.*

**Conveying no interest/taking an interest.** Family caregivers perceived that in-home providers' apparent lack of interest in getting to know them was a barrier to relationship-building. One participant regretted that her in-home provider did not show more interest in her:

*She didn't seem too interested in getting to know me while she was here. I would have liked that.*

On the other hand, in-home providers' interest in family caregivers as individuals facilitated relationship-building:

*She would say, "What did you do? Did you start out with a cow and a couple horses and did it take you a long time to pay for that farm?" She was interested in us.*

**Keeping to oneself/disclosing one's life context.** While family caregivers perceived that sharing their lives with in-home providers facilitated relationship-building, one participant indicated that such sharing did not always transpire:

*There was one [in-home provider], we didn't get to know her very well at all. Most times you hear about their kids and things like that. . . . Not this one. She kept to herself, you know. She wasn't talkative. It's nice when you can find out about people.*

At times, not having the opportunity to share life contexts contributed to feelings of apprehension and mistrust on the part of family caregivers:

*I'm still very cautious having them coming in. I still don't know them very well. . . . I keep an eye on them. I'm always watching what they're doing.*

Relationship-building was facilitated by the sharing of life histories, with family caregivers often asking questions on various topics:

*I'd ask them about their kids or how their day was going. We talked, and it wasn't all about his [the client's] care and nursing. It was about, you know, her parents and animals and whatever.*

Family caregivers would share details about themselves in return. One woman described how her in-home provider got to know her over time:

*Oh, she knows all about me and [the client]. We usually get a chance to talk before she's off to the next person. . . . I've told her about our grandkids and our farm. I think they should know [details about my life].*

In-home providers made similar efforts to share their life context with family caregivers:

*The first time she was here she talked a lot. She got me to open up by asking us questions and telling us about her. She was terrific.*

In summary, family caregivers placed high priority on getting to know their in-home providers and to being known in return. While relationship-building was impeded by perceived lack of interest and lack of self-disclosure, it was facilitated by efforts to express an interest in each other and to share life contexts.

### ***Finding Ways to Work Together***

Family caregivers perceived their ability to find mutually acceptable ways to work with providers as important for relationship-building:

*They have to know the family. They have to know them well enough to know what they'll accept, what they won't accept, who they can work with and who they can't, and what the rules of the game are and [to ensure] that everybody understands them [the rules]. We have to know them too. Then you're in business and you can come to some reasonable solutions. I think you have to meet each other halfway.*

***Withholding/expressing needs.*** However, family caregivers were not always willing to share their perceptions with providers. In particular, they often admitted to being fearful of how their views would be received:

*You have to stand up for your rights, and I found that difficult to do. . . . You worry that if you say something, then they will take it the wrong way.*

One participant believed that any voiced criticism would result in a loss of in-home services:

*Oh, some people have that mindset that if you . . . tell me off or if I don't do it the way you want, then get somebody else.*

Another shared her perception that expressing her concerns would result in the mistreatment of the senior client by in-home care providers:

*You'll pay for asking them to do it another way. . . . That's the same as your kids in school, isn't it? If you complain too much, then the teacher might take it out on them.*

However, some family caregivers were able to express their needs and expectations:

*Why would you just put up with something if you're not comfortable? I don't believe in that. If you're not comfortable, speak up — have something done about it.*

***Directing care as the expert/working things out together.*** Some participants had attempted to contribute their caregiving knowledge to the provider/family caregiver relationship but perceived it as unwelcome:

*I've been caring for him for years, and sometimes he can be a little difficult, you know. I offered to sit with him while she was giving care, to help keep him calm. She said that it wouldn't be necessary as she has had many difficult patients. . . . He ended up falling. It didn't have to happen.*



In contrast, family caregivers believed that having their experiential knowledge elicited and valued by in-home providers was beneficial for relationship-building:

*I've been caring for [the client] for years now. I think that's worth something. She [the care provider] has been great. They ask for my opinions . . . I appreciate that. I think you have to meet each other halfway. They're here for a few hours and I'm here for the rest.*

Similarly, they valued the contributions of in-home providers and often solicited their knowledge and expertise in determining how best to care for their ill relative:

*I think it's far easier to sit down and say, Gee, I don't know how to do this, or What do you think I should do about such and such? I don't think I know everything. I'm willing to learn from her experience instead of pretending that I know it all.*

In summary, relationship-building was impeded by both family caregivers' unwillingness to express their needs and expectations and in-home providers' tendency to direct care as the expert. Conversely, relationship-building was facilitated by family caregivers' and providers' willingness to share and use each other's knowledge and expertise in care delivery.

## **Discussion**

The personal and individualistic nature of interpretive research precludes generalizability. Nevertheless, the findings of this study afford several insights that may be applicable in other health-care contexts, particularly those involving in-home or other community-based health services wishing to promote relationship-building with family caregivers. The participants in this study were reluctant to be dependent on and to form relationships with in-home providers. Evidence that family caregivers tend to consider caring a private matter, deem provider assistance as intrusive (Kellet & Mannion, 1999), and resist the use of in-home services even in the face of overwhelming care demands (Kramer, 2005) may explain the reluctance observed in this study.

Many of the family caregivers were confronted with the "ideology of familism" (Ward-Griffin, 2001), perceiving themselves as duty-bound and obligated to independently meet their ill relatives' care needs within the home. Some authors suggest that, in order for family caregivers to be more receptive to having relationships with providers, independence must be understood not as the ability to perform activities for oneself without assistance but as the ability to exert control over whatever help

is needed to achieve goals and objectives (Morris, 1993). This view of independence may be an underlying factor in the family caregivers' perceived importance of their having control over type and delivery of in-home care. Some participants did appear, ultimately, to transcend the independence/dependence dichotomy in a way that accommodated a realization of the importance of forming relationships with their in-home providers. Indeed, some authors view the human condition as one of *interdependence* (Shakespeare, 2000). Kittay (1999) argues that interdependency is not an alternative to or a negation of dependency but, rather, is based on a recognition of "nested dependencies" that link those who need support with those who can provide it. The present findings also reveal that providers' use of empathy to convey recognition and understanding of family caregivers' transition to interdependence facilitates relationship-building. This insight may inform the advancement of relationship-building with family caregivers and is particularly relevant to refining practice in the context of the home, where both individual independence and family autonomy are social norms.

The findings from this study suggest that relationship-building requires that family caregivers and in-home providers perceive a need to connect with one another and make an effort to do so. While the participants had many opportunities to interact with in-home providers, the findings reveal that family caregivers and in-home providers often chose either to relate to each other or to keep a distance. Consistent with the results of previous research (Gladstone & Wexler, 2000), some family caregivers employed strategies such as being present and requesting involvement as a means to connect and build relationships with providers, while others adopted the stance that providers should build relationships with clients only and did not see a need for relationships between themselves as caregivers and the providers of client care.

Some family caregivers reported that in-home providers ignored them and focused exclusively on the client, thereby precluding the formation of a relationship. This finding highlights the importance of moving beyond a narrow, client-centred orientation, to a more relationship-centred (Nolan, Davies, Brown, Keady, & Nolan, 2004) or partnering approach (Adams & Clarke, 1999) that considers all those involved in the client's care management. This position is supported by Fine and Glendinning (2005), who contend that it may be increasingly inappropriate to focus exclusively on senior clients and ignore the needs of family caregivers.

The findings also demonstrate how providers' devaluing of relational aspects of care can undermine relationship-building. Evidence suggests that providers tend to focus on biomedical, task-oriented aspects rather than on relational aspects of care delivery (McCabe, 2003) that entail

largely invisible emotional labour (Hochschild, 1983). Devaluing of relationship-building may stem from the current focus on the acquisition of technical skills in health-care curricula (Chant, Jenkinson, Randle, & Russell, 2002), which tend not to include guidance on working positively with seniors (Wadensten & Carlsson, 2003). Given the insights into the value of relationship-building arising from this study, curricula for health professionals might be enhanced by greater focus on important aspects of human relationships such as empathy, presence, self-disclosure, and empowerment and by a clinical orientation on developing the skills that health professionals need in order to build relationships with family caregivers.

Nichols (1995) argues that the need to communicate what it is like to live in our individual, separate worlds of experience is a powerful aspect of human relationships. While the benefits of mutual knowing amongst providers and family caregivers are well documented (Gladstone & Wexler, 2002; Scharer, 1999), the findings from this study highlight the necessity of mutual self-disclosure for the purpose of relationship-building. The findings also suggest that relationship-building is facilitated when family caregivers are able to assert their own needs and when in-home providers welcome and elicit family caregivers' contributions, thereby possibly mitigating any reluctance on the part of family caregivers to express their viewpoints for fear of repercussions from in-home providers (Hertzberg & Ekman, 2000; May, Ellis-Hill, & Payne, 2001).

Lastly, this study has identified two important contextual factors that influence relationship-building, namely time for relationship-building and continuity in the assignment of service providers. Research has shown that while continuity of provider assignment facilitates relationship-building (Gladstone & Wexler, 2002; Scharer, 1999), discontinuity in provider assignment contributes to feelings of exhaustion for some family caregivers, who then lack the energy to restart the relationship-building process (Hertzberg & Ekman, 2000). If family caregivers and in-home providers are not given sufficient time and continuity, their ability to effectively build relationships may be impeded.

In-home service providers are well positioned to reshape their relationships with family caregivers. As all individuals are unique human beings, family caregivers will not have identical needs, motives, and expectations for relationships with providers of care to an ill senior. However, in-home providers need to elicit and discuss family caregivers' perceptions of their desired partnering scenario (Scharer, 1999). This may enable in-home providers and family caregivers to connect on a personal level, thereby affording an opportunity for the co-creation of care-delivery strategies that not only are more mutually acceptable but also optimize family members' caregiving potential. While relationship-building

may take time, researchers (Duncan & Morgan, 1994; Gilmour, 2002; Gladstone & Wexler, 2000; McWilliam et al., 1999; Smyer & Chang, 1999) have found that the effort positively influences the provision of services.

### Conclusion

While further research is required, the findings of this study extend our knowledge in a number of ways. For relationship-building to occur, family caregivers and providers must connect with each other. The mere presence of both family caregivers and providers in the home at the same time does not always lead to the formation of relationships, while the absence of family caregivers removes even the possibility of relationship-building. The findings demonstrate family caregivers' desire and need to share life contexts and the lack of trust caused by providers' failure to self-disclose. Lastly, the findings indicate that lack of time and frequent changes in provider assignment have the potential to undermine the ability of providers and family caregivers to form relationships. If quality in-home service is to be optimized, administrators and decision-makers will have to consider the possibility that the costs incurred in affording more staffing time for the development of provider/family caregiver relationships may be offset by more timely and personalized care delivery to seniors. Most importantly, the findings illuminate the role of family caregivers as invaluable partners in care and invite providers to attend to relationship-building efforts with family caregivers in the pursuit of this aim.

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## **Les obstacles à l'accès aux services de soutien et à leur utilisation chez les immigrantes victimes de mauvais traitements**

**Sepali Guruge et Janice Humphreys**

Le soutien social est un élément essentiel pour les femmes victimes de violence infligée par un partenaire intime. Lorsque le soutien informel qu'elles reçoivent de la part de leurs proches, leurs amis et leurs voisins est limité, les femmes dans cette situation se tournent en général vers les professionnels de la santé, les travailleurs sociaux et les services d'établissement. Dans cette étude qualitative et descriptive, des dirigeantes communautaires qui sont aussi des immigrantes de première génération au Canada décrivent les difficultés qu'éprouvent celles-ci à accéder aux services établis. On constate l'existence d'un certain nombre de facteurs qui influent négativement sur leur expérience : le manque d'information sur les services; des services et des stratégies d'intervention inadéquats; l'absence de services sensibles aux différences culturelles et linguistiques; le manque de transférabilité et de coordination des services; les préoccupations liées au respect de la vie privée; les pratiques discriminatoires et racistes ancrées dans les services et la prestation. Pour améliorer les soins aux femmes victimes de violence infligée par un partenaire intime dans un contexte postmigratoire, les professionnels de la santé devront collaborer avec les travailleurs sociaux et des services d'établissement et trouver des solutions aux obstacles structurels qui limitent l'accès aux mesures de soutien et à leur utilisation.

Mots clés : violence, culture, santé des femmes, soutien social



# Barriers Affecting Access to and Use of Formal Social Supports Among Abused Immigrant Women

Sepali Guruge and Janice Humphreys

Social support is critical for women dealing with intimate partner violence (IPV). When support from their informal sources, such as family, friends, and neighbours, is limited, women tend to access services provided by health professionals, social workers, and settlement workers. In this qualitative descriptive study, community leaders who were also first-generation immigrants describe the complexities of immigrant women's access to and use of formal supports to deal with IPV in Canada. The findings show that a number of factors negatively shape the experiences of these women: lack of familiarity with services, inappropriate services and intervention strategies, lack of culturally and linguistically appropriate services, lack of portability and coordination of services, confidentiality concerns, and discriminatory and racist practices embedded in services and service delivery. In order to improve care for women dealing with IPV in the post-migration context, health professionals must collaborate with social workers and settlement workers to address structural barriers that limit women's access to and use of formal social support.

Keywords: abuse and violence, cultural, cross-cultural and gender, culture, domestic violence and women's health, social support

## Introduction

Intimate partner violence (IPV) is the most common form of violence against women worldwide, cutting across ethnocultural and socio-economic backgrounds. Defined as threatened or actual physical, sexual, psychological, or verbal abuse by a current or former spouse or non-marital partner (Health Canada, 1999), IPV is linked to a range of physical and mental health problems that may persist long after the violence has ended. Its rates vary across communities and countries. In a recent World Health Organization (2006) study, the rates of physical or sexual violence (or both) among ever-partnered women ( $N = 24,000$ ) in 10 countries ranged from 15% to 71%. In Canada, the 2000 *General Social Survey* (GSS) of 14,269 women in 10 provinces, 37% of women who had ever been in a marital or common-law relationship experienced at least one IPV incident. In 2006 alone, police across Canada received 38,000 reports of IPV, with women accounting for 83% of all victims (Statistics Canada,

2008). Attempts to assess prevalence rates of IPV in immigrant households in Canada through secondary analysis of GSS data (Hyman, 2002), however, have been hampered by the limitations of the original survey (e.g., exclusion of those who spoke neither English nor French).

Women's responses to IPV are both individually and socially shaped. In particular, they are shaped by the supports and services that are available and accessible within a specific physical and social environment. While there is considerable health sciences literature on IPV and social supports among women born in Canada and the United States, the role of social support in Canadian immigrant women's responses to IPV, and their use of and access to such support, remain under-investigated (Cottrell, 2008; Hyman, Forte, Du Mont, Romans, & Cohen, 2009). This article (which is based on the findings of a doctoral study) reports, from the point of view of a group of first-generation immigrant community leaders who provide services to Sri Lankan (SL) Tamil women, the barriers they face in accessing and using *formal* social supports to deal with IPV.

## Background

Support can be instrumental, informational, emotional, and appraisal (House & Kahn, 1985) and can be provided by members of informal or formal social networks (Stewart, 1989, 1993; Stewart et al., 1997). Informal social networks include members of one's immediate and extended family, friends, and neighbours, whereas formal support may be provided by health professionals, crisis hotline workers, shelter personnel, police officers, social workers, or settlement workers. Social support for women dealing with IPV can include financial assistance, links to resources, information for seeking protection, and/or ways to reduce women's isolation (Fugate, Landis, Riordan, Naureckas, & Engel, 2005; Goodkind, Gillum, Bybee, & Sullivan, 2003; Kaukinen, 2002; Moe, 2007; Rose, Campbell, & Kubb, 2000). Not all women dealing with IPV have family members, friends, and neighbours with the time, information, and means to help them. In some cases informal networks can also be a source of conflict and stress if the network members do not believe the women, blame them for the abuse, minimize the abuse and its impact, maintain silence or secrecy, or discourage the women from seeking "external" help (Goodkind et al., 2003; Moe, 2007). In other cases support from family and friends may be inadequate to prevent abuse from continuing or escalating. As a result, women dealing with IPV may seek *formal* social support.

Immigration to another country results in the loss of informal social networks and supports (Simich, Beiser, Stewart, & Makwarimba, 2005),

the impact of which is compounded by language barriers, un/underemployment, unsafe living conditions, and the racism and sexism in society at large (Guruge & Collins, 2008). Under such circumstances women can become easy targets for abusive husbands (Fong, 2000; McDonald, 2000; Yoshihama, 2008). A number of Canadian and American studies have shown that the moderating role played by informal social supports in reducing the prevalence and/or the impact of IPV pre-migration may be lost post-migration. For example, in some societies wives' relatives play a strong role in imposing authority over husbands and their actions and/or in offering sanctuary to abused women (Bui & Morash, 1999; Hyman, Guruge, & Mason, 2008; Hyman, Mason, et al., 2006; Morrison, Guruge, & Snarr, 1999). The loss of such supports following migration may force women to turn to formal services. The presence of family, friends, and neighbours post-migration does not guarantee support. Therefore, women might turn to formal supports to deal with IPV. Hyman, Forte, et al. (2006) found that recently arrived immigrant women were more likely to report IPV to the police (50.8% vs. 26.0%) but less likely to use social services (30.8%) than their long-term counterparts (52.8%) (the latter group's rates being similar to those of the Canadian-born). Other studies have shown that immigrant women underutilize shelters, hotlines, and health, legal, and social services for IPV (Du Mont, Forte, Cohen, Hyman, & Romans, 2005; Erez, Adelman, & Gregory, 2009; Fong, 2000; Gillum, 2009; Hyman, Forte, et al., 2006; Landrine, Klonoff, Corral, Fernandez, & Roesch, 2006; Lasser, 2006; Lee & Hadeed, 2009; Malley-Morrison & Hines, 2007). The lower use has been attributed to multiple and intersecting barriers faced by immigrant women, including linguistic barriers, financial constraints, social isolation, and discrimination.

Building on the community's interest in addressing post-migration IPV, we conducted a study of IPV in the SL Tamil community. Sri Lanka is an island nation southeast of India. Over the past 25 years the country has suffered the consequences of an ongoing civil war between the Sinhalese government and the Liberation Tigers of Tamil Eelam, a Tamil militant/separatist group that has put forward an agenda for full independence and a separate homeland for Tamils. According to some estimates (e.g., Cheran, 2000), over the years approximately 500,000 Tamils have been internally displaced and more than a million have left Sri Lanka seeking residency in various countries. Canada has been the favourite destination and is home to the largest SL Tamil community outside of Sri Lanka.

In Sri Lanka, informal social support systems — networks of friends, family, and community members — are “the most sought after method of support” for women dealing with IPV and “are seen as a constant source of help” (Pinnewala, 2009, p. 88). Often, a woman will receive

primary support from her mother and other members of her immediate and extended family, who offer advice, shelter, and food, and even assault the abuser (Wijayatilake, 2003). Post-migration changes in social support among SL Tamils have been reported. For example, in a US study with Sri Lankans (Tamil and Sinhalese) (Meemaduma, 1999), participants expressed a hierarchical preference for support network members; without exception, if family members were available, they were the primary choice of support, followed by other Sri Lankans. Participants indicated that they had moved from a “world within which day-to-day responsibilities were shared, in which the support provided was unconditional, and in which family/kin rights and responsibilities were valued and functional” (p. 205) to a world where they had little or no informal social support. A Canadian study with SL Tamils reports similar findings, and concludes that the loss of social networks and supports post-migration can lead to an increase in both IPV and women’s vulnerability to it (Morrison et al., 1999).

Hyman, Mason, et al. (2006) and Mason et al. (2008) report SL Tamils’ perceptions of and responses to IPV. Both publications (resulting from a study conducted in Toronto) note that, irrespective of their age, participants defined IPV broadly and referred to a range of forms of IPV (consistent with those described by the World Health Organization [2006]). The authors conclude that health professionals need to understand the multiple and complex barriers that women face in dealing with post-migration IPV. However, we found no Canadian studies that explore in depth the complexity of the barriers that SL Tamil immigrant women face in accessing and using services for IPV.

### **Purpose and Research Question**

The purpose of the overall study was to examine the factors that contribute to the post-migration production of IPV in the SL Tamil community and the factors that shape women’s responses to it. The research question addressed here is: *From the perspective of first-generation SL Tamil community leaders who provide services to abused women, what are the barriers that SL Tamil women face in accessing and using formal supports to deal with IPV?*

### **Methods**

Qualitative descriptive methodology (Sandelowski, 2000) was used in this study. Data were generated through individual interviews and focus groups over an 8-month period. This article is based on the results of individual interviews with 16 community leaders, themselves first-generation SL Tamil immigrants, who had facilitated women’s access to

and use of formal social support and had advocated for abused women both within the SL Tamil community and in Canadian society. Because of their (formal) work experience and their (informal) relationships in the community, the participants were well informed about the various barriers faced by SL Tamil women at the micro, meso, and macro level of society in accessing and using formal supports for IPV.

The participants represented the demographics of the Tamil community in Canada in terms of age, birth city, time of leaving Sri Lanka, and duration of stay in Canada (see Table 1 for demographic details). They were recruited from various parts of Greater Toronto using a combination of convenience, snowball, and purposive sampling. They were interviewed at locations of convenience to them, which most often was their office before or after working hours. Overall, the interview questions were open-ended and unstructured, to allow for the emergence of ideas. (Some of the questions posed are listed in Figure 1.) Probes were used to inquire about specific topics, such as the kinds of formal social support abused SL Tamil women accessed and the types of barriers they faced.

The interviews were conducted in English and lasted approximately 2 hours on average. They were audiotaped and transcribed verbatim. Data were analyzed using inductive thematic analysis (Bryman, 2001) by reading and coding transcripts sentence by sentence, examining the codes

<b>Characteristic</b>		<b>F (%)</b>
<b>Gender</b>	Female	10 (62.5)
	Male	6 (37.5)
<b>Age Group, Years</b>	30s	6 (37.5)
	40s	5 (31.2)
	≥ 50s	5 (31.2)
<b>Birth City</b>	Jaffna	9 (56.3)
	Other	7 (43.8)
<b>Decade Left Sri Lanka</b>	1970s	1 (6.3)
	1980s	8 (50.0)
	1990s	4 (25.0)
	2000s	3 (18.8)
<b>Number of Years in Canada</b>	1–5	6 (37.5)
	6–10	2 (12.5)
	11–15	6 (37.5)
	16–20	2 (12.5)

**Figure 1** *Examples of Individual Interview Questions*

Who do Tamils turn to for help and support in Sri Lanka/Canada?  
What kind of support do Tamils expect/receive from such people?  
Who do Tamil women in Sri Lanka turn to for support to deal/cope with wife abuse, in particular? What kind of support do women experiencing abuse get from them?  
Who do they go to for such help and support after coming to Canada?  
How do you think Tamil women's responses to wife abuse are influenced by their friends, family, and neighbours, the Tamil community, and the Canadian society?  
What kinds of support do Tamil women experiencing wife abuse need/seek/get from health, social, and/or settlement workers in Canada?  
What are the barriers Tamil women face in accessing/using formal supports and services in Canada?

for the ways in which they converged or departed within and across interviews, and grouping significant codes as subthemes and themes. Strategies used to enhance trustworthiness (Lincoln & Guba, 1985) included prolonged engagement, member checking, peer review, audit trail, reflexive journaling, and thick description.

### **Findings**

The findings reveal that women experienced a number of changes in their informal social networks and associated sources of support. We will briefly describe these changes to set the context for why women are forced to seek formal social supports, before presenting our findings on the barriers they faced in accessing and using such supports.

Not surprisingly, women's social networks were smaller post-migration than pre-migration. Because of the smaller social networks and resultant social support limitations, women and their husbands often relied solely on each other for instrumental, financial, emotional, and informational support, which resulted in increased family stress and conflict. In addition, the structure/composition of the networks was changed. Prior to migration both men and women had access to their natal families. Although a woman can be the first family member to arrive in Canada, more often it is the man who immigrates first due to a number of challenges related to leaving the war-torn country of Sri Lanka and the restrictions with respect to refugee admissibility criteria.

Typically the man, once settled, sponsors his natal family along with his wife and children. This sequence of events results in a situation wherein the couple live with or near the husband's family while the wife's family might not yet have even immigrated to Canada.

In Sri Lanka, a woman's family and friends often act as a buffer against stress, conflict, and abuse and provide her with support, advice, and resources to deal with IPV. One participant described the structure of the pre-migration informal social network that serves to impose some limits on a husband's power and authority:

*If you understand our [marriage] system back home, it allows women to stay in their own house and men have to come into [wives'] house [and] into wives' network. Then he can't just do things on his own right yet. He has his power, but that doesn't mean he can do as much as he likes.*

Another participant described the kind of support an abused woman can expect from her informal social network:

*In Sri Lanka, she can leave . . . maybe to live with her parents . . . even if the parents live somewhere else . . . she can go live in neighbour's house, and the men in that house will protect her, together with the women.*

Such a system is not available post-migration, the consequence of which is reduced support for women who are the victims of IPV.

Even when their own family members were present in the Toronto area, women did not always receive adequate support to deal with IPV. The participants gave the following reasons for this: the pace of life in a large city; long work hours; travel distance and transportation challenges; and the value placed on individual rights, freedom, privacy, and family privacy in Canada:

*[In Canada] everyone is sort of cut off . . . there's very little contact within families. Even if your neighbour [from Sri Lanka] is here in Toronto, you may have to take three buses to go [and then sometimes s/he] doesn't have time to talk to you.*

*Even if they have the extended family here, we shouldn't be interfering in other persons' affairs or matters, right? That is the Canadian system. The people don't interfere in other people's matters, because it can backfire. So they just keep their distance from them.*

In Canada, as is sometimes the case in Sri Lanka as well, the presence of family placed pressure on women to remain married, even when family members were aware of the abuse, in order to preserve the family's status in the community. The conflict that is driving Tamils out of Sri Lanka has made family harmony ever more important. Participants told

of the spoken and unspoken pressure that women felt from the general community in this regard:

*This community that can be supportive is not at all supportive. Now, for example, if she leaves the husband and she attends a function, she is put aside and she's not even allowed to [take part in] the event.*

The community perception of self and being part of the community are important considerations for Tamil women (as for most women from racialized communities) because of the various forms of subtle and overt racism and “othering” based on skin colour, dress, accent, and behaviour that they experience in Canadian society.

Within this context, women dealing with IPV sought *formal* social supports. Often, however, their access to and use of such supports were negatively shaped by a number of interrelated barriers. These are discussed next.

### ***Lack of Familiarity With Available Services***

Participants remarked that formal social supports are not common in Sri Lanka. Therefore, most women, especially those who had arrived recently, who were isolated, or who were not fluent in English, were unfamiliar with the kind of supports and services available to them, such as shelters, welfare benefits, subsidized housing, legal aid, and counselling:

*Maybe the woman has language issues. If she is a woman who has contacts outside, who's going outside, and being able to talk to someone, she will know about services. Other women have no way to know who does what and what helps.*

As the excerpt suggests, a number of factors led to women's lack of familiarity with available services, which in turn shaped their responses to IPV.

### ***Inappropriate Services and Intervention Strategies***

Another limitation identified by the participants was the lack of services and interventions directed at immigrant women. One participant highlighted the lack of fit between the kind of services often offered to abused women and the kind of services often expected by an abused Tamil woman:

*We don't need to think like Westerners, that we have to go to a psychologist or a consultant and sit and talk about this experience, but maybe find some creative approaches to come together to help people, some practical ways [of dealing with] a lot of basic things like getting jobs, keeping occupied, and having some room to [have] fresh air in your mind.*



The models and frameworks for the services focusing on immigrant women were said to create barriers for women and to be a source of frustration for service providers because the models/frameworks did not necessarily capture the complexity of the women's lives or the multiple oppressions they experienced. For example, the women and their husbands faced many issues together, such as underemployment and difficulty securing safe housing owing to racism. Participants saw these common issues as meriting as much attention as the women's individual need for services.

### ***Lack of Linguistically and Culturally Appropriate Services***

Participants also highlighted the problems that women encountered in accessing and using services that were not culturally and linguistically appropriate. One participant commented on a situation that she had faced on numerous occasions:

*Even in the middle of the night the shelter workers call me to interpret. Sometimes Tamil clients couldn't express their problems or wishes to the workers, so they — in a desperate way — give my number to the worker and ask them to call me. Imagine if I say no — then the clients have to wait till the next day. So I feel obliged. But for me it's hard. I also have to cook, put my children to bed, and go to work the next day.*

Some participants worried about calls going out to the community for interpreters, since a woman's safety could be jeopardized if a message about her whereabouts were to be shared with someone connected to her family. Some women were forced to return to their abusive husbands because their family members found out which shelter they were staying at. Participants also spoke of women returning to their abusive husbands because of difficulties they encountered due to the lack of linguistically and culturally appropriate services in shelters, hospitals, and clinics.

### ***Lack of Portability of Services***

Participants noted that abusive husbands often purposefully and systematically isolated their wives by restricting their access to the telephone and/or denying them bus fare. Such women had no means of reaching providers of formal social support:

*We provide services to women. But the women have to get out of their houses and come. It's a time factor, it's a geography factor, and it's commuting.*

*It is difficult for a woman to go by bus. Even if she knows about the place and how to get there, can she go and come back before her husband comes? He will be calling to check whether she is home.*

*You know, even reaching out for help . . . where to call? Can you call [organization's name]? Can you call [organization's name]? Are they going to go to these women? No! Nobody in the world is there to go and help this woman when she is alone and she needs help. There is no such system.*

Participants said that there should be a way for health professionals, social workers, and settlement workers to meet women in their homes or nearby, in order to improve women's access to service providers without jeopardizing their safety. However, home visiting was seen as having legal implications for the service providers and their agencies — neither individual workers nor their institutions were willing to take the next step. This illustrates how policies and regulations serve to shape women's access to services and their responses to IPV.

### ***Lack of Coordinated Services***

Participants identified the lack of interconnected services and of coordination between the various health, social, and settlement organizations:

*One of the settlement workers sent this woman to the inappropriate person. She went there, then the person sent her to another person. At that place she didn't get the proper help, and she came to me. Oh my god! I felt so sorry for her. She has language problems, she is not young, she is scared, too, and her only child is not happy with her decision, and she is feeling guilty about disclosing abuse.*

A number of participants noted women's frustration with not being able to have most of their concerns addressed in one place, especially for the women who knew little about services and locations, faced language barriers, were constrained financially, and had limited access to transportation. Most of the women thus affected were those most marginalized by unequal access to socio-economic resources.

### ***Confidentiality Concerns***

Like most women dealing with IPV, abused Tamil women preferred to keep their experience confidential. This was viewed as particularly important in the case of Tamil women because of pressures from and conflicts within the community pertaining to the impact of divorce and separation on children and other family members. However, for those not fluent in English, keeping one's situation confidential within the community appeared to present a dilemma and a challenge for a number of reasons, some of which are captured in the following comments:

*I think they face a difficult dilemma during crises. They need someone who can speak the language. But still they don't want to talk to Tamil consultants, because the word may get out. So it's really difficult.*

*Whenever they talk about the woman, other clients are also there. Sometimes the volunteers move around. So, imagine, how would the women see this?*

These excerpts highlight the serious concerns about lack of respect for confidentiality. The latter comment also alludes to a lack of closed, private space in which to interview women or discuss cases — the result of insufficient government funding for agencies that serve immigrants.

### ***Discriminatory and Racist Practices***

Another concern was the various discriminatory and racist practices encountered by women seeking formal support. Failure to provide culturally and linguistically appropriate services was interpreted by participants as discriminatory and racist in that it conveys the message that the services will be provided only if one speaks English and adheres to “mainstream” cultural values and beliefs. Participants cited a number of other discriminatory practices:

*I've heard many stereotypical ideas about visible minority people. The service providers' way is to tell the women, “Do as I say.” If you don't, the services are withheld or they don't provide the services in the way the woman wants. Visible minorities are being treated differently. A lot of Tamil people functioning as interpreters have seen women go through very difficult crisis situations without an interpreter at all. Things are understood in various manners, and this creates [for] the woman even more problems, like child custody stuff.*

Participants also highlighted the challenges faced by service providers because of their heavy workload and lack of sufficient resources to help the number of clients sent to them. They indicated that services addressing the needs of immigrant women remain in the margins of government funding agendas, and that many agencies that provide services to immigrants have to reapply for funding annually. Other concerns raised by participants were related to eligibility criteria for services (such as women having to show their immigration documents), systemic intrusions into their lives (such as the need to justify their income or expenses), and the threat of deportation for breaking sponsorship as barriers to the use of such services.

## **Discussion**

### ***Limitations of Formal Social Supports and Services***

The lack of information about available services and the lack of culturally and linguistically appropriate services were highlighted in this study.

Various studies conducted in Canada and the United States (e.g., Bauer, Rodriguez, Quiroga, & Flores-Ortiz, 2000; Kulwick & Miller, 1999; MacLeod & Shin, 1990, 1993; Murdaugh, Hunt, Sowell, & Santana, 2004) have noted that women often have little knowledge about services available for dealing with IPV. According to Huisman (1996), “domestic violence agencies” in the United States often have little or no ties to immigrant communities and tend to engage in few outreach efforts. Other authors report that even when women are aware of services they may not view them as culturally or linguistically relevant (Perilla, 1999; Rodriguez, Bauer, McLaughlin, & Grumbach, 1999). Many of the women interviewed for MacLeod and Shin’s (1993) Canadian study across a number of immigrant communities expressed the view that “existing services with their emphasis on individualism and centred on North American culture and values do not validate nor recognize their cultures and value systems” (p. iii). Bui (2003), Tran and Des Jardins (2000), and Runner, Yoshihama, and Novick (2009) also highlight language barriers that immigrant women face in attempting to access and use services such as hotlines, shelters, and counselling and legal services.

In the present study as well, women experienced geographic and transportation barriers when trying to reach various agencies in order to obtain formal supports. Similar findings are reported from a Canadian study with Chinese immigrants (Fong, 2000), an American study with Hispanics (Murdaugh et al., 2004), and a recent study with African-American women dealing with IPV (Gillum, 2009). Concern about getting to services and returning home before the abusive partner returns or calls is not unique to Tamil women or to immigrant women in general. However, coupled with language barriers and not knowing where to obtain services, this concern makes accessing and using formal social supports even more difficult for immigrant women. The challenge is even greater if the woman and her children require a number of services offered at different locations, requiring multiple visits to different agencies. One of the reasons for the piecemeal approach to services for women dealing with IPV is the low priority given by decision-makers to needs that are created at the intersection of racism, classism, and sexism.

Service eligibility requirements such as proof of citizenship or knowledge of English were seen by participants as deterring SL Tamil women from accessing formal services. Similar findings are reported for immigrant women in other studies conducted in Canada (Bernhard, Goldring, Young, Berinstein, & Wilson, 2007; Fong, 2000; MacLeod & Shin, 1990, 1993) and the United States (Erez et al., 2009; Gillum, 2009; Sorenson, 1996). Also consistent with other findings (Arat-Koç, 1999; MacLeod & Shin, 1990, 1993), in the present study women’s use of formal services

was hindered by immigration policies that impose financial obligations on the sponsor/sponsored dyad and threaten deportation of both parties if expectations are not met. These policies are based more on economic interests than on human rights concerns.

The present findings also suggest the need to re-examine both the kind of interventions being prescribed by health professionals and the appropriateness of the models and theories favoured by agencies serving abused women and their families. MacLeod and Shin (1993) explain that “counselling approaches which do not emphasize practical approaches are seen by many women as all talk and no substance, as inappropriate personal intrusion by outsiders, and as patronizing” (p. ii). Fong (2000) also questions the appropriateness of implementing Western models and theories in counselling and social work, especially in the context of violence against women.

### ***Implications for Programs and Policies***

It is paramount that community-based outreach programs for health promotion and violence prevention be developed and situated in apartment buildings, schools, and other central locations in the community. Information about IPV services for women should be distributed through multiple channels, such as television programs, community newspapers, daycare centres, schools, groceries, workplaces, libraries, places of worship, and community organizations. As proposed by Hanby (2000) and Trickett (1996), health professionals should identify and build on those aspects of religious beliefs and cultural values that support non-violence and rely on community strengths. Community-based health promotion can also focus on building supportive relationships within the community and on breaking the silence around IPV and minimizing stigma. Concerns have been successfully addressed through community theatre, dance, and drama (P. Kanthasamy, personal communication, August 15, 2008; Shirwadkar, 2004). Such work, however, must be undertaken within and with communities.

In the present study, women who were able to access formal services expected to have all their concerns addressed in one place, expected services to be coordinated and interconnected, and expected to have their wishes regarding confidentiality respected. Latta and Goodman (2005) observe that “once women overcome many hurdles on the path to seeking services, these services must be able to provide adequate responses to their needs and places where they can feel safe” (p. 1458). Since not all programs will have the expertise or the capacity to provide services in one place, better coordination between agencies is needed. According to Whitaker et al. (2007), a network-based approach to integrated services facilitates referral and follow-up among agencies, ensur-

ing that women “are not forced to weave their way through a complex web of social systems” (p. 205). Furthermore, agencies that provide a range of health, social, and settlement services in one place may be able to reach women who might not seek help specifically for IPV because of the stigma attached to it.

Our study participants identified the need for culturally and linguistically appropriate services. Similarly, based on their US studies, Gillum (2009) and Ingram (2007) cite the need for culturally and linguistically appropriate interventions that address the many factors confronting women who are grappling with the multifaceted issue of IPV. Latta and Goodman (2005) note that the “one size fits all” approach to services does not address “the many different cultural and contextual factors that uniquely affect the experiences of different ethnic groups” (p. 1458). A culturally and linguistically appropriate approach must also take into account the diversity of women in each ethnocultural community and allow for the tailoring of strategies so that each woman can respond to IPV in her own way. Agencies and institutions “need activities to promote cultural competence and collaboration, specific education and outreach activities and agency-level changes in procedures and policies to facilitate more culturally competent services” (Whitaker et al., 2007, p. 191). As part of their mandate to address cultural competence and cultural appropriateness, agencies must address the racism that is inherent in the ways in which they provide services, their eligibility criteria, and their attitude with respect to which clients are “deserving” of support. In the process, IPV service providers and their agencies must address those concerns that are particularly critical for women, such as intrusion, control, trauma, and violence resulting from the threat of deportation, welfare surveillance, and systemic racism.

Community partnerships and participatory research are ideal means of developing healthy public policies that are relevant for immigrant communities. The insights gained from such approaches may also help to change policies that negatively affect women’s health and that address or even break down structural barriers. Structural barriers include lack of interpreters, confidentiality breaches, lack of safe, private space in clinics and agencies providing services to women dealing with IPV, and ethnocentrism and racism. In addition, health researchers must sharpen their focus on health promotion and violence prevention among all subgroups of the Canadian population, in order to address IPV more proactively and in the broader context of violence against women in society.

The findings of this study indicate the need for a paradigm shift in the planning, funding, and delivery of services to Canadian immigrant women dealing with IPV and suggest a number of recommendations:

- Develop programs that can be delivered at various locations and that incorporate portable modes of delivery (such as mobile health units).
- Develop programs in collaboration with the community and relevant stakeholders.
- Build and maintain complementary partnerships between mainstream and ethno-specific agencies.
- Recruit and train women who are fluent in the target language and ensure that they are aware of the nuances that can affect different communities that speak the same language.
- Institute mandatory annual training of all service agency staff in the areas of domestic violence and racism.
- Foster an environment that is conducive to the confidential sharing of information.
- Use diverse media and channels to distribute information about available services to the intended audience. Employ culturally appropriate pictures, symbols, and language.
- Develop community-appropriate health interventions that incorporate cultural values, beliefs, norms, and attitudes in the pre- and post-migration contexts. Know that these change over time.
- Deliver a range of services under one roof.
- Develop strategies and interventions that are practical and problem/solution-oriented and that address the needs of both the woman and her family. For each situation, develop solutions in collaboration with the woman herself.
- Address social determinants of health so that women can deal with IPV in a way that is appropriate for them and their families. In addressing social determinants of health, health professionals should work in partnership with social, settlement, and legal workers.
- Address various practices and rules and regulations that are based on systemic racism in the planning, funding, and delivery of IPV services to immigrant women. Conduct gender, race, and class analyses at all levels of service delivery in order to address the limitations of current policies and to develop new policies in the health, social, and immigration and settlement sectors.
- In partnership with women, men, and their communities, develop interventions that address the needs of immigrant women dealing with IPV and its aftermath and that could serve to prevent violence.

### **Limitations of the Study**

The main limitation of this study relates to the source of the data, which is not the women themselves. However, each of the participating community leaders had worked in different capacities, with many SL Tamil

women, in order to better deal with the issue of IPV. Thus, these individuals — themselves Tamil immigrants — acted in a sense as translators and cultural interpreters for the researchers, to help us more fully understand the struggles of abused SL Tamil women.

### Conclusion

Health professionals are responsible for delivering research-based care and support to persons of all backgrounds. However, the paucity of health research on IPV in the post-migration context has constrained the practice of health professionals. This qualitative study represents a step in revealing the complexities of women's access to and use of formal social supports post-migration. The limitations of formal support systems need to be addressed so that every woman can access the support she needs to deal with IPV in a way that is most suited to her unique situation. Truly appropriate and effective care for women coping with IPV post-migration is delivered in the context of the social determinants of health and is based on each woman's life priorities and lived realities. Health professionals should take into account the needs identified by women experiencing IPV and build on the women's strengths in order to advocate for the women and their families as they interface with a new environment and a new country.

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## **Le rôle du soutien paternel dans le développement comportemental des enfants exposés à la dépression postpartum**

**Nicole Letourneau, Linda Duffett-Leger et Mahin Salmani**

La disponibilité du père et sa capacité à fournir du soutien à sa conjointe lorsqu'elle souffre de dépression postpartum et, partant, à contribuer au développement de l'enfant nouveau-né, peuvent dépendre de facteurs comme le temps consacré au travail, la santé et le degré de scolarité. Dans le cadre de ce projet, qui porte sur 626 enfants et leurs familles, on a analysé l'incidence de certaines caractéristiques paternelles sur le développement comportemental de l'enfant exposé à la dépression postpartum de la mère. On a tenu compte des covariants connus, incluant le sexe de l'enfant, la structure familiale, le nombre d'enfants au sein du ménage, le revenu annuel et le fonctionnement de la famille. En ce qui touche les résultats comportementaux associés à l'anxiété, l'hyperactivité et l'agressivité, le temps consacré par le père à son travail au cours des deux premières années après la naissance de l'enfant permet de prédire de façon significative le développement de ce dernier sur une période de dix ans. Fait à signaler, le fait pour un père de travailler le week-end s'est avéré un facteur de risque, particulièrement pour les garçons. Par conséquent, les caractéristiques associées à la disponibilité du père et à sa capacité d'épauler sa conjointe lorsqu'elle souffre de dépression postpartum semblent être des facteurs de prédiction du développement réussi de l'enfant.

Mots clés : développement, famille, postpartum, soutien social

# **The Role of Paternal Support in the Behavioural Development of Children Exposed to Postpartum Depression**

**Nicole Letourneau, Linda Duffett-Leger, and Mahin Salmani**

Fathers' ability and availability to provide social support to their depressed partners and thus promote their children's development and success may be influenced by their workforce participation, health, and years of education. This study of 626 children and their families examined the influence of fathers' characteristics on their children's behavioural development, when exposed to maternal postpartum depression, taking into account known covariates, including sex of the child, family structure, number of children in the household, annual income, and family functioning. For the behavioural outcomes of anxiety, hyperactivity, and aggression, fathers' workforce participation during the children's first 2 years of life significantly predicted their development over the next 10 years. Most notably, weekend work by fathers was a risk factor, particularly for boys. Thus fathers' characteristics related to their ability and availability to provide social support for their depressed partner appear to predict children's developmental success.

**Keywords:** child health, development, family, mental health/psychosocial, postpartum care, social support

Postpartum depression (PPD), sometimes referred to as childbearing depression, affects 13% of mothers and constitutes a major health problem for families (Whiffen, 2004). Characterized by the disabling symptoms of dysphoria, emotional lability, insomnia, confusion, acute anxiety, guilt, and suicidal ideation, PPD is a strong predictor of both depression in fathers and behavioural problems in children (Goodman, 2004). Frequently exacerbating these symptoms, many women are reluctant to seek help for their PPD symptoms, even from their partner, who is most often the child's father (Letourneau et al., 2007). While it is apparent that children exposed to both PPD and paternal depression are at dual risk for developmental problems (Elgar, Mills, McGrath, Waschbusch, & Brownridge, 2007), little is known about how the availability of social support from fathers may protect children from the deleterious effects of exposure to PPD.

## **Postpartum Depression and Children's Development**

The impact of maternal PPD on child development is well documented. Postpartum depression affects maternal-infant interaction and attachment

and predicts poor social and cognitive developmental outcomes (Beck, 1998; Bialy, 2006; Campbell et al., 2004; Grace, Evindar, & Stewart, 2003; Kurstjens & Wolke, 2001; Murray & Cooper, 1996, 1997a, 1997b, 1997c, 1999; Murray, Cooper, Wilson, & Romaniuk, 2003; Murray, Fiori-Cowley, Hooper, & Cooper, 1996; Murray, Sinclair, Cooper, Ducournau, & Turner, 1999). Longitudinal research by the first author has shown that boys are particularly vulnerable to the effects of PPD, predicting increased incidence of hyperactivity and aggression between 2 and 8 years of age (Letourneau et al., 2006). Children's development is also influenced by the presence of two parents in the home, family income, and number of children in the household (Letourneau et al., 2006; Willms, 2002). Children's relationship with their father also predicts long-term behavioural outcomes (Ramchandani, Stein, Evans, & O'Connor, 2005). Fathers may promote their children's development by being sensitive and responsive to their changing needs (Goodman, 2004), protecting their partner against a depressive relapse (Misri, Kostaras, Fox, & Kostaras, 2000), or buffering their children from the negative effects of PPD (Tannenbaum & Forehand, 1994; Thomas, Forehand, & Neighbors, 1995). However, when fathers with depressed partners become depressed as well, the comorbidity can have an additive effect on child development; children residing with two depressed parents are at significantly greater risk for poor social, emotional, and developmental outcomes (Brennan, Hammen, Katz, & LeBrocq, 2002; Dierker, Merikangas, & Szatmari, 1999; Meadows, McLanahan, & Brooks-Gunn, 2007).

### **PPD and Parenting in the Postpartum Period**

Fathers whose partner suffers from PPD report increased dissatisfaction with the relationship, including sexual problems and lack of intimacy (Meignan, Davis, Thomas, & Droppleman, 1999). Men's assessment of fatherhood as either beneficial or burdensome may be directly linked to their perception of stressors and the availability of support from their partner in the postpartum period (Garfield, Clark-Kauffman, & Davis, 2006). A mother with PPD is less capable of being supportive of her partner, which in turn may reduce the father's supportiveness of his young family. Further, the emphasis on the man's role as breadwinner may be increased due to the added financial burden after the birth, which in turn may prevent the father from becoming more involved in parenting and more supportive of his partner. A sense of failure in performance at work, within the family, and sexually, as part of the emphasized male gender role, is clearly related to psychological distress and mental health problems among fathers, which can further reduce their availability to the partner (Morse, Buist, & Durkin, 2001). Postpartum depression thus



creates multiplicative risks to children's development associated with marital distress and the ability of both mothers and fathers to be adequately involved and invested in family activities that support children's development.

### **Maternal PPD and Fathers' Health in the Postpartum Period**

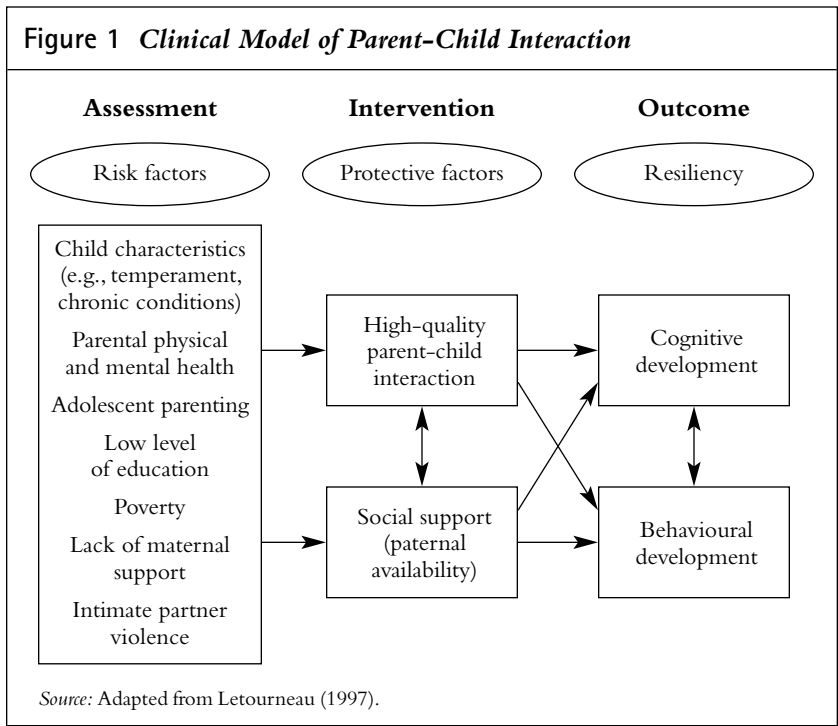
While maternal PPD has been much researched in the past decade, little is known about the impact of PPD on fathers and the consequences for child development. For fathers, increased societal expectations, demands, and responsibilities during the postpartum period create stressors that can lead to depression (Kim & Swain, 2007). A systematic review of 20 studies revealed that when mothers experience depression, 24% to 50% of their partners will also experience depression (Goodman, 2004). In a Canadian national sample, 10% of fathers exhibited symptoms of depression in the postpartum period (Paulson, Dauber, & Leiferman, 2006). Paternal depression tends to develop more gradually than maternal PPD (Kim & Swain, 2007), typically appearing with the onset of the PPD and increasing during the first postpartum year (Matthey, Barnett, Ungerer, & Waters, 2000). It is often the consequence of more severe maternal symptoms that reduce a woman's ability to look after herself and her child, thus increasing the burden on the father (Pinheiro et al., 2006). Fathers are known to underreport symptoms of depression in the postpartum period (Skrenden et al., 2008).

### **Fathers' Employment, Socio-economic Status, and Child Development**

Families affected by PPD may be particularly vulnerable to the stress associated with non-standard work schedules. Increased hours of paid employment outside the home, combined with a non-standard work schedule, may negatively affect the amount of social support fathers can provide to their partner and the amount of time they have available for family activities (Turcotte, 2005). Unlike new mothers, new fathers tend to increase their hours of work outside the home, leaving them less time to participate in leisure activities with their children (Paull, 2008). On the other hand, new fathers have been found to become more engaged in intergenerational and extended family interactions (Knoester & Eggebeen, 2006). Fathers' involvement in child care has been negatively associated with lower family income and lower paternal education (Fagan & Iglesias, 1999).

Fathers' level of satisfaction with long hours of work is an important factor in the relationship between work hours and health and well-being (Gray, Qu, Stanton, & Weston, 2004). While the standard work week has

traditionally been defined as 8 hours a day, 5 days a week, the evolution of a 24-hour economy has led to a redefinition of the typical work week, to include evenings and weekends (Costa, 2000). Maternal employment, particularly during the first year of a child's life and when it entails a non-standard schedule (Han, 2005), negatively affects children's cognitive development (Ruhm, 2004). Joshi and Bogen (2007) studied the impact of non-standard schedules (nights, weekends, or rotating shifts) of low-income mothers on the behaviour of preschool children. They found an association between non-standard schedules and a higher incidence of externalizing behaviours such as aggression and hyperactivity. Strazdins, Clements, Korda, Broom, and D'Souza (2006) found that preschool children were more likely to have emotional or behavioural difficulties if one or both of their parents worked non-standard shifts (i.e., evenings, nights, weekends), mediated by reduced family functioning. How fathers' work schedules and education level affect children's development, particularly when their partner has PPD, is unknown. We found no studies that used longitudinal population-based data to examine the effects of fathers' employment characteristics on the development of children prone to poor developmental outcomes associated with maternal depression.



### **Theoretical Model**

The Clinical Model of Parent-Child Interaction, adapted from Letourneau (1997), formed the theoretical foundation for this study. Based on concepts of risk and resiliency (Garmezy, 1985; Rutter, 1987), the model identifies: (1) Risk Factors (under Assessment) to children's development, including parental health problems such as PPD; (2) Protective Factors (under Intervention) regarding social support and quality of the parent-child relationship; and (3) Resiliency (under Outcomes), characterized by cognitive and behavioural development. In this study of families affected by PPD, fathers' characteristics (including health and workforce participation) are theorized to relate to their ability/availability to provide social support to mothers and children in the home, which in turn relates to children's behavioural development.

The purpose of this descriptive study of families affected by PPD was to determine the impact of fathers' characteristics (relative to the availability of social support) on children's behavioural development. The research question was as follows: *In the face of maternal PPD, what is the impact of fathers' health and workforce participation on their children's behavioural development, taking into account family structure, the sex of the child, number of children in the household, socio-economic status, and family functioning?*

### **Method**

Because earlier analyses revealed differences in the development of children born to mothers with and without PPD (Letourneau et al., 2006), this study was focused explicitly on families affected by PPD. Thus factors that promote children's development in families affected by PPD could be explicitly examined. Data from 626 of the families included in the National Longitudinal Survey of Children and Youth (NLSCY) were used to address the research question using logistic Hierarchical General Linear Modelling (HGLM). The NLSCY, launched by Statistics Canada in 1994, tracks the development, health, and well-being of a nationally representative sample of children. The original cohort of children were interviewed every 2 years. Six cycles of NLSCY data were available at the time of the present study: Cycle 1 (1994–95), Cycle 2 (1996–97), Cycle 3 (1998–99), Cycle 4 (2000–01), Cycle 5 (2002–03), and Cycle 6 (2004–05). In the present study, children (0 to 24 months inclusive) identified in Cycle 1 were followed through at least two subsequent cycles, up to age 149 months (12.5 years), to create growth trajectories for behavioural outcomes. Many of the predictor variables used in this study were designed to evaluate only children under 24 months, while the outcome measures were designed to evaluate children 24 months and older. Therefore, information for the predictor variables was extracted from

Cycle 1 data whereas information for the outcome measures was extracted from subsequent cycles. All data were obtained via maternal report.

### Participants

The population of interest was children whose mothers reported being depressed within 2 years of their birth. Children were eligible based on three criteria: their mothers scored high (9 or higher) on the depression measure (CES-D) or had been diagnosed as depressed in Cycle 1; their parents were partnered at the time of the birth and the children lived with at least one biological parent; and their father cohabitated with their mother at the time of the birth and during at least two subsequent cycles. Partners were eligible if they were a biological, foster, or step parent. When there was more than one child in the family, the oldest child was selected; in the event of multiple births, one child was randomly selected. The eligibility criteria also required that the person who provided survey responses, known as the person most knowledgeable (PMK), be the biological mother of the child. The sample size was maximized through the inclusion of children surveyed in Cycle 1 (for predictor variable information) and at least two subsequent cycles (2, 3, 4, 5, or 6). A total of 626 children (615 with completed data) were included in the sample. Table 1 details the cycle participation of these 626 children.

### Measures

#### *Postpartum Depression*

Maternal depression was measured using the NLSCY Depression Scale, based on the National Institute of Mental Health's Center for Epidemiological Studies Depression (CES-D) scale (Radloff, 1977). The

<b>Table 1</b> <i>Number of Children 24 Months or Younger in Cycle 1 Participating in Two, Three, Four, or Five Other Cycles of the NLSCY</i>	
	<b>Number of Children (Cases)</b>
Cycle 1 and two other cycles (total of three)	47
Cycle 1 and three other cycles (total of four)	40
Cycle 1 and four other cycles (total of five)	92
Cycles 1, 2, 3, 4, 5, and 6 (total of six cycles)	447

full CES-D (20 items; scores range from 0 to 60 and a score of 16 represents a classification of depression) was rescaled to produce a shortened version (12 items with scores ranging from 0 to 36) with a cut-off proportional to that of the full CES-D. Thus the cut-off for depression on the 12-item NLSCY Depression Scale was set at 9. Cronbach's alpha for the 12-item scale was 0.82, slightly lower than the reliability of the full 20-item scale (0.85) (Somers & Willms, 2002). In this study, the PMK (which is the biological mother for the selected subsample) was considered to be depressed if she had a score of 9 or higher on the NLSCY Depression Scale or if she reported a diagnosis of PPD.

### ***Behavioural Outcomes***

The measures of anxiety, hyperactivity, and aggression were designed to assess aspects of behaviour in children 2 years and older. The *anxiety* measure included items such as "How often would you say that your child is too fearful or anxious?" and "How often would you say that your child is worried?" Examples for *hyperactivity* include "How often would you say that your child is distractible or has trouble sticking to any activity?" and "How often would you say that your child can't sit still or is restless or hyperactive?" The *aggression* measure included the following: "How often would you say that your child gets into fights?" and "How often would you say that your child kicks, bites or hits other children?" (Statistics Canada, 1998). Possible PMK responses to these items were 1 = *never or not true*, 2 = *somewhat or sometimes true*, and 3 = *often or very true*, with higher scores indicating increased presence of the behaviour. For ease of interpretation, dichotomous variables were created for each measure. A score of 0 was assigned if the score was less than or equal to 2 and 1 if the score was greater than 2. Cronbach's alpha reliabilities for the behavioural measures in Cycle 1 are as follows: anxiety, 0.59; hyperactivity, 0.80; aggression, 0.75 (Statistics Canada, 1998).

### ***Predictors Related to Fathers' Support Availability.<sup>1</sup>***

*Workforce participation* was measured using several variables, including employment status (i.e., employed or unemployed), work schedule (e.g., Monday to Friday and standard business hours [9 a.m. to 5 p.m.]), full-time or part-time status, and weekend work. *Employment status* was measured using a dichotomous variable: 1 (employed); 0 (unemployed). Full-time status (30 hours or more per week) and part-time status (less than 30 hours per week) were measured using a dichotomous variable

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<sup>1</sup> The NLSCY contains no data that directly measure the availability of social support from fathers. Its only measure of social support is perceived availability of support from professionals and the community, not from partners.

where full-time was coded 1 and part-time was coded 0. Standard schedule was measured using a dichotomous variable where 1 corresponds to standard days and standard hours and 0 corresponds to one of the following: standard days/non-standard hours, non-standard days/standard hours, non-standard days/non-standard hours. Standard days refers to Mondays through Fridays and standard hours refers to a regular daytime schedule. A dichotomous variable was also created for fathers' weekend work, coded 1 if the father worked weekends and 0 if otherwise.

Mothers were asked to report on the state of their partner's *general health*, both physical and mental. No other measure in the NLSCY provides insight into fathers' mental health; thus this variable served as a general proxy. It was measured as a dichotomous variable with excellent (1), very good (2), and good (3) coded as 1 and fair (4) and poor (5) coded as 0.

### **Covariates**

*Sex of the child.* This dichotomous variable was coded 1 for female and 0 for male. *Family structure.* A dichotomous variable was created and coded 1 if the child lived with both biological parents in all cycles and 0 if the child lived with only one biological parent in at least one cycle. *Number of siblings.* The child's siblings range in number from 0 to 9. This variable was included to account for the declining developmental achievement of children in larger families, related to the diminished time available for parents to be supportive and involved with each child (Iacovou, 2007; Nuttall, Nuttall, Polit, & Hunter, 1976; Polit & Falbo, 1988). *Household income.* Annual income was recorded in thousands of dollars and measured as a continuous variable ranging from 0 to 90 (\$0–\$90,000). *Fathers' years of education.* Fathers' education was measured as the total number of years of formal education, ranging from 0 to 20. This variable was centred on its Cycle 1 mean of 12 years. *Family functioning.* The NLSCY's questions related to family functioning were developed by researchers at the Chedoke-McMaster Hospital of McMaster University. This scale is used to measure various aspects of family functioning — for example, problem-solving, communication, roles, affective involvement, affective responsiveness, and behaviour control. The total score may vary between 0 and 36, with higher scores indicating family dysfunction. Cronbach's alpha coefficient for the 12 items is .87.

### **Analysis**

Descriptive statistics were calculated to examine sample characteristics over time during the study period (birth to 12.5 years). Logistic HGLM

was used to model the data longitudinally, specifically to examine children's behavioural growth trajectories. Hierarchical General Linear Modelling takes into account the clustering of observations by estimating a single model that describes data at two levels: within-child and between-child (Raudenbush & Bryk, 2002). Within-child differences summarize an observed pattern of an outcome variable across measurement occasions into a trajectory or functional relationship with time. Between-child differences are specified using coefficients denoting the effects of selected predictor variables. Logistic HGLM was used to explore the relationships among predictors, covariates, and children's initial level (centred at age 6; beta 0), rate of change (beta 1), and curvilinearity (beta 2) of each behavioural outcome. Quadratic terms were added to examine curvilinearity of the children's behavioural growth trajectories.

Beta 0 (fixed effects) coefficients are interpreted as the probability (log odds) of a child having a high score on a given outcome (i.e., anxiety, hyperactivity, aggression) at 6 years of age, based on predictor scores (e.g., father's weekend employment, family functioning). Beta 1 (slope) coefficients are interpreted as the rate of change over time in the relationship between the predictor and the outcome. Beta 2 (acceleration) coefficients are interpreted as the probability that the relationship between the predictor and the outcome is curved (not linear). Perhaps most important for our understanding of statistical relationships is the need to consider the fixed effects coefficients, as these are the starting point (i.e., initial level) for the slope and curvilinearity interpretation. To interpret the direction of the relationship between each predictor and outcome, the intercept for each significant coefficient is examined to determine the starting point. Alpha was set at .05, so that significant coefficients indicated that the relationship between the predictor and the outcome was significantly greater than that observed by chance. Sampling weights were not used, as the goal of the study was to examine relationships, not to generalize to the Canadian population.

## **Results**

Table 2 contains descriptive data for demographic and predictor variables from Cycle 1. Table 3 provides the percentages of children who scored high (greater than 2) on the outcome measures in each cycle, with descriptive comparisons to national data. As is evident from Table 3, high *anxiety* scores increase up to Cycle 6, while high *hyperactivity* and *aggression* scores decrease over time. Table 4 reports significant logistic HGLM results for behavioural outcomes. Figure 2 shows graphed trajectories that

take significant sex differences into account. In general, children whose fathers work on weekends have higher scores on the behavioural outcomes; this result is most notable for boys.

<b>Covariate/Predictor</b>	<b>Statistic</b>
N	626
Intact family	68%
Family functioning	Mean = 9.98; SD = 5.37
Household income	Mean = \$44,533; SD = \$22,020
Father's years of education	Mean = 12 years; SD = 2 years
Number of siblings	Mean = 0.41; SD = 0.05; median = 1 (40%); range = 0–9
Female	49%
Father's standard work schedule	39%
Father's health = excellent, very good, or good	95%
Full-time employment	87%
Weekend work	44%
Employed	90%

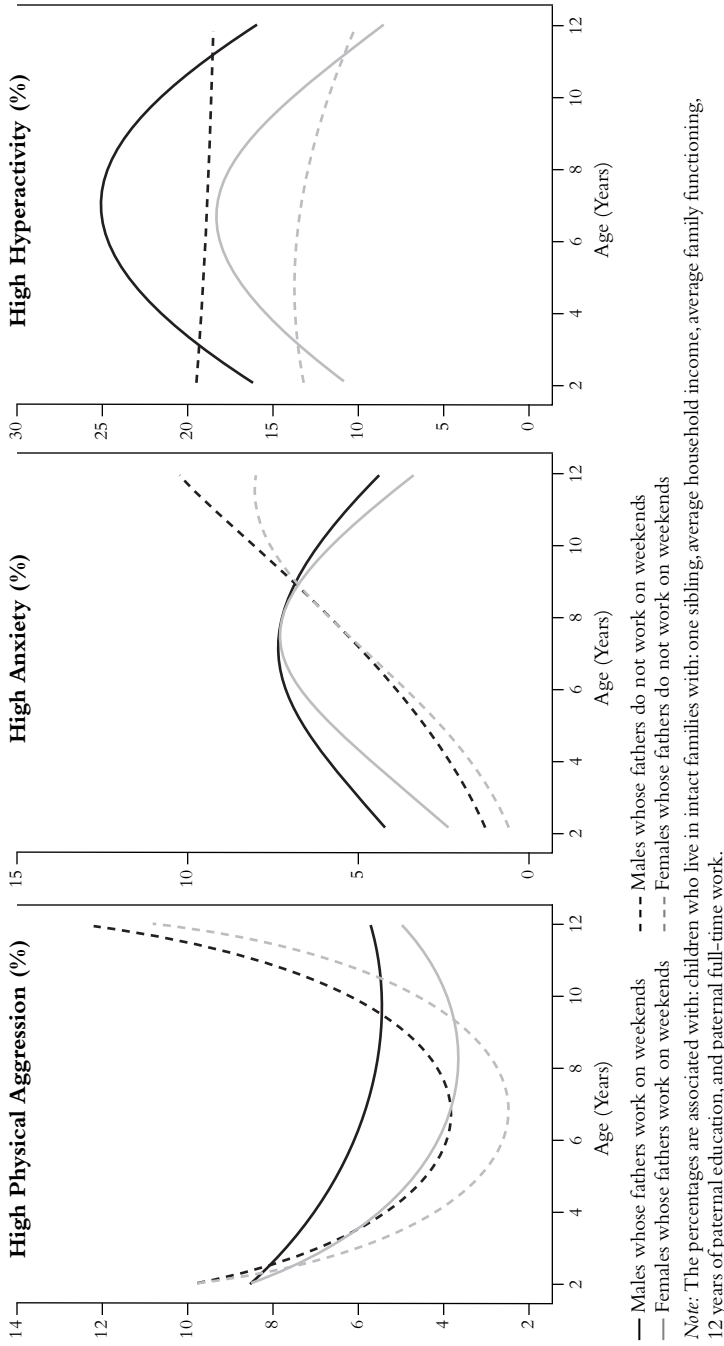
<b>Outcome Variable</b>	<b>Cycle 2</b>	<b>Cycle 3</b>	<b>Cycle 4</b>	<b>Cycle 5</b>	<b>Cycle 6</b>
Anxiety	.80 (2.2)	1.5 (1.7)	<b>4.5 (1.7)</b>	<b>5.2 (2)</b>	<b>5.6 (1.8)</b>
Hyperactivity	<b>19 (13.2)</b>	<b>17 (12.2)</b>	<b>18 (11.5)</b>	<b>18 (11.1)</b>	<b>15 (11.6)</b>
Aggression	<b>8.0 (3.3)</b>	<b>3.6 (3)</b>	2.3 (3.6)	2.0 (3.3)	2.0 (3.5)

*Note:* Parentheses denote normative comparisons with NLSCY data for the entire sample using all age groups (birth to 18 years). **Bold type** indicates significantly higher (i.e., worse) behavioural outcomes for children of depressed mothers than for all children.



<b>Table 4 Final Estimation of Fixed Effects: Significant HGLM Output for the Trajectory of Anxiety, Hyperactivity, and Aggression</b>			
<b>Fixed Effect</b>	<b>Anxiety</b>	<b>Hyperactivity</b>	<b>Aggression</b>
<i>Intercept (log odds of having high score outcome at age 6), <math>\beta_0</math></i>			
Intrcpt2	<b>-2.72</b> (0.269)	-0.476 (0.335)	<b>-3.23</b> (0.261)
Female	-0.065 (0.106)	<b>-0.371</b> (0.122)	<b>-0.373</b> (0.095)
Intact	<b>-0.394</b> (0.124)	-0.212 (0.139)	-0.047 (0.110)
Family functioning score	<b>0.036</b> (0.011)	<b>0.031</b> (0.012)	<b>0.084</b> (0.010)
Household income	-0.000 (0.002)	-0.005 (0.003)	<b>-0.006</b> (0.002)
Number of siblings	0.095 (0.055)	-0.006 (0.064)	<b>0.411</b> (0.051)
Father's years of education	<b>-0.076</b> (0.028)	-0.046 (0.028)	-0.019 (0.017)
Full-time employment	<b>-0.889</b> (0.344)	-0.691 (0.394)	0.551 (0.289)
Father works on weekends	<b>0.624</b> (0.162)	0.313 (0.198)	<b>0.426</b> (0.161)
Father's employment status	0.568 (0.417)	0.241 (0.462)	<b>-1.078</b> (0.331)
<i>Slope, <math>\beta_1</math></i>			
Intrcpt2	<b>0.316</b> (0.058)	0.045 (0.088)	<b>-0.092</b> (0.044)
Female	<b>0.062</b> (0.024)	-0.007 (0.029)	-0.043 (0.027)
Intact	<b>-0.064</b> (0.030)	<b>-0.077</b> (0.034)	-0.049 (0.033)
Family functioning score	-0.003 (0.002)	0.003 (0.003)	<b>0.006</b> (0.003)
Household income	<b>0.005</b> (0.001)	0.001 (0.001)	-0.001 (0.001)
Father's years of education	<b>-0.031</b> (0.007)	<b>-0.018</b> (0.007)	-0.008 (0.008)
Father's health	-0.032 (0.048)	-0.017 (0.071)	<b>0.219</b> (0.126)
Full-time employment	<b>-0.311</b> (0.104)	0.084 (0.114)	-0.022 (0.110)
Father works on weekends	<b>-0.157</b> (0.041)	0.054 (0.044)	0.016 (0.042)
Father's employment status	<b>0.424</b> (0.122)	-0.115 (0.126)	0.219 (0.126)
<i>Acceleration, <math>\beta_2</math></i>			
Intrcpt2	<b>-0.064</b> (0.022)	<b>-0.052</b> (0.024)	-0.008 (0.013)
Family functioning score	0.000 (0.001)	<b>-0.002</b> (0.001)	<b>-0.004</b> (0.001)
Household income	<b>-0.001</b> (0.000)	-0.000 (0.000)	0.000 (0.000)
Number of siblings	0.004 (0.006)	0.005 (0.004)	<b>-0.009</b> (0.004)
Father's years of education	<b>-0.006</b> (0.002)	<b>0.005</b> (0.002)	0.001 (0.002)
Father's standard work schedule	-0.001 (0.012)	-0.021 (0.011)	<b>-0.026</b> (0.010)
Full-time employment	<b>0.065</b> (0.015)	0.007 (0.027)	-0.040 (0.030)
Father works on weekends	-0.011 (0.012)	-0.020 (0.012)	<b>-0.032</b> (0.010)
<i>Note: Standard errors are enclosed in parentheses. Coefficients shown in bold are significant at an alpha level of 0.05.</i>			

**Figure 2 High Behavioural Outcome Scores (%) Comparing Children Whose Fathers Do and Do Not Work on Weekends**



### ***Anxiety***

The HGLM results reveal that children whose fathers work on weekends during their first 2 years of life have higher anxiety scores than children whose fathers do not work on weekends, for the fixed effect and slope coefficients. Moreover, the slope coefficient reveals that the rate of change for children whose fathers work on weekends is significant and negative; thus the slope is decelerating over time. Curvilinearity was present, but not significant, in this relationship. These data are graphed with comparisons between males and females in Figure 2. Fixed effects results also reveal that living in an intact family where the father works full-time and has more years of education lowers the probability of anxiety at 6 years of age, while living in a household with a high family functioning score (indicating more dysfunction) increases the probability of high anxiety scores for children at 6 years of age.

### ***Hyperactivity***

Fixed effects coefficients reveal that the percentage of hyperactive children is lower for girls than for boys. For all children, however, the initial probability of having high hyperactivity scores increases as family dysfunction increases. Slope coefficients suggest that being in an intact family with two parents significantly reduces the rate of change in the percentage of hyperactive children, as does fathers' years of education. Therefore, while intact family status is not significantly related to the percentage of hyperactive children at 6 years of age, the slope comparing the two levels of the variable (intact vs. single-parent family) is significantly different and favours children's development in intact families over time. The slope coefficient for fathers' years of education suggests that the slope decelerates with increasing education, thus favouring children of fathers with more education over time.

### ***Aggression***

Fixed effects results reveal that children whose fathers work on weekends have higher aggression scores than children whose fathers do not work on weekends. Girls tend to have lower aggression percentages overall. Figure 2 reveals that boys whose fathers work on weekends have higher aggression percentages from 2 to 10 years of age. Living in a household with a higher family income and an employed father lowers the probability of aggression, while a higher degree family dysfunction and having more siblings raises the probability of aggression. Slope coefficients suggest that family dysfunction significantly increases the trajectory of the relationship between family dysfunction and aggression in children. Lower health status among fathers reduces the rate of change of the slope;

however, the fixed effect coefficient is not significant, which indicates that essentially there is no difference between fathers with high and low health status in terms of children's aggression scores.

### **Discussion**

In the face of maternal PPD, what is the impact of fathers' health and workforce participation on their children's behavioural development, taking into account the sex of the child, family structure, number of children in the household, socio-economic status, and family functioning? The findings show that fathers' workforce participation in the first 2 years of a child's life has a long-term impact on the behavioural outcomes of children in families affected by PPD. We found that children's anxiety and aggression scores over time were affected by fathers' full-time work, weekend work, and employment status, taking covariates into account. Weekend work was a consistent predictor of a higher degree of behavioural problems in each outcome variable, while other non-standard work hours failed to predict behavioural outcomes. Partial support for these findings is found in previous research on the influence of non-standard work schedules on children's behavioural outcomes (Joshi & Bogen, 2007; Strazdins & Loughrey, 2007). In keeping with the theoretical framework, the availability of support from fathers during children's first 2 years of life appears to have a protective effect on their behavioural development over the next 10 years. Paternal availability thus appears to be a protective factor in children's development. This finding is balanced by the observation that full-time work also had a protective effect. Fathers need to work, but perhaps they should avoid weekend work.

Weekend work may interfere with normal family routines and the availability of support from fathers. Weekends are traditionally reserved for leisure activities, which are important to the development of strong and supportive family relationships. An ever-increasing number of new parents are working rotating shifts, perhaps in part to avoid the high costs of child care; however, the savings may not be worth the costs to the well-being of parents and their children. Perry-Jenkins and colleagues (2007) found that non-daytime shift work predicted high levels of depressive symptoms in both mothers and fathers during the first year of parenthood. In addition, the greater the reported family dysfunction, the more significant the symptoms of depression (Perry-Jenkins, Goldberg, Pierce, & Sayer, 2007). Poorly educated and low-income families tend to work more non-standard and weekend hours (Heymann, 2000). While the present study did not examine this interaction, it did find that income played a role in children's behavioural outcomes.

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

This study was limited by the lack of a measure of fathers' social support for their partner. However, the large size of the data set permitted the examination of long-term effects of fathers' characteristics associated with support availability on children's development over time. Due to the fact that only the PMK (mother) is assessed for depression, the role of possible concurrent paternal depression is unknown. In addition, maternal depressive symptoms are a factor only in Cycle 1, which does not consider the possible recurrence of maternal depression and potential compounding impacts on developmental outcomes. As well, this sample of children and partners of depressed mothers were not compared with children and partners of non-depressed mothers to assess whether the impacts of fathers' characteristics are a function of maternal depression. At the same time, the relationship between maternal depression and developmental impairments in children is well established (Beck, 1998; Letourneau et al., 2006). While only 5% of fathers were reported to be in fair to poor health, the size of the database was sufficient for robust comparison between healthy and unhealthy fathers. However, mothers may not have been aware of fathers' health problems, as fathers are known to underreport symptoms (Skrenden et al., 2008). Future work could consider improved measures of fathers' health status. While continuous (rather than binary) outcomes may have yielded more complex findings, the use of logistic HGLM nonetheless allowed for the graphing of children's behavioural growth trajectories to 12 years of age. Also, the addition of quadratic terms enabled the examination of nonlinear trends.

In spite of the above limitations, this study is the first to point to the effect of fathers' characteristics, associated with their support availability in families affected by PPD, on children's long-term behavioural outcomes.

### **Conclusion**

The results of this longitudinal study demonstrate that the negative impact of maternal depression on children's social development may be mediated by fathers' characteristics related to their availability to provide family support. Moreover, these results and the findings of other research suggest that early environmental exposure to maternal depression is associated with negative behaviours in children, extending into adolescence, that may be mediated by father involvement (Halligan, Murray, Martins, & Cooper, 2007). Further research is needed to explore the duration of PPD effects on child/youth development and how fathers' characteristics contribute to these developmental outcomes.

Much of the research exploring the effects of work schedules on children's development has looked at the impact of maternal employment on young children. Little research has been concentrated on the effects of dual-earning parents on family relationships, especially with respect to non-standard work hours and adolescent development (Davis, Crouter, & McHale, 2006). Descriptive and longitudinal research is warranted, to more fully explore how non-standard work schedules impact on father involvement and both early child development and development over time. Workplace policies should recognize the importance of flexibility and paid personal time in order for parents to maintain strong and supportive family relationships throughout childhood (Thornton, 2004). Fathers tend to be more reluctant than mothers to seek out support services (Summers, Boller, & Raikes, 2004). The evidence, while limited, suggests that interventions to promote father involvement, such as those offered through Head Start programs (Fagan & Iglesias, 1999), may be an important means of reducing the deleterious impacts of PPD on children's social and emotional development.

Almost 60% of Canadians who are employed outside the home are unable to balance their work and family demands (Statistics Canada, 2001). High levels of work-life conflict are more prevalent among those who have children, and a disproportionate number of low-income families experience difficulty striking a balance between work and home life (Heymann, 2000). Women are more likely than men to report high levels of role overload and caregiver strain; however, there is increasing evidence that fathers are having a difficult time balancing work and home life, particularly during the transition to parenthood (Knoester & Eggebeen, 2006). As expectations for fathers change and as fathers become more equal partners in child care and domestic responsibilities, they may experience higher levels of role strain that influence their ability to support both their partner and their children's healthy development.

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## **Conception et validation d'un instrument de mesure de la double tâche en matière de prestation des soins**

**Catherine Ward-Griffin, Janice Keefe, Anne Martin-Matthews, Michael Kerr, Judith Belle Brown et Abram Oudshoorn**

Les auteurs ont mis au point un instrument de mesure qui vise à élargir les connaissances sur la double tâche en matière de prestation des soins. Par double tâche, on entend la prestation de soins à des proches âgés par des professionnels de la santé qui exercent activement leur profession. L'étude présentée ici visait à vérifier les propriétés psychométriques de l'instrument en question. Les données ont été recueillies auprès d'un échantillon aléatoire de 187 infirmières autorisées de sexe féminin, qui occupent un emploi et dispensent aussi des soins à un proche âgé. Neuf facteurs contribuant à la double tâche ressortent de l'analyse exploratoire. On a relevé une corrélation moyenne entre les sous-échelles de mesure et les mesures normalisées sur la santé incluses dans l'étude. Également, on a constaté une forte corrélation négative entre l'interface vie privée – vie professionnelle en matière de prestation des soins (soit la mesure dans laquelle la frontière entre sphères professionnelle et personnelle s'efface), et le bien-être et la santé mentale. Ces résultats confirment le point de vue des auteurs sur les mesures nécessaires pour soutenir les personnes amenées à assumer une double tâche en matière de prestation des soins.

Mots clés : prestation des soins, instrument de mesure

# **Development and Validation of the Double Duty Caregiving Scale**

**Catherine Ward-Griffin, Janice Keefe,  
Anne Martin-Matthews, Michael Kerr,  
Judith Belle Brown, and Abram Oudshoorn**

In order to gain an understanding of double duty caregiving (DDC), defined here as the provision of care to elderly relatives by practising health professionals, a DDC scale has been developed. This study tests the psychometric properties of the scale. Survey data were collected from a random sample of 187 female registered nurses who were employed and also provided care to elderly relatives. Nine factors contributing to DDC emerged from exploratory factor analysis. The DDC subscales were moderately correlated with the standardized health measures included in the study. The caregiving interface (degree of blurring between the professional and personal caregiving domains) was significantly negatively correlated with well-being and mental health. This result extends our understanding of the supports needed by those providing DDC.

**Keywords:** caregiving, instrument development, feminist perspective, work-family interface

As the Canadian population continues to age, one of the challenges ahead is the care of our most frail older citizens. In 2002 more than 1.4 million Canadians over 45 years of age combined paid employment with care for elderly relatives (Fast, 2005). Furthermore, as the average age of health professionals continues to rise in Canada (Canadian Institute of Health Information, 2006), there is an increasing likelihood that health professionals will be providing care to elderly relatives. How health professionals balance their personal life, such as caring for aging parents, with their professional responsibilities has become a priority in human resource planning amongst health-care organizations (Shields & Wilkins, 2005). Although the prevalence of double duty caregiving (DDC), defined here as the provision of care to elderly relatives by practising health professionals, is currently unknown, previous research suggests that 30% to 50% of the working population provides care to elderly relatives (Martin-Matthews, 2000). Thus, an understanding of DDC and how it influences the health and well-being of health professionals is particularly important given the aging population, the aging health-care workforce, and the increasingly dire shortage of health-care providers (Keefe, Légaré,

& Carrière, 2007). To assist researchers interested in studying the social support needed by providers of DDC, we have developed a new measurement tool. In this article, we describe the conceptual basis, initial development, and psychometric validation of the Double Duty Caregiving Scale (DDCS), as well as discuss the implications for further research associated with social support for health providers caring for elderly relatives.

### **Existing Knowledge**

Although there are numerous scales measuring role strain, role stress, and caregiver well-being (Lengacher & Sellers, 2003; Tebb, 1995; Tebb, Berg-Weger, & Rubio, 2000), these do not adequately measure the phenomenon of DDC. Caregiving has different meanings for different caregiver groups (Martin-Matthews, 2000), and while role strain and caregiver burden may be common amongst employed family caregivers, the experience of simultaneous paid and unpaid caregiving and its impact on the health and well-being of caregivers may be obscured if a general tool is used. Based on a critical feminist perspective, our goal was to develop a sensitive measure capable of capturing the unique caregiving experiences of health professionals who also care for elderly relatives.

The lack of attention to DDC is due in part to the tendency to treat professional, paid caregiving and personal, unpaid caregiving as separate domains (Ward-Griffin, 2008). A critical feminist approach to caregiving explores the connections of women's domestic labour with other forms of gendered caring work (Baines, 2004; Ungerson, 1990; Ward-Griffin & Marshall, 2003) and examines how the public and private domains are interwoven and interdependent through the idea of reproduction and production (Pascall, 1986). Double duty caregivers may be caught between the public and private domains of caregiving, in an "intermediate domain" (Stacey & Davies, 1983, cited in Mayall, 1993) where complex dimensions of location and social relations are brought together in caring work.

The few studies that have looked at DDC report that most hospital and community nurses experience high levels of stress associated with caring for relatives of all ages (Ross, Rideout, & Carson, 1996); however, caring for an elderly relative is positively correlated ( $r = .39, p < .05$ ) with health problems for female nurses only (Walters et al., 1996), likely reflecting a greater sense of obligation to care, due to their professional status within the health-care system (Ward-Griffin, Brown, Vandervoort, McNair, & Dashnay, 2005).

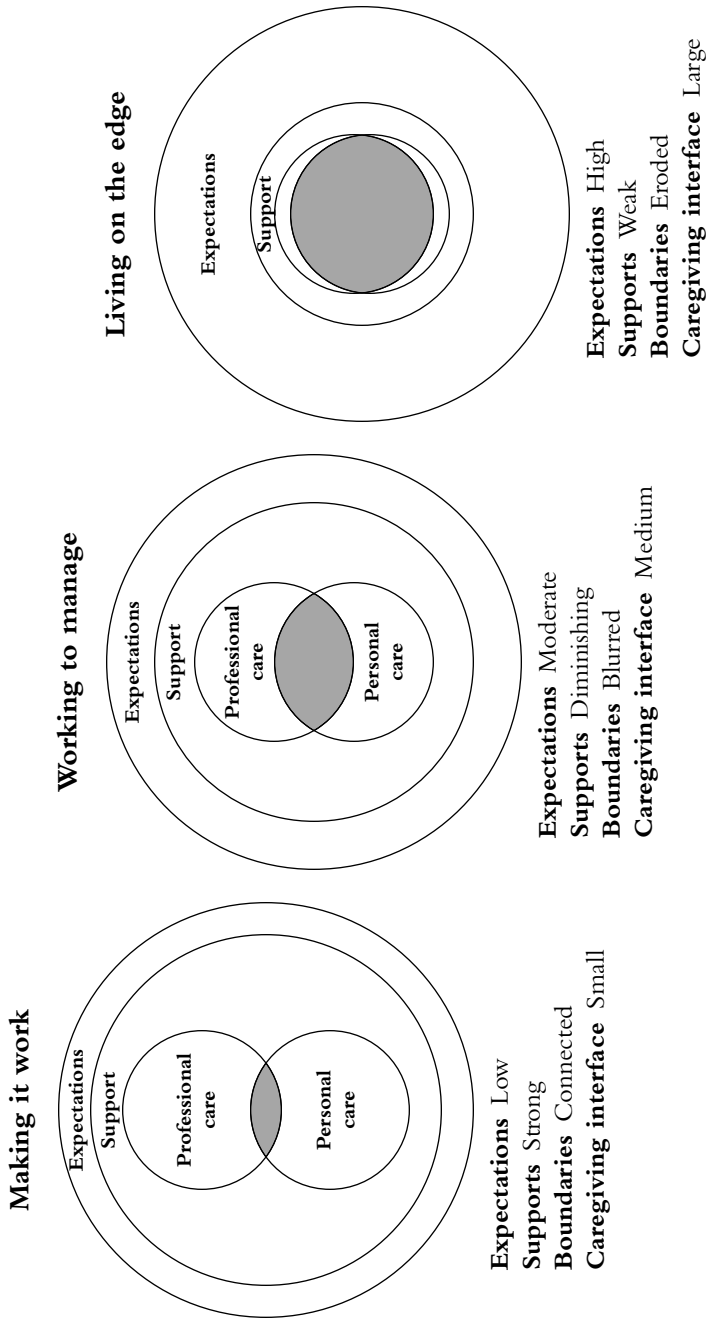
Because women are more likely than men to care for an elderly relative (Armstrong & Armstrong, 2004), they are also at greatest risk for any

negative effects of DDC. There is evidence that DDCs experience a sense of powerlessness and distress (Rutman, 1996) and must make continual adjustments to achieve equilibrium in response to the demands placed on them (Chen, Feudtner, Rhodes, & Green, 2001; Guberman & Maheu, 1999), although work-related knowledge can act as a buffer rather than as an additional strain (Phillips, Bernard, & Chittenden, 2002). Ward-Griffin (2004) found that female community nurses caring for elderly family members used a variety of coping strategies, such as setting limits on the specific care they provided. Although women in the health professions are often viewed as needing to develop coping strategies to address the stress of “balancing” or “juggling” two or more roles, attempts at setting limits often prove unsuccessful in dealing with the demands and tensions of family caregiving (Ward-Griffin, 2004; Ward-Griffin et al., 2005).

The difficulty of demarcating boundaries between professional and personal caregiving domains was particularly evident in our qualitative descriptive study with 37 female nurses, family physicians, physiotherapists, and social workers who provided care to elderly relatives (Ward-Griffin et al., 2005). Four dimensions of DDC were illuminated: Expectations, Supports, Negotiating Strategies, and Caregiving Interface. Despite using a variety of strategies for managing their DDC demands, many of the participants experienced a blurring of boundaries between their professional and personal caring work. This area of overlap was conceptualized as the caregiving interface. The extent of the interface varied for each participant, depending on the degree of expectation of familial care and on the level of support available to manage multiple caregiving demands. From this study with female health professionals caring for elderly relatives, we identified three prototypes of DDC, based on the degree of caregiving interface: *making it work*, *working to manage*, and *living on the edge* (see Figure 1). The women were able to *make it work* when the interface between the professional and personal caregiving domains was minimal; they *worked to manage* when there was moderate overlap or blurring of their professional and personal caregiving boundaries; and they *lived on the edge* when there was a high degree of overlap or interface between their personal and professional domains of care.

In our study, the women tended over time to oscillate from one prototype to another, depending on their level of expectations, support, negotiating strategies, and caregiving interface (Ward-Griffin et al., 2005). In *living on the edge*, the level of expectations to provide complex, daily care was exceedingly high. Family and workplace supports were weak or non-existent. Some participants, mostly nurses, either took time off work to provide daily family care or provided professional care on their “days off” from family care. Although setting limits and making connections

Figure 1 Prototypes of Double Duty Caregiving



Source: Ward-Griffin et al. (2005).



were used to manage increasing caregiving demands with limited supports, many women experienced a dramatic blurring of their professional and family caregiving boundaries, characterized by tension, exhaustion, and a feeling of isolation. Thus, female health professionals who provide care for elderly relatives, especially those with limited tangible supports, may experience ill health as a consequence.

Building on the existing empirical knowledge described above, and in response to the need for further research on DDC, the study had two aims. The first was to develop and validate a tool for measuring DDC with a sample of female registered nurses, capturing the variation within this population. The second was to compare the health of DDCs and non-DDCs.

### **Development of the DDC Scale**

The development of the DDCS (see Table 1) began with an examination of our previous qualitative interview data (Ward-Griffin et al., 2005). Two of the investigators (Ward-Griffin and Brown) reviewed the original transcripts, looking for specific phrases and words that reflected the four dimensions of DDC: Expectations, Supports, Negotiating Strategies, and Caregiving Interface. Item development was refined at team meetings where all investigators generated an initial item pool (57 items) intended to create four subscales to address the four dimensions. One to two negatively worded items were included in each subscale to help decrease response bias.

#### ***Expectations***

A total of 16 items were developed to address three proposed sources of Expectations to provide care to an elderly relative: expectations of self (9 items), expectations of family (4 items), and expectations from within the profession (3 items). Expectations of care include the expectations of oneself to provide care as part of one's role in the family due to credentials and professional knowledge and skills. Familial expectations may come directly from the elderly recipient of care, with his/her requests for assistance, or may come from other family members. Professional expectations may come from health professionals who are involved directly in the care of the relative or from professional colleagues or friends who are not involved directly; professional expectations include those that may be held by the DDCs themselves based on their credentials.

#### ***Supports***

Eight items were developed to assess Supports, reflecting sources of support from the personal (4 items) and professional (4 items) caregiving

Table 1 Development of the Double Duty Caregiving Scale (DDCS)

Dimensions of DDC	Initial Item Pool (n = 57)	Items Deleted Based on CVI <sup>a</sup>	Provisional DDCS (n = 49)	Items Deleted Based on EFA <sup>b</sup>	Revised DDCS Tool (n = 33)	Sample Items
1. Expectations (expectations to care for elderly relatives)	Self (9) Family (4) Professional (3)	-1 -1 0	(8) (3) (3)	-5	Familial (5) Professional (4)	Because of my health care background – I have high expectations of myself to provide care to my relative
2. Supports (supports used to manage caregiving)	Personal (4) Professional (4)	-1 -1	(3) (3)		Personal (3) Professional (3)	As a caregiver for my elderly relative – My workplace supports me to provide care to my relative
3. Negotiating Strategies (strategies used to negotiate personal/professional boundaries)	Setting limits (10) Making connections (13)	0 -3	(10) (10)	-4 -5	Awareness of boundaries (3) Active resistance (3) Making connections (5)	Because I am a health care provider who also provides care to my relative – I set a limit of what type of care I will provide my relative
4. Caregiving Interface (CI) (degree of blurring between professional and personal caregiving)	CI (10)	-1	(9)	-2	Perceptions of CI (4) Consequences of CI (3)	Because I am a health care provider who also provides care to my relative – I feel like I am caught between two worlds (professional and family)

<sup>a</sup> Content validity indices <sup>b</sup> Exploratory factor analyses

domains. Double duty caregivers usually receive some degree of emotional, informational, and substantive support from family members and friends. Although there are well-established instruments for measuring social support (Cohen, Underwood, & Gottlieb, 2000), the unique personal and professional supports received within DDC may not be fully captured using a generic standard tool. Often, siblings, spouses, children, or friends are also involved in the caregiving. Additionally, many caregivers receive professional support; this can include information or resources from one's workplace, such as flexible work hours or access to employee assistance programs.

### ***Negotiating Strategies***

The third dimension, Negotiating Strategies, addresses two main types of strategies, Setting Limits and Making Connections. These help DDCs to negotiate their professional and personal boundaries, thereby potentially moderating the negative impacts of the caregiving interface. Double duty caregivers set limits with respect to personal and professional expectations concerning the provision of familial care. Setting Limits includes strategies for keeping the personal and professional caregiving domains separate and distinct, while Making Connections examines the multiple interactions that serve to bring the two domains closer together. In Setting Limits (10 items), DDCs refuse to take on professional caregiving tasks for family members or arrange for others to provide this care. As well, DDCs increase their supports by Making Connections (13 items). These include accessing health-care information or care for one's relative, using professional knowledge and connections to obtain care, or navigating the health-care system.

### ***Caregiving Interface***

Ten items were developed to measure the caregiving interface (CI), or the degree of blurring between the professional and personal caregiving domains (intermediate domain). This dimension addresses the extent of the connections between elder caregiving and other forms of gendered caring work (e.g., nursing). The CI encompasses both feelings about the blurring of roles and the psychological impact of these feelings. Feelings about the blurring of roles can include being pulled in two different directions, being unable to escape from the caregiving role, and struggling to separate caregiving at home from caregiving at work. The psychological impact of increasing blurring of boundaries can include stress, the feeling that one's caregiving is not being recognized, and confusion regarding one's professional and personal roles.

### **Content Validation of the DDC Scale**

Because of the importance of preserving the inductively derived meaning of DDC in a quantitative instrument (Morris & Field, 1995), judgements about clarity, internal consistency, and initial content validity were made by a panel of four DDCs representing the disciplines of nursing, medicine, physiotherapy, and social work, as used in our previous qualitative study. These content experts independently rated the relevance of the provisional items on the DDCS using a four-point scale ranging from *not relevant* to *very relevant*. This review process facilitated a systematic approach to item revision. Raters also indicated whether the conceptual domain of each subscale was adequately represented by the set of items. Although consensus was reached for each of the four dimensions, the experts recommended clarification of certain items, which were subsequently reworded or deleted.

Content validity indices (CVI) for each item, subscales, and total scale were calculated, setting the criteria for item-level acceptance at .78 or higher for three or more reviewers (Polit, Beck, & Owen, 2007). The CVI ranged from .75 to 1.0 for all retained items (one item fell below .78 but was retained because it measured a key conceptual aspect of the CI subscale: recognition of professional status). Eight items were deleted due to lack of clarity, redundancy, or a relatively low CVI, thus reducing the provisional DDCS from 57 items to 49.

The provisional DDCS was constructed using a five-point Likert scale (1 = *strongly disagree*; 5 = *strongly agree*). Prior to the analysis, negatively worded items were recoded so that, for all items, a higher score reflected a higher degree of Expectations, Supports, Negotiating Strategies, and Caregiving Interface. Within each subscale, the scores were calculated by averaging the relevant individual item scores. Data imputation for missing values was not used, as non-response for the items was very low. The subscales were developed for separate use of each dimension; thus they were not combined into a single overall DDCS score.

### **Pilot Testing of the DDC Scale**

#### ***Sampling***

Following institutional ethics review board approval, the 49-item provisional DDCS was administered to an age-stratified sample of female nurses randomly selected from the registry list of the College of Nurses of Ontario. Because previous research suggested that approximately one half of the working nurse population is likely to provide care to an elderly relative, 800 female, full-time (more than 30 hours/week) registered nurses 40 years of age or older were asked to complete a mailed

survey package. The aim was to have 200 eligible DDC respondents complete and return the package, which consisted of: (1) an information letter; (2) a short demographic questionnaire, which also determined eligibility for the study; (3) the provisional DDCS described above; and (4) established comparative measures, including the Women's Role Strain Inventory (WRSI) (Lengacher & Sellers, 2003), the Caregiver Well-Being Scale (CWBS) (Tebb et al., 2000), and Health Related Outcomes (Medical Outcomes Study Short-Form, SF-12 version 2.0, acute form, 4-week recall). The time needed to complete the survey package was estimated at between 30 and 45 minutes. Each package contained a modest gift certificate as a token of appreciation. Nurses not providing care for an elderly relative or friend were asked to complete all questionnaires except the DDCS, the purpose being to generate data for comparing DDC and non-DDC nurses.

Of the 800 questionnaires mailed, 394 were returned; of these, eight respondents did not meet the eligibility criteria (two male and six unemployed), six questionnaires were blank, and three were returned to sender, yielding a sample of 377 respondents (49% response rate). A total of 193 respondents (51%) were caring for an elderly relative (i.e., the DDCs) and 184 (49%) were not (i.e., the non-DDCs). Of the 193 respondents identified as DDCs, six left sections of the DDCS blank, which led to a final usable DDC sample of 187, a total sample size that is considered adequate for instrument development analysis (Gable & Wolf, 1993).

### ***Reliability and Construct Validity Analyses***

Contingency table (chi square) analyses were performed on all categorical variables, while independent sample *t* tests were used with all continuous variables when comparing DDCs and non-DDCs. Appropriate measures of association were used to examine the relationship between theoretically relevant demographic variables (e.g., hours of employment per week, hours of caregiving per week) and the CI.

Construct validity of the provisional 49-item tool was assessed at the preliminary stage with a combination of exploratory factor analysis (EFA) using a principal components factor approach and assessment of scale reliability. Even though our previous qualitative work and initial conceptualization of DDC informed the construction of the provisional DDCS items, EFA was selected over confirmatory factor analysis (CFA). For the EFA, initial factor extraction was based on eigenvalues greater than 1.00 (Polit & Beck, 2008, p. 488). Each subscale of the provisional DDCS was then subjected to varimax rotation to select the factor structure that best represented the underlying relationship of the items within the four dimensions (Expectations, Supports, Negotiating Strategies, and Caregiver Interface). Although loadings with an absolute value of 0.40 or

higher are often used as factor loading cut-off values (Carruth, 1996), smaller values are acceptable if the item pool is large (Polit & Beck, 2008, p. 491). Cronbach's alpha reliability coefficients were also used to determine internal consistency among the items of the four subscales of the provisional DDCS. Based on these preliminary analyses, a combination of low inter-item correlations ( $< .20$ ), weak factor loadings ( $< .35$ ), and/or poor conceptual clarity, 16 of the original 49 items were removed from the provisional DDCS, yielding a tool with a total of 33 items for the remaining construct validity analyses.

We also correlated each of the DDCS subscale scores with those of the WRSI, the CWBS, and the SF-12v2. The WRSI is a previously validated 44-item, five-point Likert scale that measures role strain in female nurses with multiple roles (Lengacher & Sellers, 2003), with high reliability coefficients for the total scale (0.86–0.95) and subscales of distress (0.74–0.91), enhancement (0.79–0.89), and support (0.65–0.87). Developed and validated by Tebb et al. (2000), the CWBS-Short Version is a 16-item, five-point Likert scale that assesses activities and needs of caregivers (eight items for each subscale). Overall and for each subscale (Needs and Activities of Daily Living), the coefficient alpha was 0.94, 0.91, and 0.88, respectively. Finally, the SF-12v2 is a well-established tool that measures the perceptions and activities of acute health and well-being. It is a shortened version of the SF-36, which includes general and physical health index scores as well as eight subscales (bodily pain, general health, vitality, social functioning, physical functioning, role limitations due to physical problems, role limitations due to emotional problems, and mental health). Ware, Kosinski, Turner-Bowker, and Gandek (2002) report internal consistency reliability coefficients ranging from 0.66 to 0.90. In the present study, internal consistency reliability coefficients for each of these established instruments were 0.91 (WRSI), 0.73 (CWBS-needs), 0.78 (CWBS-activities), and 0.80 (SF-12v2).

## Results

### Sample

The sample comprised 193 DDCs (this figure includes six respondents who failed to complete all items on the DDCS but completed the demographic questionnaire) and 184 non-DDCs (see Table 2 for an overview). The typical DDC was 52.0 years old ( $range = 41-65$ ;  $SD = 4.90$ ), was married (74.2%), held a diploma in nursing (67.9%), had a mean household income of \$101,778 ( $range = \$12,500-\$300,000$ ;  $SD = \$44,093.73$ ), was employed part-time or full-time (96.8%) with a mean of 39.0 hours worked per week ( $range = 7-80$ ;  $SD = 7.86$ ), had practised nursing for 25 years or more (67.6%), and had at least one child (ranging

<b>Table 2 Overview of Development and Validation of Double Duty Caregiving Scale (DDCS)</b>			
<b>Source</b>	<b>Initial Item Pool</b>	<b>Content Validity</b>	<b>Pilot Testing</b>
	<b>Qualitative Interview Data</b>	<b>Expert Panel</b>	<b>Mailed Survey (n = 800)</b>
Sample	37 female DDCs: 15 registered nurses 9 social workers 7 physiotherapists 6 physicians	4 female DDCs: 1 registered nurse 1 social worker 1 physiotherapist 1 physician	377 female DDCs: 193 DDCs 184 non-DDCs
<i>Note:</i> DDC = double duty caregiver.			

in age from 2 to 32 years) living with her (65%). The DDC respondents provided an average of 6 hours per week of care to one (53%) or two (30%) elderly relatives, mostly parents (77%) or parents-in-law (12%) who lived nearby. The typical non-DDC respondent was 51.5 years old (*range* = 41–65; *SD* = 5.85), was married (73.9%), held a diploma in nursing (67.8%), had a mean household income of \$105,618 (*range* = \$35,000–\$770,000; *SD* = 67006.84), was employed part-time or full-time (98.9%) with a mean of 40.8 hours worked per week (*range* = 22–80), had practised nursing for 25 years or more (52.5%), and had at least one child (ranging in age from 1 to 37 years) living with her (62.0%). There were no significant differences between DDCs and non-DDCs with respect to age, household income, and number of hours worked per week.

**Preliminary Construct Validity: Step 1**

To facilitate a better understanding of the item contents of the new scale, principal components analysis was conducted on each of the four subscales of the Provisional DDCS. Although each dimension was provisionally structured as a single subscale, the results of our subsequent factor analysis suggested that Negotiating Strategies should be split into two subscales: Setting Limits and Making Connections. Nine factors were identified from our analyses (Table 3), which is consistent with our original conceptualization about the dimensionality of DDC. Two factors emerged from Expectations (familial expectations and professional expectations), accounting for 63% of the variance. Five items loaded on familial expectations, with loadings ranging from 0.58 to 0.87. Four items loaded on professional expectations, with loadings ranging from 0.49 to 0.89. As expected, this indicates that, among DDCs, there are both familial and professional expectations to provide care to elderly relatives.

**Table 3 Revised DDCS (N = 187)**

Subscale	Factors	Number of Items	Mean	SD	Item-Total Correlations	Cronbach's Alpha	Factor Variance	Factor Loading
<i>Expectations</i>	Familial expectations	5	3.78	.712	0.40-0.73	0.80		0.58-0.87
	Professional expectations	4			0.30-0.56	0.69		0.49-0.89
	Total	9			0.28-0.66	0.83	62.5	
<i>Supports</i>	Personal supports	3	3.32	.646	0.43-0.58	0.68		0.70-0.86
	Professional supports	3			0.24-0.62	0.65		0.35-0.91
	Total	6			0.31-0.52	0.71	61.7	
<i>Setting Limits</i>	Awareness of boundaries	3	3.11	.678	0.41-0.59	0.67		0.61-0.87
	Active resistance	3			0.33-0.61	0.65		0.68-0.84
	Total	6			0.34-0.58	0.71	62.9	
<i>Making Connections</i>	Making connections	5	3.89	.677	0.42-0.69	0.75	46.5	0.60-0.76
<i>Caregiving Interface</i>	Perceptions of interface	4	3.01	.826	0.48-0.71	0.81		0.80-0.84
	Consequences of interface	3			0.53-0.77	0.83		0.80-0.84
	Total	7			0.44-0.74	0.85	70.3	



Two factors emerged from Supports (personal supports and professional supports), accounting for 62% of the variance and indicating the importance of personal and professional supports to DDCs providing care to elderly relatives. Three items loaded on personal supports, with loadings ranging from 0.70 to 0.86. Three items loaded on professional supports, with loadings ranging from 0.35 to 0.91.

Two factors, labelled Awareness of Boundaries and Active Resistance, emerged from Setting Limits, accounting for 63% of the variance. Three items loaded on Awareness of Boundaries, with loadings ranging from 0.61 to 0.87. Three items loaded on Active Resistance, with loadings ranging from 0.68 to 0.84. One factor was extracted from Making Connections, accounting for 47% of the variance. Loadings for the five items on Making Connections ranged from 0.60 to 0.76. This suggests that DDCs are aware of the boundaries between their personal and professional caregiving and that, in an attempt to negotiate these boundaries, they resist providing care to their elderly relative as well as making connections to increase their supports.

Two factors emerged from CI. These were labelled Perceptions of CI and Consequences of CI, accounting for 70% of the variance. Four items loaded on Perceptions of CI, with loadings ranging from 0.54 to 0.85, and three items loaded on Consequences of CI, with loadings ranging from 0.80 to 0.84. These results indicate that DDCs both are aware of and experience consequences of the blurring of boundaries between personal and professional caregiving.

### ***Reliability***

Inter-item correlations and internal consistency (reliability) were examined for each of the subscales of the Revised DDCS. Overall, in the final version of the 33-item DDCS, inter-item correlations ranged from 0.24 to 0.77 (Table 3). Cronbach's alpha reliability coefficients of the five DDC subscales ranged from 0.85 (CI) to 0.71 (Supports and Setting Limits). Moreover, Cronbach's alpha reliability coefficients of the subscale factors ranged from 0.83 (CI-Consequences) to 0.65 (for both Supports-Professional and Setting Limits-Active Resistance).

### ***Construct Validity: Step 2***

Pearson correlations were conducted to assess construct validity between each of the subscales within the DDCS and WRSI, CWBS, and SF-12v2 (physical) and SF-12v2 (mental) (Table 3). In line with the underlying theory driving the scale, there were weak to moderate correlations in the expected direction between the Revised DDCS subscales of Expectations, Supports, Setting Limits, Making Connections, and CI and the established measures. The strongest significant correlations were

**Table 4 Correlation Between Revised DDC Subscales and Established Measures**

Scale		Expectations	Supports	Setting Limits	Making Connections	Caring Interface
WRSI <sup>a</sup>	<i>r</i>	-.34	.41**	.09	.04	-.49**
	<i>p</i>	.000	.000	.240	.625	.000
Caregiver Well-Being Scale: Activities <sup>b</sup>	<i>r</i>	-.16*	.34**	-.05	-.01	-.29**
	<i>p</i>	.03	.00	.48	.89	.00
Caregiver Well-Being Scale: Needs <sup>c</sup>	<i>r</i>	-.16*	.34**	.03	-.03	-.36**
	<i>p</i>	.04	.00	.71	.69	.00
SF12 Physical Index <sup>d</sup>	<i>r</i>	.06	.14	-.14	-.03	-.02
	<i>p</i>	.42	.06	.06	.69	.78
SF12 Mental Index <sup>d</sup>	<i>r</i>	-.26**	.26**	.09	.01	-.39**
	<i>p</i>	.00	.22	.22	.60	.00
Expectations <sup>a</sup>	<i>r</i>	1	-.12	-.07	.38**	.55**
	<i>p</i>		.095	.344	.000	.000
Supports <sup>a</sup>	<i>r</i>	-.12	1	.04	.10	-.26**
	<i>p</i>	.095		.552	.174	.000
Strategies – Setting Limits <sup>a</sup>	<i>r</i>			1	.01	-.23**
	<i>p</i>				.851	.002
Strategies – Making Connections <sup>a</sup>	<i>r</i>				1	.18*
	<i>p</i>					.013
Caring Interface <sup>a</sup>	<i>r</i>					1
	<i>p</i>					

<sup>a</sup> N = 187 <sup>b</sup> N = 174 <sup>c</sup> N = 180 <sup>d</sup> N = 176 \* p < .05 (2-tailed) \*\* p < .01 (2-tailed)

between CI and WRSI ( $r = -.49, p < .001$ ), between Supports and WRSI ( $r = 0.41, p < .001$ ), and between CI and SF-12v2 (mental) ( $r = -.39, p < .001$ ). Finally, the CI of the DDCS was also negatively correlated with caregiver well-being ( $r = -.29, p < .001$  [activities] and  $r = -.36, p < .001$  [needs]).

The strongest subscale inter-correlations (i.e., within the Revised DDCS itself) were between Expectations and CI ( $r = 0.55, p < .001$ ) and between Expectations and Making Connections ( $r = 0.38, p < .001$ ). In addition, there was a weak positive association between Making Connections and CI ( $r = 0.18, p < .05$ ) and negative associations between Supports and CI ( $r = -0.26, p < .001$ ) and between Setting Limits and CI ( $r = -.23, p < .001$ ). None of the other DDCS subscale inter-correlations were statistically significant (Table 4).

### ***Contrasted Groups Approach***

Although there were no significant differences between DDCs and non-DDCs in their overall scores for the WRSI, CWBS, and SF-12v2 (physical and mental scores), there were significant differences between non-DDCs ( $n = 67$ ) and the DDC subgroup ( $n = 84$ ) defined as *living on the edge* (i.e., those scoring above the mean on the CI subscale). Poorer health was observed for the *living on the edge* DDCs on their overall SF-12v2 mental health index score ( $t = -2.76, p < .05$ ) and on four of the eight SF-12v2 subscales: vitality ( $t = -2.37, p < .05$ ), social functioning ( $t = -2.91, p < .01$ ), role emotional ( $t = -3.06, p < .05$ ), and mental health ( $t = -2.27, p < .05$ ). Moreover, there were significant differences within the DDC group between those who were *living on the edge* and those with lower CI scores for the following SF-12 subscales: vitality ( $t = -.20, p < .05$ ), social functioning ( $t = -3.56, p < .01$ ), role emotional ( $t = -4.83, p < .01$ ), and mental health ( $t = -3.98, p < .05$ ). The *living on the edge* group also had significantly lower well-being scores for the activities ( $t = -3.63, p < .05$ ) and needs ( $t = -4.47, p < .05$ ) subscales than the other DDC respondents. While not all results were statistically significant, overall there was an observed tendency for the *living on the edge* group of DDCs to have the lowest health and well-being scores, whereas the other DDCs (e.g., *making it work*) with low CI scores tended to have slightly better health scores than the non-DDC group.

## **Discussion**

The main purpose of this study was to develop and test a tool intended to advance our understanding of DDC using a random sample of registered nurses providing care to elderly relatives.

The nine factors we identified were consistent with the theorized core DDC dimensions of Expectations (Familial and Professional), Supports (Personal and Professional), Setting Limits (Awareness of Boundaries, Active Resistance), Making Connections, and Caregiving Interface (Perceptions and Consequences), which can yield important information regarding how much variance is accounted for by the factors. However, additional analyses are required to establish the psychometric properties of the DDCS, including test-retest reliability to assess construct stability. Based on the EFA results, a measurement model of DDC will be proposed and analyzed in a future study using CFA to enhance the psychometric validation of the DDCS. For researchers looking for a shorter version of the DDCS, it is worth noting that, based on the strength and consistency of the overall findings, the seven-item CI subscale could be used to determine the extent of DDC when survey respondent burden is a key factor in instrument selection (i.e., when use of the full 33 DDCS items is not possible), adding to the potential value of the DDCS.

The positive correlation between Expectations and CI and the negative correlation between Supports and CI and between Setting Limits and CI are theoretically consistent with the conceptual model of DDC. That is, if expectations are high, both personally and professionally, with respect to caring for one's relatives, there will be greater CI, or blurring of boundaries. Conversely, if one has strong personal and professional supports, it follows that a lower degree of CI will result. Similarly, when one sets limits on caregiving, then less blurring, or a lower degree of CI, should result. However, the positive association between Making Connections and Expectations was unexpected. Perhaps high expectations lead one to increase supports by making connections, both personally and professionally, to help meet these expectations.

Comparison of the SF-12 v2 scores for *living on the edge* DDCs and non-DDCs revealed significant differences for SF-12v2 mental health and specific SF-12v2 subscales of vitality, social functioning, role emotional, and mental health. These findings suggest that DDCs who experience a high degree of blurring of their professional and personal boundaries are at greater risk for poor health than those health professionals who do not care for elderly relatives or who do not experience this blurring. In addition, those DDCs who could be characterized as *living on the edge* scored significantly higher on the same four SF-12 subscales than DDCs with lower CI scores. This observed pattern suggests two possibilities: there exists a threshold effect for the negative health effects of DDC; or manageable exposure to DDC has a beneficial effect. Further exploration of these interesting findings is warranted.

Although we conducted a systematic and comprehensive analysis to assess the psychometric properties of a new scale, further reliability and

validity studies are needed. Confirmatory validation studies with other health-care provider populations such as family physicians, social workers, and physiotherapists are particularly important as these professionals have the potential to be DDCs and their experiences, as documented in our original qualitative study of DDC, helped to formulate the theoretical underpinnings of the DDCS. In addition, research with these groups will advance our understanding of how occupational health groups may differ in terms of expectations, supports, negotiating strategies, and degree of CI. As the identification of health-advantage and health-risk factors is influenced by health and social environments, the negotiating strategies could also be examined through the use of qualitative methodologies such as in-depth interviews or focus groups.

Finally, research that draws linkages between professional and personal caregiving has the added value of furthering knowledge about employed caregiving, specifically as it relates to the relationship between health outcomes and provision of familial care by health-care providers. Although the convergence (and avoidance) of professional and personal caregiving boundaries is not a new issue in nursing and other health professions, the notion that it is the individual's responsibility to negotiate this boundary tends to predominate (Ward-Griffin, 2008). To that end, further testing and refinement of the DDCS will be helpful in identifying areas where DDCs may need specific or different types of support. It is also important to understand how specific social supports shape the health experiences of DDCs, as well as to investigate different types of social support interventions with DDCs. This information is particularly meaningful today, with the intersection of three challenges: an aging population, an aging health-care workforce, and a shortage of health professionals. Such knowledge could contribute to workplace and other health initiatives spearheaded by professional groups, policy-makers, and other key stakeholders interested in assessing and addressing the health effects of DDC.

In summary, the DDCS is a valid tool for the assessment of double duty caregiving. Such assessment is a crucial step in understanding the experience of the blurring of personal and professional boundaries of caregiving among health professionals. A quantitative study of both male and female DDCs could help us to understand the relationship between certain factors (i.e., gender, health-care occupation) and the potential health effects of DDC. Moreover, our finding that respondents with high CI scores (*living on the edge*) had significantly lower health and well-being scores than DDC respondents with lower CI scores warrants further investigation, to determine if one group of DDCs is at particular risk for developing negative health effects. Given the current climate of health-care reform in Canada, developing a better understanding of DDC and its health effects is particularly relevant for policy-makers and others who

are committed to developing health-promoting programs and policies for familial caregivers of the elderly. Clearly, now is the time to monitor the effects of changing demographics both in the general population and within the health professions, in order to develop appropriate and targeted strategies, thereby creating and sustaining healthy work environments and health-care workforces. With further refinement, the DDCS may assist with these endeavours.

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**Point de vue des étudiantes pour qui  
l'anglais est une langue additionnelle (ALA)  
sur les facteurs de motivation et de  
démotivation relatifs à la réussite des études  
en sciences infirmières**

**Tam Truong Donnelly, Elaine McKiel  
et Jihye Jasmine Hwang**

La croissance de la population immigrante au Canada s'est traduite par un accroissement, en sciences infirmières, du nombre d'étudiantes pour qui l'anglais est une « langue additionnelle (ALA) ». Même si la plupart réussissent leurs études, un petit nombre continue de connaître des difficultés en raison d'aptitudes limitées en anglais et de différences culturelles relatives aux connaissances et aux façons de faire. En dépit de ces obstacles, leur désir d'exercer la profession infirmière reste fort. Nous avons mené une étude qualitative dans le but de cerner les facteurs qui ont une incidence sur la réussite scolaire en tenant compte du point de vue de ce groupe d'étudiantes et de leurs professeurs. Quatorze étudiantes dont l'anglais est une LA ont été interrogées. L'analyse des données d'entrevue met en lumière quelques facteurs qui influent sur leur expérience au cours de leurs études en sciences infirmières. Les auteures font état des facteurs de motivation et de démotivation décrits par les étudiantes. Elles recommandent aussi des stratégies susceptibles de les aider à réussir leurs études dans ce domaine.

Mots clés : études en sciences infirmières, anglais langue additionnelle (ALA)

# **Challenges and Motivators Influencing the Academic Performance of English as an Additional Language (EAL) Nursing Students: The Perspectives of the Students**

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Canada's rising immigrant population has led to an increasing number of nursing students for whom English is an "additional language" (EAL). Although many of these students are successful academically, there is a persistent small number who struggle due to their limited English-language skills and their different cultural knowledge and practices. Despite the difficulties they experience, the students' desire to enter the nursing profession remains strong. A qualitative study was undertaken to identify factors that influence these students' academic performance from the perspectives of the students themselves and their instructors. Fourteen EAL nursing students were interviewed. Analysis of the interview data revealed factors that influenced the students' experiences in their nursing programs. The authors describe the students' perspectives on the challenges and motivators they encountered in their nursing programs. They also recommend strategies that could help EAL students to achieve success in their nursing studies.

Keywords: nursing education, English as an additional language (EAL) nursing students, English as a second language (ESL) nursing students

## **Introduction**

In 2006 immigrants made up 19.8% of Canada's total population (Statistics Canada, 2006). Virtually one in five Canadians is foreign-born. The rising immigrant population has led to an increasing number of nursing students for whom English is an "additional language" (EAL).<sup>1</sup> This can be perceived ultimately as a positive sign because a diverse body of nursing students will lead to a diverse body of registered nurses;

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<sup>1</sup> At the university where this study was conducted, the term English as an additional language (EAL) has replaced English as a second language (ESL) due to the negative connotations, such as hierarchy and inferiority, of the word "second." Also, for some students English is their third or fourth language.

in turn, it is theorized that these nurses will be able to respond to the unique needs of the diverse client population seeking health care.

Although the majority of the EAL students in our faculty have progressed well in the nursing program, a small number have experienced difficulties because of language and cultural differences. For these students, limited English skills and lack of familiarity with local cultural practices appear to be connected to their poor academic performance.

In spite of their struggles, the students' desire to become registered nurses has prevailed. They have continued to display a strong work ethic, a determination to master English, and a desire to become familiar with Canadian education and health-care practices. However, they have identified the need for help and support in overcoming their difficulties. In response to their needs and to gain a deeper understanding of their experiences, we undertook a research project to explore: (a) the learning needs, concerns, and strengths of EAL students enrolled in a bachelor of nursing program; (b) the extent to which existing resources and support networks meet the learning needs of these students; and (c) possible teaching/learning strategies for facilitating the academic performance of EAL students. The students' perspectives relative to the challenges they encountered are reported in this article. The instructors' perspectives were also explored and are presented in a separate publication.

### **Literature Review**

A literature review revealed that the academic performance of EAL nursing students is affected by many interrelated factors, including language; cultural values such as teacher-student relationships; and assertiveness, social support, and financial situation. Problems associated with limited language skills are manifested in a variety of ways, including inappropriate charting, difficulty writing examinations, difficulty understanding and following the directions of clinical instructors, and difficulty understanding and communicating clearly and effectively with clients and staff members (Bosher & Smalkoski, 2002; Cunningham, Stacciarini, & Towle, 2004; Guhde, 2003; Sanner, Wilson, & Samson, 2002; San Miguel, Rogan, Kilstoff, & Brown, 2006). Gay, Edgil, and Stullenbarger (1993) report that students educated in another culture can encounter problems with plagiarism because they may not understand the need to use primary references and may have difficulty paraphrasing the writings of others.

Cultural differences also pose academic challenges. Students may experience difficulty adjusting to an education system that is different from that in their home country (Harvey & Mac, 2006; Sanner et al.,

2002; Shakya & Horsfall, 2000). Being assertive in communication is also a challenge for EAL students (Bosher & Smalkoski, 2002; Sanner et al., 2002). EAL students sometimes have difficulty asking clients to repeat their questions or to provide further details. Bosher and Smalkoski (2002), Sanner et al. (2002), and Shakya and Horsfall (2000) report that EAL students feel uncomfortable asking questions in class because of difficulty speaking English, negative reactions of peers, or teacher-student hierarchy.

Many EAL students come from a collectivistic culture where the family, the work unit, and the community take priority over the individual. In an alien environment deprived of family and an established social network, they are likely to feel isolated (Choi, 2005; Sanner et al., 2002; Xu & Davidhizar, 2005).

Finally, financial concerns can be a source of adversity for EAL students. Financial instability, coupled with everyday academic challenges, intensifies the challenges they face (Choi, 2005; Sanner et al., 2002).

Some of the literature acknowledges the strengths of EAL students and describes them as ambitious, achievement-oriented, persistent learners (Pardue & Haas, 2003; Sanner et al., 2002). However, to help EAL students successfully complete their program, we need to first understand the experiences of EAL students in a Canadian nursing program and then implement appropriate interventions. We undertook to address the following four research questions from the perspective of both EAL students and their instructors: *What are the needs, concerns, and strengths of EAL students? How do EAL students cope with language barriers and cultural differences? What are the key factors that help them to succeed in the nursing program? What are the key factors that hinder their ability to succeed in the nursing program?*

The study was conducted in the nursing faculty of a western Canadian university. Ethical approval was obtained from the university. All participants' names used in this article are pseudonyms. Participants were informed that they could withdraw from the study at any time without repercussions.

## **Methods**

We chose a descriptive, exploratory, qualitative research design using mini-ethnography as our methodology (Gillis & Jackson, 2002) and in-depth interviews. In-depth interviewing enables research participants to describe their experiences and the meaning they attribute to them in their own words. A maximum-variation purposive sampling procedure was used (Morse, 1994). Participants were recruited by posting notices

about the study throughout the nursing faculty, sending an informational e-mail about the study to all students in the undergraduate nursing program, and repeating the invitation to students who attended the faculty's EAL support group.<sup>2</sup> Individuals interested in participating contacted the principal investigators via e-mail or faculty mailboxes.

A total of 14 students who self-identified as having English as an additional language participated in the study. Their countries of origin were as follows: Mainland China (6), Korea (2), Romania (2), Ukraine (2), Hong Kong (1), Japan (1). Of the 14 students, 11 were female and 3 male. They ranged in age from 21 to 35 years (average: 29 years) and had been living in Canada from 2.5 to 10 years (average: 6 years). English was the second language for 9 students and the third for the remaining 5. Individual interviews were conducted in English, with each interview lasting from 90 minutes to 2 hours. Prior to the interview, the interviewer described the study, gave the participant an opportunity to ask questions, and obtained informed consent. All interviews were audiotaped and transcribed verbatim. Field notes were completed by the interviewers. An effort was made to help the participants feel comfortable speaking about their experiences.

The interviews were conducted by the first author and a research assistant, both of whom had foreign ethnocultural backgrounds. Data coding, analysis, and interpretation were conducted by the two principal investigators manually and by two trained research assistants using ATLAS TI qualitative data analysis software. Audit trails were established to ensure rigour of data analysis. Several members of the research team met regularly to review the processes used to conduct the interviews, their personal reflections, analytic descriptions, and interpretations.

The manual data analysis involved line-by-line reading and recording of comments in the transcript margins to identify, refine, augment, and categorize emerging ideas, concepts, and themes. Quotes and experiential examples were noted. To generate a higher level of data conceptualization and broader theoretical formulations, emerging themes and concepts were confirmed by comparing within and across the transcripts, across research participants, and across the data set generated using ATLAS TI. An outcome of the analysis was a set of interrelated concepts and themes describing the experiences of EAL students and their instructors, including the social processes and influencing factors and structures. Themes generated using manual analysis were found to be congruent with those generated using ATLAS TI.

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<sup>2</sup> An initiative aimed at ensuring that students, faculty, mentors, and education sector decision-makers are prepared to provide the best possible learning environment for EAL nursing students.

## **Findings**

Data analysis revealed three broad categories: challenges, motivators, and students' recommendations. Themes that emerged within the category of challenges included limited language skills, cultural differences, perceived inferiority and discrimination, and lack of support systems. Motivators included existing resources such as family, supportive peers, and instructors.

### **Challenges**

**Limited language skills.** The participants identified limited language skills as a major barrier to good academic performance, especially during the first half of the nursing program. Several students explained that their lack of English skills interfered with virtually every learning process. They identified difficulty understanding textbooks, lectures, teachers' expectations, and the wording of written examinations and difficulty with writing papers in the APA style and expressing thoughts and opinions in grammatically correct sentences. Sometimes these challenges were confounded by the use of jargon and colloquialisms in professional and everyday contexts. One participant pointed out that students had to achieve a minimum TOEFL score but that passing the TOEFL did not guarantee English proficiency for academic purposes:

*I don't know some of the common words that Canadians talk with each other . . . when I talk to the RN, there are lots of words I don't understand. More often a jargon that nurses talk, I don't hear every day.*

The students said that effective communication skills are essential for learning and providing competent nursing care but that language barriers prevented them from communicating clearly, effectively, and assertively. The majority of the participants reported difficulty speaking up in clinical group discussions and engaging assertively with peers, instructors, and clients. Several participants said that they possessed the knowledge but needed time to process, extract, and translate the received information and then put their thoughts into proper English before speaking:

*There is some translation in my mind when I talk to people. Internally, I have to translate it. I don't really aware of it . . . I have to really paying attention to what they say . . . Some slangs or some way of expression is not quite the same that I learned. . . . So you want to say something but you may not be able to express.*

In some clinical situations, difficulty communicating challenged the students' ability to provide safe, competent nursing care. One participant

said that EAL students with limited language skills may doubt their ability to assess clients with mental illness:

*In the mental health [unit], you really don't know if [the patients] are confabulating or is it delirium. You don't understand the words [they speak]; you feel it's not logical. [I] don't know [if] it's part of my fault because I cannot understand proper English, or it's a symptom.*

Another challenge was writing scholarly papers that are grammatically correct and adhere to APA style. The students described lack of familiarity with both citing references and the need to do so. Many had come from countries where creativity and subjective thought are more valued than referencing someone else's work. Some were frustrated when writing papers because what was considered good writing in their homeland is not considered good writing in Canada:

*I was trying to write the way we were taught back home, what was considered very good writing. It's supposed to be creative, not supposed to be stuffed with citations . . . Or something I said, "There is current shortage of nurses." And, like, "Where is the citation?" And that was very frustrating . . . it would sometimes take me half the time to write the paper, to do all this APA stuff, and that seem to me like very unnecessary, waste of energy and time. It was my first paper. The big problem was not really English grammar. It was about how to refer. They say that I did plagiarize, because I didn't know how to properly refer in APA format. I receive this feedback . . . and I feel like I was accused of cheating, but I didn't know.*

**Cultural differences.** Success in the nursing program is highly dependent on *cultural knowing*. Students are expected to acquire nursing knowledge and practise nursing within the Canadian context. Even though Canadian society is demographically multicultural, it has a strong Anglo-European base that may seem foreign to some EAL students. Theome said:

*They talk about hockey. I don't know hockey but I could talk about soccer. They talk about drinking and driving but I don't know that lifestyle.*

When instructors constructed scenarios as a means of teaching nursing (e.g., an adolescent patient with an eye injury caused by a hockey puck, or a health promotion project addressing drinking and driving), students such as Theome had difficulty situating the issue in context.

The students also pointed out that one cannot understand a language without understanding the culture, because language and its symbolic meanings are embedded in the culture. They said that if an object or its name was unfamiliar to them, then they had trouble understanding



patients' needs, even around something as simple as what type of food to offer:

*What do they normally eat . . . or the type of food they eat. They would ask, "I would like to have this." And you have to go ask RN what it is. Normally people know, most of my colleagues, they know what it is. . . . Again, what does the patient want, the common thing that you have to deal with, that's the hard part.*

Participants noted that different cultural groups have different ways of expressing emotion and interacting with others. Christy said that sometimes she did not know what people were really thinking or doing because of the different style of social interaction. This confusion prevented EAL students from engaging with their classmates and caused a sense of "otherness" and social isolation, ultimately reducing the number of opportunities for them to understand Canadian culture and integrate into Canadian society. Christy said:

*Making friends is harder for us . . . Sometimes you say something or do something — maybe it's a cultural taboo here — you're not supposed to, or maybe people say something not offensive but then you take it as offensive. I find it's harder to make good friends here compared to when I was in [home country]. . . . So a lot of times I'm on my own. I think that [is] a challenge.*

Some students said that even though social interaction in Canada appears to be relatively informal and friendly, they sensed distance and hierarchical positioning. The feeling of being different was an emotional challenge for EAL students. Many of them reported feeling isolated and culturally segregated:

*Feeling like a stranger in a strange world, not really accepted . . . I was in the lab . . . no one want to pair with us, so we remain . . . We feel lonely here. We don't have many friends. We don't have family . . . If I feel something bad in school, I have no one I can talk to.*

Some of the students struggled to communicate and interact with instructors in an assertive manner. Many came from cultures where their opinions were not sought by their instructors, where they had been taught to show respect by not speaking until spoken to, and now found themselves in an environment where their instructors expected them to question and to offer alternative perspectives. They were ill prepared to participate in interactive learning and uncomfortable doing so. They worried that if they asked questions their instructors would interpret it as "not knowing what they should know." Their different cultural orientation, coupled with their limited language skills, served to intensify their

learning challenges, preventing them from speaking up in class and asking questions:

*After each lecture some students would ask professor question on a one-to-one base. I was always scared to ask questions despite the fact that I always have something in my mind. I was scared the professor would not understand me. I was kind of shy to do it.*

Previous experience with nursing greatly influenced the students' learning experiences. Several participants explained that nursing in Canada is very different from nursing in their homeland. For them, holistic nursing care was a new concept and one that was difficult to reflect in their assignments:

*I took nursing back home, so I can compare both systems. I can tell you that they are extremely different . . . It wasn't easy for me to manage those difficulties . . . I didn't understand what my professor really required from me, holistic approach towards caring for my patients. . . . In my country, ability to understand the physiology and provide medication is priority. . . so it was a surprise that nurses here are close to social work, psychology. . . . This part of nursing was surprising for me and hard to understand.*

**Perceived inferiority and discrimination.** Participants spoke of being discriminated against in their struggle to learn nursing. Several of them identified discrimination on the part of both peers and instructors:

*I was feeling excluded . . . A group, four or five people, one of the girls ask me, "You can come and join our group," and another person said, "We are so many — that girl, she barely understand English." Right in front of me. I was surprised. . . . Some of my classmates, when they didn't realize that I'm an ESL student, they asked, "Why so many ESL students were admitted in this program?" . . . I felt that I'm somehow inferior, or my language is defective, and that would always make me tense. . . . That could be a constraining factor to express, to stand up and make a comment, or even make a contact, approach peers.*

Participants expressed a wish to become more involved in classroom activities and in extracurricular activities with peers. However, they remained silent and unengaged in order to avoid feeling alienated and uncomfortable as a result of their accent and poor articulation in English. Students also spoke of feeling nervous, fearful, uncertain, incompetent, and frustrated when they perceived they were being discriminated against by the instructors:

*Instructors vary. Some are very nice, very supportive, very knowledgeable, caring, understanding. Others [are] unfair, hard to deal with, hard to get*

*along with. [They] don't focus on positive things, pick on you when you make a mistake, and make you feel nervous by watching. . . . The instructors have bias, and they judge you because you cannot speak well.*

From the perspective of the students, the instructors practised discrimination through avoidance, negative tone of voice, impatience, distancing, failure to make contact, reluctance to communicate, negative comments, and walking away or spending little time with them:

*Because the language, because the culture, sometimes you find yourself in a very hard situation. You want to be treated fairly. . . . I see those instructors, they won't keep eye contact on you. They pay more attention, or they have very good relationships with other students . . . and she is reluctant to talk to you or turn towards you. . . . From her behaviour, facial expression, [and] eye contact, she is more interested in other students . . . they give you all these [negative] comments . . . that kind of things make me thinking this instructor is not supportive, kind of discriminate against our colour.*

**Lack of support systems.** The students had expected that academic supports would be readily available in the nursing faculty. However, this was not the case. All of the participants spoke at length about their difficulty with writing papers. Sue said it was the end of the second year before she knew what was expected of her and writing became easier for her. Other students related similar experiences. They learned to write mainly through trial and error, receiving little help from the academy. When asked what academic resources they were accessing, most of the participants identified the Effective Writing Centre<sup>3</sup> as offering help with academic writing; however, this help was insufficient due to lack of human resources, severe time constraints, and lack of proofreading services.

Family circumstances, jobs, and financial situations were also described as examples of adjustment difficulties. Many of the participants had taken on multiple roles and responsibilities such as maintaining a home, looking after children, working, and supporting a family. Most were either married or living alone. Due to limited academic and familial support systems, they found it challenging to study, complete assignments on time, and build relationships with peers:

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<sup>3</sup> An academic resource that offers free individual tutorial assistance to students wishing to improve their writing skills. Although the instructors at the Effective Writing Centre respond to students' general questions about assignments in progress, they do not engage in a detailed review or editing of drafts without the permission of students' course instructors.

*I'm on my own, so all the things I have to take care of myself. Take care of the house, cooking . . . It's just a very busy situation, so I can rarely socialize with classmates a lot and go out with them. We are economically tight so we didn't really want to go out.*

### **Motivators**

Despite the challenges they encountered, the students had made significant progress in their nursing program. They attributed their success to supportive partners in learning; other support systems such as family, church, and ethnic community; and their personal strengths and management skills.

**Partners in learning within the university.** Participants gave a variety of accounts of instructors and peers as partners in their learning. In the clinical setting, instructors who were patient, approachable, and aware of students' strengths and needs were described as very helpful. Helpfulness took the form of giving students time to express themselves, listening to and addressing their questions and concerns, providing feedback consistently, acknowledging improvement, and basing grades on final performance rather than deducting for an early weakness that had been corrected. A partnership based on trust was important to the students:

*It's the most amazing thing that I found is professors willing to help, to participate at any activities that student is involved, and it makes our life much, much easier. . . . Professors were very helpful. . . . Some of them have lots of life experience. They may say, "You should do this little bit differently, it can be helpful . . . if you have difficulty, you should go to this person and this person will be able to answer all your questions."*

They spoke of supportive classmates as partners in their learning. Peer support took the form of answering questions, proofreading papers, correcting pronunciation, sharing concerns, and "debriefing" stress and negative emotions:

*I carpool with someone. We communicate all the time, every single day, so even though I had a really bad day, I share it and . . . she will correct me if I have a wrong belief. If I think that's my fault, and she says that's not my fault, kind of someone who can . . . clarify the situation.*

Many participants commented that the EAL support group connected them with supportive faculty members willing to provide academic assistance. They said the support group provided them with opportunities to gain insight into their own challenges and those of their EAL peers, a non-threatening environment in which to converse in English, and opportunities to debrief difficult emotions. Some students said that

the interview for the present study was therapeutic in that it helped them to reflect on and analyze their experiences:

*In the group, students communicate with each other about how to study, what courses to take, what difficulties, what kind of barriers you going to encounter, and what you can do. It's including everything; it's better . . . Just give them a chance that they can meet each other.*

**Other support systems.** Participants spoke of the support they received from parents, a spouse, or a sibling. One student said:

*My support networks is not as strong because I don't have extended family here — just me, my husband, and my little one. But I do have family in [home country]. They support us spiritually and financially, because my father, he is a doctor. And I get support from my sister because she spent 6 or 7 years in Germany to study. Whenever I have a difficult situation, she can always find a way to comfort me, like it's not the end of the world.*

For some, church and their ethnic community were significant resources. The support could be financial, psychological, social, spiritual, but rarely academic. One participant spoke of another source of support. She had met a nurse from her home country who had practised in Canada for 5 years and was “doing fine.” The participant felt encouraged, believing that if she tried hard and gained more experience then success would follow.

**Personal strengths and strategies.** *Finding a way.* Watching television and reading English books were among the strategies that students used to upgrade their English. These activities were found to be helpful but did not facilitate speaking, which was identified as the bigger problem. The students needed to move out of their comfort zone, to increase their activities and social contacts. Theome cited the importance of making friends with those who have “a passion for other cultures,” offer help with proofreading, and deepen understanding by discussing and explaining. He said that such interactions helped him to express himself, and “if you're not expressing yourself, then the culture isn't accepting you; you're being isolated.”

*I can do it. I am okay.* The students all spoke about gaining confidence, but confidence alone was not the hallmark of feeling *I am okay*. For some students, feeling okay seemed to be equated with accepting that their grades could be no higher or that their clinical evaluations could be no better in spite of their many hours of hard work. Sue said that she did the best she could with her theory courses and was prepared to accept whatever came; this was a way of dealing with stress. Theome said, “I can do it; maybe I could do it better, but I'm okay.” Many participants were

aware of their strengths and limitations and demonstrated realistic learning goals, self-trust, and optimism. Christy said:

*You have to realize how much progression you have made . . . looking at a positive side instead of the negative side and sometimes just have to lower the bar a little bit to make yourself comfortable . . . just a way to remind me why I'm here . . . I mean, you passed even though you didn't get a good mark . . . considering where I came from . . . I'm still making a lot of progress. Just looking back and see how you have coming through, give you a lot of strengths and confidence. . . . I do feel so proud of myself. I would not let myself fail for sure.*

The students acknowledged their strengths, such as a determination to learn and succeed in their new country. Determination with regard to education and career was a source of power to them. They consistently dealt with stressful situations and learned to remain strong and positive about the various challenges they faced in their lives. For one student, persevering, refusing to give up, and remaining hopeful were vital to the pursuit of her academic and career goals:

*I'm pretty determined . . . you must relate back to your previous experiences that were successful . . . so believe in yourself, don't give up. I don't give up . . . I'm going to survive it. I know I'll handle it somehow, just keep on trying.*

Converting weaknesses into strengths was a strategy identified by the students. The participants spoke of language and cultural barriers but at the same time were sensitive to the issues confronting immigrants and ethnic groups. They saw their ability to speak different languages as a means to provide culturally appropriate and meaningful care. They viewed the difficulties and challenges confronting them as crucial steps in the achievement of their goals. Most of the participants considered their overall learning experience meaningful in terms of personal growth and the acquisition of knowledge and communication skills:

*I still decide to go on with nursing, because I believe I have ability to be a nurse. And I think it's just that I need to go through some difficult time to learn, and make myself better. So, it is stressful, but it's more of how you handle life.*

### **Recommendations**

The students knew, in retrospect, what they should have done and what supports they would have needed in order to do it. They would have needed instructors and peers who were patient, open, and sensitive to their needs. The supports were there for some but not at all times; they

were especially lacking in the first and second years. It appears that once the students achieved clarity about expectations and once they became knowledgeable about sources of help and became comfortable accessing them, they began to achieve more success. However, getting to that point was slow and stressful.

The experiences of the students led to valuable recommendations with respect to strategies for enhancing the academic performance of EAL students. These recommendations can be placed in three categories: those for peer EAL students, those for instructors, and those for the nursing faculty.

***Recommendations for peer EAL students.*** The students all spoke about actively learning, seeking help, and being confident. They said they would advise their peer EAL students to be prepared for each lecture, to look up anything they do not know, to build knowledge, and to know their own strengths and limitations prior to entering clinical practice and share these honestly and openly with the instructors in order to set realistic expectations and learning goals:

*Be honest, let your instructor know what you think is your problems and let them know what you are trying to do to improve. That seems really help. Be open to each other. Like, if you can tell me what kind of difficulty you have before I notice that, I probably will be more understanding of your situation and willing to give you more help in that specific area.*

Many students emphasized the need to be courageous and not afraid to seek help. Mai said:

*If you are not willing to talk about the problems, you are not going to receive any help. . . . So seek help everywhere. Be patient. Don't feel wrong about asking all the questions.*

Lack of support and resources was a major issue for all the participants. The students cited the need to build stronger networks as a strategy for obtaining help. They spoke about spending time with classmates, being open to communicating and expressing needs, participating confidently in group activities, and immersing oneself in Canadian culture:

*Get involved. Spend time with other students . . . you feel more accepted and you could learn things from their culture . . . The attitude will be very important. If I feel that my culture cannot be blend in with others, then that will be a big barrier. Have to open up, be fair to others, not just stand and do nothing. . . . Open up so they know where you are and who you are so that the friendship will come. Once the friendship clicks, they'll treat you differently.*

Finally, students spoke about the importance of moving on instead of dwelling on bad memories. One student said that remaining positive and concentrating on hopes and possibilities help to neutralize disappointments and difficulties and serve as motivators to push forward:

*Don't lose self-esteem because you don't speak well. Be brave, be more positive . . . you have to believe in yourself. If I think about those days when I overcome those mistakes, then maybe there's a chance to do better next time. Do not hold onto the bad memories.*

**Recommendations for instructors.** *Minimize weaknesses and maximize strengths.* From the students' perspectives, instructors who acknowledged the barriers and challenges facing EAL students were a great support. The participants cited the need for instructors to realize that the language skills of EAL students cannot equal those of Canadian-born students and to convey that understanding to the EAL students. The students hoped that, instead of pointing out errors and lack of English skills, their instructors would focus on their strengths such as ability to speak different languages, willingness to work hard, and commitment to becoming excellent nurses. Students commented that when instructors focused on weaknesses, their challenges were magnified and their self-esteem and confidence level diminished.

*Supportive strategies.* The need for academic and emotional support was paramount in the minds of the participants. They recommended that instructors be patient, allow more time, offer help and encouragement, and provide immediate, specific, and frank advice:

*The teachers' attitudes have impact on me. If the instructor is very patient [and] is willing to listen to me, that encourages me a lot.*

Many participants spoke of difficulty asking instructors for help. They had hoped that their instructors would approach them first and ask, "Do you need any help?" One student remarked that encouraging words such as "good job," "super," or "I trust you" made a difference in her clinical and academic performance by allaying her fear of asking questions and increasing her sense of security and her comfort level. As for a strategy to facilitate active involvement in the group process, students requested that instructors acknowledge the need for and allow students time to express themselves:

*If the instructors ask me, I will do really well. The instructor gives each person a chance to present the patient, so it was really a good thing. I did the best among the group . . . But if I don't get the chance, other people take all the chances to speak . . . And it also takes time to think when the person asks a question. I need more time to think.*



Finally, participants recommended that instructors treat EAL students fairly. From their perspective, it is unfair for instructors not to devote extra time to EAL students because it takes time away from other students. They believed it is only fair that their unique challenges and needs be acknowledged and addressed:

*Treat us fairly. If we have language barrier, try to help us. We need support from the instructors. . . . Understand your students better, what they're going through.*

**Recommendations for the nursing faculty.** *Promote support within the faculty.* Many of the participants recommended mentorship activities among EAL and non-EAL students. They said that a support group as well as professional and social events would promote unity and benefit both groups of students:

*They can help each other. Canadian students shouldn't be afraid of interact with the EAL students and try to help them, [and] the EAL students shouldn't be afraid of the Canadian students and afraid of offending them . . . openness to each other and communication about culture and background is really important. Let them see the long-term benefits of both . . . For Canadian students, it's eye-opening to see other students have a lot to bring to the faculty.*

*Provide academic support.* Participants reported that the greatest need for help occurs during the first half of the nursing program, when unclear expectations and the lack of guidance cause anxiety. They recommended investment in workshops and orientation programs regarding concepts, such as APA style, that are new to EAL students, in order to clarify expectations about academic writing and to provide survival or study tips.

Participants suggested that faculty administrators should not assume that every student is familiar with APA style or knows how to locate and access learning resources. Some participants said they did not know about the EAL support group until their second year and recommended that learning resources be promoted through e-mails and class announcements. Some hoped that the EAL support group would provide opportunities for students to learn clinical communication skills and Canadian colloquialisms. Many participants also favoured the availability of informal support people or faculty counsellors who are knowledgeable about the unique challenges facing EAL students and are prepared to answer questions, offer help, or make referrals:

*The faculty has to admit that there is a need. ESL students are not the same . . . because language, background, culture, age — they are different.*

*We ask for understanding from the faculty members to see the difference and help them to get through this program.*

**Other recommendations.** Some participants spoke of the need for a course on cultural diversity. They suggested that cultural education would promote understanding and collaboration among EAL and non-EAL students and prevent cultural segregation. They wished both to learn about Western culture and for others to have a better understanding of cultural diversity and associated issues. Finally, participants cited the need for a more rigorous admission screening process, one that includes comprehensive assessment of language proficiency to ensure that students are able to progress through the program without undue difficulty. They expressed the view that it is the responsibility of the nursing faculty to nurture language competency throughout the program.

### **Discussion**

The findings from this study are consistent with those published by Bosher and Smalkoski (2002), Cunningham et al. (2004), Guhde (2003), Harvey and Mac (2006), Sanner et al. (2002), Shakya and Horsfall (2000), and Templeton, Estes, and Stullenbarger (1993). The difficulties with language skills and cultural differences reported by nursing students are stressors that threaten to impede their progress. Lazarus (1993) suggests that how individuals manage stressors depends on how they evaluate them, because evaluation is influenced by cultural and social background, type of stress, and perceived outcomes of the stressors. According to Aldwin (1994), an individual's personal coping resources, his/her appraisal of cultural and social factors — including the resources provided by the culture — and the reactions of others determine the choice of coping strategies and mechanisms for handling stress. In the context of the present study, therefore, how EAL nursing students deal with problems arising from their limited language skills and cultural differences would depend on (a) how they appraise the problems and the consequences for their academic progress and their nursing career; (b) their individual social and material resources; (c) the resources provided by the nursing faculty and by the university; and (d) how teachers, clients, nursing staff, and other students react to their problems. The intervention strategies recommended by the participants address all of the above factors and provide clear direction for action.

We acknowledge that the unique learning needs of EAL students are best served through deliberative interventions. Support systems need to be improved to enhance the classroom and clinical learning experiences of EAL students. Our participants identified language limitations, cultural differences, and lack of support and resources as the main barriers to their

successful completion of the nursing program. Considering that language and cultural barriers are not easily lifted, it is essential that supportive learning environments for EAL students be established. Research has shown that it is important to have a good orientation program in the first year and nursing faculty mentors who can discuss academic and clinical difficulties (Shakya & Horsfall, 2000). There is a dire need for institutional supports that promote both resource development and cultural awareness. It has been found that learning among EAL nursing students would be greatly facilitated through the development of English classes centred on conversation skills, nursing and medical terms, and colloquialisms as well as workshops and seminars on cultural diversity, student support groups and buddy systems, and increased cultural awareness within the faculty (Bosher & Smalkoski, 2002; Cunningham et al., 2004; Guhde, 2003; San Miguel et al., 2006; Soroff, Rich, Rubin, Strickland, & Plotnick, 2002). Malu and Figlear (2001) conclude that a peer support system will benefit EAL students and provide non-EAL students with valuable cross-cultural experience and expose them to the challenges faced by their EAL classmates and by culturally diverse patients.

Another recommendation is that a cultural awareness course for all students and instructors be developed, to promote understanding of diverse cultures. Such a course could help one to reflect on one's own cultural perspectives and expose the impact of any assumptions and biases on the learning process of EAL students. Ultimately, it could serve to reduce ethnocentrism, racism, stereotyping, and prejudice.

Time and resources may well prohibit the development of a new course. Robinson (2000) found that guest lectures by minority nurses and class discussions on issues of cultural diversity in the health-care system greatly increased her students' sensitivity to prejudice, racism, and cultural diversity. She reports that such opportunities to learn about cultural issues heightened awareness of blatant racism and led her students to reflect on their values, beliefs, and biases. Abriam-Yago, Yoder, and Kataoka-Yahiro (1999) suggest that academic failure on the part of EAL students may be related to the inability of faculty to identify and address their learning needs. In the present study, instructors who took the time to learn about students' cultural and academic backgrounds, expertise, expectations and goals, interests, extracurricular activities, and family responsibilities were better able to structure appropriate learning activities, leading to more favourable outcomes. Many of the teaching strategies implemented by instructors were viewed by the students as very helpful. For example, encouraging students to ask questions and allowing them sufficient time to formulate their answers served to reduce the students' anxiety and resulted in improved academic performance. The participants also favoured the initiation of more rigorous admission

screening to identify EAL students and expansion of the EAL support group. Such interventions would facilitate earlier identification of students in need and subsequent referral.

Finally, the results of this study challenge nurse educators to adopt perspectives and philosophies that build upon strengths, promote diversity, and reduce ethnocentrism, racism, stereotyping, and prejudice. It is crucial that EAL nursing students be empowered to share their cultural diversity, value their own strengths and resources, and bring their strengths and their wisdom to the Canadian health-care system. Their determination, perseverance, and work ethic speak of their ability to practise nursing in a way that is ethical, competent, and holistic.

### **Conclusion**

*We are not special but we are different than other nursing students.  
We need more information, more practice, more time.*

The growing demands and preferences of health-care consumers for culturally and ethnically congruent care are documented in the literature. The increasing number of immigrants in the Canadian population has created a need for the recruitment of nurses who are culturally and linguistically competent. Therefore, it is imperative that we foster diversity in the nursing profession and recruit nurses who are culturally knowledgeable and sensitive. However, many EAL students lack the support systems and academic resources necessary for them to succeed academically. It is essential that nurse educators, education sectors, and practice arenas address the growing demand for intercultural nursing care, acknowledge issues unique to EAL nursing students, and trust the ability of EAL nursing students to become competent professionals. Nurse educators and education sectors can promote the success of EAL students by developing education infrastructures that support and encourage learning environments that respond to their personal and professional learning needs.

Although the findings from this qualitative study cannot be generalized to EAL nursing students in other universities, the insights and recommendations generated by the study could be examined for their applicability in similar contexts. In future research, implementation of the recommendations with formative and summative evaluations of the outcomes will be examined.

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## **Les cas de violence au travail rapportés par les infirmières canadiennes**

**Lucie Lemelin, Jean-Pierre Bonin et André Duquette**

Cette étude avait pour but de déterminer la prévalence, les causes et les formes de la violence au travail, en prenant appui sur les cas rapportés par des infirmières évoluant dans un milieu de soins actifs, dans la province de Québec, au Canada. Le système de santé québécois connaît actuellement une pénurie d'infirmières qualifiées, ce qui a donné lieu à un environnement de travail oppressif, marqué par la violence envers les infirmières. L'étude, de nature descriptive, se fonde sur un échantillon de 181 infirmières (sur une possibilité de 300). Les données ont été recueillies en 2003 à l'aide d'une traduction française du questionnaire Workplace Violence Events. Elles montrent que 86,5 % des infirmières ont été victimes d'un incident violent à plus d'une reprise. Ces actes avaient un caractère physique (10,6 %), psychologique (86,4 %) ou sexuel (30,7 %); ils ont été infligés par un collègue (65,9 %), un supérieur (59,6 %) ou un médecin (59,1 %). Les infirmières devraient être sensibilisées à la prévalence de la violence au travail. Il faudrait aussi instaurer de toute urgence des mesures préventives pour veiller au bien-être de tous les membres de la profession.

Mots clés : oppression, violence, infirmières, milieu de travail



# **Workplace Violence Reported by Canadian Nurses**

**Lucie Lemelin, Jean-Pierre Bonin, and André Duquette**

The purpose of this study was to determine the prevalence, origins, and forms of workplace violence reported by nurses working in acute-care settings in the Canadian province of Quebec. The Quebec health-care system is currently undergoing a shortage of qualified nurses that has resulted in an oppressive work environment marked by violence towards nurses. A descriptive study design was used with a sample of 181 nurses (out of a possible 300). The data, collected in 2003 using a French translation of the Workplace Violence Events Questionnaire, show that 86.5% of the nurses were victims of violent incidents on more than 1 occasion. The nature of the abuse was physical (10.6%), psychological (86.4%), or sexual (30.7%), inflicted by a colleague (65.9%), a superior (59.6%), or a physician (59.1%). Nurses should be made aware of the prevalence of workplace violence. Preventive measures are urgently needed for the well-being of the nursing profession.

Keywords: oppression, violence, work safety (security), Freire, nurses, workplace, working conditions

## **Introduction**

Several studies have identified work-related health problems in the nursing population, including physical trauma (Baumann et al., 2001; Bourbonnais & Mondor, 2001; Langerstrom, Hansson, & Hagberg, 1998) and resulting in increased absenteeism (Baumann et al., 2001; Bourbonnais & Mondor, 2001; Burke & Greenglass, 2001) and burnout (Duquette, K rouac, Sandhu, & Beaudet, 1995; Healy & McKay, 1999). It has been shown that nurses are affected both psychologically and physically by their work and that they present more work-related health problems than other health professionals (Baumann et al., 2001). A direct link has been established between nurses' work environment and their work-related health problems (Baumann et al., 2001). The studies cited above have identified several structural and instrumental factors related to nurses' malaise, including the organization of work, workload, degree of professional autonomy, recognition of efforts made, and scheduling flexibility. Based on these results, nurse managers have attempted to reorganize nurses' work to achieve a more efficient distribution of the workload among nurses and other care providers and thus reduce the level of work-related health problems. However, work dissatisfaction has persisted (Bourbonnais, Brisson, Malenfant, & V zina, 2005). This situa-

tion can be explained by a difficult work environment resulting from budget cutbacks and the workplace disruptions of the 1990s (Baumann et al., 2001).

Some authors argue that workplace dissatisfaction can be explained by other elements, beyond the known structural and instrumental factors (Bent, 1993; Gordon Clifford, 1992; Kutlenios & Bowman, 1994; Roberts, 1997). The characteristics of oppression within the nursing profession include a rigid management hierarchy, with most power residing with doctors — a situation that can result in vertical violence (Goertz Koerner, 1994). The abuse inflicted on nurses is believed to result in unexpressed anger or passive-aggressive behaviour that is manifested in depression, workplace dissatisfaction, and violence-tinged behaviour. After repeated exposure to abuse and domination, members of an oppressed group may use violence in an attempt to dominate their colleagues, resulting in horizontal violence (Roberts, 1997). Several studies on workplace violence have concluded that women are the victims of violence more often than men (Arnetz, Arnetz, & Söderman, 1998; Björqvist, Österman, & Hjelt-Bäck, 1994; Spratlen, 1995). However, few studies have measured the extent of internal violence, or violence that is inflicted by members of the same organization or profession, which in the case of nursing is composed mostly of women.

Guided by Freire's (1971) theoretical framework, this study was intended to determine the extent of internal violence experienced by nurses. This framework offers a new perspective, in that it permits a description of the origins and forms of workplace violence. This approach also promotes general awareness of the problem, allowing those involved to reflect on their situation.

Freire's (1971) model uses a sociological approach to both analyze the interactive and oppressive forces behind violence and raise awareness about these factors among the general public. For Freire, violence is defined by domination and oppression, occurs when any group or person takes advantage of another group or person and prevents them from asserting themselves, and can be physical, emotional, psychological, or economic. While Freire's framework has been used previously (e.g., Roberts, 1997, 2000), this study is the first of its type to use it.

## **Background**

### ***Workplace Violence***

Two different types of aggressors can perpetrate violence in the workplace. The first is the external type, which refers to clients or people outside of the organization. The second is the internal type, or those working within the organization. The data available in Canada come

almost exclusively from investigations commissioned by labour organizations, rather than from independent scientific studies (Centrale de l'Enseignement du Québec, 1998; Damant, Dompierre, & Jauvin, 1997; Pizzino, 1994; Quebec Federation of Nurses, 1995).

In an exploratory study, Damant et al. (1997) found that 57% of the violent incidents reported by interviewees were perpetrated by an internal aggressor. Arnetz et al. (1998) state that 31% of their respondents reported violence in the workplace and that nurses experienced more violence than other respondents. Braun, Christle, Walker, and Tiwanak (1991) compared the verbal abuse experienced by nurses with that directed towards paramedics. They found that 96% of nurses suffered verbal abuse, compared with only 69% of paramedics.

In a quantitative study, Cox (1991) demonstrated that 82% of nurses experience verbal abuse. The Quebec Federation of Nurses (1995) conducted an inquiry into occupational violence experienced by nurses in Quebec. The results were compiled using a non-standardized questionnaire and reveal that 78% of nurses had suffered internal violence in the workplace. It appears that internal violence in the workplace is an integral part of the reality of the health-care system currently and that nurses are frequently exposed to it.

### ***Vertical Violence***

A hierarchical structure predisposes its members to use violence (Björkqvist et al., 1994; Keashly, Trott, & MacLean, 1994). In a study by Björkqvist et al. (1994), 55% of respondents who reported being victims of workplace violence identified their aggressor as someone in a position superior to their own. These results are comparable to those reported by Quine (1999), who found that 54% of the cases of intimidation in the workplace were caused by superiors and 34% by colleagues. Damant et al. (1997) estimate that 20% of workplace violence is perpetrated by superiors.

Certain factors appear to play a role in fostering violent behaviour. Leymann (1996) and Spratlen (1995) maintain that a rigid hierarchy, an authoritarian management style, and an uncertain leader are factors that may lead to violent behaviour in the workplace. Baron and Neuman (1998) found that superiors were responsible for 31% of reported violent acts. They claim that frustration with vertical violence is positively correlated with aggression towards others as well as hostility and sabotage behaviour. Unjust treatment by a superior can cause frustration, which may in turn lead to aggressive behaviour. Baron and Neuman also note that incidents of verbal abuse can lead to resentment; the incidents they report on mostly involved superiors (35%), colleagues (22%), and to a lesser extent doctors (7%). The literature does not specify a magnitude of

vertical violence in the workplace for nurses. However, studies with other groups of professionals have shown that vertical violence accounts for over 40% of internal violence in the workplace (Anderson, 2002; Baron & Neuman, 1998; Björqvist et al., 1994; Boyd, 1995; Kutlenios & Bowman, 1994; Quine, 1999; Skilling, 1992).

### ***Horizontal Violence***

Horizontal violence is defined as hostility and aggressive behaviour perpetrated by one member of a group towards another. According to Hastie (2003), such violence is a phenomenon that is endemic to the work environment. Horizontal violence is rarely physical; it manifests through other hostile behaviours (Duffy, 1995; Freire, 1971) and is a symptom of the oppression and lack of power of certain groups in the workplace. A case study by Lee and Saeed (2001) supports the idea that nurses engage in horizontal violence as a result of the oppression inflicted upon them. Skilling (1992) defines horizontal violence, in the context of nursing, as conflicting relationships between nurses. The conflicts grow out of oppressed group strategies and are thought to originate in dissatisfaction and lack of power. The dissatisfaction results from the patriarchal medical system and the rigid hierarchy of nursing management. Wilson (2000) concludes that nurses who are victimized by a lack of control and power become frustrated, developing anger and defensiveness towards an environment that is hostile towards them.

### ***Medical Violence***

Uneven power distribution is the key element in explaining difficult relations between doctors and nurses (Manderino & Berkey, 1997). Aggressors gain power over others mostly through verbal abuse. Manderino and Berkey (1997) report that 90% of the nurses they interviewed said that they had been victims of verbal abuse inflicted by a doctor. These results are similar to those obtained by Cox (1991), who found that 78% of nurse respondents reported that the verbal abuse they experienced was inflicted by doctors. Braun et al. (1991), however, estimate a lower incidence of doctor-driven verbal abuse (28%). In a quantitative study, Diaz and McMillin (1991) found that 64% of surveyed nurses had been victims of verbal abuse inflicted by a doctor. It should be noted that the same study found that 30% of nurses were victims of abuse of a sexual nature, 5% received threats, and 2% suffered physical abuse.

An investigation led by the Quebec Federation of Nurses (1995) found that relationships between doctors and nurses were marked by contempt and abuse of power and that the dominating role of doctors confined nurses to a role of carrying out orders. Many of the studies that

have looked at workplace violence have identified three forms of abuse: physical, psychological, and sexual. However, few studies of internal violence in the workplace have specifically examined nurses. These few studies have nevertheless demonstrated that nurses are victims of workplace violence (Arnetz, Arnetz, & Patterson, 1996; Arnetz et al., 1998; Braun et al., 1991; Cox, 1991; Graydon, Kasta, & Khan, 1994).

The literature review revealed that workplace violence is indeed a reality and that it takes several forms, both horizontal and vertical. Several studies have attempted to describe different forms of violence, but few of these were carried out in Quebec and of those that were, some were commissioned by labour organizations or employed small samples (Lee & Saeed, 2001). This is the first study to describe internal workplace violence affecting Quebec nurses.

## **The Study**

### ***Aim***

The aim of the study was to determine the prevalence, sources, and forms of occupational violence reported by Quebec nurses working in acute-care facilities. The specific research questions were: 1. *What is the prevalence of the horizontal violence perceived by nurses, whether physical, psychological, or sexual in nature?* 2. *What is the prevalence of the vertical violence perceived by nurses, whether physical, psychological, or sexual in nature?* 3. *What is the prevalence of the doctor-driven violence perceived by nurses, whether physical, psychological, or sexual in nature?* 4. *What are the sociodemographic factors (sex, age, years of nursing experience, education level, workplace type, work shift) associated with occupational violence inflicted on nurses?*

### ***Design***

A descriptive, self-report postal survey was administered to members of the Quebec Order of Nurses in April and May 2003.

### ***Instrument***

The survey used the Workplace Violence Events Questionnaire by Anderson (2002). Minor changes were made, as the survey was originally written in English (reliability = .84) but was administered in French. A back-translation method was used to ensure translation reliability (Vallerand, 1989). The reliability of the translated survey presented a Cronbach's alpha coefficient of .88 and the instrument was pretested with a group of six nurses. The translated instrument demonstrated good content validity. The pretest also showed that the survey could be completed within an acceptable time frame (approximately 30 minutes).

### **Participants**

Quebec's total nurse population is approximately 20,000. The inclusion criteria were: (1) providing direct patient care in a hospital unit and membership in the Quebec Order of Nurses; (2) practising in a general or specialized health facility; (3) working part-time (approximately 15 hours per week) or full-time on day, evening, or night shift; and (4) understand French.

### **Data Collection**

A random sample of 300 nurses was generated from the electronic database of the Quebec Order of Nurses. Using the program GPOWER (Erdfelder, Faul, & Buchner, 1996), we determined that 252 respondents were needed for a medium effect size (.25; alpha = .05; power = .95). Of the 300 nurses approached, 181 responded, for a response rate of 63.3% and an effect size of .30, which is considered moderate (Cohen, 1992).

### **Ethical Considerations**

The study was approved by the research approval committee for the nursing faculty and the ethical research committee for health science studies at the Université de Montréal.

### **Data Analysis**

The descriptive statistics, such as frequency distributions of discrete variables, as well as central tendency and variability of continuous variables, are presented below. The inferential statistics used were: *t* test for dichotomous variables, ANOVA for other sociodemographic variables, and Pearson correlation for continuous variables. All the statistical calculations were performed using on SPSS for Windows, Version 8.0, and the statistical tests were considered significant when  $p = < 0.05$ .

## **Results**

Analysis of the sociodemographic variables showed that the average age of respondents was 32.63 years (ET = 10.18), 65.0% of respondents had less than 10 years of nursing experience, and 68.5% of respondents had college-level nursing education, which is similar to the rate found in the general population of nurses in Quebec.

Almost 87% of respondents reported being exposed to at least one of three forms of violence (physical, psychological, or sexual). The results show that 65.9% of respondents were victims of horizontal violence, while 59.6% had experienced vertical violence and 59.1% had been victims of violence inflicted by a doctor. These figures represent incidents that occurred more than once in the preceding 3 months.

<b>Number of Violent Incidents</b>	<b>Frequency</b>	<b>%</b>
<b>Physical (n = 180)</b>		
0	175	97.2
1 to 4	5	2.8
<b>Psychological (n = 181)</b>		
0	74	40.9
1 to 3	54	29.8
4 to 20	53	29.3
<b>Sexual (n = 179)</b>		
0	149	83.2
1 to 3	27	15.1
4 to 6	3	1.7
<b>Total<sup>a</sup> (n = 178)</b>		
0	72	40.4
1 to 3	40	28.1
4 to 25	56	31.4
<sup>a</sup> The sum of physical, psychological (verbal), and sexual abuse inflicted by a superior.		

<b>Number of Violent Incidents</b>	<b>Frequency</b>	<b>%</b>
<b>Physical (n = 181)</b>		
0	173	95.6
1 to 3	8	4.4
<b>Psychological (n = 181)</b>		
0	64	35.4
1 to 3	50	27.6
4 to 21	67	37.0
<b>Sexual (n = 179)</b>		
0	147	82.1
1 to 3	27	15.1
4 to 20	5	2.8
<b>Total<sup>a</sup> (n = 176)</b>		
0	61	34.1
1 to 3	50	27.9
4 to 29	70	39.8
<sup>a</sup> The sum of physical, psychological (verbal), and sexual abuse inflicted by a co-worker.		

<b>Number of Violent Incidents</b>	<b>Frequency</b>	<b>%</b>
<b>Physical</b> ( <i>n</i> = 181)		
0	174	96.1
1 to 3	7	3.9
<b>Psychological</b> ( <i>n</i> = 177)		
0	76	42.9
1 to 3	54	30.5
4 to 15	47	26.6
<b>Sexual</b> ( <i>n</i> = 180)		
0	150	83.3
1 to 3	27	15.0
4 to 12	3	1.7
<b>Total<sup>a</sup></b> ( <i>n</i> = 176)		
0	72	40.9
1 to 3	53	30.1
4 to 17	65	36.9

<sup>a</sup>The sum of physical, psychological (verbal), and sexual abuse inflicted by a doctor.

The results show that 86.4% of respondents had suffered psychological abuse, 10.6% physical abuse, and 30.7% abuse of a sexual nature.

Two independent variables, gender ( $r = -.17; p = .05$ ) and education level ( $r = .16; p = .05$ ), yielded weak but significant correlations with psychological violence inflicted by superiors, doctors, and colleagues (Pearson correlation). Women seemed to be exposed to psychological abuse more than men. It appears that, for men as well as for women, more advanced education resulted in less exposure to workplace violence. It was also found that, compared to older nurses, younger nurses were exposed to more physical abuse, as well as abuse of a sexual nature inflicted by colleagues. No correlations were found with any of the other sociodemographic variables.

Overall, significantly more women than men reported having experienced all types of violence combined. For psychological abuse, education level appeared to be the dominant variable, with three cases of psychological violence significantly associated with education level, namely being made to feel bad by a colleague ( $r = .18; p = .05$ ), being ridiculed or humiliated by a colleague ( $r = .17; p = .05$ ), and having a doctor slam a door during a disagreement ( $r = .18; p = .05$ ).

The results of simple correlation show that psychological violence had a weak relationship with the nurses' amount of experience ( $r = -.13;$



$p = .05$ ), with more experience being associated with less exposure to psychological violence. Physical violence, however, was linked to age ( $r = .13$ ;  $p = .05$ ). As for sources of abuse, violence inflicted by doctors was associated with age ( $r = -.15$ ;  $p = .02$ ) and education level ( $r = 0.13$ ;  $p = .04$ ). Younger nurses were more exposed to doctor-inflicted violence than older nurses. Finally, violence inflicted by colleagues was related to number of years of experience ( $r = -.12$ ;  $p = .05$ ). Less experienced nurses were more exposed to workplace violence.

## **Discussion**

### ***Extent of Workplace Violence***

The extent of violence revealed in this study is greater than that found in previous studies. This finding may be partly explained by the fact that the respondents were approximately 10 years younger than the average Quebec nurse. Arnetz et al. (1998), Boyd (1995), Diaz and McMillin (1991), and Spratlen (1995) all note that younger nurses are at higher risk for violence. The number of years of nursing experience seems to be a determining factor as well, since more experienced nurses are older and thus less exposed to violence (Diaz & McMillin, 1991). Anderson (2002) and Graydon et al. (1994) attribute a lower prevalence of violence to better problem-solving abilities, which could be related to higher level of education.

Of the respondents, 86% had experienced more than one form of internal violence. In general, more incidents of violence were reported in this study than in other studies (Arnetz et al., 1998; Damant et al., 1997; Graydon et al., 1994). This could be related to the young age of the sample or to the dearth of resources available within the Quebec health-care network (Bourbonnais, Comeau, Vézina, & Dion, 1998), which suggests that rationing could serve to increase the incidence of workplace violence and place co-worker relations under stress. Future studies should analyze the organizational factors associated with internal workplace violence.

### ***Forms of Violence***

These results underscore the high level of psychological violence present in the workplace. Psychological violence was the form of abuse most frequently reported, which is consistent with the findings of Jauvin (1999). The incidence of psychological violence (86%) is similar to that reported in the literature (Braun et al., 1991; Cox, 1991; Quebec Federation of Nurses, 1995).

Of the respondents, 30.7% stated they had been victims of sexual abuse. The Quebec Federation of Nurses (1995) found that 44.8% of sur-

veyed nurses had been victims of sexual abuse at some point in their careers, but that survey covered a longer period of time. This study reports results similar to those of other studies with regard to the prevalence of sexual abuse (Diaz & McMillin, 1991; Duncan, Estabrooks, & Reimer, 2000).

Duquette and Delmas (2001) found that nurses' work can cause intense stress and that interpersonal conflict is one of the stressors. This type of conflict can bring nurses dangerously close to emotional burnout and can lead to professional burnout. It is in nurses' best interest to be aware of these potential consequences of psychological violence and to search for ways to eliminate it.

### ***Sources of Violence***

Fifty-nine percent of respondents reported being victims of violence inflicted by a superior in the preceding 3 months. This rate is slightly higher than that reported by other studies (Björqvist et al., 1994; Quine, 1999; Spratlen, 1995). This may be explained by the restructuring of the Quebec health-care system, which nurse managers are responsible for implementing. According to Roberts (2000), nurse managers make up a marginalized elite of the nursing workforce. Once they have access to power, they tend to maintain a climate of group dominance — a culture inherited from the medical system. Roberts (1997) explains that this behaviour relates to the fact that nurse managers actually have little power. In order to maintain their leadership and the limited power they do have, they turn to dominating behaviours, which leads to vertical violence in the workplace. Management style should not be underestimated in health-care organizations; these organizations exert considerable pressure on nurse managers to improve performance and efficiency.

Turning to doctor-driven violence, 59% of respondents claimed to have been victims of this type of abuse. Studies of doctor-driven violence have focused primarily on verbal abuse (Cooper, Saxe-Braithwaite, & Anthony, 1996; Cox, 1991; Diaz & McMillin, 1991; Manderino & Berkey, 1997). Kutlenios and Bowman (1994) describe the phenomenon of doctor-driven violence as a product of domination by the medical team in the health-care sector. The current health-care system is paternalistic, while nursing is predominantly a profession chosen by women. Nurses work in a health-care system run and dominated by the men who make up the medical teams. This domination is endorsed and reinforced by hospital administrators, who depend on doctors to treat the hospital's clients. Doctor-driven violence could be exacerbated by the lack of experience and/or training among young nurses, making it difficult to meet the increasingly complex demands of health-care institutions.

According to Kutlenios and Bowman (1994), nurses' typical response to domination and intimidation by doctors is anger, which can lead to verbal abuse among co-workers. Co-worker violence is the form of violence that should raise the most concern. The results of the present study ought to serve as a red flag, since they indicate that the rates of violence against nurses are higher than those reported in the literature (Baron & Neuman, 1998; Damant et al., 1997; Quine, 1999). The lack of qualified personnel, as well as the rationing of resources in the Quebec health-care system, may help to explain the prevalence of horizontal violence found in this study. Horizontal violence is also a symptom of the domination of nurses within a paternalistic health-care system run by doctors, administrators, and a small number of nurse managers (Freshwater, 2000; McCall, 1996; Roberts, 1997; Skilling, 1992). According to Freshwater (2000), McCall (1996), Roberts (1997), and Skilling (1992), horizontal violence is a result of oppression, and for the victims it acts as a form of release from this oppression. In summary, horizontal violence is the result of frustration and repeated conflict on the part of the victim.

### ***Study Limitations***

The generalizability of the findings is limited because of a possible self-selection bias, which is inherent in any study that relies on volunteers. The nurses who volunteered to participate in the study may have been more exposed than other nurses to incidents of workplace violence. It is also possible that the ongoing changes taking place within Quebec's health-care system exacerbated relational tensions on the wards. In addition, the instrument used is rather new and may need more validation.

### **Conclusion**

The prevalence of violence in nurses' workplaces in Quebec gives cause for concern. Less experienced nurses and nurses with lower levels of education seem to be at particular risk of falling victim to such violence. These results offer a glimpse into the nature and extent of the phenomenon of workplace violence within the context of nursing, deepen our understanding of what nurses experience in their daily work lives, and identify issues that need to be addressed in nursing practice, management, and research. It is crucial that nurses realize that their professional well-being is influenced by the workplace climate and by the expression of violent behaviours.

Nurses are strongly advised to denounce violence and refuse to tolerate it. They should be encouraged to speak out about the violence that they experience and to take action that will promote good relationships with their co-workers. A sense of solidarity should be developed in order

to counteract the violence. Value should be placed on loyalty and the need to rally to the defence of a co-worker who becomes the victim of workplace violence.

Nurse managers are urged to intervene with nurses who appear to be in distress and encourage them to denounce the violence around them. It is important to offer any support that victims may require and also to make it easier for them to denounce all forms of workplace violence. It is advisable to address all specific situations and conflicts manifesting within the workgroup. Nurse managers must be creative in developing initiatives to address workplace violence, by establishing prevention programs, identifying risky situations, preventing the escalation of existing conflicts, and educating staff (Jauvin, 1999; Quebec Federation of Nurses, 1995).

Nurse managers might consider identifying key factors that favour the development and implementation of programs aimed at preventing workplace violence. Various violence-prevention programs are already available, some implemented by trade unions or occupational health and safety services. However, these programs need to be better publicized, because in many cases employees are not even aware of them.

Future research should focus on examining the origins of the psychological violence that is so common among colleagues and on identifying factors that are likely to defuse this type of violence.

Finally, we underscore the importance of implementing the above recommendations, so that nurses may become increasingly aware of the violence they face. These recommendations are meant to help the entire nursing workforce to combat occupational violence. They are ultimately designed to foster quality care delivery in an environment that is empathic and respectful.

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## **Accéder aux services de santé quand on vit avec le VIH/sida : la stigmatisation en tant que conjonction de facteurs**

**Judy Mill, Nancy Edwards, Randy Jackson, Wendy Austin,  
Lynne MacLean et Frances Reintjes**

La stigmatisation associée au VIH/sida a de lourdes conséquences. Nous avons cherché à examiner les pratiques qui, au sein des établissements de santé, sont perçues comme étant stigmatisantes par les personnes vivant avec cette maladie. De nature exploratoire et descriptive, notre étude s'inscrit dans une approche de recherche-action participative. Nous avons mené des entrevues et des groupes de discussion auxquels ont participé 16 Autochtones et 17 non-Autochtones vivant avec le VIH/sida, ainsi que 27 prestataires de soins de santé. La stigmatisation ressentie par de nombreux participants se conjugue souvent à d'autres facteurs qui accentuent cette perception, et qui sont associés au comportement, à la culture, au sexe, à l'orientation sexuelle ou à la classe sociale. On a constaté également que les politiques organisationnelles contribuaient à la stigmatisation et qu'elles se conjugaient parfois aux facteurs individuels. Les expériences de la stigmatisation et de la discrimination sont façonnées par les politiques organisationnelles (précautions universelles, modèles de prise en charge) ainsi que par l'aménagement (la disposition matérielle) des lieux où sont dispensés les soins. On a relevé dans les témoignages des participants un certain nombre de paradoxes relatifs au respect de la vie privée, au cadre de prestation des soins et à la conjonction des facteurs de stigmatisation.

Mots clés : accès aux services de santé, VIH/sida, Autochtones



# **Accessing Health Services While Living With HIV: Intersections of Stigma**

**Judy Mill, Nancy Edwards, Randy Jackson, Wendy Austin,  
Lynne MacLean, and Frances Reintjes**

AIDS stigma has serious consequences. This study explored those practices within health-care organizations that persons with HIV perceive as stigmatizing. It used an exploratory, descriptive design using a participatory action research approach. Interviews and focus groups were conducted with 16 Aboriginal and 17 non-Aboriginal persons living with HIV as well as with 27 health-care providers. The AIDS stigma perceived by many participants often intersected with other forms of stigma, related to behaviour, culture, gender, sexual orientation, or social class. In addition, policies at the organizational level contributed to AIDS stigma and at times intersected with stigma at the individual level. Participants' experiences of stigma and discrimination were shaped by the organizational policies (universal precautions, models of care) and design (physical layout) under which care was provided. Several paradoxes associated with secrecy, health-care settings, and the layering of stigma emerged in the reported experiences.

Keywords: access to care, AIDS, chronic illness, health services, HIV Aboriginal

## **Introduction**

Early in the AIDS epidemic, the stigmatizing of individuals with HIV was identified as a serious concern (Herek & Glunt, 1988). It was reasoned that AIDS stigma was due to the association of the disease with death and with marginalized groups such as gay men. Since that time, there has been much discourse on the phenomenon of AIDS stigma. Stigmatization is a social process “characterized by exclusion, rejection, blame or devaluation that results from an adverse social judgment about a person or group . . . based on an enduring feature of identity attributable to a health problem” (Weiss & Ramakrishna, 2001, p. 4). The concept of stigma and its application has been challenged as stigmatizing itself, and the notion of discrimination has been proposed as a more appropriate descriptor of the social process of exclusion (Sayce, 1998).

The purposes of this study were to explore stigmatizing practices within health-care organizations from the perspective of persons living with HIV (PHAs), both Aboriginal (APHAs) and non-Aboriginal, and

health-care providers (HCPs) and to recommend interventions to mitigate AIDS stigma. This article highlights experiences of both stigmatization and discrimination.

AIDS stigma is important for HCPs because of its serious consequences: Stigma has the potential to limit prevention (Des Jarlais, Galea, Tracy, Tross, & Vlahov, 2006), to act as a barrier to diagnosis and appropriate treatment (World Bank, 2007), and to induce psychological stress and reluctance to access health services (Des Jarlais et al., 2006; Mwinituo & Mill, 2006). Individuals who are HIV positive may conceal their diagnosis in an attempt to mediate the effects of stigma (Des Jarlais et al., 2006; Mwinituo & Mill, 2006; Ware, Wyatt, & Tugenberg, 2006). Thus, concealment is a primary pathway linking the experience of stigma and health-care utilization. Concealment has profound implications for the individual and, in the case of stigmatized conditions that are infectious, implications for public health (Des Jarlais et al., 2006).

Health-care providers have been identified as a significant source of stigmatization and discrimination for PHAs (Mwinituo & Mill, 2006), and health-care practice is the most common context in which PHAs experience stigmatization (Reidpath & Chan, 2005a). Stigma can be exhibited through poor quality of service or differential treatment by HCPs (Rutledge & Abell, 2005). Research on the attitudes of HCPs towards individuals with HIV infection, however, has identified both supportive and stigmatizing attitudes (National AIDS Research Institute, 2003). Although HCPs may have positive attitudes towards PHAs, they can display behaviours that result in their clients being stigmatized or perceiving that they are being stigmatized (Mawar, Saha, Pandit, & Mahajan, 2005). This apparent lack of congruence between attitude and behaviour may be partially explained by the difference between “enacted” and “felt” stigma. Enacted stigma refers to individual or collective sanctions against an individual, whereas felt stigma refers to fear of enacted stigma (Green, 1995).

Individuals who are already marginalized in society and who develop a stigmatizing condition such as HIV infection may experience a layering or double burden of stigma (Mawar et al., 2005; Reidpath & Chan, 2005b). Reidpath and Chan (2005b) argue that “there needs to be an understanding of the layering of stigma so that informed policies and interventions can be developed that will address the entire experience of stigma” (p. 431). AIDS stigma may be layered with and connected to race, sexual orientation, physical dis/ability, class, and gender (Skinner & Mfecane, 2004).

Globally, many authors and reports have highlighted the stigmatization and discrimination experienced by persons with HIV and AIDS (Bereket et al., 2006; Herek, Capitanio, & Widamen, 2002; Holzemer et

al., 2007; World Bank, 2007). Despite the vast literature on the stigmatizing experiences of PHAs, there has been limited rigorous research on the impact of stigma on AIDS care (Holzemer & Uys, 2004). Although Canadian studies (Olivier & Dykeman, 2003; Worthington & Myers, 2003) have documented stigmatization and discrimination with respect to PHAs, we found no published research exploring this phenomenon.

In this article we present findings related to the intersections of stigma at the individual and organizational level and highlight paradoxes that emerged in relation to the participants' experiences of stigma. Illustrative quotes (using pseudonyms and with identifying information removed) are used to highlight themes. Findings related to the unique experiences of Aboriginal persons living with HIV (APHAs) will be published separately.

### **Design and Methods**

An exploratory, descriptive design using a participatory action research (PAR) approach was employed. Participatory action research helps to ensure research relevance for individuals and communities and is an appropriate research design for use with Aboriginal communities (Macaulay et al., 1998). Its fundamental principles include a collaborative relationship with the research partners (Reason, 1994) and a valuing of popular experience and knowledge (Fals-Borda, 1991). Participatory action research is a spiralling process that involves planning, acting, observing, and reflecting (Kemmis & McTaggart, 2005). Several strategies were employed throughout the project to develop and maintain collaborative relationships with our partners and to ensure that their knowledge and experience were used. Following ethical approval, community advisory committees (CACs) were formed at each site to provide guidance on ethical implications, cultural perspectives, implementation, analysis, and dissemination strategies for the study. The CACs included representatives of Aboriginal communities, PHAs and APHAs, consumer groups representing PHAs and APHAs, and agencies providing services to PHAs and APHAs. Terms of reference for the CACs were developed in consultation with the committees.

Community consultation workshops were also used to engage our community partners. Following preliminary data analysis, 97 Aboriginal and non-Aboriginal community partners attended a 1-day workshop in one of three Canadian cities. The purpose of the workshops was to meaningfully engage HCPs and decision-makers providing health services to APHAs and PHAs in the design of an intervention to reduce AIDS stigma. Following an overview of the key findings from the research project, the workshop participants were asked to help design the

intervention. The development of best practice guidelines (Mill et al., 2007) for the provision of health services to PHAs and APHAs was an outcome of this process and is described elsewhere.

In-depth interviews and focus groups were used to collect data between 2003 and 2006 at two study sites, Edmonton and Ottawa, Canada. At each site, four health-care organizations were purposively selected. These included both small and large organizations using a variety of approaches to care delivery (e.g., acute care, primary health care) and providing access to Aboriginal populations. Recruitment within these organizations helped to ensure the inclusion of Aboriginal peoples, who are over-represented in HIV and AIDS statistics (Public Health Agency of Canada, 2007). Convenience and network sampling were used to recruit participants. During an interview, PHAs were asked to relate their experiences with HIV generally and their experiences accessing services specifically. Following initial analysis, HCPs were asked to participate in an interview or focus group in order to reflect on the themes identified in the PHA interviews, including those practices that had been identified as stigmatizing. The interviews were conducted primarily by the research coordinator at each site and lasted 1 to 2 hours. Focus groups with HCPs took place on the premises of one of the participating organizations, were conducted by two members of the research team, and lasted approximately 2 hours. All interviews and focus groups were conducted in English. Guiding questions were used to maintain a balance between consistency and flexibility (May, 1991). The data-collection process was iterative and reflective, with data from the PHA interviews informing and guiding data collection with the HCPs.

The inclusion criteria for PHAs were: over the age of 18; English- or French-speaking; not currently a hospital in-patient; living in Canada at least 3 years; having accessed health services in the past 2 years. Inclusion criteria for HCPs were: English- or French-speaking; health professional or community worker at one of the participating organizations. Due to resource limitations, the research team was unable to conduct interviews in an Aboriginal language.

Ethical approval was obtained from the research ethics boards at the University of Alberta and the University Ottawa, while community approval was provided by the CACs. Each PHA was given \$25 as compensation for his or her time, while compensation for the HCPs' time was provided to their organization, to minimize the likelihood of HCPs feeling coerced to participate. One person at each organization assisted with recruitment. Informed consent was obtained from all participants. The interviews and focus groups were audiotaped and transcribed verbatim. The principal investigator, members of the research team, and

the research coordinators developed a coding framework that was revised during team meetings. The principal investigator worked closely with the research coordinators and re-analyzed several of the interviews analyzed by them to ensure accuracy. The analysis process took place simultaneously with data collection, using the qualitative software program QSR\*<sup>®</sup>N6 to assist with labelling, revising and retrieving codes, and writing memos. Matrix methodology techniques described by Miles and Huberman (1994) were applied. First-level analysis was used to assign a descriptive code (label) to a segment of the data to give it meaning. As the researchers became more familiar with the data, pattern coding was used to label emerging themes. An inductive approach was used to analyze the data involving, iteratively, coding and identifying themes and discovering relationships among themes via systematic comparisons using negative cases and extreme cases. Decisions made during analysis were documented to ensure that the process was auditable, thereby enhancing consistency of the analysis (Sandelowski, 1986).

Strategies to ensure rigour in conducting research with marginalized populations (Meleis, 1996) were incorporated into the research design. The study attempted to document one aspect of the *context* of the lives of PHAs. The literature review substantiated the *relevance* of the issue of stigma for PHAs and its potential impact on access to health services. Providing opportunities to address the goals of not only the researchers but also the participants resulted in *reciprocation*. The involvement of PHAs and the use of CACs also helped to ensure that the relevance, context, and reciprocation criteria were met. In addition, the CACs helped to ensure that any *power differentials* between the research team and the participants were acknowledged. Inviting representatives from consumer groups to participate in the CACs fostered the *empowerment* of PHAs. The use of open-ended interviews was congruent with the *communication styles* of the Aboriginal participants in that it acknowledged traditional storytelling methods. A *flexible approach to time* was necessary throughout the study to enable the development of collaborative relationships based on trust and respect. Ensuring confidentiality of the data and anonymity of the participants also helped to build trust and to encourage participants to *disclose* their experiences. Finally, the use of PAR, the development of Principles for Research Collaboration for both community and academic partners, adherence to the principles of Ownership, Control, Access, and Possession (Patterson, Jackson, & Edwards, 2006), and the involvement of Aboriginal investigators helped to ensure that the research was authentic, rigorous, and culturally appropriate.

## Findings

The sample included 16 Aboriginal and 17 non-Aboriginal PHAs. The term Aboriginal as used in this study includes individuals who identify as Métis, First Nations, or Inuit regardless of Treaty status (Ermine, Sinclair, & Jeffrey, 2004). The average age of PHAs was 40.6 years (range: 31–56 years) and their gender was male (22), female (9), or transgender (2). The primary mode of HIV transmission for the sample was injection drug use (IDU) ( $n = 17$ ) and men having sex with men ( $n = 16$ ). The sample also included 27 HCPs (3 male; 24 female) from diverse disciplines: nursing, medicine, social work, psychology, community development, dentistry, infectious diseases, and laboratory medicine. Of the 27 HCPs, 7 took part in focus groups and 20 in individual interviews. The HCPs were recruited from the eight participating organizations reflecting a wide range of work settings, including small community health centres, infectious disease clinics in large referral hospitals, and AIDS service organizations (ASOs). A few of the HCPs worked in non-specialized health-care settings and provided care for PHAs as required.

Persons living with HIV described both physical and emotional responses to their HIV diagnosis. Many of the participants were dealing with a dual diagnosis, including hepatitis C or tuberculosis. Almost all of the participants reported cyclical periods of wellness punctuated by bouts of illness. Emotional responses to HIV and AIDS were related to the fear of dying or being rejected and were manifested in feelings of hopelessness, depression, and social withdrawal, with some participants increasing their substance use as a means of coping.

Participants believed that negative societal views of HIV and AIDS were based on ignorance, including ignorance about the difference between HIV and AIDS, and negative media portrayal of PHAs. Ethan (age 36) captured the essence of this sentiment: “If you’re HIV positive, you’re treated like you were never part of the status quo in society.” Several of the participants stated that the public still puts the blame on individuals who are HIV positive, depending on how they have become infected.

### *Intersections of Stigma*

**Individual layering of stigma: “You’re a triple target.”** The AIDS stigma experienced by many of the participants often intersected with other forms of stigmatization and discrimination, resulting in layering, or a double (or triple) burden of stigma. This occurred when an individual became infected through a behaviour that was highly stigmatized (e.g., IDU, commercial sex work), belonged to a culture (Aboriginal), gender (female), sexual orientation (e.g., transgendered, gay), or social

class (e.g., poor, prisoner) that was vulnerable to stigmatization, or had another illness (e.g., mental illness) that was stigmatized. There was a sense that overt stigmatization and discrimination had decreased over time. Interestingly, some participants believed that being gay and/or an IDU was more stigmatizing than being HIV positive. For example, one man believed that his associates were more shocked by his homosexuality than by his HIV disclosure, while another stated that there was “more stigma . . . in my life right now with regard to being a drug addict than there is [with] my HIV and hep C status” (Louis, PHA, age 43). Some PHAs did not believe that they were treated differently due to their membership in “other” groups (e.g., gay, IDU, Aboriginal) or were unsure which of their personal attributes resulted in stigmatization. Oliver, who was gay, summed up the layering of stigma in a powerful manner:

*Hatred is a terrible thing, and when you're a victim — if you're Black, or a religious designation, or social or sexual orientation, and somebody picks on you and you don't know who it is . . . So you've got to be very careful when you fall into a category . . . imagine if you're Jewish with HIV and you're gay — you could be . . . a triple target in certain areas of society. Or how Natives are picked on and . . . stereotyped . . . (Oliver, PHA, age 45)*

A number of participants experienced discrimination because they were gay, Aboriginal, or female. Some participants described negative encounters with homophobic HCPs. Aaron had had a traumatic experience with a nurse during hospitalization:

*I kept my voice down and I said, “Well, I'm HIV positive.” And she went, “What?” I said [whispering], “I said, I'm HIV positive.” And she just had a blank look on her face and she walked out to another nurse and she said, “Why didn't you tell me there's a fag in there that has AIDS?” (Aaron, PHA, age 37)*

Several participants commented on the heightened stigma surrounding AIDS in Aboriginal communities. One woman said, “Natives are scared to tell their family . . . because their family won't have anything to do with them” (Megan, PHA, age unknown). Some Aboriginal participants shared racist comments that had been directed at them. Fred was dealing with multiple stigmas:

*. . . I caught it. It was really kind of like a Black labelling almost. “Watch that guy, he's HIV,” you know, like there was a lot of ignorance toward it. I just didn't want to be put in that category, because I was already dealing with a lot of other issues . . . one, being Native, [pause] two, being in jail because I'm, you know, a Native. (Fred, PHA, age 32)*

A few Aboriginal participants, however, did not feel that they had been treated differently:

*No, I don't think so. I don't think I've ever had an experience where someone's treated me differently . . . because I'm Aboriginal. No, I've never. No, it's never been a problem.* (Otto, PHA, age 31)

Gender intersected with AIDS stigma through societal attitudes towards women. Jane, an HCP, believed that women experienced more stigma and discrimination because an HIV diagnosis is associated with being “loose” and having “slept with a lot of men.” This view was echoed by several of the PHAs, who felt that women were discriminated against when they accessed health services.

**Organizational layering of stigma: “Radar, radar.”** Policies and practices at the organizational level contributed to AIDS stigmatization and discrimination, and at times intersected and overlapped with stigmatization at the individual level. Participants’ experiences were shaped by the organizational policies (universal precautions, models of care) and design (physical layout) under which care was provided. The consistent use of universal precautions was considered essential to safe practice yet also stigmatizing. Decision-making related to the use of gloves was a complex issue for some HCPs. For example, an HCP might decide not to use gloves to demonstrate their comfort with the HIV-positive patient, thus protecting neither themselves nor the patient. One HCP said that a client told her, “As soon as I say I’m HIV positive, they double-glove.” Another HCP recalled that some of her colleagues used the phrase “radar, radar!” to communicate a client’s HIV status to other HCPs. Despite universal precautions, participants’ experiences revealed that fear of contagion can result in inequitable treatment. A dentist recalled a disturbing incident in her private practice. She was seeing a client with hepatitis C when a colleague approached her and said:

*“Be careful, he’s hep C positive.” I was almost disgusted with that. I just said to her, “You know, it really doesn’t matter. It shouldn’t matter to you whether he’s [got] hepatitis C . . . Are you not as careful with all your other patients? Because they just may not be telling you if they have a transmissible disease.”* (Belinda, HCP)

Health-care providers suggested that models of care, including specialized HIV services, impacted on stigmatization and discrimination. They expressed a preference for AIDS-specific organizations or units where staff are knowledgeable about the diagnosis and treatment of HIV and AIDS:



*If they go to a facility or place that doesn't routinely provide care to HIV-positive people, then it's like there's this level of discomfort that the staff have, because they don't do it on a day-to-day basis, so they don't think about how their behaviour might make a person feel. (Eunice, HCP)*

However, another HCP suggested that treating HIV-positive clients differently is discriminating in itself. Some PHAs also said that being treated differently based on HIV status might contribute to discrimination. For example, Fiona felt very uncomfortable when offered different food at a shelter:

*When I have to get special foods at a shelter, . . . they [non-HIV-positive clients] get jealous. . . . I used to get mad and say, "Hey, you can have what I eat if [you] want my disease . . . I don't wish it on you." (Fiona, PHA, age 40)*

All participants, HCPs and PHAs alike, suggested that a flexible approach to service provision was essential to delivering non-discriminatory health services. Many of the HCPs reported that their own organization tried to adopt this approach. For example, several of the organizations tried to accommodate clients who were "under the influence" as long as they were not disruptive. The smaller ASOs, health centres, and drop-ins were very aware that the client behaviours they tolerated would not be acceptable to mainstream organizations. Their tolerance reflected a commitment "to serve the most difficult to serve" (Brian, HCP). The following comment by Wilma reflects this flexibility and the "harm reduction" philosophy of her organization:

*Normally when we have [traditional Aboriginal] medicines in our room, people under the influence shouldn't actually be coming in, but I've been really flexible in allowing them to come . . . because if they come a little bit under the influence of something today, next week they may make an effort to come sober or to come clean. (Wilma, HCP)*

The design and organization of services, including physical layout, could also contribute to an individual's experience of stigma. The assurance of confidentiality was particularly important in relation to physical layout. Participants explained that they were reluctant to verbally state why they had an appointment when they arrived at an organization:

*She [receptionist] wants to know why you want to see your doctor. There's a room full of junkies and people behind me, no partition in between us, and she wants to know or she wants me to explain to her why I'm there to see my doctor. I don't see what business it is of hers. If I want to see my doctor, that's my right. (Ethan, PHA, age 36)*

Similarly, participants did not want to be identified as HIV positive because they were accessing care at a particular organization:

*Having . . . our building identified [as an ASO] is appalling to me. I don't think that we need to put "HIV" up at the front of our building . . . People need to be able to come in and out of here without that stigma being attached to them. (Dennis, PHA, age 41)*

Some of the health-care facilities addressed this concern by ensuring that non-HIV services were offered at the same time as AIDS-specific services:

*We were always infectious disease, but there were certain days just HIV. So what we try to do now is we put other patients in, so we have different clientele in the waiting room. So this way, you don't know why [a person is] there. (Haley, HCP)*

As participants described their experiences of stigma, several paradoxes emerged in relation to their strategies to mitigate stigma and the types of services that they accessed.

### **Paradoxes of Stigma**

**Secrecy versus disclosure.** There was tension between the participants' need to keep their HIV diagnosis secret and their need to disclose it to family members and health-care workers. This created a paradox in that some PHAs used secrecy to mitigate the impact of stigma and others saw disclosure as an essential strategy for reducing stigma. Ethan argued that secrecy accentuates stigma:

*You're encouraged not to tell people because of the stigma attached to it. But if more people would tell people, there would be less stigma because more people are involved. Confidentiality is the creator of some of the stigma that surrounds our illness. (Ethan, PHA, age 36)*

Failure to disclose HIV status was associated with failure to access health services and with treatment delays. Decisions about disclosure were often made on a "need to know basis":

*I haven't told anybody that didn't need to know. I wouldn't, like, walk down with a placard on my back saying, "I've got HIV. What do you think of me?" I wouldn't want to try that — probably end up dead. (Cecil, PHA, age 48)*

Participants with more than one infectious disease sometimes kept their HIV status secret but disclosed a less stigmatized illness. A hepatitis B or C diagnosis was perceived to garner less stigmatization and discrimination and therefore was at times disclosed instead of the HIV-positive

diagnosis. Both Dorothy and Cecil had been advised by HCPs not to disclose their HIV status:

*[The doctor] was very good about [it], but he told me if I ever go to the hospital or anything else just tell them I have hepatitis C, do not tell them I have HIV . . . When I came in the hospital I said, "I have hepatitis C," and they were really good . . . and then I told them I had HIV and their attitude completely changed. (Dorothy, PHA, age 45)*

*The doctor said, "You don't have to go out and tell them you've got HIV now, because they already know you have hep C. They'll take the same precautions as if — as they do for HIV." (Cecil, PHA, age 48)*

For Dorothy and Cecil, hepatitis C was used as a means to mitigate stigma.

**Health-care settings.** The care setting provided another paradox of the stigma experience. Several of the participants had different experiences, depending on whether care was provided in rural or urban settings. However, the findings were not consistent. Most participants found that care in a smaller setting was more stigmatizing. Aaron had had a disturbing experience while on vacation:

*I was rushed to hospital in [small town]. It's a country hospital and I whispered very quietly to the emergency room nurse, "I'm HIV positive." And she goes, "Okay, the kid's HIV." And she yells it out and it's busy and it was my first time since this whole thing started — outside my little cluster — that I've had to deal with non-professionalism. (Aaron, PHA, age 37)*

A few participants, on the other hand, found care in a small town to be superior to that in a larger centre. Ethan shared an experience accessing care in a small town:

*I had a lung infection while I was out there, and I had to go to a small-town hospital. And I got better care there than I ever received in the city. And yet they don't deal with it on a daily basis [laughs] . . . But there was no freaking out. There was none of this "Quick — get the gloves!" . . . [laughs] There was none of that kind of stuff from them. They were very professional. (Ethan, PHA, age 36)*

This finding challenges the premise that urban settings are more likely to have health-care providers who are experienced and educated in AIDS care and who consequently are less likely to provide discriminatory care.

With the changing epidemiology of the illness, more HIV-positive women are accessing health services. Despite this change, a few participants noted that HIV-positive heterosexual women might have more

difficulty accessing care because they are identified as part of mainstream culture. Also, because many of the AIDS services have been developed by and for gay men it was thought that women might not feel comfortable using them. Aaron summed up the issue:

*The people who get the raw end of the deal, really, are straight women whose partners or husbands cheat on them, become carriers, [and] infect the women. These women have no place to go, because they're not lesbians, they're not gay.* (Aaron, PHA, age 37)

At times, AIDS services that had been developed primarily in response to the needs of gay men became stigmatizing and non-responsive to the needs of women.

**Layering of stigma.** Although layering was a potent force in fuelling stigma, the relationship between each element of the layer was complex and at times unexpected. For example, Ethan was living with both mental illness and HIV and he was able to obtain some financial benefits because of his HIV diagnosis:

*They're much more giving to people that are [HIV] positive than to people that have mental illnesses . . . I could not function in society because of my mental health. I was depressed, anxious, and paranoid . . . but that's not a reason to put a person on [disability income].* (Ethan, PHA, age 36)

The physical diagnosis of HIV, in comparison to the less visible diagnosis of mental illness, provided the evidence he required to qualify for disability benefits.

## Discussion

The findings on the physical and emotional responses to HIV reinforce our existing knowledge, while those related to the intersections and paradoxes of stigma provide new insights into this complex phenomenon. Both covert and overt forms of stigma were described by the participants. A recent Canadian study (Bereket et al., 2006) also documents the ongoing presence of stigma while suggesting that stigma may be more “difficult to detect and insidious” now (p. 17) than it was during earlier phases of the epidemic. Similarly, an American study (Herek et al., 2002) reports that during the 1990s expressions of overt stigma declined while more covert forms of stigma persisted and in some cases increased.

Disclosure of HIV status continues to be problematic due to fears about stigmatization and discrimination. Participants in a recent American study (Ware et al., 2006) invested a great deal of effort in concealing their HIV status to avoid stigma, and even compromised adher-

ence to antiretroviral therapy in order to safeguard social relationships. Our findings are of particular concern because of the difficulties encountered by PHAs in disclosing their HIV status not only to families and communities but also to HCPs. These results have profound implications for the provision of care and treatment of HIV and AIDS.

The findings suggest that AIDS stigma presents several paradoxes. *Secrecy* was considered by some participants to be essential to mitigate stigma when accessing HIV treatment. However, some participants viewed secrecy as the “creator of stigma surrounding the illness” (Ethan, PHA, age 36). A *health-care setting* established specifically for the gay community became stigmatizing for women who were heterosexual and thus a minority in that setting. *Rural health services* were more stigmatizing for some participants, while others found them to be superior to those in urban settings. Finally, although *layering of stigma* is assumed to increase its burden, for some participants the dual diagnosis of HIV and hepatitis B or C may have served to mitigate AIDS stigma.

Layering, or the double burden of stigma experienced by persons with HIV, was identified early in the epidemic (Kowalewski, 1988) and is consistent with our findings related to the intersection of multiple stigmas. Women with HIV may well be enduring more stigma than men (International Center for Research on Women, 2006). Researchers have argued that disentangling and assessing the layers of HIV-related stigma are critical to the development of effective interventions (Reidpath & Chan, 2005b). They suggest that stigma may be unique (e.g., related to IDU or bisexuality), shared (overlapping stigma from two attributes), or synergistic. Reidpath and Chan’s conceptualization of stigma, though an important contribution, fails to acknowledge stigma that operates beyond the individual level.

In our study, AIDS stigma at the individual level often intersected with social stigma related to gender, Aboriginal background, sexual identity, and organizational policies and norms. Conceptualizations of stigma must move to explanatory frameworks that acknowledge the social and structural influences on AIDS stigma (Parker & Aggleton, 2003). Interventions to address AIDS stigma must “be complemented by actions that have as their starting point the deeper social, political and economic causes of stigma and discrimination” (Parker & Aggleton, p. 21).

The experiences of stigma at the individual level intersect and overlap with the broader context of health care, including health-care providers, the health-care system, and society. This makes it difficult for HCPs and PHAs to mitigate stigma. The development of effective interventions must be predicated on an understanding of the context of AIDS stigma (Skinner & Mfecane, 2004). Holzemer and colleagues (2007) conclude that stigmatization occurs in the context of the environment, the health-

care system, and individual agents. The narratives of the participants in our study demonstrate the complex and layered nature of AIDS stigma and the complexity of the task of disentangling those layers to develop interventions.

During the process of analyzing the data, the research team became increasingly aware that the narratives of the PHAs were very similar to those of the HCPs, even though the guiding questions were different. The similarity may be related to the data-collection settings. Because they were recruited from settings that provide services to PHAs, the HCPs may have been particularly sensitive to the issues faced by this population. This finding may highlight a limitation of the study: homogeneity of participating sites. We recommend that future researchers sample a wider range of health-care organizations, to ensure that the HCPs have a broad range of experience in working with PHAs. Also, given the variety of Aboriginal groups and provincial health-care systems across the country, and their intersections with the federal health-care system dedicated to Aboriginal needs, future research could include replication in other regions. This not only would allow for comparison across sites but would elicit information on specific intervention needs across Canada. Generalization using quantitative methods could be explored as well. Further research is also needed to determine the best entry point for reducing stigma when it is layered, as well as to evaluate the interventions designed as a result of the community consultation workshops.

## Conclusion

The findings from this study provide a compelling account of the ongoing experiences of multi-layered stigma among persons living with HIV and AIDS in Canada. The use of universal precautions, the model of care, and the design of services could either contribute to or reduce the experience of stigma. The findings also suggest that AIDS stigma presents many paradoxes. Therefore, a single approach to health-care delivery intended to reduce AIDS stigma will be insufficient to meet the needs of all clients. The development of interventions to create an environment of care that mitigates AIDS stigma is a complex and multi-level process. This is the goal of the next phase of our project and will be the focus of a future publication.

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**L'égalité d'accès aux services de santé :  
l'expérience des réfugiées et  
des demandeuses d'asile qui s'occupent  
d'un enfant d'âge préscolaire malade**

**Ellen Olive Wahoush**

On sait peu de choses sur l'accès aux services de santé des enfants d'âge préscolaire issus de familles de réfugiés ou qui ont présenté une demande d'asile au Canada. Dans le cadre de cette étude fondée sur une approche à méthodes mixtes, nous avons recueilli des données auprès d'un échantillon choisi à dessein constitué de 55 mères habitant dans une ville de deuxième rang de la province de l'Ontario. Ces données soulèvent des questions sur l'accès de ces familles aux soins primaires. Des facteurs autres que les besoins déterminent si une mère accédera ou non à des soins pour son enfant. Même si tous les enfants avaient vu un médecin au cours de l'année précédente et que 78 % disposaient d'un prestataire de soins attiré, leurs mères avaient éprouvé des difficultés à obtenir des soins lorsque le besoin se présentait. Ces difficultés sont liées au faible revenu, aux problèmes relatifs à l'assurance-maladie, à la méconnaissance des services offerts, à la peur d'être jugée en tant que parent et à la discrimination perçue. Ces observations comportent des implications pour les prestataires de soins, dont les personnes qui travaillent dans les services d'établissement, la protection de l'enfance et la santé publique.

Mots clés : accès aux soins de santé, réfugiés

# **Equitable Health–Care Access: The Experiences of Refugee and Refugee Claimant Mothers With an Ill Preschooler**

**Ellen Olive Wahoush**

Little is known about access to health services for preschool children in refugee or refugee claimant families living in Canada. This mixed-methods study collected information from a purposive sample of 55 mothers living in a second-tier city in the province of Ontario. The findings raise questions about equitable access to primary health care for these families. Factors other than need determined whether a mother was able to access care for her child. Although all the children had been seen by a doctor during the preceding year and 78% had a regular care provider, mothers faced difficulties accessing care when needed. These difficulties were related to low income, problems with health insurance, lack of knowledge about available services, fear of being judged as a parent, and perceived discrimination. The findings have implications for care providers, including those working in settlement services, child protection, and public health.

Keywords: health-care disparities, health-care access, child health, refugee, asylum seeker

The number of immigrants entering Canada in the past 10 years has been estimated at close to 2.4 million, far more than in any decade since 1931 and accounting for two thirds of the country's population growth. Accompanying this increase in the number of immigrants is a dramatic shift in source countries — from the United Kingdom, the United States, and Europe to Africa, Southeast Asia, and South America. The Canadian health-care system must now address the health needs of new arrivals from a host of cultures and speaking an array of languages.

Refugees are an important subgroup of immigrants, comprising 11% to 13.9% of the annual total (25,120 to 32,686) (Citizenship and Immigration Canada, 2005). Refugees are either “Convention” refugees — those who meet the United Nations definition of “refugee” and come to Canada sponsored by the government, their families, or community groups; or refugee claimants — those who arrive in Canada and then seek refugee status. Approximately 50% of all refugees in Canada arrive as refugee claimants, and almost all become Canadian citizens.

Experiencing very high levels of disadvantage in income, housing, and access to employment, refugees face many challenges as they settle into

Canadian communities (Chui, 2003; Jenson, 2000; Papillon, 2003; Picot & Hou, 2003). These challenges should raise concerns about their health, health behaviour, and access to care, particularly in relation to their preschool children, who constitute 5% of all refugees. However, there is almost no research literature on the health practices of refugee families (Hyman, 2001; Mulvihill, Mailloux, & Atkin, 2001). Indeed, empirical evidence on the health practices of parents on behalf of their young children is extremely limited in Canada.

This article describes a mixed-methods study of health behaviours of refugee mothers responding to an acute minor illness in their eldest child under 4 years of age. A total of 55 mothers who were Convention refugees ( $n = 27$ ) or refugee claimants ( $n = 28$ ) participated in either a focus group ( $n = 22$ ) or a semi-structured interview ( $n = 33$ ). At the time of the study, which was conducted between August 2004 and May 2005, all participants lived in Hamilton, Ontario.

The objective was to generate evidence about equity and access to health services for preschool children in refugee families. Three research questions informed the objective: 1. *How do refugee and refugee claimant mothers respond when their preschool child has an acute minor illness?* 2. *What factors influence mothers' choices and actions in helping their child to recover?* 3. *What problems or barriers do mothers encounter in seeking access to health services for their child?*

The selection of concepts for study was guided by the Andersen Model of Health Behaviour, a socio-ecological model widely used in health research with vulnerable populations (Andersen et al., 2002; Beiser, Dion, Gotowiec, Hyman, & Vu, 2002; Brown et al., 2004; Gelberg, Andersen, & Leake, 2000). In brief, this all-encompassing model outlines a relationship between four broad concepts: environment, population characteristics, health behaviour, and outcomes. Three aspects of population characteristics have been shown to predict most health behaviours. These are predisposing characteristics such as age and gender; enabling factors such as health insurance, transportation, and having a regular health-care provider; and perceived need (Andersen et al., 2002). In this study, enabling factors and the health behaviours of the mothers were the prime areas of interest. Selected concepts included socio-economic factors; enablers such as health insurance; having a regular health-care provider; and health behaviours.

### Literature Review

Convention refugees are sponsored by government, family members, or community groups, have access to provincial health insurance and support services to facilitate their settlement in Canada, and are rarely

able to return to their homeland. Refugee claimants apply for refugee status upon or after their arrival in Canada. They must prove that they meet the United Nations definition of “refugee” while remaining in Canada, a process that can take years. Refugee claimants have no access to settlement support services but may obtain health insurance through the Interim Federal Health Program (IFHP), which offers more limited coverage than provincial plans. Refugee claimants were included in this study, as almost half of all claimants make successful claims and become permanent residents. Convention refugees and refugee claimants are a vulnerable population in Canada and their numbers are increasing.

Refugees are under-researched in Canada (Gagnon, 2002; Hyman, 2001). Most research on refugees has focused on settlement issues related to housing, income (Picot & Hou, 2003), and access to employment (Friesen et al., 2002; Frisken & Wallace, 2002; Kilbride, 2001). Research on the health of refugees has concentrated on the mental health of adults (Rios et al., 2000; Yuan, Rootman, & Tayeh, 2000), seniors, and adolescents (Beiser, Shik, & Curyk, 1999; Beiser et al., 2002) or on reproductive health (Gagnon et al., 2007). There have been few studies examining health-care access for young children, and little is known about health-care access for refugee children in Canada.

Studies of immigrant health fall into two categories: secondary analyses of large surveys, and small studies with specific ethno-racial groups. Large-scale surveys such as the Canadian Community Health Survey focus on older adolescents and adults (Statistics Canada, 2002, 2003a). The National Longitudinal Survey of Children and Youth focuses on children but does not identify refugees (Statistics Canada, 2005) and the Longitudinal Survey of Immigrants to Canada (Chui, 2003) is restricted to Convention refugees and does not include children. Findings from studies with specific ethno-racial groups are so narrowly focused that they reveal little that is applicable to refugees in general or the response of the health-care system to their needs (Robertson et al., 2006; Simich, 2004; Spencer & Le, 2006). In view of the fact that, in the general population, primary health care is used more frequently by younger children than by older children, the dearth of research on use of health services represents a gap in the literature (Brownell et al., 2002; Casanova & Starfield, 2003; Polivka et al., 2000).

In summary, evidence concerning health-care access by children is limited. Effective and appropriate care of common acute minor illnesses is important for maintaining child health. This article presents results from a study of refugee mothers’ attempts to meet the needs of their preschool children during an acute minor illness. The study was intended to address the lack of empirical evidence on the use of primary health care by

refugee mothers in Canada and the response of the health-care system to their needs (Hyman, 2001).

### **Methods**

This mixed-methods study employed a retrospective cross-sectional semi-structured interview design supplemented with three focus groups. Purposive sampling was used to promote the inclusion of the most informative participants, refugee and refugee claimant mothers of a preschool child. A network recruitment approach using multiple start points was selected, to achieve a maximally diverse sample of mothers, to minimize the risk of ethnocentric and researcher bias, and to reach mothers who might not use conventional health care. To accommodate their preferences and facilitate recruitment, mothers were offered a choice: they could either attend a focus group meeting or have a personal interview.

The interviews were audiotaped to enable cross-checking of handwritten notes for completeness and accuracy. Three interpreters were trained by the principal investigator to ensure that mothers understood the questions and had an opportunity to respond in their own "voice." The principal investigator conducted those interviews and focus groups where interpretation was not needed. When an interpreter was needed, the principal investigator attended, took field notes, and was available to answer questions. Ten interviews and two focus groups required interpreter assistance in one of six languages.

Qualitative data were transcribed verbatim. The principal investigator and two research associates identified key concepts by means of content analysis. These concepts were grouped thematically using an inductive approach described by Miles and Huberman (1994). Three interview transcriptions were independently analyzed by an expert nurse researcher. Differences were resolved through a review of field notes, discussion, and consensus. Potential risks to rigour and trustworthiness associated with the use of interpreters were addressed through the inclusion of cross-checking elements in the interview guides, the training of interpreters in the use of standard methods, and attendance by the principal investigator at each interview for the purpose of recording detailed field notes for post-interview clarification. Quantitative analysis was performed using SPSS version 12 to generate the descriptive information presented in the study.

To be eligible, mothers had to be living in Hamilton, to meet the criteria for status as Convention refugees or refugee claimants, and to be able to communicate in English or one of the six languages for which interpreter support was available (Arabic, Farsi, French, Somali, Spanish, and Tigrinya). Explanations were provided in the mother's language or in

English. Informed consent was requested of all participants at the time of the interview. Ethical approval was obtained from the University of Toronto Research Ethics Board. For families with more than one preschool child, mothers were asked to respond in relation to the older (or oldest) child.

### **Findings**

Fifty-five mothers participated in one of three focus groups ( $n = 22$ ) or in a semi-structured interview ( $n = 33$ ). Refugee mothers were evenly divided between interviews and focus groups (14 vs. 13), whereas refugee claimants were more represented in interviews ( $n = 19$ ) than in focus groups ( $n = 9$ ).

Collectively, mothers represented all immigrant source regions. Roughly half were Convention refugees. A majority had settled in Hamilton upon arrival (56%). Among those who had moved to Hamilton from another location in Canada (secondary migrants) (44%), most had come from Toronto (Table 1). Almost half of the children in the study had been born in Canada. More than half of all mothers did not know anyone in Canada when they first arrived and many were lone parents. More than half of the mothers had college or university education and one quarter had less than high school or no formal education. Approximately two thirds of mothers had Ontario provincial health insurance (OHIP), while the remainder had IFHP insurance. Over 90% of the mothers lived below the poverty line.

#### ***Mothers' Responses to Their Child's Acute Minor Illness***

In rank order, the most common illnesses that mothers attempted to treat on their own, at least initially, were fever, coughs and colds, diarrhea, rashes, sore throat, and earache. There was no difference in the types of illness that led to a consultation with a health-care provider. The key factors that led mothers to consult a provider were duration of the illness, perceived severity of the illness, and perceived threat associated with the illness.

Mothers used an array of strategies in response to the illness. These can be placed in two broad categories: personal health practices, and health-services access (Figure 1). Personal health practices, which were common during the initial phase of the illness, comprised three main roles. The role of interventionist included seeking advice and providing therapies to restore the child's health. The role of monitor had mothers checking the child's well-being, watching the child, and waiting for the child to recover. Finally, in the role of comforter the mothers attended to the child's need for rest or for special attention.

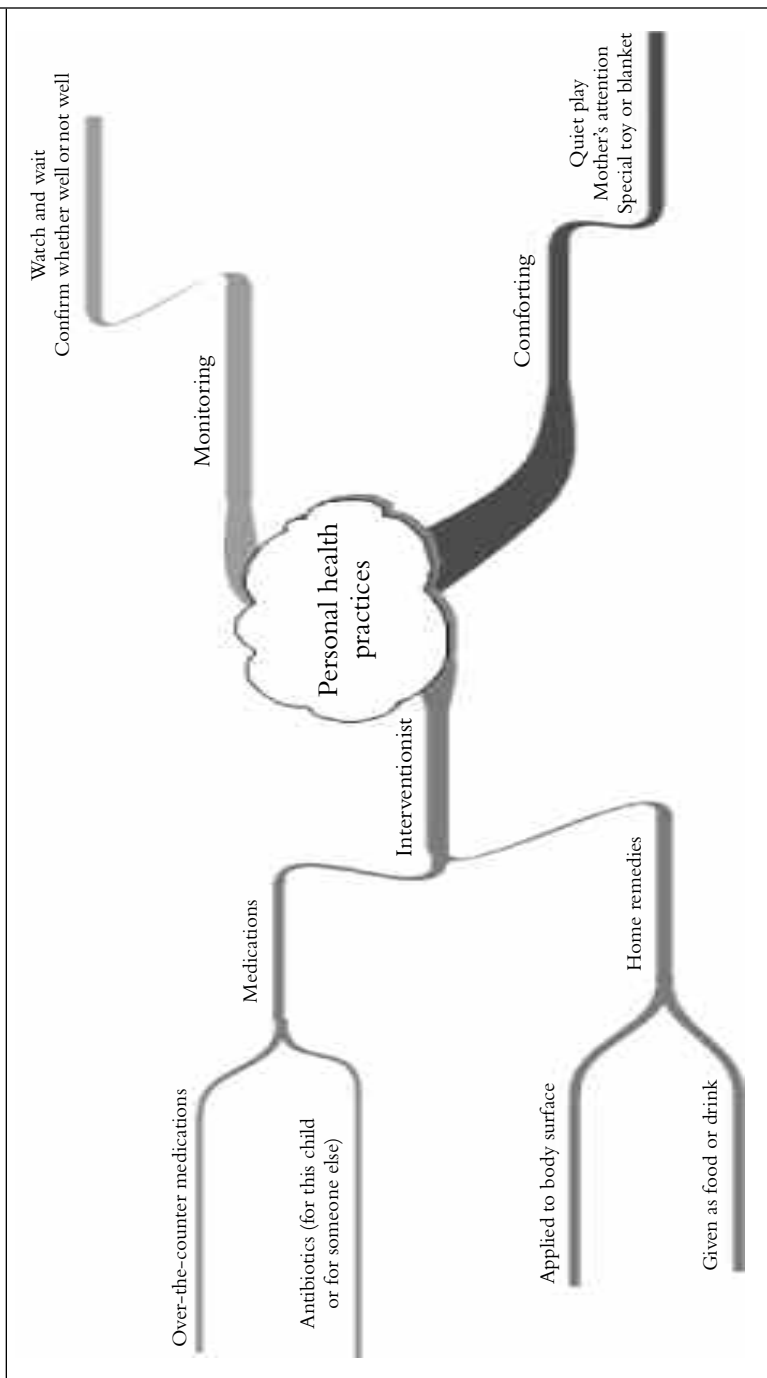
<b>Table 1 Sociodemographic Data</b>				
<b>Source Region of Mothers</b>	<b>Convention Refugees n = 27 (%)</b>	<b>Refugee Claimants n = 28 (%)</b>	<b>Total N = 55 (%)</b>	<b>Survey of Refugees<sup>a</sup> n = 9,800 (%)</b>
Africa	91.5%	39.3%	33 60.0	23.6
Asia and Middle East	18.5%	28.6%	13 23.6	52.0
Europe	0	14.3%	4 7.3	17.2
Pacific	0	3.6%	1 1.8	n/a
South and Central America	0	14.3%	4 7.3	n/a
<b>Social Contacts in Canada</b>				
Knew no one pre-arrival	14 51.9	16 57.1	30 54.5	24.6
Lone parent	15 55.6	11 39.3	26 47.3	24.8
<b>First Location in Canada</b>				
Hamilton	20 74.0	11 39.3	31 56.4	
Toronto	4 14.8	12 42.9	16 29.0	
Other	3 11.1	5 17.8	8 14.6	
<b>Child's Place of Birth</b>				
Canada	13 48.1	16 48.5	29 52.7	
Not Canadian-born	14 51.9	12 42.9	26 47.3	



*Health-Care Experiences of Refugee Mothers With an Ill Preschooler*

<b>Education</b>						
None or less than high school					14	25.5
High school					12	21.8
College					18	32.7
University					11	20.0
						37.8
						28.3
						22.2
						11.5
<b>Time in Canada</b>						
Less than 24 months	20	74.0	9	32.1	29	52.7
Between 25 and 48 months	5	18.5	16	57.1	21	75.0
More than 48 months	2	7.4	3	10.7	5	17.9
<b>Health Insurance<sup>b</sup></b>		<b>n = 14</b>		<b>n = 19</b>		<b>N = 33</b>
Mother IFHP	4	28.6	8	42.1	12	36.4
OHIP	10	71.4	11	57.9	21	63.6
Child IFHP	3	21.4	5	26.3	8	24.2
OHIP	11	78.6	14	73.7	25	75.8
						n/a
						n/a
<b>Household Income<sup>b</sup></b>						
< \$20,000	11	78.6	14	87.5		
> \$20,001	3	21.4	2	12.5		
Below LICO (low income cut-off)	13	92.9	18	94.7 <sup>c</sup>	31	93.9
						52.4
<p><sup>a</sup> Information from Longitudinal Survey of Immigrants to Canada 2001 (Chui, 2003).  <sup>b</sup> Information from mothers who were interviewed (n = 33).  <sup>c</sup> Excludes three mothers who said they did not know; if included as income above LICO, the percentage below LICO is 84.8.</p>						

Figure 1 *Personal Health Practices of Mothers*



The following example of a mother seeking advice while waiting to see if her child would recover or would need to see a doctor illustrates the value placed on experience:

*I've been just calling the women from church, some of whom are grandmothers. They have been a good group I can always rely on. I am not . . . a person that runs straight . . . to the doctor. My mom never did that. . . . I would ask women first, before I rush to the doctor, you know. Sometimes that is good, sometimes that is bad. I really don't have the expertise. It could be something major and I don't know.* (refugee claimant; mother of 3-year-old girl)

This mother had no relatives in Canada. For the majority of mothers, their first source of advice was a health professional, a friend, or a family member. Health professionals were most often a family doctor, a public health nurse, or a nurse practitioner at a community health centre. For almost one third of the mothers, the Internet and Telehealth Ontario were important sources of information. Telehealth Ontario is a 24-hour telephone service that connects Ontario residents to a registered nurse for information or advice. All mothers in the study had access to a telephone.

The mothers all described similar therapies (Table 2), which included fluids, over-the-counter medications, rest, and special foods made at home. Home remedies were described by all the mothers. Remedies such as herbal teas, massages, specially prepared foods, and substances applied to the skin were common interventions as mothers watched and waited to see if their child showed signs of recovery or needed to see a doctor:

*I give honey mixed with bareqa (poppy seed oil) to sweeten it. Honey and garlic and geet oil. I can get it at [name of local pharmacy]. I give this to her to drink before eating, rub olive oil on chest. If diarrhea, I give Pedialyte and yogurt. Home medicines work well.* (refugee; mother of 3-year-old girl)

Mothers used a variety of interventions before deciding to consult a doctor. Some worried about being judged negatively if they delayed too long, while others worried about being seen as “not coping” if they acted too soon. Some women expressed concern that their child would be “taken away.”

Mothers seeking health care most often visited a doctor; few used community health centres (see Table 2). More than half the mothers were able to visit or otherwise access a health professional for advice immediately (the same day).

<b>Table 2 Health Behaviour of Mothers</b>					
<b>Actions at Home</b>	<b>Convention Refugees n = 14 (%)</b>		<b>Refugee Claimants n = 19 (%)</b>		<b>Total N = 33</b>
Advice from family outside Canada	6	42.9	6	31.6	12
Fluids/fluids only (2)	11	78.6	11	57.9	22
Over-the-counter medications	8	57.1	16	84.2	18
Comfort measures (bath/massage)	11	78.6	13	68.4	24
Rest	8	57.1	14	73.7	22
Special food	6	42.9	9	47.4	15
None; always see doctor	2	14.3	1	5.3	3
<b>Total Responses</b>	<b>46</b>		<b>64</b>		<b>110</b>
<b>Medications at Home</b>					
None	3		1		4
1 to 2	5		11		16
3	1		5		6
4	5		2		7
<b>Total Respondents</b>	<b>14</b>		<b>19</b>		<b>33</b>
<b>Health-Care Provider Consulted</b>					
Family doctor	12		10		22
Walk-in clinic	4		10		14
Emergency department	4		8		12
Community health clinic	2		4		6
Urgent care	1		0		1
Nurse clinic	0		1		1
Father, sister, friends	0		1		1
<b>Total Responses</b>	<b>23</b>		<b>34</b>		<b>57</b>
Health-care needs unmet	2		6		8
<b>Total Respondents</b>	<b>14</b>		<b>19</b>		<b>33</b>

When describing what they did to help their child recover, mothers included details that highlight the impact of living in poverty, social networks, and awareness of available services.

***Factors Influencing Mothers' Choices and Actions in Helping Their Child to Recover***

Enabling factors in the Andersen model include personal, family, and community-based factors. Personal enabling factors are perceived need, awareness of available health services, and the means to access health services. More than 90% of the participants rated their child's health status as good to excellent, indicating a low level of perceived need (Table 3). Few mothers were aware of the full range of services available. The health-care sources most consistently identified were family doctors and emergency departments. Much less frequently mentioned were community health centres and walk-in clinics. For most participants, social supports were limited, at least initially, as few of the mothers knew anyone in Canada before they arrived and almost 50% were lone parents.

Most mothers reported the following as enabling factors: living in the same city (since arriving in Canada), community-based factors such as public transit, and the help or advice of friends. The most frequently reported transportation choice was buses. Some health services were more available than others. Excluding emergency departments, walk-in clinics had the most after-hours availability, while most other providers had some evening and weekend hours. There was no difference between refugees and refugee claimants in the proportion of children with a regular health-service provider, and all mothers had consulted a health professional, usually a doctor, about their child during the preceding year.

Mothers identified a number of features as important in a health-service provider. These included language ability (five doctors) or interpreter support (at community health clinics); the ability to be seen without an appointment; health-care provider acceptance of IFHP; comprehensiveness of services; "knows us"; and proximity to home.

***Problems or Barriers Encountered by Mothers Seeking Access to Health Services***

The absence of enabling features, perceived high cost, and negative prior experiences with providers were barriers to care for mothers looking after an ill child. Eight mothers, mostly refugee claimants ( $n = 6$ , 31.6%, vs.  $n = 2$ , 14.3%), were unable to obtain health care for their child when they believed it was needed because they had no interpreter support ( $n = 2$ ), no means of transport ( $n = 2$ ), or insurance problems ( $n = 2$ ). Mothers reported being turned away by providers because they had

<b>Table 3 Health and Health Care of Preschool Children</b>						
	<b>Convention Refugees n = 27 (%)</b>	<b>Refugee Claimants n = 28 (%)</b>	<b>Total N = 55 (%)</b>	<b>Refugees (LSIC)<sup>a</sup> (%)</b>	<b>General Population<sup>b</sup> (%)</b>	
<b>Mother's Rating of Child's Health (n = 55)</b>						
Excellent/very good	14 51.9	19 67.9	33 60.0	78.0	58.6	
Good	11 40.7	7 25.0	18 32.7	19.0	28.8	
Poor/fair	2 7.4	2 7.1	4 7.3	3.0	12.4	
<b>Interviewed Mothers</b>	<b>n = 14</b>	<b>n = 19</b>	<b>N = 33</b>			
Regular provider	11 78.6	15 78.9	26 78.8 <sup>c</sup>		91.2	
<b>Interpreter Support</b>						
Needed	9 64.3	8 42.1	17 51.5			
Offered	3 33.0	2 25.0	5 29.4			
<b>Transportation</b>						
Own car			11 33.0			
Bus			13 39.4			
Walk			9 27.6			

<b>Missed Meals</b>								
Once or twice/week	2	14.3	3	15.8	5	15.1		
Once or twice/month	3	21.4	10	52.6	13	39.4		
Never	9	64.3	6	31.6	15	45.5		90.0
<b>Sources of Advice</b>								
Doctor	14	100.0	19	100.0	33	100.0		
Nurse	7	50.0	13	68.4	20	63.6		
Pharmacy staff	8	57.1	11	57.8	19	57.6		
Friend	9	64.3	12	63.1	20	63.6		
Family	4	28.6	11	57.8	15	45.5		
Internet	2	25.0	7	36.8	10	30.3		
Telehealth Ontario	3	21.4	5	26.3	8	24.2		
							80.8	81.8
								12.8

<sup>a</sup> Longitudinal Survey of Immigrants to Canada 2001 (Chui, 2003).

<sup>b</sup> Statistics Canada (2003), Cycle 2.1.

<sup>c</sup> Includes three emergency departments as regular providers; if excluded, 69.7% of children had regular health-service providers.

IFHP insurance only. The following mother was unaware of available no-fee health and dental services close by:

*She had a toothache. I could not afford a dentist and I did not know where to go or that dental service is possible without a fee. I tried to distract her, make her comfortable, and gave pain medication until the tooth stopped hurting — 3 days. . . . It was a baby tooth and temporary.*  
(refugee claimant; mother of 3-year-old girl)

This mother had no relatives in Canada and few people available to advise her.

Mothers encountered two problems when helping their child to get better: cost, and negative experiences during health-service encounters.

Cost was a significant barrier for many mothers, in particular refugee claimants. Five refugee claimants reported having to pay a fee to be seen by a doctor. Fees ranged from \$25 at a walk-in clinic to more than \$200 at an emergency department. Emergency departments were the only health service available after 10 p.m. and on weekends. The cost of over-the-counter medications such as Tylenol or cough syrup had a significant impact. For up to 50% of the mothers, this cost resulted in missed meals on a monthly basis. Mothers also reported that their partner and older children missed meals so that younger children would not go hungry (Table 3).

Negative experiences reported by more than one third of mothers included witnessing or being the object of racism and discrimination in the health-care system. "They pretend they do not understand me," said one refugee claimant, who was aware of her accented English. Two mothers identified prolonged waiting in an emergency department as evidence of racism. All other reports of racism concerned the attitude of health-service providers. More refugee claimants than Convention refugees reported such incidents.

## Discussion

In general, the participants appeared to have acted similarly to most mothers of a preschool child with an acute minor illness (Janicke, Finney, & Riley, 2001; Yearwood, 2007). However, detailed analysis revealed differences relating primarily to refugee status. Health insurance, though important, was not sufficient to ensure access to health services. Even mothers of children who were born in Canada and were covered by OHIP had little or no information on health services available to them. As a consequence, they engaged in extensive problem-solving to manage their child's illness.



Equitable health care means that services are accessible based on need (Andersen, 1995). This study found that factors other than need determined whether a mother was able to access health care for her child. All mothers faced challenges related to income and awareness of the range of health-service providers available.

All mothers described personal health practices they used to help their child recover, and all had contacted a doctor for their child at least once during the preceding year. This is higher than the proportion reported for the general population or in previous immigrant surveys (Chui, 2003; Statistics Canada, 2003a) and suggests that access to health care was not a problem for mothers in the study. However, this finding may reflect increased need due to the age of the child (Brownell et al., 2002; Casanova & Starfield, 2003) or may suggest that the needs of refugees and refugee claimants are greater than those reported for the general population.

Although all the children had health insurance, both OHIP and IFHP are limited in terms of the services they cover. Furthermore, for the participants in this study, policy guidelines were not always followed in the granting of insurance coverage. Some Convention refugee mothers were still insured by IFHP when they should have been covered by OHIP. The 90-day wait for OHIP coverage was eliminated for Convention refugees in May 2004 (Ministry of Health and Long Term Care Ontario, 2005). Yet mothers reported that they had been told they were not eligible for OHIP. This finding is supported by the literature (Gagnon, 2004; Wayland, 2006). OHIP coverage had one important advantage: It was accepted by all health-service providers. All children born in Canada had OHIP coverage but differences in health insurance among members of the same family were common.

Approximately 75% of the children had a regular health-care provider. This is a lower percentage than that reported for the general population. It may reflect the fact that the mothers of these children were new to the community, or it may indicate reluctance on the part of health-service providers to accept refugee or refugee claimant families as patients.

Poverty among mothers in this study was much greater than reported for recent Convention refugees in the Longitudinal Survey of Immigrants to Canada (Chui, 2003) and almost four times the rate for the general population of young children in Hamilton (Statistics Canada, 2003b). The impact of poverty on access to health care is compounded by limited access to employment that offers health insurance benefits (Tolley, 2003). Consequences of low income were dire when mothers had little or no health insurance and little awareness of available services. However, Convention refugees are provided settlement and integration services for at least their first year in Canada (Ministry of Citizenship,

2002; Simich, Beiser, Stewart, & Mwakarimba, 2005) and most of the mothers in this study had been in the country less than 2 years.

In addition, most mothers lacked information about potentially useful health resources. The exclusion of refugee claimants from settlement support services prevents them from connecting with important sources of support and information or with other people in similar circumstances. The refugee claimant mothers in this study developed small social support networks consisting of women they met at a clinic or shelter or through their church. These informal networks were similar to those reported by Simich (2004).

In spite of the fact that only refugee claimants were charged for health services, more women in this group than in the Convention refugee group reported visiting an emergency department, even during daytime hours when other, less expensive options were available. This could be due to lack of information about community health centres and walk-in clinics, or it may suggest that these mothers did not know how to access such services (Hatton & Bacic, 2001). These health behaviours may also reflect a desire to be seen as a “good” parent or as “not greedy or needy” (Harney, 2003).

In addition to factors that may have inhibited access to health services for all of the mothers, individuals with IFHP face provider refusal to accept the fee offered by the plan. Having to wait to be seen in the emergency department, or being turned away because of inadequate insurance coverage, led to dissatisfaction and was perceived by a few mothers as evidence of racism. Participants stated that they would seek a different provider next time; this example of outcomes influencing future health-service use supports the Andersen (1995) model.

The findings of this study have implications for care providers, including those working with settlement services or in child protection or public health settings. Refugee mothers are not fully aware of the health services available to them at little or no cost and of their entitlements to health insurance. Also, they are fearful of child protection services in Canada, largely due to misconceptions about the role of these organizations. Care providers are well positioned to address the informational needs of refugee mothers. In addition, health practitioners should be informed about the impact of health-service experiences on the willingness of mothers to seek care for their children. When mothers with IFHP coverage are refused care, they are unlikely to return and may be unable to locate an alternative provider, compromising their child’s health. Health-care staff need to be trained in working with refugee and other immigrant groups. In addition, sensitive explanation of expected delays and wait times may help prevent these being interpreted as racist or discriminatory.

This study may be the first to focus on the health of preschool children in refugee and refugee claimant families. Locating the study in a second-tier city is consistent with immigration policy, which is now promoting the dispersal of refugees to smaller, more welcoming communities. However, the findings have limited transferability due to the small size of the sample, the restriction of the study to a single urban setting, and the fact that policies on immigrant and refugee health care are undergoing rapid change. In addition, reform measures recently instituted in Ontario include the introduction of a new multidisciplinary team for primary health care (Meuser, Bean, Goldman, & Reeves, 2006), which has the potential to improve access for vulnerable families. Future research could include other settings and examine the impact of primary health care reform on the refugee and refugee claimant population.

The findings of this study raise questions about equity of access to primary health care for refugees compared to other immigrants and the general population. When health insurance was adequate, the needs of most of the children were met during a medical visit. The health-care needs of the children in this study were similar to those of children generally. However, the responses of their mothers were affected by immigration policy and health-care policy. Despite these and other challenges, the participants exhibited strong coping skills in looking after their children.

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