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EDITORIAL

Made in Canada? In Search of a National Research Identity

To even the most casual observer of nursing internationally, the embracing of research by nurses as a guide for practice decisions over the past decade has been nothing short of remarkable. But a common response to the absence of "home-grown" research in many countries has been to borrow thinking and writings from the West, in particular from the United States. That is, up until now. Automatic recourse to American nursing texts and publications is being rapidly replaced by varying degrees of resistance to, and even antagonism towards, American research, theoretical work, and educational trends. Separate or special editions of American textbooks tailored to academic markets in Canada and other countries are now seen widely in nursing and other disciplines. This development raises some intriguing questions if we look beneath the surface, beyond the reflex to read "Canadian" (or at least to not automatically read "American"). What, for instance, makes scholarship Canadian? What purpose or purposes does the label "Canadian" serve? How can academic nationalism, if you will, be a positive force in moving the discipline of nursing forward?

Pose a question along the lines of "What makes Korean research Korean?" in virtually any country but the United States and a lively debate is likely to ensue. At least two streams of discussion will emerge. One will deal with the geographical origin of a piece of scholarship and the other will address notions of how place influences the origins and expression of ideas, the interpretation of data, and so forth.

Is a research project automatically Canadian because its subjects are North Americans who reside above the 49th parallel? Are there topics that are inherently "of" a particular country or region, because of history, geography, and politics? One immediately thinks of the Canadian health-care system and its enduring values and problems. We could easily add the experiences of the Aboriginal people in Canada and those of nursing students and their professors in CEGEPs (the junior college system in Quebec). These experiences may be similar to those of Aboriginal peoples in Australia or the United States and nursing students and professors in associate degree programs in the United States, but there may be things about them that are truly distinct. Which of the distinctions are truly important, and why? Is the social context of the nursing profession in Canada so different, in terms of definitions, constraints, and cultural values, that virtually any nursing research study conducted on Canadian soil qualifies as "Canadian"?

Perhaps a research study is Canadian because of the nationality of the researchers conducting it, or their institutional affiliations at the time of the study, or because of the population that is being studied or the location of the study, or because of all four of these factors. It is well accepted that any pretence of bias-free research is foolery. But is there something about being born in, living in, being trained as a researcher in, or working as a researcher in a specific culture that leads to a particular research slant? Thus, is a US national working in Canada Canadian? What about a Canadian-trained researcher working in the United States? One could argue that the historical, geopolitical, and economic realities of Canadian society lead researchers to discover a reality filtered through a Canadian lens. Otherwise put, perhaps a particular study is Canadian because of the cadences and inflections used by the researchers in asking and answering their research questions. The flavour of nursing scholarship in Australia appears to have been heavily influenced by historicism, critical theory, and postmodern philosophies and methodologies. How does this relate to Australia's history and political realities, and its systems of nursing and nursing education? Are there tendencies, biases, or filters that researchers bring to the framing of a research question or the interpretation of data that could be considered uniquely Canadian?

Why even attempt to answer any of these questions? We think that important opportunities are missed for researchers, consumers of research, and indeed the profession itself when questions of place and nationality are sidestepped. Ultimately, we need to ask whether there are universal experiences of the human phenomena and the nursing care that nurses study, and whether universal elements in the development and execution of research projects transcend cultures. Surely there must be some commonalities. But where are national differences important and where are they trivial? In what ways are our clients, our care, and our approach to scholarship dependent on where we work? Do we really understand cultural differences at all, or are we merely pretending that our work has universal meaning and applicability? Is there such a thing as context-free nursing research?

The notion that country of origin should have more influence in determining the audience for a piece of work than the quality of ideas and their development is, of course, responsible for at least one stream of anti-Americanism in the academic world. But at what point does a focus on what is Canadian and what is not become insular and parochial? At what point does it lead to a research enterprise that is self-perpetuating and self-satisfied? Open questions all. The real ones for us and for you are whether national distinctions serve the interests of science and the extent to which research reporting advances or undermines the pursuit of cultural competence and better care for nursing's clients. All of these issues need to be probed.

We both began our careers at a time when there were few or no Canadian nursing texts to be assigned, and when few researchers worked in Canada and even fewer purposely identified themselves or their research projects as Canadian. Ensuring a "home" for Canadian work can stimulate local pride (especially in the next generation of scholars) and can provide an outlet for researchers who may not have the resources or support to "compete" on a larger scale. We cherish the Journal's place as a home for scholarly work for the growing community of nurse researchers in Canada. However, the *CJNR* will consider publishing sound scholarship from any country in the world. It always has and, under our editorship, always will. Never in our recollection has any acceptable manuscript been turned away, whether from a Canadian or Canadian-based scholar or from a scholar living or working in another country.

If we may be so bold as to generalize, Canadians pride themselves on their sensitivity to national and cultural identity and their often heroic efforts to be outward-looking citizens of the world. In that spirit, we would like to make a modest proposal to the authors who submit papers to the *CJNR* as well as to our readers and the wider constituency of nurse scholars at all levels across Canada and the world. Let's consider specific elements of research questions and study designs and research reports that are uniquely Canadian (or Australian or American, whatever the case may be). Let's attempt to write clearly about the experiences or phenomena we believe are shared with other countries and regions and the ones we believe are distinct. Let's make more effort to explore similarities and differences in the experience of health and illness, in health-care delivery systems, and in the practice of nursing across countries and cultures, instead of taking for granted that we (and all of our readers) truly understand cross-cultural and cross-national issues in our work.

In the coming years, as a result of efforts to extend the Journal's reach and influence, you'll be seeing more research papers and integrative essays that take a comparative cultural approach to nursing scholarship. In the meantime, we encourage you to begin thinking more broadly about the role of nationality and culture in the research enterprise. Ask yourself, your students, and your colleagues what exactly is meant when the label "Canadian" is used in your scholarly endeavours. Proud nationalism can be a great positive force, but open-mindedness and intellectual curiosity about the world beyond and how others see it are essential parts of the nurse scholar's toolkit in any country or culture.

Sean P. Clarke,
Associate Editor

Laurie N. Gottlieb,
Editor-in-Chief

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GUEST EDITORIAL

Advancing Nursing Scholarship in Diversity: Complexity and Equity

Colleen Varcoe

Diversity is a broad yet powerful idea that encompasses the ideas of difference and complexity. Multiple forms of diversity are important in nursing and health care, yet it is often only "cultural" diversity that comes to mind and commands attention. As culture is often conflated with ethnicity, attention to cultural diversity often focuses narrowly and defines people by nation, ethnicity, or race. In contrast, this issue of the Journal offers a panoply of differences of concern to nursing.

Diversity is of critical concern to Canadian society in general and Canadian health care and nursing in particular, because of our expressed commitment to justice and equity, especially in health care. Because inequities occur along the lines of difference — in relation to age, ability, income, ethnicity, sexual orientation, geography, and other forms of difference — attention to diversity is fundamental to a lessening of health inequities. Analyses of diversity and difference thus invariably lead to questions of equity — questions that are addressed skilfully in relation to health throughout the papers in this issue of the *CJNR*. Indeed, the importance of diversity, in all its forms, to health care, nursing practice, and nursing research is evidenced by the large number of submissions received for this issue and the range of concerns they addressed.

To address equity, analyses of diversity must attend to language, power dynamics, the intersections among various forms of inequity, and the specific contexts within which inequities occur. The contributors to this issue of the Journal turn their attention to diversity with conscious analysis of how various forms of diversity and difference intersect, and how language, taken-for-granted ideas, and dominance operate to foster inequity based on difference.

The papers included in this issue illustrate how language functions within the politics of difference and can serve to create and sustain inequity. Most importantly, Anderson offers a critique of a discourse that constructs "diversity" only in terms of categories of oppression such as "marginalized" or "racialized" and uses such categories in fixed and binary ways. Consistent with this critique, other papers in this issue draw attention to the complexity of diversity and the ways in which people and identities fluidly move across and thus challenge fixed and binary categories. For example, Canales reports that identities and one's connecting to a sense of Nativeness varied greatly among the women in her study, and she shows how such connection led the women towards and also away from both biomedical approaches and traditional approaches to health and healing.

Each paper focuses upon a different primary concern, but all draw attention to intersecting inequities and the contexts within which they arise. For example, Hyman and her colleagues carefully examine the intersections of gender and migration in the political context of immigrating to Canada from Ethiopia. Each contribution also shows how taken-for-granted ideas and practices can serve to sustain inequity. Molzhan and her colleagues demonstrate that the conflating of culture and ethnicity can lead health-care providers and researchers to approach Aboriginal people in ways that overlook identity, diversity, and complexity. Similarly, Kirkham and her colleagues argue that conflating culture, ethnicity, and religion and replacing religious care with "spiritual" care may have the unintentional effect of writing out the experiences of non-English-speaking and non-Western people with strong creedal religious affiliations, thus perpetuating Western and largely Christian dominance. A number of the papers show how other well-intentioned practices can serve to sustain inequity. For example, Kinch and Jakubec, in their exploration of the intersections among age, gender, and racism with regard to older women, argue that while programs offered by religious and philanthropic organizations break through the loneliness experienced by older women, they can paradoxically increase isolation and obscure meaningful access to services.

All the contributions examine the institutionalization of inequity and many point to the ways in which health-care providers perpetuate inequity. For example, Sinding and colleagues report that difficult cancer-care experiences for lesbians may be less a consequence of targeting and overt homophobia and more a consequence of pervasive, taken-for-granted, institutionalized heterosexism. Fulford and Ford-Gilboe illustrate that health-care providers contribute to the stigma experienced by young mothers in ways that may increase their marginalization and social isolation, undermining their well-being.

The authors thus draw our attention to the importance of both reflexivity and collective action. Urging us to pursue conscious awareness of our biases and assumptions, they model such reflexivity. Beginning with Peternelj-Taylor's thoughtful reflection on her own participation in "othering," each paper shows the careful, honest thinking that is required in striving towards equity in the context of diversity.

Together, these papers show that diversity is not a neutral concept and offer a profound and complex understanding of how dominance is maintained. The authors help us to move beyond merely challenging stereotyping and discrimination and beyond the binary of oppressor/oppressed. Each contribution calls for analysis and change at the level of the complex historical, social, political, and economic contexts of people's lives, for the direct involvement of the people we serve in such analysis and change, and for nurses to examine their own complicity and experiences with oppression and to take action at all levels. Together the authors model and call for what is needed in our scholarship and practice — more complex analyses of diversity and difference, explicit attention to power and language, and the political will to achieve equity. As these authors show, through attention to diversity we can better respect and foster the health of all.

I am greatly privileged to have been able to collaborate with the authors whose work is published in this issue of the *CJNR* and with the excellent reviewers who provided invaluable input. I would like to thank the authors and reviewers, Dr. Laurie Gottlieb for her guidance, and Ms. Joanna Toti for her superb management of the entire editorial process.

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Discourse

The Conundrums of Binary Categories: Critical Inquiry Through the Lens of Postcolonial Feminist Humanism

Joan M. Anderson

The topic of diversity has gained widespread attention in health-care discourses in the late 20th and early 21st centuries. While in many instances it has been treated as a neutral concept devoid of political ramifications, critical discourses such as those on poststructuralism, postmodernism, postcolonialism, and feminism have challenged us to critically examine what we mean by the term and have shown us that a number of truths can be contingent upon history and setting (Fox, 1999). Steadfastly held notions of how we know, and what we know, have been questioned, not in the sense of debunking knowledge from modernist perspectives, but rather to claim the legitimacy of different forms of knowledge and to redefine who has the authority to speak, and for whom. These analytic perspectives have made visible how socio-historical-political positioning enters into the everyday to determine life chances and opportunities and the experiencing of health and well-being. But as we move into the 21st century we must ask whether these perspectives will suffice to address the complex issues that confront us. Disparities between rich and poor, continuing neo-colonization, poverty, violence, and deep-seated structural inequities continue to challenge us despite our growing awareness of the ways in which social and economic inequities affect health and well-being. Any discussion of "diversity" and health must be underpinned by a critical understanding and examination of these issues.

As we ponder the way forward, other issues come to the fore. A rereading of the Call for Papers for this issue of the Journal led me to reflect not only on what we mean by the word "diversity" but also on the specific terms that have been linked to it — for example, "marginalized," "immigrant," and "racialized." I will argue here that these associations are problematic and must be held up to scrutiny. For example, what do we mean by "immigrant"? Is a middle-class person fluent in either of

Canada's two official languages an immigrant in the same sense as a working-class person who speaks neither language? In what contexts do we invoke the label "immigrant"? Who is *really* an immigrant? Is a white academic from the United States or Great Britain categorized similarly to an academic from India? Is "immigrant" a euphemism for the racialized Other — does the term mask hidden racisms? Are white middle-class people included in the discourse on diversity, and if not, why not? And how does racialization function? Can a white middle-class man be disenfranchised through the process of racialization, and be at increased risk for health problems? My colleagues and I wrestled with this last question as we sifted through ethnographic data from one of our research studies. Our data showed us that racialization can cut both ways — an apparently privileged white middle-class family can be disenfranchised through the process of racialization (Anderson et al., 2003).

These are not easy matters to confront, especially when we have entrenched ideas about masculinity, about immigrant or Aboriginal people, and about the process of racialization and racism. There is a very real concern that drawing attention to the aforementioned issues will minimize and depoliticize the experiences of, as Homi Bhabha (1994) puts it, "those who have suffered the sentence of history — subjugation, domination, diaspora, displacement" (p. 172). I would argue, however, that far from minimizing human suffering, such analyses expose the nature of oppression in ways that allow us to address specific oppressions based on race, gender, class, age, sexual orientation, religion, and other forms of oppression, as they intersect and operate structurally and in the everyday, and, in so doing, offer the hope of eventual social justice. Furthermore, critical scholarship demands that we "unpack" the concepts that we use in ways that will make them transparent.

The writings of scholars such as Brewer (1993), Collins (1990, 2004), Gandhi (1998), Gilroy (2000), and McConaghy (2000) give us the tools to rethink concepts such as diversity and to question assumptions about the relationship between diversity and oppression. In this paper I offer a critique of a discourse on diversity that constructs it solely in terms of racialization and marginalization. Furthermore, I want to question these as fixed categories, which would suggest that some people are marginalized while others never have this experience. Such conceptualizations present the very real danger of setting up binary categories that undermine the competencies and human agency of those considered marginalized or racialized. The above-mentioned scholars help us to see that it is no longer useful, for *analytic* purposes, to think in terms of dichotomous categories (e.g., oppressed/oppressor). Rather, we need to examine *specific* oppressions at *specific* sites (McConaghy). This is not to say that these categories should not be invoked, but we must ask for what purpose, in what contexts, and with what analytic value. A very real issue with dichotomous thinking and setting up categories as distinct entities is that those of us constructed as marginalized by virtue of the category in which we are placed may see this as our right to lay claim to a moral superiority by virtue of our "oppression" and, in so doing, perpetuate even more virulent forms of oppression. This is because what we do, as members of "oppressed groups" or "marginalized groups," may go unchallenged and unquestioned by reason of our perceived diminished social positioning. We must remain mindful that "depending on the context, an individual may be an oppressor, a member of an oppressed group, or simultaneously oppressor and oppressed" (Collins, 1990, p. 225); no one of us can claim, in an uncritical way, that we belong solely to one or the other category. We need to be aware, through critical self-reflection, of the ways in which each of us can be an "oppressor," can abuse power or collude in the abuse of power, can be a "racist," can be morally bankrupt. In other words, we need to move beyond an *analysis* that positions people without critical examination of the specific context of oppression.

But I would like to raise other questions to encourage critical questioning and reflection. Might there be "value" for those who see themselves as members of a privileged group ("the centre") to construct a marginalized Other? Does this reinforce the *position of power at the "centre"*? I am suggesting that fixed binaries might privilege some at the same time that it keeps others "marginalized" by reproducing colonizing relations. But what happens when the marginalized Other "steps out of line" (e.g., resists being categorized) to contest and claim the space at the centre? What resistances and tensions from the "centre" arise as privilege is contested? Such questions are raised for reflective and analytic purposes and are by no means meant to suggest that scholars, researchers, or clinicians deliberately construct "marginality" to maintain their position of privilege. Rather, I want to question the ways in which we might, unwittingly, reinforce the very power structures we seek to dismantle, by undermining resistances "at the margins," human agency, and the competencies of those from whom many lessons can be learned. Black feminist scholars such as bell hooks (1984, 2004) and Patricia Hill Collins (1990, 2004) have shown how the view from the margins can offer new insights into the dialectic between margin and centre. As bell hooks puts it in writing about growing up in the segregated South:

> Living as we did — on the edge — we developed a particular way of seeing reality. We looked both from the outside in and from the inside out. We focused our attention on the center as well as on the margin. We understood both. This mode of seeing reminded us of the existence of a whole universe, a main body made up of both margin and center.

> Our survival depended on an ongoing public awareness of the separation between margin and center and an ongoing private acknowledgement that we were a necessary, vital part of that whole. (1984, Preface)

This understanding of both offers a particular vantage point for critical scholarship. What I also understand from hooks is that marginality is not a static concept — there is movement to and fro, from margin to centre.

So how might we move forward as we work towards a liberatory discourse? I suggest that we need to demystify the "hard categories" of marginalized and privileged, to expose how privilege is retained by some and denied to others, and the conditions of all of our vulnerabilities. This, I maintain, can be done by making situated experience the starting point of analysis, instead of the "categories" in which we are positioned. Such an analysis might well unmask the fluidity between "margin" and "centre" as identified by hooks and Collins. The example from our ethnographic research (Anderson et al., 2003) also helps to show the movement between margin and centre — a person of privilege can be made vulnerable through illness and may not be able to get the help he or she needs because of our assumptions about those we see as privileged. This is not to deny that the "social space we occupy has been historically generated" (Skeggs, 1997, p. 8). Rather, it is to show how the mediating circumstances of the everyday intervene to disrupt taken-for-granted social positions and put us at increased risk for poor health.

By pressing for the exposure of situated vulnerabilities, I hope to open an inclusive discourse on diversity that sees discrimination and social injustice not as the prerogative of those assigned to certain categories but as germane to all. No one is exempt from the discourse on diversity. Nor is anyone immune to the experience of marginalization, dehumanization, and human suffering. Scholars such as Paul Gilroy (2000) remind us that divisions along racial lines have "amputated" our common humanity — such divisions have dehumanized all of us. Postcolonial feminist authors draw our attention to interlocking systems of oppression, an approach that, as Collins (1990) puts it, "fosters a paradigmatic shift of thinking inclusively" (p. 225). Collectively, these scholars provide the conceptual lens for moving us beyond binary thinking, divisive categories, rigid boundaries, and reified identities that obscure the ways in which various oppressions and discrimination function.

I argue that a scholarship that draws on the theoretical underpinnings of postcolonial feminism and a "new" humanism, as discussed by Paul Gilroy (2000), exposes past and present injustices, and, without naivety, promises to move us towards recognizing our common fragile corporeal existence:

> This is not the humanism of existentialists and phenomenologists.... Indeed, mindful of raciological associations between past humanisms and the idea of progress, this humanism is as unfriendly toward the idea of 'race' as it is ambivalent about claims to identify progress that do not take the de-civilizing effects of continuing racial division into account....This humanism is conceived explicitly as a response to the sufferings that raciology has wrought. (pp. 17–18)

To underscore Gilroy's point — this is not a humanism that foregoes an analysis of racism, sexism, classism, ageism, and other forms of oppression. It is a humanism that is possible precisely because analysis makes explicit the specific, rather than falling back on what is assumed to exist in predetermined binary categories. We are liberated from the tensions that arise around "hierarchies of oppression" (e.g., my oppression is greater than your oppression) or from seeking a common ground where there is none. A postcolonial feminist humanism holds out hope for the opening up of a discursive space for diverse voices, resistances, and praxis that might move us towards inclusivity and social justice.

References

Anderson, J., Perry, J., Blue, C., Browne, A., Henderson, A., Khan, K.B., et al. (2003). "Re-writing" cultural safety within the postcolonial and postnational feminist project: Toward new epistemologies of healing. *Advances in Nursing Science, 26*(3), 196–214.

Bhabha, H. (1994). *The location of culture.* London and New York: Routledge.

Brewer, R. (1993). Theorizing race, class and gender: The new scholarship of black feminist intellectuals and black women's labor. In S. M. James & A. P. A. Busia (Eds.), *Theorizing black feminisms: The visionary pragmatism of black women* (pp.13–30). London and New York: Routledge.

Collins, P. H. (1990). *Black feminist thought: Knowledge, consciousness, and the politics of empowerment.* Boston: Unwin Hyman.

Collins, P. H. (2004). Learning from the outsider within: The sociological significance of black feminist thought. In S. Harding (Ed.), *The feminist standpoint theory reader: Intellectual and political controversies* (pp. 103–126). New York and London: Routledge.

Fox, N. (1999). *Beyond health: Postmodernism and embodiment.* London and New York: Free Association Books.

Gandhi, L. (1998). *Postcolonial theory: A critical introduction.* New York: Columbia University Press.

Gilroy, P. (2000). *Against race: Imagining political culture beyond the color line.* Cambridge, MA: Belknap Press of Harvard University Press.

hooks, b. (1984). *Feminist theory: From margin to center.* Boston: South End.

hooks, b. (2004). Choosing the margin as a space of radical openness. In S. Harding (Ed.), *The feminist standpoint theory reader: Intellectual and political controversies* (pp. 153–159). New York and London: Routledge.

McConaghy, C. (2000). *Rethinking indigenous education: Culturalism, colonialism and the politics of knowing.* Flaxton, Australia: Post Pressed.

Skeggs, B. (1997). *Formations of class and gender: Becoming respectable.* London/ Thousand Oaks, CA/New Delhi: Sage.

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Résumé

Importance de l'autochtonicité : Influence de l'identité des Amérindiennes sur leurs décisions en matière de santé

Mary K. Canales

Les Amérindiennes font face à des injustices sur le plan de la santé physique, mentale, et de la spiritualité. Bien que cette étude ait pour but d'examiner le processus de prise de décision chez les Amérindiennes du Nord-Est des États-Unis en ce qui concerne la mammographie, le rôle joué par l'identité autochtone dans les décisions prises en matière de santé en général a été jugé suffisamment significatif pour faire l'objet d'un rapport distinct. Les résultats d'une étude théorique à base empirique effectuée auprès de 20 Amérindiennes a servi de base à une analyse des complexités entourant la question de l'identité et de la prise de décision en matière de santé. Le thème de l'importance de l'autochtonicité reflète l'influence au plan individuel et collectif de l'identité autochtone sur les décisions prises par les femmes en matière de santé. Le document traite de ses répercussions pour les chercheurs et les cliniciens, notamment les liens entre les événements historiques et la construction de l'identité actuelle, la nature fluide de l'identité et l'impact du racisme sur les décisions relatives à la santé.

Mots clés : Amérindienne, prise de décision, théorie à base empirique, identité, Autochtone, racisme, femmes

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Connecting to Nativeness: The Influence of Women's American Indian Identity on Their Health-Care Decisions

Mary K. Canales

American Indian women experience health inequities within the physical, mental, and spiritual realms. Although the purpose of this study was to examine mammography decision-making processes among Native women in the northeastern United States, the role of Native identity in health-care decision-making in general was identified as significant and is therefore being reported independently. The findings of a grounded theory study with 20 American Indian women formed the basis for an examination of the complexities surrounding identity and health-care decision-making. The theme of Connecting to Nativeness reflects the individual and communal influences of Native identity on women's health and health-care decisions. Implications for researchers and clinicians, including the relationship between historical events and current constructions of identity, the fluid nature of identity, and the impact of racism on health-care decisions, are addressed.

Keywords: American Indian, decision-making, grounded theory, identity, Native, racism, women

Introduction

"A woman's identity in traditional Indian life was firmly rooted in her spirituality, extended family, and tribe" (LaFromboise, Heyle, & Ozer, 1990, p. 457). Women conveyed cultural knowledge to younger generations and cared for their children and relatives. Although women in traditional Native cultures are perceived as the "givers of life," their own health is increasingly threatened (Grace, 2003).

According to recent data from the United States (Centers for Disease Control and Prevention, 2003), "American Indian communities bear a greater burden of health risk factors and chronic disease than other racial/ethnic minority populations" (p. 2). For example, prevalence rates for hypertension, elevated blood cholesterol, cardiovascular disease, and diabetes are higher in this population than in other racial/ethnic minorities. In addition, American Indian women bear a disproportionate cancer burden, with the lowest survival rates of any racial group in the United States (Risendal, Dezapien, Fowler, Papenfuss, & Giuliano, 1999).

Considering that data-collection mechanisms often misclassify and consequently under-report disease prevalence (Hampton & Friedell, 2001), these inequities are particularly alarming; more American Indians may be at risk or in need of care than is currently thought.

Aboriginal peoples in Canada suffer similar inequities. According to a recent report released by the Canadian Population Health Initiative, Aboriginal people in Canada can expect to live 10 years less than non-Natives, on average, and infant mortality rates in Indian and Inuit communities are three times the national average (Picard, 2004). In addition, Aboriginal women in Canada are disproportionately affected by chronic conditions. For example, Registered Aboriginal women in Ontario are more likely than the general population of women to die as a result of alcoholism/cirrhosis, motor vehicle crashes, pneumonia, homicide, suicide, and diabetes (Grace, 2003). Also, cervical and gallbladder cancer rates are 73% and 50%, respectively, higher in Aboriginal women than in the general population of women in Ontario (Grace).

In addition to these physical disparities in health, some Native women have experienced an "idiom of loss," feelings of distress related to a loss of moral relations with persons, community, and the land (Willms et al., 1992, p. 331). In their research with Native women of the Nishnawbi-Aski Nation of Northern Ontario, Willms and colleagues report that the women experienced a profound sense of loss, a "grieving for lost traditions, dreams and hopes" (p. 332). The women's physical, mental, and spiritual health was compromised by the rapid changes occurring within and outside their Native community. Yet despite these heavy burdens, the Nishnawbi-Aski women carried on in the hope that their continued engagement with the community would lead to positive change.

Many Native women experience health inequities within the physical, mental, and spiritual realms. Research that focuses strictly on physical health inequities ignores the traditional belief among some Native women that health is a balance between mind, body, and spirit. Yet Native identity itself has often contributed to disharmony, as many Native women struggle to reconcile their identity as "Native" in the face of conflicting messages from the dominant culture that label them as different or as "Other" (Barrios & Egan, 2002). This struggle affects how they view themselves in relation to others, including health-care providers, the majority of whom belong to the dominant culture.

In the present study I also address constructions of "identity" in a Native context. According to Mihesuah (2003), "there was and is no such thing as a monolithic, essential Indigenous woman. Nor has there ever been a unitary 'worldview' among tribes or, especially after contact and interaction with non-Natives, even among members of the same group" (p. xv). Identity is complex; it is fluid rather than static. Individuals shape and are shaped by internal and external forces, reconfiguring their identity over time. For some, the focus of this reconfiguration is issues of personal renegotiation, while for others it is the power of the dominant society to define "Native" (Squire, 1996). For the women in the present study, this fluid construction of identity was the cornerstone for understanding the relationship between health-care decision-making and identity.

I have chosen to use the descriptors "American Indian" and "Native." "American Indian" is the term currently used by many tribal groups in the United States to describe themselves. It is also the term used by the US Census Bureau when presenting health indicators and statistical data (Roubideaux, 2002). The term "Native" is more complex. According to Mihesuah (2003):

> There is no voice among Natives because there is no such thing as a culturally and racially monolithic Native woman. The label "Third World Women" is a large umbrella under which another umbrella, "Natives," may fit, but underneath that umbrella are each of the three hundred or so modern U.S. tribes and, still further under, each female member of those tribes. Thousands more umbrellas are needed to account for the tribal and individual socio-cultural changes that occur over time. (p. 7)

As it is not possible for me to present all of those "umbrellas," I have chosen the "Native" one. While acknowledging that there may be issues with this choice, I believe this umbrella term reflects the diversity of women in the study, as well as those in the research reviewed, and is acceptable to American Indian scholars such as Squire (1996) and Mihesuah.

Extending the analysis beyond the physical, to the relationship between Native identity and health-care decision-making, may help us to understand the complexities inherent in Native identity; for example, Native identity may be contributing to both the resiliency and the despair that some Native women experience.

The impact of identity on health-care decision-making will be the focus of this paper. Following a review of the literature, the findings of a study with American Indian women from Vermont will provide the basis for an examination of the complexities surrounding identity and health-care decision-making. Concluding remarks will address nurses' role in maintaining health inequities and some strategies for eliminating health inequities in Native populations.

Literature Review

It is clear from the literature that many different terms are used to describe study populations. The choice of language varies with each study — from specifically naming the tribe to which the participants belong, to using government-determined labels, to applying broad terms that encompass many different groups of people. These variations remind us that language does more than simply convey information; it plays a significant role in constructing meaning. This is especially relevant when the focus is identity, when how one is named has a tremendous impact on how one sees oneself and is seen by others. As Kirkham and colleagues (2002) state, "Language itself is not a neutral vessel of communication but a social power and an active site of contestation through which meanings are made and remade" (p. 229).

For consistency and clarity, I have chosen to retain the terminology used by each study to describe its population. I remind the reader, however, that, throughout the world, members of the dominant society have lost, changed, imposed, or simply ignored the names of Native peoples. According to Allen (1986), namelessness is significant: "An Indian without a name is powerless indeed" (p. 142).

Although I located no research specifically examining the relationship between identity and health-care decision-making, I did identify research that supports the goals of the present study. For example, Bartlett (2003) focused on the impact of colonization on Aboriginal groups in Canada. She suggests that the destructive influence of colonization, such as sociopolitical identity conflict between Aboriginal groups, inhibits the collective movement of Aboriginal peoples towards the attainment of a more secure future in Canada. Bartlett argues that a careful examination of cultural understandings, and how culture has been affected by sustained contact between groups, is needed in order to design appropriate, culturally grounded approaches to improving the health and well-being of Aboriginal peoples.

Identity has also been shown to be contextual, contingent, and shifting over time. For example, Long and Nelson (1999) focused on resiliency among Native Americans. The purpose of their study was to establish the reliability, validity, and utility of the Ethnic, Culture, and Religion/Spirituality Questionnaire for Native American culture. Their focus was on measuring American Indian family resiliency based on a relational worldview. In this secondary data analysis examining cultural resiliency, they compared non-Native and Native Americans (cross-group), as well as urban and rural Native Americans (within-group). Three factors were measured to assess cultural resiliency: religious identification and community activities, language, and ethnicity/cultural identity. The authors found differences between individual tribes, particularly rural compared to urban dwellers, suggesting that residence affects traditions, culture, and language. Although Long and Nelson reason that these differences indicate that rural dwellers were in the process of seeking tribal identity and were therefore more conscious of traditions, they assume that similar scores for reservation-based and urban Native Americans indicate that they were more unconsciously accepting of traditions and culture as a way of life. Considering the variations between reservation dwellers and urban dwellers, especially in terms of tribal identity, it seems premature to categorize these distinct groups in the same manner.

Several studies identified the theme of reconnecting or reclaiming. For example, Barrios and Egan (2002) explored the experiences of Native American women, living in the majority culture, of being Native and of being Native women. The participants reported that they experienced a "process of reconnecting" with their Native heritage (p. 223) in adulthood, and thus were able to construct a sense of self as Native. As adults, they sought modes of expression and learning that would bring them closer to their Native heritage and empower them as women. The authors did not address the impact of this reconnecting process on health or health-care decision-making.

Napholz (2000), in her study with urban American Indian working women, describes a similar process, labelled "reclaiming the self," in which women developed a sense of self in concert with family and the American Indian community (p. 259). The development of self was enhanced through retraditionalization efforts that fostered a positive American Indian identity. Through retraditionalization, the participants "obtained emotional support and strength to help cope with multiple-role commitments" (p. 264). For these women, positive self-image and psychological well-being were reinforced and supported by involvement in traditionally based practices. They achieved balance by reclaiming their American Indian identity.

Valuing Native women as cultural bearers was a theme in several studies. For example, Browne and Fiske (2001) examined encounters between First Nations women from northwestern Canada and mainstream health-care providers. Affirming encounters were perceived as those in which health-care providers showed respect for the participants as women with a unique cultural heritage. The authors report that providers who validated women's self-identity and cultural pride "signaled a willingness to listen to the patient and to understand her health within the social and cultural dimensions that she defined as most important to her" (p. 141). According to Browne and Fiske, these Native women felt validated by having the expertise and traditional healing knowledge of women elders recognized.

In contrast to these experiences of reconnection and validation, in Shaver's (1997) study with Native American women elders in Oklahoma, the participants reported conflict between their Native American perspectives and mainstream social perspectives. These women recounted family stories that revealed "diminishing respect for women elders from one generation to the next" (p. 165) as traditional roles changed and families lost their native culture. Shaver concludes that society, and the Indian Health Service system in particular, does not value women elders and consequently lacks respect for them as individuals and disregards their health needs.

In summary, the literature indicates that Native identity plays an important role in the health and well-being of Native women. It contributes to their physical, psychological, and spiritual health, and helps them to maintain balance in their lives. The present study was designed to contribute to the existing body of research by extending it to the relationship between identity and health, in order to address health-care decision-making.

Procedure

A grounded theory study was conducted in the US state of Vermont with 20 women who identified themselves as American Indian. Strickland (1999) states that grounded theory is "an important research method for advancing understanding and meeting the health needs of American Indian communities, especially women" (p. 524). She concludes that grounded theory is a qualitative method that holds promise for advancing research that is culturally appropriate for Indian people. This paper reports on an influencing condition of the generated theory, Connecting to Nativeness, that strongly impacted women's decisions concerning mammography and other health-care issues.

Approval for the study was received from the sponsoring university and from the peer review committee of the Vermont Breast Cancer Surveillance System (VBCSS), a state-wide database of women who have received a mammogram in Vermont since 1994 (Geller, Worden, Ashley, Oppenheimer, & Weaver, 1996). To ensure anonymity, a numerical coding system was developed, based on the order of enrolment in the study. This system was used throughout the data-collection and analysis processes. The number that appears at the end of each quote is the number that was used in the original transcript for tracking and referral purposes.

Initial recruitment approaches included informal networking and snowball sampling. Cannon, Higginbotham, and Leung (1991) identify these as outreach strategies that, although labour-intensive, are particularly successful in recruiting minority women. They identify personal contact as a means of assuring minority women that "neither they nor others would be exploited by the research process or its products" (p. 113). Later recruitment approaches for reaching breast cancer survivors included use of the VBCSS. Neither federal nor state recognition of tribal affiliation was required for participation in the study.

I must state at the outset that I am not American Indian. Although I initially thought this would inhibit my recruitment and data-collection efforts, I learned that my personal outreach efforts prior to beginning the study, and my decision not to work through official Indian channels, enhanced my connections with the many Native groups in the state. When questioned by participants regarding my interest in the health of Native women, I explained that I am Mexican American and very concerned about the health of underserved populations, women of colour in particular. Although I believe my identity as "Other" (Canales, 2000) provided a certain level of trust, I recognize that participants decide what to share and that all interviews are only partial "givings" of the self (Ellsworth, 1989).

A semi-structured interview guide was developed for the study. It included broad, open-ended questions intended to explore participants' perspectives of health in general and breast health and mammography in particular. During the 1-year study period, I conducted 20 face-to-face interviews with women in their homes, at their work sites, and in Native community spaces. The interviews ranged from 45 minutes to 1 hour and 45 minutes in length. In addition to the interview, the women completed a brief demographic form. They were compensated for their time with a $25 cheque and a gift bag containing breast health information, including literature specific to American Indian women.

Data were analyzed using the constant comparative method and line-by-line dimensional analysis (Caron & Bowers, 2000; Strauss, 1987). A line-by-line analysis of interview transcripts allows the researcher to discover and describe the dimensions of the phenomenon as conceptualized by the participants (Bowers, 1988). The software program *NVivo* (Qualitative Sources Research, 1999) was used to systematically organize and manage individual interview data; it enabled analytic comparison of the interviews and facilitated examination of the emerging themes and relationships between the influencing factors.

The participants reported various tribal affiliations, including Abenaki, Mohawk, Sioux, and Cheyenne. More than half (12/20) described themselves as "a mixture" or of "mixed race," usually European and American Indian ancestry, the remainder (8/20) identifying themselves as American Indian only. The women's ages ranged from 39 to 75 with a mean age of 53. Six of the 20 women were breast-cancer survivors. Several women reported having a limited income that affected their ability to access medical care. Educational level ranged from completion of 5th grade to master's degree. The majority of women resided in rural areas. In summary, the sample represented a diverse group of women in terms of Native ancestry, health status, economic status, educational level, and geographic residence.

Results

In Vermont, Native women often live in isolation from other American Indians. The state and federal governments do not recognize the Native tribe that is predominant in the state, the Abenaki. Consequently there are no reservations, designated lands, or defined geographic areas for American Indians, and women who identify as American Indian may or may not have local connections to other Native people. This isolation distinguished the participants from Native peoples residing on government reservations or reserves.

This isolation, combined with a history of eugenics in the state of Vermont (Gallagher, 1999), often negatively influenced the women's ability to maintain connections with tribal family members and traditions. The Eugenics Survey, a study led by Dr. Henry Perkins, was an attempt to find and isolate village- and farm-dwelling families perceived to have "bad" genetic traits (Wiseman, 2001, p. 147). American Indians, particularly the Abenaki, were targets of this ethnic intolerance. In order to survive, many Native people renounced their Indian ancestry or "passed into other, less despised segments of society" (Wiseman, p. 149). This disconnection led to a lack of knowledge of family history, traditions, and tribal ancestry among many of the study participants and played an important role in the efforts of some to reconnect with their Native culture and re-establish their Indian identity.

Once again the issue of language must be addressed. During the interviews, the women used a variety of words to describe themselves, their American Indian friends, and their community. Some used the word "Indian," others "Abenaki," still others "Native" or "Native American." This range reflects the various ways in which the women viewed their Native heritage and their various constructions of "Indian." The terms "American Indian" and "Native" will be used interchangeably throughout this analysis. Although some women referred to their American Indian friends simply as "community members," this reference did not apply to all of the women interviewed. It is a confusing term when used without sufficient context. During the interviews I often used the term "Native" to clarify the meaning of community. The women responded to this term and never once reacted negatively to it. I therefore chose to use this word, often to distinguish American Indian friends and community from the community at large.

Finally, the issue of rigour is especially relevant when data are being collected from members of a marginalized population. Throughout the research, the analysis was evaluated using interpretive evaluation criteria (Guba & Lincoln, 1989). The parallel or foundational criteria used to judge the adequacy of the study included credibility, transferability, dependability, and confirmability (Guba & Lincoln). For example, credibility was assured through debriefing between the author and a research mentor during monthly meetings throughout the study; monitoring the researcher's developing theory through regular memos; and checking the results with the participants, in both written and verbal formats. Transferability was established through the thick description and richness of the generated theory. Dependability and confirmability were pursued through the use of a numbering system to track quotes incorporated into the analysis; the coding, management, and storage of data using *NVivo* software; and detailed memos of the processes for developing the analysis, as well as the emerging analysis itself. All criteria were met through presentation of the research findings in venues where the participants and other American Indian women were present and where the results were confirmed.

Connecting to Nativeness

> *[Native culture] reinforces everything I've thought of for years, because I see the full connection between the physical, the mental, the spiritual — to have complete health. Before, it was…just, this is your physical health, and now it all balances.* [04]

The women described various degrees of connection to their Native culture and traditions. Connecting to Nativeness had a greater influence on health-care decision-making among women who identified very strongly with their American Indian ancestry. Although all the women identified themselves as American Indian, some felt the connection more than others. Therefore the participants experienced various degrees of Connecting to Nativeness. On this score, the women ranged from those who did not perceive themselves as Native in terms of their interactions with others and their beliefs about and participation in traditional practices:

> *I guess because I don't feel culturally connected…I didn't feel that I needed to be exploring, you know, those Native Americans…* [03]

to those who were becoming reacquainted with their tribal heritage:

> *I didn't become interested in it in an organized way more or less until they [the children] were older…in college and…out of the household.* [07]

to those who became immersed in cultural practices after Connecting to Nativeness through family members, Native leaders, courses, or self-exploration:

> *The grown-up calls you. It's more spiritual than anything else. You feel…for me, I felt I came home when I saw the powwow and started to feel the vibrational healing and they just invited me in.* [04]

> *It's interesting, because she [mother] never ever said anything to me…growing up. But I shared a few things with my cousin, who was up there at the time, and she seemed to be very interested. And she said, "I understand what you're saying." I wish we'd had this connection years and years ago.* [12]

to those who had been raised Native and had always thought of themselves as such:

> *My grandmother taught us a lot of things. She used to drink a lot of chamomile tea and I can remember her telling us different things for different ailments and stuff.* [09]

> *My dad used to talk about how the last Native American sweat that was done in our area…in the early Thirties. He was probably…12 years old. And he said then they stopped. A lot of people went in deep hiding.* [11]

The degree of Connecting to Nativeness influenced the women's health-care decision-making in terms of their beliefs about health, their ability to treat themselves and their families, and their desire to integrate traditional healing practices into their lives. Consequently, their health-care decisions were often influenced by their degree of Connecting to Nativeness and the extent to which they integrated Native traditions and beliefs into their personal philosophy of health and healing. The women were Connecting to Nativeness both individually, by independently exploring their Native heritage, and collectively, by participating in Native events such as women's circles and powwows and assuming leadership roles in their local Native community. These processes of connecting will be described below.

Individually Connecting to Nativeness. For some women, particularly those with strong family ties to their Native culture, Connecting to Nativeness was simply part of who they were as women. These women had been raised in traditional ways, with Native beliefs and practices part of everyday life. For them, Connecting to Nativeness was not a choice or a decision they had come to as adults; it was part of their being from birth:

> *I have trouble in my regular life, hiding that I'm not a real person, that I'm not a real white person. I've had that problem all my life… If you're raised by the people I was raised by…it's hard to fit in and be a white person.* [16]

Some of the women who had been raised as American Indians strengthened their Connecting to Nativeness as they aged, deciding that their overall health could be improved through integration of and participation in Native health practices:

> *Instead of going on blood pressure medicine I'll go have a sweat done, which will take a lot of the anxiety…and then I'll go to the doctor and she'll check my blood pressure and I'm fine.* [11]

Some used traditional health practices in an effort to counter the perceived negative effects of conventional treatments:

> *With X rays I just feel it's just too much…it doesn't feel natural to go through it. They'd [mammograms would] be putting more chemicals into my body and…I'm trying to get those chemicals out from all the years of going through X rays. It's just scary.* [11]

One participant who had been raised traditionally moved away from Native practices when she became part of "corporate America":

> *I'm a little ragged on the spirit side right now because I spent the last 10 or so years making money. I used to be more of a drifter…jobs wherever…hung out in more of a Native American community, you know, drumming and things… I moved to Seattle. I lost contact with all my older friends and I started just working. Working, working, working. I've just been working for corporate America and not doing anything like that any more.* [16]

Yet her connections to and interest in her Native heritage never waned:

> *Never less [important], just less time for it when you're…paying a mortgage and you just have less energy.* [16]

Prior to her breast cancer diagnosis, however, she reconnected to her Nativeness by making a labyrinth, a traditional walking path:

> *I began learning how to draw these labyrinths on paper. It's very soothing. And so I said, by damn I'm going to make a labyrinth in that yard, in that field. I made the ancient type. And I made the labyrinth, I began walking it, and 20 days later I felt the lump and then a week or so later I*

> *found out I had cancer. And labyrinths are traditionally used for cancer walking. So I began walking it all the time until it snowed…that was my entry back into doing that.* [16]

These women identified additional options for health and healing as their connections to their Native heritage strengthened as they grew older.

In contrast, some women had been raised traditionally but, as they grew older, decided that conventional health care was more appropriate:

> *You take care of your body. Your number one priority is to take care of your body. And if that means having a mammogram to be one step ahead, then that's what you do.* [09]

> *Speaking for myself, I didn't want to live like everybody else does. …I want to get help if I need it.* [08]

The above participant wanted to live differently from her parents and women of previous generations. She described other Native women as "more stubborn than I am and try to doctor on their own," in terms of health care. In contrast, she wanted to be able to access conventional health care if need be. For some participants, therefore, Connecting to Nativeness had less influence, in terms of health-care decision-making, as they grew older. These women believed it was important they have access to health care and not necessarily mimic the behaviour of previous generations of women, who did not avail themselves of technological advances.

Other women, however, had been raised within Euro-American society yet chose to learn about and become more involved in their Native culture as adults. They believed that their Native heritage had been purposefully hidden from them, although usually they did not know why or could not explain their family's behaviour. For these women, Connecting to Nativeness was a more recent process:

> *So as far as being out, I mean, we always knew it. But as far as really being vocal, it wasn't until probably '91, '92, and my cousin…always was very vocal about being Native and travelled out west and that kind of thing.… So we just kind of got started and then we started a women's group of Abenaki women or Indian women.* [06]

> *He [son] got interested…because he knows we're Native too, but…he's not sure of what. I'm not sure of what… He was into it probably about 4 or 5 years, even 6 years, before I even got into it. I've probably been into it for about 6 years.* [14]

One participant described her increased interest and participation in traditional practices during the preceding 8 years as "reacquainting" [07].

These women engaged in a process by which they came to understand and see themselves as Native and incorporated, to varying degrees, this Native identity into their personhood:

> *It had been, about 10 years ago, a really intense period of being in touch with my roots, where I spent a lot of time in the woods…a lot of time. …that's what my focus was for almost a year.* [02]

> *…that started with a college professor I had who was doing a Native American Histories and Cultures class, an anthropology course, and she introduced me to it all.* [04]

> *I don't know if my cultural beliefs itself affect it [health behaviour]. But the way that my culture, the way I live, affects it. I'm very much into the herbology section of my culture.* [05]

This participant, who had been exploring her Nativeness for 6 years, described her culture in "sections," which suggests that her Native culture was not yet all-encompassing but affected only certain aspects of her life. For her, Native culture could be applied or tapped into. At this point in her evolution as Native, integrating herbal plants was the part of her culture that directly affected her health-care decisions. This woman's experience illustrates the fluid nature of identity.

For another participant, a nurse, her increased acceptance of her own Nativeness affected her relationships with her patients:

> *…it's just an awareness…that their cultures are quite a bit different, you know, than, say, the person in the next bed or the next room…To see their medicine man come in or [their] family remain with them…is something that I now…have a tendency to just accept and realize it's very much a private culture. So it's just being more familiar with some of the cultures and a little more understanding of them.* [07]

It is apparent from this comment that the participant was not connecting to her own Nativeness to the same degree that some of her patients were connecting to theirs. She accepted "their cultures" instead of perceiving herself as part of those cultures. This comment highlights the extent to which Connecting to Nativeness was an ongoing process for some of the women.

Another nurse participant did not perceive herself as Native and consequently was not Connecting to Nativeness at all. Although her cultural heritage did not affect her personal health-care decisions, she was willing to assist her family members and patients connect to their Nativeness:

> *When my mother-in-law was living with us and had lymphoma and was definitely terminal, she wished she had some essiac tea that she wanted to*

> *take. We'd already checked and there was no contraindication in how it would affect her care. It was important to her, so I was willing to do that. And maybe…some of my cultural aspects made me more willing to follow that. …But I don't think it [cultural heritage] affects my own personal care in any way.* [03]

However, although she was not Connecting to Nativeness at the time of the interview, the possibility for future connecting existed:

> *It's just something to look at and puzzle about. And I say, well, maybe some day I'll investigate that.* [03]

The above participant agreed to participate in the study as a spokesperson for the financial constraints affecting mammography use among local Native and non-Native women. Consequently, her health-care decisions were influenced more by economics than by any connection to her Native culture.

The women's degree of Connecting to Nativeness affected not only their health-care decisions, but also the quality of the care they and their family members received and their interactions with health-care providers:

> *When they can't find the problem they…want to send you to mental health because it's all in your head type thing. And that's the way they are out there… What's the sense of going? They're not going to help you.* [08]

> *If you treat them like a dummy… "You can't heal yourself with all your own medicine." Well, that's not true, you know. They've been doing it for centuries. Treat them with some respect. Try to add their agenda into yours.* [09]

> *Within a 7-year span I've just watched [Native] people be treated like dirt. I wanted to make a difference for people, and I think that's why I got so involved in health-care stuff, because I've seen them [health-care providers] tell extended family…you need mental health… You walk out of there and you take them to [a different hospital]…and then they're admitted for 9 days because they have a blood clot, poisoning their body. And you just sit back and wonder why nobody even noticed this.* [11]

Consequently, for some women, their identity as Native marked them as Other in the minds of some local health-care providers. The racism they experienced in these encounters ultimately discouraged them from using conventional health services. The majority of participants did not have visible features that would readily identify them as American Indian. However, while the ability to move between cultures without having their Nativeness recognized afforded a degree of protection against racism, some of the participants were identified in the community as Native because of their families or because of their Native practices:

> *By the time we got in there to see the doctor, I ended up literally crying because I asked him if we had to take this stuff, this ridicule out there, sitting in the waiting room — people making fun of you behind the desk. It was comments and I didn't like it, and I felt we didn't have to be treated that way. We're just as human as anybody else even though we're different… But we're Native American so… Oh yeah, we've felt that way a good many times…you get to the point where you hesitate going there.* [08]

These racist encounters influenced participants' personal health-care decisions and ultimately their view of the health-care system:

> *I guess we're kind of hesitant because we had a lot of bad experience [at the] hospital here. Well, one night my husband was really in a lot of pain so I said, "Come on, I'll take you to outpatients." So I took him. We brought him in. All they did was ask him if he — "Do you take drugs? Do you got needle tracks?" Never got to the issue that was bothering him. Sent him home. And I know my husband. He walked into the house, never took his coat off, nothing. Stopped in the chair. And I said a bad word and I said, "We're going to [a different ER]." Well, if I hadn't took him [to the different ER] that night he would have died because his bladder would have erupted.* [08]

> *I guess trust is the biggie for me. And I still don't really fully trust them. I mean, it's hard to trust people who have turned against you. So, being Native, yeah, I think it plays a big role when people walk into [the local hospital].* [11]

Consequently, those women who were known as American Indian sometimes had to base their decisions on whether to seek conventional care on the seriousness of the health condition as well as their ability to withstand the racist attitudes they might encounter.

Several participants said that racism compounded their Connecting to Nativeness efforts and heightened their feelings of mistrust:

> *Because of racism you might be doing this kind of religious practice [sweat lodge] where you live, at home, and somebody's going to call the fire department on you because you have a fire without a permit, and they're going to find a way to harass you. Or some Christian person is going to say that you're worshipping the devil and you should be, like, shot. Unless of course you're a white person who is stealing the ceremony, and then everything is okay. So it's really hard. You feel very vulnerable and you don't know who to trust.* [01]

> *People get ostracized terrible for admitting they're Native around here — by the rest of the town. They've been trying to get me out of my home for 10 years now. They've stolen trees, destroyed property, my mailbox has disappeared… I've had my…tepee…slashed.* [04]

> *I could pass very easily as being Scotch or whatever. So for me it [racism] wasn't ever a problem until just last year when I went to a town planning board meeting.* [06]

The above participant's Connecting to Nativeness efforts had not been an object of racism in the past. Recently, however, despite her physical invisibility as American Indian, her very visibly Native actions had provoked racist responses. Racism increased as an issue for the women as they became more connected to their Nativeness. This consequence of Nativeness had not been anticipated by those who had not been perceived as Indian within their community.

Several women discussed the lingering influence of the Vermont eugenics movement on Native perceptions of health, health-care decisions, and participation in research:

> *Some Native women…believe that this [mammography] is a way to actually try and kill women. That it's the government doing this, and if, for example, some white researcher wants to ask you a bunch of questions or to encourage you to get a mammogram, don't do it, because it's the government. Or it's like eugenics. Or it's like what they did to the Alaskan Natives who have gotten multigenerational thyroid disease from being used as guinea pigs [in] radiation studies.* [01]

> *Especially [with] my generation and the older generation, there was so much with eugenics program and all those things that went on that they still have that mistrust of government, mistrust of doctors, mistrust because of the sterilization… They know it, they keep it within their families, but want to stay in the background. And they'll do things and they'll have their own gatherings or they'll come to a gathering but if you said to them, "Are you Abenaki?" they'd say, "No."* [06]

For many Native people, the past continues to influence the present and cannot be dismissed or ignored. Connecting to Nativeness has real consequences for Native people in the racialized world of health-care delivery.

For many participants Connecting to Nativeness was an individual process that they engaged in over time and to varying degrees. For some, health-care decisions were limited to their individual Connecting to Nativeness. For others, however, health-care decisions were influenced by their collectively Connecting to Nativeness efforts.

Collectively Connecting to Nativeness. Although collectively Connecting to Nativeness was not necessary for all participants, the majority of women described the importance of collectivity in their lives and their efforts to connect with Native groups:

> *You have to have that [community]. It's very, very, very hard to live totally traditionally in terms of your health care… Very hard. You can't do it independently. It's interdependent.* [01]
>
> *…women's groups that I'm in that are Native American groups. They're a group of women that meet…stay in touch with and reacquaint ourselves with some of the traditions that have become lost along the way.* [07]
>
> *I have some wonderful sisters and brothers and elders in this area, and…being back here has been wonderful as far as being able to be freer…to feel freer to be okay with who I am. …A reconnection with [a Native friend]…too, being invited to Thanksgiving gatherings, and it's just great.* [12]

Collectively connecting with a Native community while individually connecting with their Nativeness was important for these participants. This interconnection between individually and collectively Connecting to Nativeness was especially relevant for women who had decided to integrate more traditional practices into their health regimen:

> *I know a person who went into a sweat lodge with diagnosed kidney stones, came out, went to the doctor a few days later and they were all gone. I've seen this kind of thing happen. But you can't just do those things on your own. It's the power of a group of people who get together, who all understand what's going on. They have good hearts and good minds.* [01]
>
> *And of course we have contact with other Native people from Canada. There's a man and a lady that come and they do sweats and everything every year. She teaches me a lot of things about different herbs for different ailments. So I do know quite a bit.* [09]
>
> *I've just gained so much. Connection. What you can learn from others and what I learn I hopefully am passing on to those working in the school systems.* [12]

Some women who were collectively connecting with Native friends and communities sought their opinions when trying to make health-care decisions:

> *Mainly what I need to hear from…community people is that they've been there and they feel very comfortable. And their comments usually are,*

> *they're just, like, community people. And then I might take the chance. …I really value their opinions.* [10]

It was important for these Native women to learn from family members or Native friends about health-care providers who were perceived as trustworthy before seeking out their services.

Some women found it difficult to connect to Native individuals and groups, due either to rural isolation or to fear because of historical practices that dispersed Native people in the area:

> *Unfortunately I don't know a lot of people because I really am pretty isolated.* [02]

> *There's a lot involved in exploring your culture, and it still brings up some negative thoughts by some elderly family members. People just don't admit that they have any Native American [blood], because it wasn't that many years ago that if you were Native American you were looked down on, so…family members…did not pass on that there was any Native American in you. I remember talking with my great-grandfather and he was starting to bring up some of the old family past and then my great-grandmother suppressed him. So I don't know a lot about my cultural past. Because they were afraid, they didn't share it.* [03]

> *…it's not like you're on a reservation where they're just all there… It isn't that way here. Everybody's dispersed and half of them won't admit to their heritage. It's not really safe.* [04]

> *In most Abenaki families and communities there's…a whole community behind what is on the surface level. So there's usually a representative here or there, in most enclaves, that are the up-front people. And then there are the kind of in-between that are a little bit up-front. …and then there are the ones that remain hidden and completely unknown and want to be.* [06]

Because of the dispersal of the New England Abenaki and members of other Native tribes, many participants had a desire to collectively connect with a Native community, to develop networks of Native friends across the continent:

> *So that helps to take away the isolation. If I didn't have the Internet, I don't know… I can hear from other people and read what they say. It really helps to sort things out.* [01]

> *They're not just…here, just in Vermont. We've got friends in Maine. We've got friends in Florida. We've got friends in New York. There's people that come from the Rosebud Reservation.* [05]

> *We have people that we consider part of the community from Sherbrooke [in Quebec], from Massachusetts, from New Jersey, from Maine, New York State. A lot of them we've met have come out for things…we've met on the powwow circuit. And a lot of them we've never met but that just write, through letters and e-mail.* [06]

These comments reflect the nature of the communities that participants had developed. For some participants, collectively Connecting to Nativeness occurred at different levels. They connected to Native friends in Vermont and expanded their Native community to other states and provinces through the powwow circuit, newsletters, and the Internet.

Several participants who had no local Native community perceived that if they lived on or near a reservation they would be able to strengthen their connections to their Native heritage:

> *I can imagine if I had gone, if we go west, it will be totally mind-boggling…We wanted to move to South Dakota, out to Pine Ridge, and live close to the reservation. So that would be helpful.* [05]

> *I've often wanted to go to a reservation and ask some women there… "Okay, look at me. I'm part Mohawk. Could you just talk to me about this thing that I felt I had to make, this mask, and why? What should I do?" But maybe they don't know.* [16]

One woman believed that closer ties to a Native group would affect her health-care decisions:

> *I wouldn't need allopathic medicine, I don't think, if I was living in a group situation where I was surrounded…like on a reservation. They have so many elders who do this work. I could go to that person, get my medicine from them. Even if I pay for it, that's not a problem. It's the right kind of medicine.* [01]

Some women believed that living near a recognized tribal group would help them in their individual Connecting to Nativeness efforts and strengthen their Indian identity, which, in turn, would increase their health-care options.

Some women with strong connections to a Native community believed that conventional health care was not always necessary:

> *Well, some really, really traditional people would say that you don't need to do any of these things. I have seen incredibly healthy people…live into a long age and never have any screenings and be totally healthy. …it's because…they're involved enough that they can see what's going on in their own bodies — sometimes they can see what's going on in other people's bodies — and they don't need technology.* [01]

This participant had connected with Native elders and made them a part of her life. Although she stated that she did not possess the abilities she witnessed, the longevity and overall good health of the elders were, for her, evidence that health was not necessarily dependent on conventional health care.

Discussion

Ethnic identity and self-identification are inherently linked. How one defines oneself in relation to one's ethnic group influences how, or if, one identifies ethnically. According to Phinney (1992), "Individuals who use a given ethnic label may vary widely in their sense of belonging to their group, their attitudes toward the group, their ethnic behaviors, and their understanding of the meaning of their ethnicity" (p. 159). For the participants in the present study, clearly, variations in self-identification as "Indian" existed and changed over time. This finding sits in contrast to the results of an ethnic-identity study with high-school and college students, which found that ethnic identity "consolidates with age" and stabilizes early in adulthood (Phinney). Considering that, for many of the women in the present study, the process of connecting with one's ethnic group persisted well into adulthood, nurse researchers must be cognizant of the fact that identity is not a static state, but evolves as attitudes about self and others develop and evolve. Nurses must consider this fluidity when planning research studies with Native women.

Although this study focused on the influence of Native self-identification on health decisions, it is important for nurse researchers to acknowledge that for many Native people identity as "Indian" is externally imposed and officially dictated. In the United States, for example, the government imposed the use of blood quantum — the percentage of Native blood by biological inheritance — as a criterion for entitlement to federal benefits (Barrios & Egan, 2002). The US government still uses blood measurements to "officially mark" Native peoples today (Strong & VanWinkle, 1996). In Canada, the 1876 *Indian Act* continues to "regulate who is entitled to be 'Indian' and controls First Nations peoples' lives to a significant degree" (Krosenbrink-Gelissen, 1995, p. 198). Consequently, identification as "Indian" influences much more than health-care decisions; it can mean the difference between belonging and not belonging to one's tribe.

Distinctions between and within tribal groups based on government tribal designations also influence identity. For example, in the United States self-identification can change when "a formerly 'unrecognized' tribe becomes federally recognized by Congress, when tribal enrollment ordinances change, or when tribal enrollment ordinances change regarding paternal versus maternal lineage" (Burhansstipanov & Satter, 2000, p. 1722). These government and tribal definitions of "Indian" have an impact on self-identity as well as access to health-care services, including eligibility for Indian Health Service care, federal funding for housing, and casino profits (Metz, 2003). When developing studies, planning recruitment strategies, and analyzing data, nurse researchers must be cognizant of the historical relationship between Native identity and government recognition, the impact of official identity determinations on eligibility for federal resources, including health-care services, and the tensions that exist between Native peoples who are officially recognized and those who are not.

Similar to the findings of Barrios and Egan (2002), in this study Connecting to Nativeness was an empowering experience for many of the participants. Although many of the women did not have Native adult female role models, they constructed their own sense of Native identity through self-education, formal education, and connections with elders or medicine people within their Native network. Acknowledging Native identity as a source of strength and resiliency rather than as a barrier to health-care services can be the first step in developing respectful interventions. As Blaeser (1997) contends, "If we truly understand connection and interdependence we will develop respect for other beings" (p. 561).

Nurses who view Connecting to Nativeness as a source of empowerment for Native women can incorporate this process into their efforts to build trusting relationships with their clients. Nurses who recognize Native women's internal sources of strength, acknowledge the many ways in which they maintain health, including their traditional practices, and provide care in a non-judgemental, respectful manner will begin to gain the trust so vital to the nurse-client relationship. Concurrently, nurses can begin their own reflective journey, examining the multiple positions they occupy as members of the dominant culture (in many cases) and dominant health-care system, the power inherent within these positions, and the impact of this power on the nurse-client relationship. This form of self-reflection challenges nurses to critique their own worldviews as well as their self-identities (Canales, 1998). In this way, individual racism can be addressed and trusting relationships fostered.

Although identification as Native was a source of strength for many women in the study, it was also a source of mistrust. It is imperative that nurses caring for Native women acknowledge the colonizing practices that forced many American Indians to hide their identity and the subsequent trust issues that developed for Native women connected to or in the process of connecting to their Nativeness. This historical context explains the tensions experienced by some Native women as they decide whether to seek conventional care. Unless nurses acknowledge the fear and mistrust of Native women, and the historical context of that fear and mistrust, their efforts to develop positive relationships will be thwarted. Browne, Johnson, Bottorff, Grewal, and Hilton (2002) offer several strategies nurses can employ to identify discriminatory practices and build more trusting relationships. These include developing critical consciousness, monitoring the language used to refer to people who are different, and exploring approaches to naming and discussing racism and other forms of discrimination.

Finally, even though Connecting to Nativeness was an empowering process for many of the women, the racism they experienced must be addressed. They found these experiences humiliating, terrifying, and potentially life-threatening. These findings are similar to those reported by Browne and Fiske (2001) in their study with First Nations women in northwestern Canada and by Shaver (1997) in her study with Oklahoma Native American women elders. The health of women who identify with, and are identified by, their Native heritage is further jeopardized by the health-care system. Nurses can no longer "afford ignorance about one of the major factors that contribute to multiple health inequities — racism" (Porter & Barbee, 2004, p. 10). Individual and institutional racism continue to influence access to services and the quality of services received by racial and ethnic populations in the United States (Institute of Medicine, 2002) and Canada (Canadian Institute for Health Information, 2004). "Nurses, in order to actively participate in eliminating disparities, must consider critically the issue of how race and racism within the broader contexts of power relations and social inequality influence the quality of their services" (Porter & Barbee, p. 10). Once nurses have critically analyzed these relationships, they must take active steps to address them.

Conclusion

Examination of the influence of identity on health and health-care decision-making is becoming more important as members of Native groups reclaim their ancestral lands, traditions, language, and identity. According to Bartlett (2003), "since the earliest continuous contact with newcomer Europeans, original peoples have been erroneously identified by externally designated and often misleading names such as Indian, Eskimo, and Half-breed. This has resulted in poor self-image for individuals and groups who have in some cases, in order to survive, gone underground with their identity" (p. 166). Some Native people, however, are seeking to reclaim their identity as Native, constructing a self that enhances their own image and that of their community. Through Connecting to Nativeness, the women in the present study were reclaiming their Native identity, living the words of Paula Gunn Allen (1986): "We daily demonstrate that we have no intention of disappearing, of being silent, or of quietly acquiescing in our extinction" (p. 193).

Eliminating health inequities among Native populations will require an understanding of the social, political, historical, and economic issues that affect these groups as well as a willingness to examine nursing's role in perpetuating the inequities. Nurses can play a greater role in addressing health inequities by working in tandem with Native communities to design research studies and develop interventions that are grounded in the needs of the community and that are reflective of the diverse identities of Native peoples. Flaskerud and colleagues (2002) report that these types of studies "also provide a valuable resource to communities and their members by sharing power with them and involving them in knowledge and skills that are translatable into action" (p. 83).

Finally, the present findings remind us that if we are to eliminate health inequities we must confront the institutional racism that persists within the health-care system and beyond. Nurse researchers are challenged to extend the analysis from the micro, individual, level to the complex social, economic, historical, and political intersections in which human lives are experienced. As Campbell, Copeland, and Tate (1998) state, "If researchers are to understand what people tell them about their lives, their troubles, or their health care experiences, then the inquiry must include not just people's stories but how powerful outside forces shape their experiences" (p. 96). This approach is especially salient for Native peoples whose very existence has been threatened by "outside forces," including the health-care system.

References

Allen, P. G. (1986). *The sacred hoop: Recovering the feminine in American Indian traditions*. Boston: Beacon Press.

Barrios, P. G., & Egan, M. (2002). Living in a bicultural world and finding the way home: Native women's stories. *Affilia, 17*(2), 206–228.

Bartlett, J. G. (2003). Involuntary cultural change, stress phenomenon and Aboriginal health status. *Canadian Journal of Public Health, 94*(3), 165–166.

Blaeser, K. M. (1997). Like "reeds through the ribs of a basket": Native women weaving stories. *American Indian Quarterly, 21*(4), 555–565.

Bowers, B. (1988). Grounded theory. In B. Sarter (Ed.), *Nontraditional research methods in nursing* (p. 33–59). New York: National League for Nursing.

Browne, A. J. & Fiske, J. A. (2001). First Nations women's encounters with mainstream health care services. *Western Journal of Nursing Research, 23*(2), 126–147.

Browne, A. J., Johnson, J. L., Bottorff, J. L., Grewal., S., & Hilton, B. A. (2002). Recognizing discrimination in nursing practice. *Canadian Nurse, 98*(5), 24–27.

Burhansstipanov, L., & Satter, D. (2000). Office of Management and Budget racial categories and implications for American Indians and Alaska Natives. *American Journal of Public Health, 90*(11), 1720–1723.

Campbell, M., Copeland, B., & Tate, B. (1998). Taking the standpoint of people with disabilities in research: Experiences with participation. *Canadian Journal of Rehabilitation, 12*(7), 95–104.

Canadian Institute for Health Information. (2004). *Improving the health of Canadians.* Ottawa: Canadian Population Health Inititative.

Canales, M. (1998). Cultural allies: Creating allegiances across borders. *Nursing Praxis in New Zealand, 13*(1), 33–46.

Canales, M. K. (2000). Othering: Towards an understanding of difference. *Advances in Nursing Science, 22*(4), 16–32.

Cannon, L. W., Higginbotham, E., & Leung, M. L. A. (1991). Race and class bias in qualitative research on women. In M. M. Fonow & J. A. Cook (Eds.), *Beyond methodology: Feminist scholarship as lived research* (pp. 107–118). Bloomington: Indiana University Press.

Caron, C. D., & Bowers, B. J. (2000). Methods and application of dimensional analysis: A contribution to concept and knowledge development in nursing. In B. L. Rodgers & K. A. Knafl (Eds.), *Concept development in nursing: Foundations, techniques, and applications* (pp. 285– 319). Philadelphia: W. B. Saunders.

Centers for Disease Control and Prevention. (2003). Health status of American Indians compared with other racial/ethnic minority populations: Selected states, 2001–2002. *Morbidity and Mortality Weekly Report, 52*(47), 1148–1152.

Ellsworth, E. (1989). Why doesn't this feel empowering? Working through the repressive myths of critical pedagogy. *Harvard Educational Review, 59*(3), 297–324.

Flaskerud, J. H., Lesser, J., Dison, E., Anderson, N., Conde, F., Kim, S., et al. (2002). Health disparities among vulnerable populations: Evolution of knowledge over five decades in nursing research publications. *Nursing Research, 51*(2), 74–85.

Gallagher, N. (1999). *Breeding better Vermonters: The eugenics project in the Green Mountain State.* Hanover, NH: University Press of New England.

Geller, B., Worden, J. K., Ashley, J. A., Oppenheimer, R. G., & Weaver, D. L. (1996). Multipurpose statewide breast cancer surveillance system: The Vermont experience. *Journal of Registry Management, 23*(4), 168–174.

Grace, S. L. (2003). A review of Aboriginal women's physical and mental health status in Ontario. *Canadian Journal of Public Health, 94*(3), 173–189.

Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation.* Newbury Park, CA: Sage.

Hampton, J. W., & Friedell, G. H. (2001). Cancer surveillance. A problem for Native Americans and Appalachian populations. *Cancer Supplement, 91*(1), 242–246.

Institute of Medicine. (2002). *Unequal treatment: Confronting racial and ethnic disparities in health care.* Washington: National Academy Press.

Kirkham, S. R., Smye, V., Tang, S., Anderson, J., Blue, C., Browne, A., et al. (2002). Rethinking cultural safety while waiting to do fieldwork: Methodological implications for nursing research. *Research in Nursing and Health, 25,* 222–232.

Krosenbrink-Gelissen, L. E. (1995). Native women have other things to care about: The struggle for a distinct identity. *Yumtzilob, 8*(3), 196–213.

LaFromboise, T. D., Heyle, A. M., & Ozer, E. J. (1990). Changing and diverse roles of women in American Indian cultures. *Sex Roles, 22*(7/8), 455–476.

Long, C. R., & Nelson, K. (1999). Honoring diversity: The reliability, validity, and utility of a scale to measure Native American resiliency. *Journal of Human Behavior in the Social Environment, 2*(1/2), 91–107.

Metz, A. (2003). *Survival of tribes at stake as strict rules weed out members.* Available: www.Newsday.com, 1–5.

Mihesuah, D. A. (2003). *Indigenous American women: Decolonization, empowerment, activism*. Lincoln: University of Nebraska Press.

Napholz, L. (2000). Balancing multiple roles among a group of urban midlife American Indian working women. *Health Care for Women International, 21,* 255–266.

Phinney, J. S. (1992). The Multigroup Ethnic Identity Measure: A new scale for use with diverse groups. *Journal of Adolescent Research,* 7(2), 156–176.

Picard, A. (2004). The rich are healthier, live longer, report says. *Globe & Mail,* February 26, A9.

Porter, C. P., & Barbee, E. (2004). Race and racism in nursing research: Past, present, and future. *Annual Review of Nursing Research, 22,* 9–37.

Qualitative Sources Research. (1999). *NUD*IST Vivo (Nvivo)*. Melbourne: Author.

Risendal, B., Dezapien, J., Fowler, B., Papenfuss, M., & Giuliano, A. (1999). Cancer prevention among urban southwestern American Indian women: Comparison to selected year 2000 national health objectives. *Annals of Epidemiology, 9*(6), 383–390.

Roubideaux, Y. (2002). Perpsectives on American Indian health. *American Journal of Public Health, 92*(9), 1401–1403.

Shaver, L. D. (1997). The dilemma of Oklahoma Native American women elders: Traditional roles and sociocultural roles. In H. S. N. Al-Deen (Ed.), *Cross-cultural communication and aging in the United States* (pp. 161–177). Mahwah, NJ: Lawrence Erlbaum.

Squire, M. R. (1996). *The contemporary western Abenakis: Maintenance, reclamation, and reconfiguration of an American Indian ethnic identity*. Ann Arbor, MI: UMI Dissertation Services.

Strauss, A. L. (1987). *Qualitative analysis for social scientists*. New York: Cambridge University Press.

Strickland, C. J. (1999). The importance of qualitative research in addressing cultural relevance: Experiences from research with Pacific Northwest Indian women. *Health Care for Women International, 20,* 517–525.

Strong, P. T., & VanWinkle, B. (1996). "Indian blood": Reflections on the reckoning and refiguring of Native North American identity. *Cultural Anthropology, 11*(4), 547–576.

Willms, D., Lange, G. P., Bayfield, P., Beardy, M., Lindsay, E. A., Cole, D. C., et al. (1992). A lament by women for "the people, the land" [Nishnawbi-Aski

Nation]: An experience of loss. *Canadian Journal of Public Health, 83*(5), 331–334.

Wiseman, F. M. (2001). *The voice of the dawn: An autohistory of the Abenaki Nation.* Hanover, NH: University Press of New England.

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Résumé

Une exploration de la relation entre les pratiques de promotion de la santé, le travail lié aux soins de santé et le stigmate ressenti chez les familles dirigées par une mère adolescente

Adrienne Fulford et Marilyn Ford-Gilboe

Cette étude à pour objectif d'examiner les liens entre le stigmate et la promotion de la santé chez les familles composées d'enfants d'âge préscolaire et dirigées par une mère adolescente, en testant les hypothèses issues du *Developmental Model of Health and Nursing* [modèle développemental de la santé et des soins infirmiers] et en explorant, de façon descriptive, l'expérience du stigmate auprès d'un échantillon de 63 mères adolescentes vivant dans des communautés du Sud-Ouest de l'Ontario, au Canada. Les mères ont répondu verbalement à des questions portant sur le stigmate ressenti selon une gradation établie, le travail liés aux soins de santé familiale, les pratiques de vie saines et à un questionnaire démographique au cours d'une entrevue structurée. Leurs expériences de stigmate ont ensuite été explorées lors d'une brève entrevue dialogique. Conformément à la théorie, la recherche a révélé une relation modérément positive entre le travail lié à la santé familiale et le mode de vie sain des mères ($r = 0{,}52$, $p < 0{,}001$). Le stigmate ressenti ne portait pas sur le travail liés aux soins de santé ni sur la présence d'un mode de vie sain dans l'ensemble. Le stigmate ne semblait pas non plus avoir d'effets directs sur les efforts de promotion de la santé familiale mais influait sur d'autres aspects de la vie des participantes, de façons positives et négatives. Des implications relativement à la pratique et aux futures recherches ont été identifiées.

Mots clés : mères adolescentes, *Developmental Model of Health and Nursing,* promotion de la santé familiale, stigmate

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An Exploration of the Relationships Between Health Promotion Practices, Health Work, and Felt Stigma in Families Headed by Adolescent Mothers

Adrienne Fulford and Marilyn Ford-Gilboe

The purpose of this study was to examine the relationship between stigma and health promotion in families with preschool children headed by adolescent mothers, by: (a) testing hypotheses derived from the Developmental Model of Health and Nursing, and (b) descriptively exploring the experience of stigma in a community sample of 63 adolescent mothers in southwestern Ontario, Canada. The mothers verbally responded to established measures of felt stigma, family health work, healthy lifestyle practices, and a demographic questionnaire during a structured interview. Then their experiences of stigma were explored during a brief dialogic interview. Consistent with the theory, a moderate positive relationship was observed between family health work and mothers' healthy lifestyle ($r = .52$, $p < .001$). Felt stigma was not related to either health work or global healthy lifestyle. Stigma did not appear to affect family health promotion efforts directly but influenced other aspects of the participants' lives in both positive and negative ways. Implications for practice and future research are identified.

Keywords: adolescent mothers, Developmental Model of Health and Nursing, family health promotion, stigma

Historically, childbearing during adolescence was socially and culturally acceptable (Kitzinger, 1978). However, over the last 3 decades in Western society, adolescent motherhood has come to represent personal irresponsibility and social pathology (Smith Battle, 2000). In Canadian society, the stigma associated with adolescent motherhood remains pervasive (Kelly, 1996) and is linked to a range of perceived disadvantages for mother and child. Adolescent mothers are often presumed to be ineffective parents, uneducated, unemployed, and financially dependent on the social system (Hechtman, 1989; Kelly, 1996). The stigma of adolescent motherhood may marginalize the mother and undermine her confidence and motivation, negatively affecting her development, parenting, and health promotion practices (Sword, 1997; Whall & Loveland-Cherry, 1993).

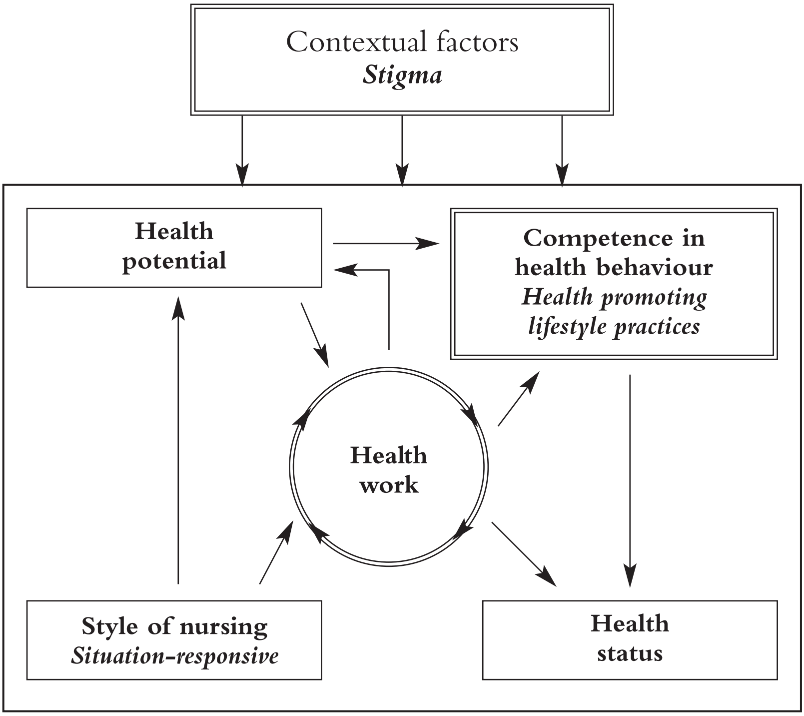
Health promotion is defined as the process of enabling people to increase control over and improve their health, with an emphasis on the building of resources and capacities needed to support these goals (World Health Organization, Canadian Public Health Association, and Health and Welfare Canada, 1986). Families have been found to play a key role in the development of health promotion behaviour (Duffy, 1988; Pender, 1996) and there is growing evidence that the period between birth and age 5 is a critical one for promoting optimal child health and development (McCain & Mustard, 1999). Few studies have examined factors affecting family health promotion processes, particularly in families headed by adolescent mothers. Yet health promotion strategies may be crucial in offsetting the negative effects of disadvantage on health while supporting the establishment of health practices that persist into adulthood. This study examined the relationship between one type of disadvantage, stigma, and the health promotion efforts of families with preschool children headed by adolescent mothers.

Literature Review

The Developmental Model of Health and Nursing (DMHN) (Allen & Warner, 2002; DeMarco, Ford-Gilboe, Friedman, McCubbin, & McCubbin, 2000; Ford-Gilboe, 2002a), with its distinctive focus on family health promotion, served as the theoretical framework for this study. A theoretical extension of the McGill Model of Nursing (Allen, 1983; Gottlieb & Rowat, 1987), the DMHN has as its purpose the generation of knowledge on the nature of healthy development in individuals and families and the role of the nurse in supporting this process. In the DMHN the focus is on process and the family is viewed from a strengths perspective. The theoretical propositions of the DMHN have been supported in studies with families featuring various structures and socio-economic backgrounds (Ford-Gilboe, 2002a), including two recent studies (Black & Ford-Gilboe, in press; Sgarbossa & Ford-Gilboe, 2004) with families with preschool children headed by adolescent mothers.

In the DMHN, health is viewed as a family characteristic — a way of living that is learned in the social context of family life (Allen & Warner, 2002). The pattern of health within families is complex and best represented by a number of dimensions: health potential, health work, competence in health behaviour, and health status (Ford-Gilboe, 2002a) (Figure 1). The central concept in the DMHN, health work, is an active process through which a family achieves healthful living by learning to cope with health situations and by setting and striving towards goals for healthy individual and family development (Allen & Warner; Ford-Gilboe, 2002a). For example, in the case of adolescent mothers, health

Figure 1 ***Key Concepts and Proposed Relationships in the Developmental Model of Health and Nursing***



Source: Modified from Ford-Gilboe (2002a). ═══ Variables addressed in current study.

work may be seen as how the mothers respond to the challenges of understanding and responding to their child's cues, developing satisfaction in their parenting role, or instituting new family routines. The extent to which a family participates in health work is influenced by its health potential (i.e., internal and external capacities) and, when present, the assistance of the nurse in supporting its ability to respond to everyday health situations in a way that builds its capacity for healthy growth and development (Ford-Gilboe, 2002a). As participation in health work increases over time, families adopt new problem-solving and development strategies and incorporate them into their repertoire of skills and behaviours (DeMarco et al., 2000; Ford-Gilboe, 2002a), ultimately affecting health status. Thus, competence in health behaviour, an outcome of health work, reflects the family's effectiveness in managing health situations and achieving health goals and in adopting healthy ways of living that are consistent with its health needs and priorities (Ford-Gilboe, 2002a). Therefore, family health promotion can be understood as both a process (i.e., health work) and an outcome (i.e., competence in health behaviour), including lifestyle behaviours.

Previous studies with single-parent families, including families headed by adolescent mothers, have provided some description of their health promotion processes. In a grounded theory study with 56 single-parent families headed by women, Duffy (1984) found that the families engaged in health promotion processes on a continuum that ranged from choosing existing options in order to promote stability, to transcending existing options in order to embrace personal growth and change. Duffy (1986) further identified lack of social support and role overload as barriers to primary prevention behaviours and health maintenance. Similarly, mothers' internal resources, including resilience, optimism, and general self-efficacy, have been found to be positively associated with both family health work and health outcomes, including health promoting lifestyle practices and general family functioning (Black & Ford-Gilboe, in press; Ford-Gilboe, Berman, Laschinger, & Laforêt-Fliesser, 2000). However, most studies of health promotion in families headed by adolescent mothers have focused on parenting practices. For example, adolescent mothers have been found to seek preventive health care for their children (Hermann, Van Cleve, & Levisen, 1998), to use various anticipatory coping strategies to problem-solve and secure support that facilitates their transition to parenting (Panzarine, 1986), and to engage in more effective interactions with their children when they have access to adequate support (Dormire, Strauss, & Clarke, 1988).

Lifestyle practices of adolescent mothers and their children may also be key in promoting healthy growth and development. According to Pender (1996), a health promoting lifestyle is a multidimensional pattern of self-initiated actions and perceptions that are directed towards maintenance or enhancement of one's well-being, personal fulfilment, and productive living. Mothers' healthy lifestyle practices and attitudes have been found to influence not only the health promotion behaviours of their families, but also the health practices of their children (Duffy, 1986, 1988; Loveland-Cherry, 1986). Children's health behaviours are shaped and acquired in the context of the family, including the manner in which it responds to health or illness situations (Allen & Warner, 2002; Mullen, 1983). In studies with single-parent and two-parent families with young children, health work has been found to be positively associated with mothers' health promoting lifestyle practices (Ford-Gilboe, 1997; Ford-Gilboe et al., 2000; Monteith & Ford-Gilboe, 2002). A limited body of research has identified additional factors that influence healthy lifestyle practices in adolescents, including perceived self-efficacy (Gillis, 1997) and parental role modelling of positive health practices (Donovan, Jessor, & Costa, 1991; Gillis). Similarly, adolescent mothers who maintain a relationship with the child's father are more likely to participate in preventive health care (Kelly, 1995). However, few studies have focused specifically on the development of healthy lifestyles in adolescent mothers.

In the DMHN, the broader context of family life is purported to influence family health, although the nature of this influence is thought to be situation-dependent (DeMarco et al., 2000; Ford-Gilboe, 2002a). Consistent with an ecological perspective, context includes: (a) characteristics of the family; (b) characteristics of the immediate environment; and (c) socio-political forces affecting family life, including cultural biases, stereotyping, and social policies (DeMarco et al.). Stigma is a common feature in the lives of adolescent mothers and, thus, an important context for health promotion in families headed by these mothers.

Stigma refers to those attributes of an individual or group that engender negative evaluation of one's social identity (Crocker, Major, & Steele, 1998). Felt stigma, the feelings of shame associated with being different, is more distressing than enacted stigma, which features actual instances of discrimination or labelling (Scambler & Hopkins, 1986). In contemporary society, stigma is typically associated with conditions for which people are considered culpable (Scambler, 1998). With the advent of reproductive options, such as contraception and abortion, adolescents who choose to give birth and raise their child may be blamed for their circumstances. Findings from qualitative studies suggest that such young women experience stigma in the form of social exclusion (Whitehead, 2001) and negative labelling by their families (Kaplan, 1996), the public (Hyde, 1998), and health professionals (Farber, 1991). Stigma may disrupt relationships within support networks, which have been found to facilitate adolescents' adjustment to motherhood (Dormire et al., 1988; Mercer, 1986) and the development of effective parenting (Turner & Avison, 1985). However, there is a dearth of research on stigma experienced by adolescent mothers. Further study is needed in order for us to better understand its impact on family health and development, including efforts to promote health.

Although the direct health impact of stigma on adolescent mothers has not been studied, research conducted with adults experiencing various physical and mental illnesses suggests that stigma is associated with low self-esteem (Fife & Wright, 2000), poor physical and emotional health (MacDonald & Anderson, 1984), limited social interaction (Jacoby, 1994), and lower quality of life (Rosenfield, 1997). Further, stigma has been found to be associated with lower self-esteem in adolescents (Gershon, Tschann, & Jemerin, 1999; Westbrook, Bauman, & Shinnar,

1992) and with tense social interactions and poorer mental health among young single women who are pregnant (Hyde, 1998).

Stigma has also been found to negatively affect health promotion behaviours, such as seeking preventive health care or screening, due to fear of harm or labelling by health professionals (Barth, Cook, Downs, Switzer, & Fischhoff, 2002; Stevens & Hall, 1988; Van Hook, 1999). Responses to stigma vary from secrecy and selected social avoidance to disclosure in an attempt to educate others, alleviate the stress of secrecy, or cope with the experience (Goffman, 1963; Joachim & Acorn, 2000). Thus, the energy and resources expended in managing stigma may divert or impede health promotion activities. For families that differ from the "nuclear ideal," stereotyping and social expectations are powerful factors that can hamper healthy family development (Kissman & Allen, 1993). A broader understanding of how stigma influences health promotion in families headed by adolescent mothers is crucial in developing programs and services that support the development of healthy family living.

Based on a review of the literature and the DMHN, this study addressed the following hypotheses and research questions. The theoretical variables under consideration include health work, competence in health behaviour (operationalized as health promoting lifestyle practices), and felt stigma (an aspect of the broader social context).

Hypothesis 1: *Family participation in health work is positively related to adolescent mothers' use of health promoting lifestyle practices.*

Hypothesis 2: *Adolescent mothers' felt stigma is negatively related to family participation in health work.*

Hypothesis 3: *Adolescent mothers' felt stigma and health promoting lifestyle practices are negatively related.*

Research question 1: *What is the experience of stigma and how does it affect the lives of adolescent mothers and their children?*

Research question 2: *What are the relationships between selected demographic variables (age, living arrangement, mother's level of education, employment status, social support, marital status, partner involvement with children) and adolescent mothers' felt stigma, family health work, and health promoting lifestyle practices?*

Method

Design and Sample

A mixed method design was used to examine the meaning and context of felt stigma, including its relationship with health promotion efforts, experienced by adolescent mothers. Data were collected using structured self-report measures of the study variables followed by open-ended questions about their stigma experiences during a brief dialogic interview. Quantitative data obtained from the self-report measures enabled hypothesis testing, while qualitative data obtained in a more exploratory way was used to more fully describe variation in the participants' experiences of stigma, providing a context in which the quantitative findings could be more readily interpreted.

A convenience sample of 63 adolescent single mothers was recruited from urban and rural communities in southwestern Ontario, Canada. Sample size was based on a power analysis using a moderate effect size of .30, alpha of .05, and power of .80 (Cohen, 1988). Mothers were eligible to participate if they were English-speaking, were no more than 21 years of age, and had custody of at least one child between the ages of 6 months and 5 years. Women were recruited using: (a) contacts in health and social agencies that provide services to adolescent mothers and their children, (b) advertisements placed in public settings, and (c) referral of other adolescent mothers by the study participants. In all cases, potential participants were given information about the study and directed to the research team. Of the 65 mothers who expressed an interest in participating, 63 (97%) completed an interview, one failed to attend a scheduled interview, and one relocated and could not be found.

The mean age of mothers was 19 years (*SD* = 1.57, range 15–21) at the time of the interview, and 17 years (*SD* = 1.67, range 14–21) when they had given birth to their first child. The number of children per family ranged from one to four, with the majority of families (*n* = 51, 81%) having one child. Most mothers reported being "single and never married" (*n* = 53, 84%). However, almost two thirds (*n* = 40, 63.5%) were currently in a relationship, approximately half (*n* = 22, 55%) with fathers of their children. Slightly more than half of the participants (*n* = 36, 57%) reported regular contact between fathers and children, through either frequent visiting (*n* = 14, 22%) or co-parenting (*n* = 18, 29%).

Mothers had completed an average of 11 years of formal education (*SD* = 1.66), with 60% (*n* = 38) enrolled in school at the time of the interview. Of the 25 mothers who were not enrolled in school, 17 (68%) had already completed secondary school. Three quarters (*n* = 47, 75%) of the participants were unemployed, with the majority (*n* = 42, 67%) reporting social assistance as their main source of income. Only 35% of mothers (*n* = 22) received financial assistance from fathers of their children, although half of the participants (*n* = 33, 52%) received financial assistance from extended family members. Sources of support most frequently identified by participants were their own mothers (*n* = 44, 70%), followed by friends (*n* = 33, 52%), partners and extended family members (*n* = 25, 40%), health professionals, their own fathers (*n* = 21, 33%), and their siblings (*n* = 16, 25%).

Instruments

Data were collected using established summated rating scales to measure felt stigma, health work, and health promoting lifestyle practices. A brief dialogic interview was used to explore mothers' experiences of stigma. Information on selected personal and family characteristics — including family composition; sources of income and support; and mother's age, education, employment status, marital status, relationship status, and living situation — was collected using a demographic profile.

The Health Options Scale (HOS) (Ford-Gilboe, 1997, 2002b; Laudenbach & Ford-Gilboe, 2004) is a 21-item scale designed to measure family participation in health work. Responses are scored on a four-point Likert scale ranging from "strongly disagree" to "strongly agree" and indicate the extent to which families engage in health promoting lifestyle practices consistent with health work. Items are arranged in three subscales: Attending, which reflects the family's active involvement in health matters (8 items); Goal Attainment, which reflects identification and pursuit of health goals (6 items); and Experimenting, which reflects the use of problem-solving in the management of health situations (7 items). Concurrent validity has been established through moderate correlations with several established measures of theoretically related concepts, including the Health Promoting Lifestyle Profile (HPLP) (Walker, Sechrist, & Pender, 1987), a measure of individual health promoting lifestyle practices ($r = .66$); the Problem Solving Inventory, a measure of individual problem-solving style ($r = -.35$) (Heppner, 1988); and the Family APGAR ($r = .29$), a measure of global family functioning (Smilkstein, 1978; Ford-Gilboe, 1997, 2002b). Internal consistency has been acceptable for total scores (alpha > .70) but more variable for subscales across families of various life stages and contexts. The HOS has been used in studies with both single- and two-parent families (Ford-Gilboe, 1997; Ford-Gilboe et al., 2000; Monteith & Ford-Gilboe, 2002), including two studies with families headed by adolescent mothers (Black & Ford-Gilboe, in press; Sgarbossa & Ford-Gilboe, 2004). In the present study, Cronbach's alpha was .85 for the total HOS, while subscales ranged from a low of .59 for Experimenting to .68 for Goal Attainment and .80 for Attending.

The 52-item HPLP II, a revised version of the 48-item HPLP (Walker et al., 1987), was used to measure mothers' participation in health promoting lifestyle activities in six areas: Health Responsibility (9 items), Nutrition (9 items), Spiritual Growth, (9 items), Interpersonal Relations (9 items), Physical Activity (8 items), and Stress Management (8 items). Participants rate the frequency with which they engage in health behaviours on a four-point Likert scale ranging from "never" to "routinely." Using data from 712 adults aged 18 to 92, the six-dimensional structure of the HPLP II was confirmed through factor analysis. Construct validity was also supported through the positive correlations between the HPLP II and the Personal Lifestyle Questionnaire ($r = .68$) and measures of perceived health status and quality of life. Internal consistency was .94 for the total scale and .79 to .87 for the subscales. Test-retest reliability over a 3-week interval was .89 (Walker & Hill-Polerecky, 2001). For the present study, internal consistency using Cronbach's alpha coefficients was .89 for the total scale, with four subscales greater than .70; two subscales, stress management and nutrition, approached acceptable levels of .67 and .68, respectively.

The Stigma Scale (Jacoby, 1994) is a three-item measure of individual perceptions of felt stigma that has been used in several studies with adults who have epilepsy. In the present study, the Stigma Scale was modified from its original yes/no response format to a five-point Likert scale ranging from "never" to "always," in order to enhance sensitivity of measurement with respect to feelings of stigma based on status as a "young mother." Concurrent validity of the Stigma Scale has been supported through significant negative correlations between scores on the Stigma Scale and scores on the SF-36, a measure of general health status (Ware & Sherbourne, 1992), as well as positive associations between stigma and negative feelings about life and worry in a study with adults who have epilepsy (Baker, Brooks, Buck, & Jacoby, 1999). In the present study, the Cronbach's alpha coefficient for the Stigma Scale was higher (.86) than that reported by Jacoby (.72) in a sample of adults.

A brief dialogic interview using two open-ended questions and a series of prompts was conducted with all participants in order to more fully explore the nature and extent of stigma in their lives. The women were asked if they had been judged or treated differently because they were "young mothers" and, if so, to describe their experiences. Prompts were used selectively to identify those who had this experience and the circumstances surrounding it. The participants were then asked what effect, if any, such experiences had on their own and their family's physical or mental health, routines or practices, relationships, and feelings about themselves.

Procedures

Ethics approval was obtained from the Research Ethics Board at the study site. After informed consent had been obtained, standardized measures of the study variables were administered to each participant and her responses recorded by the interviewer on a copy of each tool. The participant was then asked to describe her experiences of stigma. This part of the interview was audiotaped and transcribed verbatim. Interviews were conducted in a quiet location selected by the participant, most often the home, and lasted from 30 to 60 minutes. To acknowledge the value of participants sharing their personal experiences, a $15 cash honorarium was provided at the end of the interview.

Data Analysis

Descriptive statistics appropriate to the level of data were calculated for all study variables. Pearson's r correlations were used to test the study hypotheses. The relationships between study variables and selected demographic characteristics were examined using appropriate measures of association. The level of significance for all statistical analyses was $p < .05$.

Content analysis was used to summarize participants' descriptions of their stigma experiences (Sandelowksi, 2000). Two interviews were inaudible and could not be transcribed, while nine mothers did not identify stigma experiences, leaving 52 interviews (83%) for inclusion in the qualitative analysis. The participants' responses were reviewed using data management and analysis approaches described by Miles and Huberman (1994), and initial themes were inductively generated from the data that described the salient aspects of the stigma experience. Transcripts were then coded using initial themes and commonalities and differences noted. Finally, matrices were created to help identify patterns in the data across participants in an attempt to better understand the relationships between the quantitative data and the emerging qualitative themes. Qualitative findings were shared with a subgroup of participants ($n = 8$) during two focus-group sessions and modified slightly based on their feedback.

Results

Descriptive statistics for the study variables are presented in Table 1. The mean score for health work was moderate (2.9/4) and comparable to that reported in previous studies with single adolescent mothers of preschool children (Black & Ford-Gilboe, in press) and single- and two-parent families (Ford-Gilboe, 1997). The mean score for health promoting lifestyle practices was also moderate (2.7/4) and comparable to the results obtained in studies with families with preschool children (Monteith & Ford-Gilboe, 2002) and families headed by adolescent mothers (Black & Ford-Gilboe). The mean score for felt stigma was moderate (2.6/5). Comparative data for felt stigma were not available.

Table 1 ***Descriptive Statistics for Study Variables (N=63)***

	Mean			**Range**	
Variable	**Overall**	**Scale**[a]	***SD***	**Possible**	**Actual**
Felt stigma	7.9	2.6/5	2.63	3–15	3–15
Health work	61.2	2.9/4	6.48	21–84	48–77
Attending	23.9	3.0/4	3.03	8–32	17–30
Goal attainment	17.0	2.8/4	2.47	6–24	11–23
Experimenting	20.3	2.9/4	2.21	7–28	15–26
Health promoting lifestyle practices	138.2	2.7/4	18.81	52–208	104–178
Health responsibility	23.1	2.6/4	5.03	9–36	13–36
Physical activity	18.6	2.3/4	4.69	8–32	10–32
Nutrition	22.8	2.5/4	4.79	9–36	12–31
Spiritual growth	27.3	3.0/4	4.17	9–36	18–36
Interpersonal relations	28.1	3.1/4	4.05	9–36	16–36
Stress management	18.4	2.3/4	4.18	8–32	8–29

[a] Mean score converted into the scale of measurement for ease of interpretation.

Few demographic variables were related to study variables. Moderate negative relationships were observed between felt stigma and mothers' age both at the time of interview ($r = -.38, p = .002$) and at the time of the birth of her first child ($r = -.35, p = .005$). Mothers who reported receiving partner support had lower levels of felt stigma than those who did not t (2, 61) = 2.63, $p = .011$. Women with lower felt stigma also reported frequent involvement by the children's fathers, while those with high felt stigma reported little or no involvement by fathers $\Pi^2(1, 63) = 6.02$, $p = .014$, Kendall's tau-$b = -.31$, $p = .008$. Health work was also higher in families in which fathers were involved compared to those in which there was no such involvement t (2, 61) = -2.50, $p = .015$.

Tests of the Hypotheses

Correlations among the study variables are presented in Table 2. Consistent with theoretical expectations, a moderate positive relationship was found between family health work and mothers' health promoting lifestyle practices ($r = .52, p < .001$), providing support for hypothesis 1. Each dimension of health promoting lifestyle practices was positively

Table 2 ***Correlation Matrix of Study Variables (N=63)***

	HWORK	attend	goal	exper	HPLP	healthresp	activity	nutrition	spiritual	interpersonal	stress	STIGMA
HWORK	1.0	.91*	.84*	.75*	.52*	.31*	.30*	.46*	.47*	.35*	.30*	.03
attend		1.0	.68*	.54*	.45*	.22*	.27*	.43*	.41*	.27*	.31*	-.01
goal			1.0	.41*	.48*	.22*	.33*	.49*	.44*	.39*	.16	-.05
exper				1.0	.39*	.35*	.14	.20	.32*	.24*	.27*	.16
HPLP					1.0	.65*	.72*	.72*	.83*	.75*	.53*	.12
healthresp						1.0	.26*	.38*	.46*	.44*	.13	.29*
activity							1.0	.53*	.65*	.42*	.12	.02
nutrition								1.0	.47*	.29*	.27*	.12
spiritual									1.0	.62*	.34*	.01
interpersonal										1.0	.46*	-.02
stress											1.0	.04
STIGMA												1.0

* $p < .05$

HWORK = health work; attend = attending; goal = goal attainment; exper = experimenting; HPLP = health promoting lifestyle practices; healthresp = health responsibility; activity = physical activity; nutrit = nutrition; spiritual = spiritual growth; interpersonal = interpersonal relations; stress = stress management; STIGMA= felt stigma.

related to health work (r = .30–.47). Likewise, moderate positive relationships were observed between overall health promoting lifestyle practices and each of the dimensions of health work (r = .39–.48). Felt stigma was not related to health work or any dimension of health work. Thus, hypothesis 2 was not supported. Similarly, no relationship was observed between felt stigma and health promoting lifestyle practices, resulting in a lack of support for hypothesis 3. The health responsibility dimension of health promoting lifestyle practices was positively associated with felt stigma (r = .29, p = .01), but in the opposite direction to that predicted in the hypothesis.

Mothers' Experiences of Felt Stigma

Full presentation of qualitative findings is beyond the scope of this paper. Instead, a brief description of findings related to the mothers' stigma experiences is presented in order to illuminate key aspects of these experiences and enhance interpretation of the quantitative findings. The mothers' descriptions of their stigma experiences were categorized according to source, basis, mechanism, response, and impact. Table 3 identifies dimensions according to frequency of report, along with mothers' comments. The majority of participants (n = 52, 83%) were able to describe at least one stigma experience, with some relating multiple and varied experiences.

Sources of stigma. The mothers described their stigma experiences as arising from two sources — the general public or strangers (including professionals), and people known to them. The majority of participants (n = 45, 87%) identified strangers, particularly "older people," as key players in their stigma experiences and public transit as a common site for these experiences. Most of the participants were linked with some form of health or social services and more than one third (n = 19, 37%) reported stigma experiences arising from contact with nurses, doctors, teachers, or social assistance counsellors. Few mothers identified family members (n = 8, 15%) or friends (n = 6, 12%) as sources of stigma.

Bases of stigma. Mothers most often identified their youth (n = 29, 56%) as the reason for negative judgements about them, with some (n = 14, 27%) making a link between their youth and the perception that they were not fit to be parents. Some mothers (n = 11, 21%) said that they had been judged as immoral or deviant because they were unwed, had had sexual relations before marriage, and were presumed to use drugs or to shoplift. Finally, 15% (n = 8) of the mothers described irresponsibility or dependence on the welfare system as a reason for negative judgements about them.

Mechanisms of stigma. Stigma was experienced in three different forms: non-verbal expressions (n = 30, 58%), such as "looks" or "glares"

Table 3 *Stigma Experiences of Young Mothers (N = 52)*

Dimension	**Frequency**	**Examples**
Sources		
Strangers	45	"One time when I was on the bus…it's usually older people, and they were sitting behind me and talking 'children having children,' and I overheard them."
Professionals	19	"The nurse called me out of the waiting room and said to me that she didn't know what I expected them to do for me…and being me and pregnant, I just left."
Family/ friends	14	"My aunt…phoned me and said she wouldn't have a shower for me as a 15-year-old having a baby is a tragedy, not a celebration."
Bases		
Youth/poor parent	43	"Everybody thinks that because I'm young I'm just neglecting her…and that I don't know how to take care of her."
Immoral/ deviant	11	"People see me with my baby [in public] and they are just, like, 'gross, you had sex, you're a pig' kind of thing."
Irresponsible/ social dependency	8	"I just got my child support. I had tons of groceries with me. We were getting off the bus and a lady said, 'Oh, welfare cheque day?'…they just assumed I sit at home and that I'm on welfare."
Mechanisms		
Non-verbal expressions	30	"When I'm out in public and people see that I'm a kid…then they just sort of give you a look like you're disgusting, looks you don't want to get, dirty looks."
Verbal comments	26	"Older people…sometimes say things like, 'I can't believe you have a baby, you're so young, you should have waited, it's not good,' kind of thing… They say it kind of mean too."
Ill treatment	19	"One of the nurses was very curt with me, very abrupt and treating me like I couldn't do it myself... They just seemed that they would rather help all the other mothers that were a little bit older."

Responses		
Physical	20	"When I'm walking down the street I'm, like, trying to hide." "I will not dress my daughter in donated clothes. She always wears Gap…because I don't want people to look down on me and stereotype me… If she's in her play clothes people give me dirty looks. If she's in her regular clothes they don't even give me a second glance."
Cognitive	19	"It hurt my feelings a little bit, but everybody has their own opinion so it doesn't really matter what everybody else thinks."
Emotional	13	"It almost seems I am hard as a rock but I can get upset really easily and they may not see that, but as soon as they are out of sight and turn that corner, the tears are coming."
Challenge		
Stigmatizers	10	"…older people [on a bus] talking 'children having children,' and I overhead them. I turned around and said, 'I'm a 24-year-old, married, successful,' and then they apologized and said my daughter looked like a happy, healthy baby."
Self	5	"I've been out on my own for a year and a half just because I'm so hell bent on proving everybody wrong, that there are people out there my age who can do it and I can do it."
Impact		
Social isolation	31	"It took me a long time, but now it's just like I've kind of put up a wall." "A lot of my friends who are the same age as me don't have kids…so it's like I can't relate to half of my friends any more."
Emotional/ mental health	27	"Sometimes it affects my mental health because I worry about what other people think." "Like my emotions went up and down… I was really down because of the looks that you got and the things the nurses would say, things that made you feel you were less than everybody else."
Positive life change	8	"I'm a one hundred percent different person than I was the day before I found out I was pregnant. I changed totally… I just pretty much bettered my life from there."

conveying a judgement of inadequacy; verbal comments (*n* = 26, 50%), such as insensitive questions or unsolicited advice; and ill treatment (*n* = 19, 37%), such as rudeness, avoidance, or inappropriately intense monitoring.

Responses to stigma. The mothers described a variety of responses to these expressions of stigma. The majority attempted to conceal the stigma they felt by cognitively, emotionally, or physically distancing themselves. Few mothers chose to challenge either the perpetrators or themselves. Cognitive concealing, reported by 37% (*n* = 19) of the mothers, consisted of reframing their experience as unimportant, often by telling themselves that others' opinions "don't matter" or that they "don't care what other people think." Affective or emotional concealing, identified by one quarter (*n* = 13) of the mothers, involved either suppressing their emotions in public or protecting themselves from emotional harm and "not let it bother me." Physical concealing was the most frequent response identified by participants (*n* = 20, 38%). The mothers described using strategies to avoid others and to fit in and be less visible in public. For example, several mothers said they dressed themselves and their children in better clothing in order to "blend in."

Only 20% (*n* = 10) of the mothers reported attempts to confront the stigma. Most of these challenged the people they perceived were judging them, by trying to explain themselves, by offering themselves as role models, or, in one instance, by lying about their age and marital status. A small group of mothers (*n* = 5, 10%) described their stigma experience as an impetus to challenge themselves and make changes in their lives in order to prove those who would sit in judgement of them wrong.

Impact of stigma. The participants described their stigma experiences as affecting their health and their social relationships. However, they identified both positive and negative outcomes. The most striking negative outcome was social isolation. In attempting to minimize the stigma, the mothers often put up physical and emotional walls around themselves. The mothers' isolation stemmed from both their responses to stigma and their changing relationships with friends. Most of the participants described an asynchrony or poor fit between themselves and their old friends but attributed this to changes in their life course and a loss of common interests, rather than to negative judgements on the part of their friends. Half of the participants (*n* = 27) reported that stigma affected their emotional or mental health by increasing their feelings of stress or depression and eroding their self-confidence. Despite the negative impact of stigma on their emotional health and interpersonal relationships, several of the young mothers acknowledged that motherhood had its positive aspects, such as giving them an opportunity to dramatically change their lives for the better.

Discussion

Support for the relationship between health work and competence in health behaviour, operationalized as mothers' health promoting lifestyle practices, offers further validation for proposed relationships in the Developmental Model of Health and Nursing (DHMN) (Allen & Warner, 2002; Ford-Gilboe, 2002a). The positive relationship found in this study between family health work and mothers' health promoting lifestyle practices (*r* = .52) is consistent with findings from several previous studies with young families with children (Ford-Gilboe, 1997; Ford-Gilboe et al., 2000; Monteith & Ford-Gilboe, 2002), including two studies with single adolescent mothers of preschoolers (Black & Ford-Gilboe, in press; Sgarbossa & Ford-Gilboe, 2004). It has been suggested that health work, which includes broad problem-solving and goal-attainment activities, provides the foundation for helping family members develop and sustain a healthy lifestyle (Ford-Gilboe, 2002a). Consistent with this premise, research examining family management style in families with chronically ill children suggests that when families use proactive strategies and build on previous successes, members are more competent in self-care (Knafl, Breitmayer, Gallo, & Zoller, 1996). Similarly, findings of both quantitative and qualitative studies with single-parent families support the relationships between family processes of growth and change, testing of new health behaviours, and making healthy lifestyle choices (Duffy, 1984, 1986, 1994). Thus, in setting goals and working through problems, families and their members have the opportunity to develop effective health behaviours and thus healthier lifestyles. The adolescent mothers in the present study were in the early stages of learning to parent, and these experiences may have provided a context for considering goals and priorities and changing lifestyle practices as they incorporated the developmental tasks of mothering with those of adolescence.

The majority of mothers in the present study defined "family" broadly when responding to questions about health work. Thus, the pattern of health work captured in the study was primarily that of the family of origin and the social network rather than that of the emerging family of "procreation." The participants identified these same people — their own mother, friends, partners, and extended family members — as sources of support. Their extended family relationships may have encouraged them to develop patterns of health work by providing them with a reservoir of established problem-solving and goal-attainment means they could draw upon when faced with new challenges, such as parenting, education, or career-development issues. Previous research has shown that supportive extended-family relationships positively affect adolescent mothers' coping (Kelly, 1995) and facilitate the transition to motherhood (Mercer, 1986;

Panzarine, 1986). Extended family members may have also served as role models, not only for problem-solving but for developing healthy lifestyles. Parental role modelling of positive health behaviours has been found to be associated with healthy lifestyle practices among adolescents (Donovan et al., 1991; Gillis, 1997). Findings from this study suggest that, even in the context of developmental and situational challenges associated with adolescent parenting, family health work has a positive impact on the adoption and maintenance of healthy lifestyle practices.

The results of this study provide a basis for considering what role, if any, contextual factors such as felt stigma play in family health promotion. The complexity of and wide variation in the stigma experiences described by the adolescent mothers support the contention that this population is heterogeneous (Arenson, 1994). Most participants reported responding to feelings of stigma by concealing themselves through cognitive reframing, suppression of emotions, and physical distancing or social isolation, yet some challenged themselves to develop their potential as women and as mothers by setting goals and striving to meet them. However, qualitative analysis showed no consistent pattern of a relationship between their responses to stigma and health work when inspected across the analysis matrix. Thus, it is possible that no relationship exists between felt stigma and health work, that such a relationship exists only under certain conditions, or that such a relationship is manifested in other variables. It is also possible that the effect was too small to be detected or that the Stigma Scale, a brief, newer instrument, may not have adequately captured key dimensions of stigma experienced by adolescent mothers. Further research is needed in order to examine factors that mediate the relationship between stigma and health promotion efforts, such as self-esteem, resilience, and father involvement.

Although felt stigma was not directly related to health work or global health promoting lifestyle practices, father involvement was positively related to health work and negatively related to felt stigma, raising the possibility that felt stigma indirectly affects health work through father or partner involvement. Involvement of the children's fathers has been found to contribute to higher levels of self-esteem (Thompson & Peebles-Wilkins, 1992) and life satisfaction (Unger & Wandersman, 1988) in mothers, and to improved child development and behavioural outcomes (Unger & Cooley, 1992). Fathers of children are key players in providing functional and interpersonal support for adolescent mothers (Chen, Telleen, & Chen, 1995). It is possible that the presence of the children's father in the lives of participants lessened the perceived stigma, perhaps because it made them seem part of a nuclear family and transformed them from unwed mothers into "good girls" with a proper future (Addelson, 1999). Lower feelings of stigma may have caused the mothers to be more open to assistance from the child's father and others, supporting the development of health work.

Both the qualitative findings of this study and the literature support the premise that stigma affects two personal strengths — self-esteem and resilience. Higher levels of stigma have been associated with lower levels of self-esteem in adolescents (Gershon et al., 1999; Westbrook et al., 1992). In this study, similarly, the adolescents who reported higher levels of felt stigma described themselves with less confidence than those who reported lower levels of felt stigma. Self-esteem has been found to be positively associated with parental competence (Sadler, Anderson, & Sabatelli, 2001) and coping strategies used by teen mothers in managing living arrangements, finances, and illnesses (Colletta, Hadler, & Gregg, 1981). Self-esteem is an internal strength that increases adolescent mothers' ability to manage normative life transitions associated with parenting. Thus, it is possible that self-esteem mediates the relationship between felt stigma and health work, ultimately resulting in positive parenting behaviours.

Resilience may also mediate the relationship between stigma and health work. Resilience is the capacity to adapt and grow in the face of adversity, and is associated with flexibility, self-reliance, determination, and the ability to derive meaning and satisfaction from life (Kadner, 1989; O'Leary, 1998, Wagnild & Young, 1990). In studies with single adolescent mothers (Black & Ford-Gilboe, in press) and single adult mothers (Ford-Gilboe et al., 2000), resilience has been found to positively affect both health work and healthy lifestyle practices. Felt stigma may cause distress (Scambler & Hopkins, 1986) and place those experiencing it at risk for negative outcomes, creating a context of adversity. Yet several participants in the present study reported that their stigma experiences, in conjunction with their new motherhood role, prompted them to change their life courses and better themselves, which suggests that stigma may engender resilience. The idea that parenting promotes positive transformations in adolescent mothers echoes the findings of other qualitative studies (Clemmens, 2003; Smith Battle, 1995), although not exclusively related to the perceived stigma of teen motherhood. Resilience may cause those mothers who possess it to take a greater interest in their health, in spite of adversity, and to strive towards healthy personal and family development.

The unanticipated finding of a direct positive relationship between felt stigma and health responsibility suggests that felt stigma may provide an impetus for young mothers to adopt health-seeking behaviours. Health responsibility is the most visible dimension of health promoting lifestyle, as it entails the seeking of health information or care from professionals in the public domain (Walker et al., 1987). Findings from qualitative studies suggest that young mothers are acutely aware of the sanctions associated with involvement with health or social service agencies, including the risk of having their children removed by child protection authorities (DeJonge, 2001; Hanna, 2001). Thus, felt stigma may serve to increase awareness of risk and cause the adolescent mothers to take proactive measures, such as seeking health services, in order to publicly demonstrate parental competence and responsibility. No such public action is associated with more personal health promotion practices, such as nutrition or stress management, none of which have been found to be related to felt stigma.

While the results of this study contribute to the knowledge base on the health promotion practices of adolescent single mothers, several limitations should be considered. Use of a correlational design precludes causal inferences, while the use of a small convenience sample of primarily Caucasian, English-speaking, educated mothers of preschool children, most of whom were connected with a variety of community service programs, limits the generalizability of the findings to those with similar characteristics. Further, the mothers most often defined their family broadly, so that their reported health work reflects patterns within their families of origin and social network, as opposed to within a nuclear family structure. Thus the relationship between health work and health promoting lifestyle practices, and the effects of felt stigma on these variables in the nuclear family, is not known. Although the DMHN holds that "family" should be defined by the person, varied definitions of family pose a challenge to the measurement of health work and interpretation of findings. Since the participants may have sought to portray themselves in the best light, self-report bias is possible. Finally, the qualitative findings related to stigma provide no more than a glimpse from the perspective — obtained during a single encounter — of adolescent mothers who were well connected with community services.

Conclusions and Implications

Consistent with a review of media stories (Kelly, 1996), the majority of participants described experiences with stigma in their everyday lives that affected their emotional and social health. Despite the apparent difficulty of living under continual scrutiny, the adolescent mothers participated in both family and individual health promotion activities at levels similar to those reported by older and/or more advantaged women and their families (Ford-Gilboe et al., 2000; Monteith & Ford-Gilboe, 2002). The participants rose to the challenge of their life circumstances by parenting while attending school or working, seeking assistance and support through a range of community services and promoting health by taking responsibility for themselves and their children. These findings are consistent with the premise that adolescent motherhood can provide an opportunity for growth and positive change (Clemmens, 2003; Smith Battle, 2000). According to the DMHN (Allen & Warner, 2002), support for the development of health work may help both adolescent mothers and their families to make healthy lifestyle choices by providing them with opportunities to develop and engage in coping and goal-attainment processes.

Most of the participants reported experiences of stigma from various sources, including service providers. It is important that health-care professionals working with adolescent single mothers be cognizant of these feelings and perceptions. Attention to both verbal and non-verbal communication is essential, so that stigma is not perpetuated, resulting in further discrimination. Experiences of stigma may also contribute to the marginalization and social isolation of families headed by adolescent mothers. Nurses and other health-care professionals, particularly those working in public health, have a unique opportunity to identify these families and to support the development of connections within the community.

Nurses and other professionals must also advocate for adolescent mothers and their families on a broader scale in order to reduce barriers to effective services and dispel the negative stereotyping that pervades society. The present findings suggest that felt stigma may, in fact, motivate adolescent mothers to assume responsibility for health, but that stigma is a complex phenomenon and may affect other aspects of their lives. Further, this study was the first to explore stigma with regard to adolescent mothers and offers only a glimpse into its effects and its potential impact on health promotion. More in-depth or sophisticated schemas of the phenomenon may exist but were not discovered. More research aimed at describing the influence of stigma on the lives of families headed by adolescent mothers and identifying factors that buffer the effects of stigma on health outcomes is needed. As found in this study, relationships between stigma and family health promotion may be mediated by personal qualities such as self-esteem or resilience. Future studies should examine the interrelationships between these and other personal or family capacities on feelings of stigma and health promotion in families headed by adolescent mothers, including those experiencing varied contexts such as single-parenting, limited support networks, living with chronic illness, or families with older children. Additionally, longitudinal studies would be beneficial, in order to examine the evolution of health promotion in these families as both the mothers and their children grow and develop and in order to identity any association between changing resources and family strengths.

The results of this study contribute to an evolving knowledge base on health promotion in families headed by adolescent mothers and provide insight into the impact of contextual factors, such as felt stigma, on family health promotion efforts. A comprehensive understanding of factors that both enhance and hinder the health promotion efforts of these families is needed, to assist health and social service professionals to provide services that support, rather than undermine, the healthy development of adolescent mothers and their children.

References

Addelson, K. P. (1999). How should we live? Some reflections on procreation. In J. Wong & D. Checkland (Eds.), *Teen pregnancy and parenting: Social and ethical issues* (pp. 81–98). Toronto: University of Toronto Press.

Allen, M. (1983). Primary care nursing: Research in action. In L. Hockey (Ed.), *Recent advances in nursing: Primary care nursing* (pp. 32–77). Edinburgh: Churchill Livingstone.

Allen, M. F., & Warner, M. (2002). A developmental model of health and nursing. *Journal of Family Nursing, 8*(2), 96–135.

Arenson, J. D. (1994). Strengths and self-perceptions of parenting in adolescent mothers. *Journal of Pediatric Nursing, 9*(4), 251–257.

Baker, G. A., Brooks, J., Buck, D., & Jacoby, A. (1999). The stigma of epilepsy: A European perspective. *Epilepsia, 41*(1), 98–104.

Barth, K. R., Cook, R. L., Downs, J. S., Switzer, G. E., & Fischhoff, B. (2002). Social stigma and negative consequences: Factors that influence college students' decisions to seek testing for sexually transmitted infections. *Journal of American College Health, 50*(4), 153–159.

Black, C. J., & Ford-Gilboe, M. (in press). The relationships among mothers' resilience, family health work and mothers' health-promoting lifestyle practices in families led by adolescent mothers. *Journal of Advanced Nursing.*

Chen, S. P. C., Telleen, S., & Chen, E. H. (1995). Family and community support of urban pregnant students: Support person, function and parity. *Journal of Community Psychology, 23,* 28–33.

Clemmens, D. (2003). Adolescent motherhood: A meta-synthesis of qualitative studies. *MCN: American Journal of Maternal Child Nursing, 28*(2), 93–99.

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum.

Colletta, N. D., Hadler, S., & Gregg, C. H. (1981). How adolescents cope with the problems of early motherhood. *Adolescence, 16*(63), 499–512.

Crocker, J., Major, B., & Steele, C. (1998). Social stigma. In D. Gilbert, S. T. Fiske, & G. Lindzey (Eds.), *The handbook of social psychology* (4th ed.) (pp. 504–553). New York: McGraw-Hill.

DeJonge, A. (2001). Support for teenage mothers: A qualitative study into the views of women about the support they received as teenage mothers. *Journal of Advanced Nursing, 36*(1), 49–57.

DeMarco, R., Ford-Gilboe, M., Friedmann, M. L., McCubbin, H., & McCubbin, M. (2000). Stress, coping and family health. In V. Rice (Ed.), *Handbook of stress, coping and health: Implications for nursing research, theory and practice* (pp. 295–334). Newbury Park, CA: Sage.

Donovan, J. E., Jessor, R., & Costa, F. M. (1991). Adolescent health behaviour and conventionality-unconventionality: An extension of problem-behaviour theory. *Health Psychology, 10*(1), 52–61.

Dormire, S., Strauss, S., & Clarke, B. (1988). Social support and adaptation to the parent role in first time adolescent mothers. *Journal of Gynecology and Neonatal Nursing,* July/August, 327–337.

Duffy, M. E. (1984). Transcending options: Creating a milieu for practicing high level wellness. *Health Care for Women International, 5,* 145–161.

Duffy, M. E. (1986). Primary prevention behaviours: The female-headed, one-parent family. *Research in Nursing and Health, 9,* 115–122.

Duffy, M. E. (1988). Health promotion in the family: Current findings and directives for nursing research. *Journal of Advanced Nursing, 13,* 109–117.

Duffy, M. E. (1994). Testing the theory of transcending options: Health behaviours of single parents. *Scholarly Inquiry for Nursing Practice, 8*(2), 191–202.

Farber, N. B. (1991). The process of pregnancy resolution among adolescent mothers. *Adolescence, 26*(103), 699–716.

Fife, B. L., & Wright, E. R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behaviour, 41,* 50–67.

Ford-Gilboe, M. (1997). Family strengths, motivation, and resources as predictors of health promotion behaviour in single-parent and two-parent families. *Research in Nursing and Health, 20,* 205–217.

Ford-Gilboe, M. (2002a). Developing knowledge about family health promotion by testing the Developmental Model of Health and Nursing. *Journal of Family Nursing, 8*(2), 140–156.

Ford-Gilboe, M. (2002b). *Development and psychometric testing of the Health Options Scale*. Unpublished manuscript, University of Western Ontario.

Ford-Gilboe, M., Berman, H., Laschinger, H. K. S., & Laforêt-Fliesser, Y. (2000). *Testing a causal model of family health promotion behaviour in mother-headed single-parent families.* Unpublished manuscript, University of Western Ontario.

Gershon, T. D., Tschann, J. M., & Jemerin, J. M. (1999). Stigmatization, self-esteem and coping among adolescent children of lesbian mothers. *Journal of Adolescent Health, 24,* 437–445.

Gillis, A. J. (1997). Determinants of health-promoting lifestyles in adolescent females. *Canadian Journal of Nursing Research, 26*(2), 13–26.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity.* Englewood Cliffs, NJ: Prentice-Hall.

Gottlieb, L., & Rowat, K. (1987). The McGill Model of Nursing: A practice-derived model. *Advances in Nursing Science, 9*(4), 51–61.

Hanna, B. (2001). Negotiating motherhood: The struggles of teenage mothers. *Journal of Advanced Nursing, 34*(4), 456–464.

Hechtman, L. (1989). Teenage mothers and their children: Risks and problems: A review. *Canadian Journal of Psychiatry, 34*(6), 569–575.

Heppner, P. (1988). *The problem solving inventory.* Palo Alto, CA: Consulting Psychologists Press.

Hermann, M. M., Van Cleve, L., & Levisen, L. (1998). Parenting competence, social support, and self-esteem in teen mothers case managed by public health nurses. *Public Health Nursing, 15*(6), 432–439.

Hyde, A. (1998). From mutual pretence awareness to open awareness: Single pregnant women's public encounters in an Irish context. *Qualitative Health Research, 8*(5), 634–643.

Jacoby, A. (1994). Felt versus enacted stigma: A concept revisited. *Social Science and Medicine, 38*(2), 269–274.

Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing, 32*(1), 243–248.

Kadner, K. D. (1989). Resilience: Responding to adversity. *Journal of Psychosocial Nursing, 27*(7), 20–25.

Kaplan, E. B. (1996). Black teenage mothers and their mothers: The impact of adolescent childbearing on daughters' relations with mothers. *Social Problems, 43*(4), 427–443.

Kelly, D. M. (1996). Stigma stories: Four discourses about teen mothers, welfare and poverty. *Youth and Society, 27*(4), 421–449.

Kelly, L. E. (1995). Adolescent mothers: What factors related to level of preventive health care sought for their infants? *Journal of Pediatric Nursing, 10*(2), 105–113.

Kissman, K., & Allen, J. (1993). *Single parent families.* Newbury Park, CA: Sage.

Kitzinger, S. (1978). *Women as mothers*. Oxford: Fontana.

Knafl, K. A., Breitmayer, B., Gallo, A., & Zoeller, L. (1996). Family response to childhood chronic illness: Description of management styles. *Journal of Pediatric Nursing, 11*(5), 315–326.

Laudenbach, L., & Ford-Gilboe, M. (2004). Psychometric evaluation of the Health Options Scale with adolescents. *Journal of Family Nursing, 10*(1), 121–138.

Loveland-Cherry, C. (1986). Personal health practices in single parent and two parent families. *Family Relations, 35,* 133–139.

MacDonald, L. D., & Anderson, H. R. (1984). Stigma in patients with rectal cancer: A community study. *Journal of Epidemiology and Community Health, 38,* 284–290.

McCain, M. N., & Mustard, J. F. (1999). *Reversing the real brain drain – Early Years Study Final Report*. Toronto: Publications Ontario.

Mercer, R.T. (1986). Predictors of maternal role attainment at one year postbirth. *Western Journal of Nursing Research, 8*(1), 9–32.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage.

Monteith, B., & Ford-Gilboe, M. (2002). The relationships among mothers' resilience, family health work and mothers' health-promoting lifestyle practices in families with preschool children. *Journal of Family Nursing, 8*(4), 383–407.

Mullen, P. D. (1983). Promoting child health: Channels of socialization. *Family and Community Health, 5,* 52–68.

O'Leary, V. E. (1998). Strength in the face of adversity: Individual and social thriving. *Journal of Social Issues, 54*(2), 425–446.

Panzarine, S. (1986). Stressors, coping and social supports of adolescent mothers. *Journal of Adolescent Health Care, 7,* 153–161.

Pender, N. J. (1996). *Health promotion in nursing practice* (3rd ed.). Stamford, CT: Appleton & Lange.

Rosenfield, S. (1997). Labeling mental illness: The effect of received services and perceived stigma on life satisfaction. *American Sociological Review, 62*(4), 660–672.

Sadler, L. S., Anderson, S. A., & Sabatelli, R. M. (2001). Parental competence among African American adolescent mothers and grandmothers. *Journal of Pediatric Nursing, 16*(4), 217–233.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health, 23,* 334–340.

Scambler, G. (1998). Stigma and disease: Changing paradigms. *Lancet, 352,* 1054–1055.

Scambler, G., & Hopkins, A. (1986). Being epileptic: Coming to terms with stigma. *Sociology of Health and Illness, 8,* 26–43.

Sgarbossa, D., & Ford-Gilboe, M. (2004). Mother's friendship quality, parental support, quality of life and family health work in families led by adolescent mothers with preschool children. *Journal of Family Nursing, 10*(2), 232–261.

Smilkstein, G. (1978). The family APGAR: A proposal for a family function test and its use by physicians. *Journal of Family Practice, 6,* 1231–1239.

Smith Battle, L. (1995). Teenage mothers' narratives of self: An examination of risking the future. *Advances in Nursing Science, 17*(4), 22–36.

Smith Battle, L. (2000). Developing a caregiving tradition in opposition to one's past: Lessons from a longitudinal study of teenage mothers. *Public Health Nursing, 17,* 85–93.

Stevens, P. E., & Hall, J. H. (1988). Stigma, health beliefs and experiences with health care in lesbian women. *Image: Journal of Nursing Scholarship, 20*(2), 69–73.

Sword, W. A. (1997). Enabling health promotion for low-income single mothers: An integrated perspective. *Clinical Excellence for Nurse Practitioners, 1*(5), 324–332.

Thompson, M. S., & Peebles-Wilkins, W. (1992). The impact of formal, informal, and societal support networks on the psychological well-being of black adolescent mothers. *Social Work, 37*(4), 322–328.

Turner, R. J., & Avison, W. R. (1985). Assessing risk factors for problem parenting: The significance of social support. *Journal of Marriage and the Family, 47*(4), 881–892.

Unger, D. G., & Cooley, M. (1992). Partner and grandmother contact in black and white teen parent families. *Journal of Adolescent Health, 13,* 546–552.

Unger, D. G., & Wandersman, L. P. (1988). The relation of family and partner support to the adjustment of adolescent mothers. *Child Development, 59,* 1056–1060.

Van Hook, M. P. (1999). Women's help-seeking patterns for depression. *Social Work in Health Care, 29*(1), 15–34.

Wagnild, G., & Young, H. M. (1990). Resilience among older women. *Image: Journal of Nursing Scholarship, 22*(4), 252–255.

Walker, S., & Hill-Polerecky, D. M. (2001). *Psychometric evaluation of the Health Promoting Lifestyle Profile II.* Unpublished manuscript, University of Nebraska Medical Center.

Walker, S. N., Sechrist, K. R., & Pender, N. J. (1987). The Health-Promoting Lifestyle Profile: Development and psychometric characteristics. *Nursing Research, 36*(2), 76–81.

Ware, J. E., & Sherbourne, C. D. (1992). The MOS 36-item Short-Form Health Survey (SF-36): Conceptual framework and item selection. *Medical Care, 30,* 473–483.

Westbrook, L. E., Bauman, L. J., & Shinnar, S. (1992). Applying stigma theory to epilepsy: A test of a conceptual model. *Journal of Pediatric Psychology, 17,* 633–649.

Whall, A. L., & Loveland-Cherry, C. J. (1993). Family unit-focused research: 1984–1991. *Annual Review of Nursing Research, 11,* 227–247.

Whitehead, E. (2001). Teenage pregnancy: On the road to social death. *International Journal of Nursing Studies, 38,* 437–446.

World Health Organization, Canadian Public Health Association, and Health and Welfare Canada. (1986). *Ottawa Charter for Health Promotion.* Ottawa: Health and Welfare Canada.

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Résumé

Les changements postimmigration dans les rapports sociaux entre les sexes chez les couples éthiopiens au Canada

**Ilene Hyman, Sepali Guruge, Robin Mason,
Judy Gould, Noreen Stuckless, Taryn Tang,
Hiwot Teffera et Girma Mekonnen**

La communauté éthiopienne à Toronto, au Canada, a identifié la prévention de conflits maritaux et de la violence conjugale comme une question prioritaire. Des recherches antérieures et des discussions au sein de la collectivité suggèrent que les changements dans les rapports sociaux entre les sexes survenant après l'immigration contribuent à l'incidence de conflits maritaux et de violence conjugale. Cette étude communautaire pilote avait pour objectif d'explorer les changements postimmigration dans les rapports sociaux entre les sexes chez les couples éthiopiens, en vue de contribuer à l'élaboration de stratégies visant à prévenir la violence. L'étude a été réalisée selon des méthodes de recherche et des analyses qualitatives. Des entrevues en profondeur et des discussions en groupes ont été menées avec la collaboration de huit couples mariés en Éthiopie et installés à Toronto. Les résultats indiquent une modification des rapports sociaux entre les hommes et les femmes après l'immigration, ainsi que des tendances de changement concordantes et discordantes. La recherche révèle que l'incidence de changements est associée à des facteurs comme l'âge, le nombre d'années de vie conjugale, l'expérience de vie dans un pays en développement, et la socialisation relativement aux rôles assignés à chacun des sexes. Les implications sur le plan des futures recherches et de la pratique infirmière font l'objet de discussions.

Mots clés : immigration, rapports sociaux entre les sexes, conflits maritaux, violence conjugale

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Post-migration Changes in Gender Relations Among Ethiopian Couples Living in Canada

Ilene Hyman, Sepali Guruge, Robin Mason, Judy Gould, Noreen Stuckless, Taryn Tang, Hiwot Teffera, and Girma Mekonnen

The Ethiopian community of Toronto, Canada, has identified the prevention of marital conflict and partner abuse as a priority issue. Previous research and community discussions suggested that changes in gender relations following migration contribute to both marital conflict and partner abuse. The objective of this community-based pilot study was to explore post-migration changes in gender relations among Ethiopian couples in order to inform the development of violence-prevention strategies. Qualitative research methods and analyses were used. In-depth interviews and focus-group discussions were conducted with 8 couples who had been married in Ethiopia and migrated to Toronto. The findings indicate changes in gender relations following migration as well as concordant and discordant patterns of change. Change was found to be associated with factors such as age, number of years married, experience in a third country, and gender-role socialization. Implications for future research and nursing practice are discussed.

Keywords: immigration, gender relations, acculturative change, marital conflict, partner abuse

Introduction

Violence against women is present in every society and culture (Locke & Richman, 1999). Some studies have suggested that post-migration changes in gender relations affect the power dynamics between men and women, thereby increasing the risk of marital conflict and partner abuse in newcomer couples (Bui & Morash, 1999; Morash, Bui, & Santiago, 2000; Morrison, Guruge, & Snarr, 1999; Narayan, 1995; Oxman-Martinez, Abdool, & Loiselle-Leonard, 2000; Raj & Silverman, 2002; Tang & Oatley, 2002; West, 1998). Concerns about changes in gender relations as possible contributors to marital conflict and partner abuse have also been identified by the Ethiopian community in Toronto, Canada. In 2001 a partnership was formed between the Ethiopian Association in Toronto (EAT) and academic researchers to further explore this phenomenon. The objective of this community-based pilot study was to examine the ways in which gender relations change after migration to Canada, patterns of change, and factors associated with change. It was hoped that the findings would enhance the cultural and gender-based sensitivity of nurses working with newcomer families in Canada and inform the development of community-based violence-prevention strategies.

We will present a brief overview of the literature, followed by a description of the background, design, and results of the study, a general discussion, and some implications of the findings for research and clinical practice.

Literature Review

It is well established that immigration to and settlement in a new country entail significant stress and a period of adjustment, particularly in the area of social relations (Canadian Council on Multicultural Health, 1989; Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees [Canadian Task Force], 1988). At the same time, immigration offers some people the opportunity to recreate, reinvent, and negotiate established gender roles. Changes in gender roles, in turn, have a profound effect on gender relations within couples (Bui & Morash, 1999; Canadian Council on Multicultural Health; Canadian Task Force; Morash et al., 2000; Morrison et al., 1999; Sorenson, 1996).

The results of previous work suggest that changes in gender relations following migration are associated with marital conflict and increased risk of abuse in immigrant and refugee populations. Changing gender roles is cited as a contributor to increasing levels of conflict, divorce, and domestic violence among Southeast Asian refugees (Kulig, 1994). Morash et al. (2000) found that physical abuse was reported in 37% of Mexican immigrant families when one of the partners changed gender role expectations. Data from pilot interviews with Chinese immigrant women and service providers show that when his role as breadwinner is threatened, a husband may reassert his power and control through physical and psychological forms of abuse (Tang & Oatley, 2002). Raj and Silverman (2002) suggest that changes in gender relations not only serve as a justification for partner abuse but also increase women's vulnerability to abuse. Yet other research suggests that immigration offers the possibility of change in traditional gender roles that otherwise would be difficult to negotiate and may offer women previously unavailable or suppressed employment opportunities (Krulfeld, 1994).

As a result of civil war, since the mid-1970s an estimated 1.25 million Ethiopians have fled to neighbouring countries such as Sudan, Kenya, Djibouti, and Yemen, while a smaller proportion have immigrated to

Europe and North America (McSpadden & Moussa, 1993). As in the home country, the Ethiopian community in Toronto is characterized by tremendous diversity with respect to ethnicity and religion. According to the EAT, the current Ethiopian population of Toronto is 35,000 (B. Menkir, Executive Director, Ethiopian Association in Toronto, personal communication, December 20, 2002).

In 2001, the EAT identified prevention of marital conflict and partner abuse as a priority concern. Post-migration stresses such as poverty, underemployment, minority status, and discrimination, which increase the vulnerability of women to partner abuse, have been noted in the literature (Bui & Morash, 1999; Morash et al., 2000; Morrison et al., 1999; Narayan, 1995; Tang & Oatley, 2002; West, 1998). However, these were factors that the EAT believed it could not address. Although empirical data were unavailable, a decision was made by the EAT staff and board members and the research team to focus this study on exploring the ways in which gender relations changed after migration to Canada, patterns of change, and factors associated with change. The findings would be used primarily to inform the development of community-based violence-prevention strategies.

Methods

In this community-based pilot study, all phases of the research, development of objectives, recruitment, development of research/interview questions, and analysis were determined together with the EAT staff. Since relatively little was known about the issue in question and since this was an exploratory study, qualitative methodology was chosen. Participants were recruited via newspaper advertisements, flyers distributed at EAT headquarters, and word-of-mouth.

Ethics approval for the study was obtained from the Sunnybrook and Women's College Ethics Board. In order for a couple to be eligible, both partners had to be immigrants, both partners had to agree to participate, the couple had to have been married/living together prior to migration, and both partners had to be of Ethiopian origin. After having all the risks and benefits of participation explained to them, the participants provided written informed consent and were offered an honorarium for their contribution to the study. Data were collected by two (one male and one female) Ethiopian (Amharic-speaking) research assistants (RAs) trained in interview and focus-group techniques.

The interview schedule consisted of two sections: a short questionnaire on socio-demographics and migration history; and a set of open-ended questions on gender roles in Ethiopia and Canada, relationship changes, and types and sources of support. Eight Ethiopian couples living in Toronto participated in the in-depth individual interviews. The couples were interviewed separately to ensure that the presence of a partner would not influence responses. During pre-testing it was determined that participants did not have a gender preference regarding the interviewer, so the same person interviewed both partners in each couple. The interviews took between 1.5 and 2.5 hours to complete. After completion of the in-depth interviews and preliminary data analysis, two focus groups (one for men and one for women) were formed. Each focus group consisted of five participants and the discussion lasted between 2 and 3 hours. Six participants who had been interviewed were unable to attend the focus-group discussion due to family or work commitments. The two RAs facilitated the discussions, the purpose of which was to confirm the themes that emerged during the initial data analysis and to generate data for ongoing analysis. All interviews and focus-group discussions were audiotaped, transcribed, and translated into English (with the exception of two interviews conducted in English).

Data Analysis

The two RAs cross-checked and validated all interview data. Data from the interviews and focus-group discussions were organized using N6 software. Concepts noted in the literature served as an initial guide for the development of a coding scheme. Additional codes were developed as the first interviews were coded and significant codes were grouped as subthemes. The coding scheme initially consisted of more than 120 codes. These were later reduced to 11 subthemes. Subthemes were then collapsed and condensed into themes. The findings reported here are those pertaining to three themes: main areas of change, patterns of change, and factors associated with change. Regular team meetings of all the investigators and the two RAs were held in order to discuss and reach consensus on the codes, subthemes, and themes, and on the terminology to be used in describing them.

Results

Characteristics of Sample

The participants varied with respect to age, number of years married, and number of years in Canada. Less heterogeneity was observed with respect to educational and religious background. Most participants were well educated, though men more so than women. The majority of participants were members of the Ethiopian Orthodox Church. All of the women and most of the men were employed. The sample was fairly homogeneous with respect to socio-economic status in Ethiopia and was indica-

Table 1 ***Characteristics of Sample***

Age	27–71 years (*mean* = 47 years)
Education	High school graduate to doctorate
Religion	Ethiopian Orthodox (15) and Protestant (1)
Number of years married	3–42 (*mean* = 21)
Number of years in Canada	3–20 (*mean* = 13)

tive of the Canadian immigration selection process — that is, based on who has the means to immigrate. Thus, for example, all of the couples had pre-immigration "instrumental support," which was not the case once they arrived in Canada. Table 1 summarizes the main characteristics of the participants.

In the interviews, the participants were asked to describe their roles and responsibilities as a wife/husband in Ethiopia. The findings indicate that the women were primarily responsible for taking care of the household and children, or "inside" matters, while the men were primarily responsible for supporting the family financially, or "outside" matters. The majority of men did not share household tasks, and those who did so performed tasks such as gardening or household repairs. According to both male and female participants, in Ethiopia there were no expectations that men would or should share in household tasks. One of the male participants pointed out that as a child he had been reprimanded if he "smelled of smoke" — the result of wandering into the kitchen. During the focus-group discussion the women said that as young girls they had been encouraged to acquire domestic skills but that boys had not.

The majority of female participants (80%) had been employed in Ethiopia and fulfilled a double role, responsible for both contributing financial support and running the household. However, both male and female participants reported that the man had been considered the primary breadwinner, with the woman's income being seen as supplementary.

The reliance on instrumental support in Ethiopia was acknowledged by both male and female participants as an important contributor to the smooth functioning of the household. This instrumental support was provided by both hired help and extended family.

Main Areas of Change

Three main areas of change in gender relations in Canada were identified: household (inside) responsibilities, work (outside) responsibilities, and marital interactions.

Household (inside) responsibilities. The findings suggest that men share in more household tasks in Canada but overall responsibility remains with women. One female participant said: "70% of the work is mine…in Canada we both are working but I still take on most of the responsibilities." Most of the men indicated that they helped with shopping, cleaning, and child care.

Work (outside) responsibilities. While the majority of the women had been employed in Ethiopia, all were employed in Canada, a significant difference being that in Canada, unlike in Ethiopia, the woman's contribution to the household income was considered essential and as important as the man's. The focus-group data show that the men believed that women should be employed, for the well-being of both the woman herself and the family, and that most of the men considered their wife's income necessary to make ends meet. The majority of female participants reported that they worked both out of financial necessity and because it gave them more autonomy. Both male and female participants observed that many women derived other benefits from employment, such as reduced isolation and increased adaptation, besides bringing in necessary income.

> *When somebody stays home, you know, the condition of this country… you can't have the kind of socialization we have had in our culture. Therefore, she won't be comfortable if she is not working, she can't share ideas with anybody unless she is working. If she always stays home while I am working and coming home, it will create for her some sort of stress. It is because to work and come home and staying home do have big difference. Besides, it also brings some additional income if she works.* [40-year-old man]

Marital interactions. The marital relationship was a major area of change, both positive and negative, for the majority of couples. One of the positive changes was described as an increase in joint decision-making. Although in Ethiopia there had been some shared decision-making on major financial issues, most male participants indicated that they had much more decision-making power in Ethiopia than their wives. A 60-year-old female participant stated:

> *We always discuss whenever we want to do something, like I may say what if we give this much for this wedding? We also discuss the money that we give for the church. We discuss everything. I don't hide anything from him and he doesn't hide anything from me.*

Another positive change in some relationships was that husbands and wives were spending more time together and growing closer. The same 60-year-old woman stated:

> *There are a lot of changes, like usually we spend the evenings together, my husband and I. He doesn't say, "Now I am going with my friends"… He is always with me and I am always with him. We go for a walk together and even sometimes we go to bars together. It very much brought us together.*

On the negative side, some couples faced new stresses and experienced conflict as a result of their different work schedules, long working hours, and fatigue, as described by a 39-year-old female participant:

> *Of course you would be happy if you could spend some time with your husband and if you could talk and chat with your husband, whatever the topic. But when you can't do that because of shortage of time, you may say until when? …you may spend alone most of the time and you may tend to say, what is the difference if I live alone or with him?*

Patterns of Change

The men and women adapted to their new roles and responsibilities in Canada in different ways. The different patterns were most apparent with respect to household tasks and were clearly important in the couples' lives. Both concordant and discordant patterns of change were observed. Concordant patterns included acceptance of the old ways and negotiation of new ways.

Acceptance of the old ways. Acceptance of the old ways meant that both partners were comfortable with or at least accepted the traditional division of responsibilities and tasks. This allowed for a relatively harmonious relationship with minimal stress:

> *Regarding activities in the house, I am telling you frankly, as far as the woman can do the job it is not necessary to impose on him. This is our culture; we get used to it since childhood. If they are willing to learn and help, that would be great, but it is not necessary to lose your long-term relationship because he is not doing it now.* [39-year-old woman]

Negotiation of new ways. According to this pattern, couples negotiated tasks and responsibilities in Canada using criteria such as: Who does it better? Who has more time? Who enjoys doing the task? A 41-year-old male participant explained:

> *If your wife is a good cook and you are a lousy cook, it should be your wife that is doing the cooking. But if she is a lousy cook and you are better, then you should do it.*

Discordant patterns of change included one partner resisting change, making sacrifices, and/or tolerating the old ways.

Resisting change. This pattern was most evident among male participants, with some of the men frequently expressing an unwillingness to take up certain responsibilities and tasks, particularly those they felt belonged to women. For example, one man stated that he did not mind making coffee using a percolator but that it was a woman's job to make it the Ethiopian way, accompanied by the traditional coffee ceremony. An example provided by a 71-year-old participant concerned the traditional bread, *enjerra,* an Ethiopian staple:

> *The reason why I am not baking* enjerra *is that first of all my body doesn't even accept it; it is a matter of acceptance. But if I [am] compelled to do so and if I am in a situation where I feel that somebody could be in danger if I don't do that, then I may consider doing that; but I don't know because that hasn't happened yet.*

Sacrifice. Some female participants expressed a willingness to take on the double burden of inside and outside work in order to maintain household harmony. They accepted the idea that their primary mission in life was to do whatever was necessary to raise their children and provide them with a good education:

> *He used to say to me... "You work at night and come back home, you have to get some sleep and you have to take care of the kids and you have to come fetch me; this is not good." At one point I was not even able to open my eyes but I did not want to show it to him... So I never said I was tired. I worked and I took good care of my kids.* [48-year-old woman]

Tolerance. This pattern was observed when female participants spoke about wanting change but believed that, in order to avoid conflict, women must be patient and not make demands on their husbands:

> *So we hold on to the idea of not going for divorce. So, to avoid such mishap, I tolerated. I believe that it was patience that prevented me from taking that kind of major decision — my silence, my working without complaining. He then started saying, "What?" So we were able to get to this stage. It wasn't because my husband was nice to me around the time we came here or that he had changed automatically. It was because I tolerated...* [53-year-old woman]

It was evident from the interviews and focus-group discussions that the patterns of change were not fixed; couples adopted different patterns at different points during the process of settling in a new country. Indeed many couples themselves recognized that this process was dynamic. Analysis revealed three distinct stages of change, not necessarily corresponding to number of years in Canada. The first stage consisted of maintaining the division of tasks as they were in Ethiopia as a way of maintaining links with the culture. The participants reported that during this stage most men did not help with household tasks, expecting their wives to run the house on their own. However, adherence to traditional roles and patterns of behaviour required agreement by both parties. During the first stage, the women had no expectations that their husbands would or should help with housework. As described by one of the male participants: "If you see couples who just came here for the first time, soon after they came the women don't even allow you to get into the kitchen." The female participants also found it difficult to ask their husbands to help, because "it is a little difficult to break that barrier and say to men, 'Do this.' They might think, 'She is giving me an order'," which would not have occurred in Ethiopia. A number of participants noted that cultural adaptation is a gradual process.

During the second stage, mutual discussion and joint decision-making emerged as indicators of change in the relationship. As one of the male participants pointed out, "things are decided together." Interestingly, the participants also indicated a growing recognition that, in light of the absence of instrumental help, husbands now had to help their wives. One 53-year-old female participant recounted how her husband had changed over time:

> *I think he watched me through the window going far pushing the cart. He felt it and started saying, "Does she have to do all this by herself?"*

During the third stage, tasks were described as having become routine or "carried out simply by habit," resulting in a decrease in the gendered division of labour. As a 42-year-old male participant put it:

> *For example, if the man does ironing clothes one or two times, first she will say, "Please do also these ones," but later it will specifically be his task and continue doing that.*

Factors Associated with Change

Data analysis revealed several factors associated with patterns of change. Age and length of marriage were perhaps the strongest influences on change. The older women tended to be more patient, tolerant, less demanding, and more accepting of the traditional gender division of tasks. Both men and women who had been married a long time stressed the importance of mutual understanding and were much more comfortable with the traditional division of labour than those who had not been married long. The older women did not expect their husbands to help out at home, while the younger women did. The former were reluctant to ask for help, citing their partner's age and/or consideration for his social status back in Ethiopia. Older participants were much more vocal on this point than their younger counterparts, and were critical of them.

Experience in a third country also played a part in couples' adaptation to their new roles in Canada. Those who had lived in a Western country before coming to Canada adapted more quickly and smoothly to their new role because of their exposure to different lifestyles. Even those who had lived in another non-Western country observed that the process of migration facilitated change. For example, when the participants were asked how the traditional division of tasks had changed for them in Canada, one woman responded:

> *We have come through a different country. Since both of us did housework, we were hired by families to do housework. When we come here, it is not a big deal for my husband to do housework. All of us started working right away — equally.*

Finally, it was apparent that gender socialization influenced patterns of change among the couples. Most of the female participants accepted the fact that they had more responsibilities because this was part of woman's "nature." They maintained they had more household responsibilities than their husbands because they had taken it upon themselves to do more. Many male participants also expressed a belief in a "natural" division of labour and, regardless of their age or educational background, showed a resistance to change.

Discussion

The purpose of this community-based pilot study was to explore changes in gender relations, patterns of change, and factors associated with change in a sample of Ethiopian couples living in Toronto. The findings indicate strong evidence of change following migration, particularly in the areas of housework, paid work, and marital interactions. In Ethiopia, the men had been the principal breadwinners and were accorded more authority in relationships as a result of education, income, and cultural influences, while the women had fulfilled the dual role of wage-earner and household manager, though usually with the support of hired help and family members. In Canada, there was strong evidence of change in the gendered assignment of household tasks, though change was frequently described in terms of sharing specific tasks rather than sharing overall responsibility.

For most couples the marital relationship was a significant source of change, with participants reporting both positive and negative changes. Concordant and discordant patterns emerged with regard to changes in the couples' relations. Concordant patterns of change were those in which both partners either accepted the old ways or negotiated new ways, while discordant patterns were those in which one partner resisted change, made sacrifices, and/or tolerated the old ways. Although discordant patterns might be considered less adaptive, it must be stressed that all eight of the sample marriages were still intact, indicating that the couples had developed effective strategies for resolving their differences.

The findings also indicate that the process of change was dynamic and that one partner or both may have gone through several different stages of change during the resettlement period. According to Berry (1995), individuals acquire, retain, and relinquish the behaviours and values of their traditional culture and the new culture to which they are adjusting. Thus, newcomer couples are continually striving to balance and combine the heritage and host cultures, creating diverse patterns of change, some of which may invoke risk while others may offer security. According to Dobash and Dobash (1997), without fundamental changes in gender relations, we may continue to experience a legacy of violence. The effects of different patterns of change on outcomes such as marital conflict or partner abuse were not assessed in the present study. However, new analyses of the 1999 General Social Survey conducted by our research team (M. M. Cohen, Principal Investigator) have found that recent immigrant women (less than 10 years in Canada) experienced significantly lower rates of intimate partner violence than their Canadian-born counterparts (Hyman, 2003).

Previous studies with Ethiopian immigrants support our finding that gender relations change following migration and that such change may involve marital conflict and partner abuse (Matsuoka & Sorenson, 2001; McSpadden & Moussa, 1993). In interviews with Ethiopian and Eritrean women and men in Toronto, Matsuoka and Sorensen found evidence of changes in gender roles and relations within couples that altered expectations and contributed to marital tension. Many of the women believed that in Canada, unlike in Ethiopia, it was impossible to work full-time while raising a family without help from their partner. Although some of the men accepted a new role for women in Canada, clear lines of demarcation persisted. Some of the men found that women's employment threatened their traditional ideas concerning male economic power. McSpadden and Moussa conducted qualitative interviews with Ethiopian immigrant families to explore their experiences with immigration and resettlement. Although they did not directly address the issue of partner abuse, McSpadden and Moussa attribute the growing incidence of wife abuse to male anger and frustration evoked by racism and un/underemployment, as well as loss of authority and respect within the family. Neither of these studies examined concordant and discordant patterns of change in Ethiopian immigrant couples.

No previous research has examined factors associated with post-migration changes in gender relations. Well-established research on the determinants of health has identified factors, such as education, gender, environment, and health services utilization, that affect the health of Canadians (Health Canada, 2002). Of particular importance to immigrant health are determinants such as income, social support, and stress, and a recognition that heterogeneity within immigrant communities in Canada may affect both health and access to health services (Hyman, 2004). The present study has identified additional and multiple factors that directly contribute to change, and thus indirectly affect health — namely, previous experience in a third country and gender role socialization.

Some limitations must be noted. Because our sample was restricted to couples who had been married in Ethiopia prior to migrating to Canada, we were unable to examine other types of marital relationships within the Ethiopian community. For example, the data may not reflect challenges that face newly married Ethiopian couples in Canada. The interviews carried out as part of the present study and informal discussions with members of the Ethiopian community suggest that newly married individuals may experience more marital conflict than couples who were married in Ethiopia. In addition, the majority of the sample had lived in another country prior to coming to Canada. The experiences of migrating together and facing common challenges in Canada appear to strengthen couples' relationships and marital resiliency. Finally, the sample did not include individuals who had separated or divorced post-migration; therefore, we could not ascertain the extent to which changing gender relations contribute to divorce or separation. This will be the focus of the next phase of the project.

Implications

These findings have implications for research and practice. They lay the groundwork for future research on marital conflict and partner abuse in immigrant populations. Further research is needed to address questions about the mediating factors identified in this study (i.e., age, previous experience in a third country, and gender socialization) and to determine whether concordant and discordant patterns of change are associated with different outcomes. Research is also necessary to extend these findings to other types of marital relationships within the Ethiopian community, including the relationships of those who marry in Canada. Finally, similar research should be conducted with couples from other immigrant communities, to determine whether the patterns identified have meaning beyond one particular community.

In terms of practice, nurses must recognize that immigrant couples frequently experience changes in their roles and relationships following migration and that these changes can be a source of strain and conflict. Crisis counsellors and mental health nurses are in an ideal position to identify individuals/couples at risk and to make suggestions or introduce interventions to diffuse tensions and improve communication between partners. Sensitivity to the dynamic nature of change and the factors associated with change is critical, in order to break down barriers and improve the accessibility of support services for women who experience marital conflict and/or partner abuse.

The findings are currently being used by the EAT to inform the development of culturally appropriate and gender-sensitive violence-prevention strategies, to increase community awareness of changes in gender relations following migration and the impact of migration, both positive and negative, on marital relationships.

In conclusion, this study represents a first step in addressing information gaps related to post-migration changes in gender relations within immigrant communities. The findings will be used mainly to inform the development of community-specific preventive strategies and programs to better meet the needs of Ethiopian couples experiencing marital conflict and partner abuse. Further research is necessary to determine the extent to which changing gender relations contribute to marital conflict and partner abuse in immigrant populations, and to examine the various strategies that couples develop to resolve conflict and adapt to changing gender relations.

References

Berry, J. W. (1995). Psychology of acculturation. In N. R. Goldberg & J. B. Veroff (Eds.), *The culture and psychology reader* (pp. 457–488). New York: New York University Press.

Bui, H. N., & Morash, M. (1999). Domestic violence in the Vietnamese immigrant community: An exploratory study. *Violence Against Women, 5*(7), 769–795.

Canadian Council on Multicultural Health. (1989). *Canadian cultures and health: Bibliography.* Toronto: Author.

Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees. (1988). *After the door has been opened: Mental health issues affecting immigrants and refugees in Canada.* Ottawa: Ministry of Supply and Services.

Dobash, R. E., & Dobash, R. P. (1997). Violence against women. In L. L. O'Toole & J. R. Schiffman (Eds.), *Gender violence: Interdisciplinary perspectives* (pp. 266–278). New York: New York University Press.

Health Canada. (2002). *Population health.* Available: http://www.hc-gc.gc.ca/hppb/phdd/

Hyman, I. (2003, December 10). *Intimate partner violence (IPV) among minority cultural communities.* Women's Health Research in Progress Seminar Series, Centre for Research in Women's Health and Department of Medicine, University of Toronto.

Hyman, I. (2004). Setting the stage: Reviewing current knowledge on the health of Canadian immigrants: What is the evidence and where are the gaps? *Canadian Journal of Public Health, 95,* 15–17.

Krulfeld, R. M. (1994). Changing concepts of gender roles and identities in refugee communities. In L. Camino & R. M. Krulfeld (Eds.), *Reconstructing lives, recapturing meaning: Refugee identity, gender and culture change* (pp. 71–96). Washington: Gordon & Breach.

Kulig, J. C. (1994). Sexuality beliefs among Cambodians: Implications for health care professionals. *Health Care for Women International, 15,* p. 69–76.

Locke, L. M., & Richman, C. L. (1999). Attitudes toward domestic violence: Race and gender issues. *Sex Roles, 40,* 227–247.

Matsuoka, A., & Sorenson, J. (2001). *Ghosts and shadows: Construction of identity and community in an African diaspora* (pp. 13–14). Toronto: University of Toronto Press.

McSpadden, L., & Moussa, H. (1993). I have a name: The gender dynamics in asylum and in resettlement of Ethiopian and Eritrean refugees in North America. *Journal of Refugee Studies, 6,* 203–225.

Morash, M., Bui, H. N., & Santiago, A. M. (2000). Cultural-specific gender ideology and wife abuse in Mexican-descent families. *International Review of Victimology, 7,* 67–91.

Morrison, L., Guruge, S., & Snarr, K. (1999). Sri Lankan Tamil immigrants in Toronto: Gender, marriage patterns and sexuality. In G. Kelson & B. Delaureat (Eds.), *Gender, immigration and policy* (pp. 144–160). New York: New York University Press.

Narayan, U. (1995). "Male-order" brides: Immigrant women, domestic violence and immigration law. *Hypatia, 10,* 104–119.

Oxman-Martinez, J., Abdool, S. N., & Loiselle-Leonard, M. (2000). Immigration, women and health in Canada. *Canadian Journal of Public Health, 91,* 394–395.

Raj, A., & Silverman, J. (2002). Violence against immigrant women: The roles of culture, context, and legal immigrant status on intimate partner violence. *Violence Against Women, 8,* 367–398.

Sorenson, S. B. (1996). Violence against women: Examining ethnic differences and commonalities. *Evaluation Review, 20*(2), 123–145.

Tang, T. N., & Oatley, K. (2002, August 22). *Transition and engagement of life roles among Chinese immigrant women.* Paper delivered at American Psychological Association Annual Convention, Chicago.

West, C. M. (1998). Lifting the "political gag order." In J. L. Jasinski & L. M. Williams (Eds.), *Partner violence: A comprehensive review of 20 years of research* (pp. 184–209). Thousand Oaks, CA: Sage.

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Résumé

Sorties d'une marginalité multiple : les femmes d'âge mûr s'affirment sur le plan des soins de santé

Janice L. Kinch et Sonya Jakubec

Cette étude phénoménologique féministe explore le sens des expériences vécues par les femmes d'âge mûr au fil de leurs négociations avec le système de santé. Plusieurs entrevues réalisées auprès de divers groupes de femmes d'âge mûr (immigrantes, autochtones, canado-japonaises et les femmes qui adhèrent à des groupes communautaires et sociaux) ont révélé que les négociations qu'elles devaient mener pour obtenir des soins de santé correspondant à leurs besoins constituaient un processus difficile qui nécessitait l'apport d'un soutien mutuel. Des facteurs liés à l'accès aux services, au pouvoir et à la pauvreté influaient sur leurs expériences en matière de soins. Les entrevues axées sur une approche interactive ont stimulé chez plusieurs participantes des prises de conscience, un désir de militer et une réflexion. Les résultats suggèrent que de telles réflexions peuvent aider d'autres femmes à comprendre le concept de « marginalité multiple » (être d'âge mûr, être femme, être membre d'une minorité visible) qui contraint et rend difficile leur accès à des soins de santé.

Mots clés : femmes d'âge mûr, accès, pauvreté, féministe, phénoménologie

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Out of the Multiple Margins: Older Women Managing Their Health Care

Janice L. Kinch and Sonya Jakubec

This feminist phenomenological study explores the meaning of older women's experiences as they negotiate health care. Several interviews with diverse groups of older women (immigrant, First Nations, and Japanese-Canadian women and those involved in community and social clubs) reveal that negotiating to have their health needs met was a challenging process requiring mutual support. Their health-care experiences were influenced by issues surrounding access to services, power, and poverty. For many participants, the conversational interview format served to inspire consciousness-raising, activism, and reflection. The findings suggest that such reflection may help other women to understand the "multiple margins" (being older, being a woman, being a member of a visible minority) that constrain and challenge their access to health care.

Keywords: older women, access, poverty, feminism, phenomenology

Background

This study continued a program of research initiated by the first author to explore older women's health-care experiences and how older women manage their health and health care. The program of research is intended to ultimately enhance the accessibility to health care for underrepresented and marginalized groups of older women, including poor women, lesbian women, women of colour, and disabled women. Future studies must include these groups to ensure that their voices are heard and their needs are met.

In the course of previous research interviews (Kinch, 1997, 1999) and in clinical nursing practice, many older women recounted that their specific health-care needs had not been addressed. Older women are rarely included in the planning of their health care or in the planning of health-care reforms. In fact, their health concerns are often trivialized. In the research interviews (Kinch, 1997, 1999) they expressed the view that they were not listened to when they gave their reasons for seeking care. Older women bear the burdens of invisibility and inaudibility as they journey through the health-care system (Blow & Barry, 2002; Hunt, 2001; McCormick, 2002; Sharpe, 1995; Worcester & Whatley, 2000). The difficult relationships that older women develop with health-care providers stem largely from the way in which women have been socialized to be passive and submissive (Baslow, 2000; Smith, 1999). The feminization of aging and poverty is well documented (Fukuda-Parr, 1999; Gonyea, 1994; Harman, 1999; Weitz & Estes, 2001; Worcester & Whatley), and it is fair to say that older women are at heightened risk of receiving less than optimal health care (Blow & Barry; Hunt; McCormick; Rosser, 1994).

While women in Canada are living longer, as they grow older they experience more chronic disabilities than men, use health-care services more often than men, spend more time in hospital than men, and are more likely than men to end their days in a long-term-care facility (Ratcliff, 2002; Statistics Canada, 2003; Trypuc, 1994). As well, many women use alternative therapies such as chiropractic, massage, herbal remedies, and acupuncture (Kinch, 1997).

Kinch (1997, 1999) found that many older women experienced lack of trust in a health-care practitioner, often because their long-time physician had moved, retired, or died, and that many spent long periods accessing health care because of a shortage of physicians and long waiting lists. As well, many people are known to access the health-care system through the "illness door," seeking care only when they are ill, as opposed to seeking preventive or health-promoting care. Sharpe (1995) found that older women's "disadvantaged status" (p. 9) within the health-care system has contributed to the combined forces of sexism, ageism, and racism that have led ultimately to "patronizing care" in the form of programs that are ill-suited to the needs of this neglected population. Hunt (2001) asserts that, while some biologic measures have been developed in recent years, subjective accounts of older women's health are still elusive. The present study was intended to add to our knowledge base concerning the subjective world of older women's health.

Purpose of Study

Conversational relationships with older women occur in many contexts — social, personal, and professional. Questions brought to this study from conversations between the first author and older women in social, personal, and professional contexts were: *How do older women manage their health care? How do they access health care, and for what reasons? Who do they ask for advice and assistance in meeting their health-care needs? What are the barriers that prevent them from receiving the care they want and need?*

The purpose of the study was to engage with older women in a peer-group setting in order to explore the meaning of health and health-care issues in their lives, how they manage their health, and the health-care challenges they face. The ultimate goal was to give voice to older women as they suggest ways in which their health status might be managed differently, in order to recommend ways to facilitate and enhance their health care.

Design

A feminist phenomenological approach was used to elicit the meaning of health, health-care issues, and challenges in the lives of older women. We sought to involve women in a discussion of how they met their health-care needs and to learn from their lived experiences with the health-care system. Such experiences are considered unique and context-driven. Phenomenology explores the lived experience of human beings as they go about their daily lives (van Manen, 1990). Feminist research is that which is about and for women, usually conducted by and with women (Chinn, 1995; Gustafson, 2000), reflects issues in women's lives that are central to the feminist concerns of power, change, and domination (Campbell & Bunting, 1991; Hedin & Duffy, 1991; Hekman, 1999; Reinharz, 1992), and pertain to the centrality of women's experience (Chinn, 1989; Mohanty, 1995). We met with small groups of older women who were interested in sharing their health experiences and needs using a collective approach. Such an approach is consistent with feminist methodology (Chinn, 1995).

Method

Consistent with van Manen's (1990) approach for exploring lived experience and Munhall's (1994) guidelines for exploring human life, the participants were interviewed in small groups by the principal investigator and/or a research assistant. Conversations were initiated by the participants, with the interviewer playing a facilitative, participative role.

Sample

The sample comprised 32 women aged 65 years and over who spoke English well enough to understand and be understood in a group setting. The women lived within a short driving distance of a large western Canadian city.

Recruitment was initially carried out by publicizing the study through a letter or poster in locations where older people tend to congregate, such as seniors' centres, social centres, agencies, or churches, and through word-of-mouth, or "snowball effect." An attempt was made to ensure the inclusion of women from diverse cultures and ethnicities and women of compromised socio-economic status by advertising in diverse newsletters and at diverse centres. Formal and informal presentations were then made at two seniors' centres. These sessions, together with the input of seniors' activity coordinators, succeeded in attracting women from five seniors' groups. Those who agreed to participate, after hearing a description of the study, were invited to meet with the researchers in small groups of their peers in order to discuss their experiences. All participants chose to be grouped with their acquaintances and to meet in their own social environment, thus expressing a desire for familiarity and convenience. The result was five self-selected groups meeting in five venues. Table 1 provides a profile of the sample.

Table 1 *Profile of Sample*

Group	Number	Age Range (Years)	Ethnicity	Site of Interview
1	5	66–76	Caucasian	Common room, community pool
2	11	65–83	Ismaili	Subsidized apartment building
3	9	68–74	Caucasian	Community seniors' centre
4	3	65–74	Aboriginal	Health centre on Native reserve
5	4	66–83	Japanese	Seniors' centre

Morse (2000) recommends that the number of participants be based on the scope of the study, the topic, the quality of the data, and the study design. For a phenomenological study in which interviews are expected to generate large amounts of data, Morse suggests groups of 6 to 10. Reinharz (1992) suggests that feminist groups (similar to focus groups) consist of fewer than 12 people. Krueger (1994) holds that 6 to 10 people is ideal but that a range of 4 to 12 is acceptable. Our group sizes were within these guidelines.

Ethical Considerations

Ethical requirements were met through approval by the Conjoint Health Research Ethics Board and through informed consent. The participants were assured of confidentiality and anonymity. They were informed that no names would be used in any document, transcript, report, or article submitted for publication. Pseudonyms were allocated in all documentation. The women were reminded of the need for respect of privacy and confidentiality within the group setting. They were informed of their right to withdraw from the study at any time, without penalty. There was no financial reward for participation.

Data Collection

The principal investigator and/or a research assistant facilitated each group interview of 1.5 to 2.5 hours, at a time and place convenient for the participants. Most interviews were held in a private room at a seniors' centre, community centre, or health centre. The interviews were audiotaped with the participants' permission and later transcribed by a qualified transcriptionist. Relational conversations were initiated, with the facilitator generally discussing concerns that are often raised by older women and then inviting the participants to share stories about their health, health-care experiences, and health-care management. Conversation flowed with occasional prompts from the facilitator, such as "How did that feel?" or "Can you tell us more about that situation?"

At the request of a seniors' representative at one of the organizations, a follow-up meeting was held with five members of a group that had originally consisted of nine women. The women had requested this meeting as they were compelled to continue the conversations they had begun. This follow-up meeting represented an opportunity for the researchers to present some of the study's findings. It also yielded further insights for analysis, which are reported in the Findings section.

Data Analysis

The researchers read the transcribed data and then read them again while listening to the audiotapes. The researchers met regularly to review the tapes and transcripts, seeking the occurrence and recurrence of common and diverse themes. When data are analyzed by more than one person, it is crucial that agreement be reached on the essence of the experiences. Through qualitative phenomenological analysis, one seeks meaning, commonality, and difference, rather than statistical relevance. In the present study, analysis was guided by the approaches recommended by van Manen (1990) and Munhall (1994).

Findings

Themes identified within and across the interviews were: *femininity, relationships, and means of support; health information and the politics of access to care; the supportive role of faith, religion, and tradition;* and *abuse and power.* Two general concerns identified were: not being taken seriously or not being listened to, and the need for advocacy, including self-advocacy. Every interview highlighted the power of collective advocacy, such as women getting together to strive towards a goal.

Femininity, Relationships, and Means of Support

Many of the women reported that while they had been meeting with friends and in social groups for years, they had never before been asked to participate in an organized discussion. They were intrigued by the concept of sharing their stories in this way. Thus the notion of women supporting each other at new levels was evident in the interviews, and meaningful data were generated on how women perceive their relationships and roles. In this research approach, the group interview is both a data-collection and an advocacy/support intervention (Banister, Tate, Wright, Rinzema, & Flato, 2002; Banks-Wallace, 1998). It became clear that this supportive approach was beneficial for the participants during the group meetings, where statements such as the following were the norm:

> *We always get together and we sit around and talk, but never discussing the things like this…the personal things.* [Irene]

It might be that "personal things" do not get discussed during encounters with health-care providers, for example, because the providers simply do not ask the right questions or listen to the responses.

During a discussion of what they considered "personal" matters, the women spoke of the loneliness they endured after spending years in various relationships, in both their working lives and their personal lives. Having experienced dramatically changed roles and multiple losses (of parents, children, partners, friends), some of the women described a state of loneliness and a drastically altered sense of self in relation to others. They clearly empathized with those experiencing extreme loneliness and made a connection between this social phenomenon and that of widespread depression.

Health Information and the Politics of Access to Care

Two areas stood out under the theme of health information: technologies of support and isolation, and access to health care. These women had grown up in an era when technology was relatively primitive. Personal computers were unheard of, and most Canadian homes did not even have television sets until the mid-1950s or early 1960s.

Technologies of support and isolation. Some participants used computers and other technology such as television to mediate support in the face of their isolation. Assistive technology and the Internet are new means of increasing contact and support and providing a sense of camaraderie (Bradley & Poppen, 2003). While all of the women had access to television, several also reflected on the resources, both social and informational, offered by the Internet:

> *I do miss having someone to do things with…but as far as being on my own in the house, well, I've got my computer and I've got different things to keep me company.* [Louise]

But technology cannot replace human contact. The women repeatedly described a sense of loneliness and pervasive sadness. Margaret explained:

> *Living alone, you get so lonely and you get attached to your TV and it's much easier to stay at home than get out and explain to people what's going on in your life.*

Roberta added:

> *I used to have a lot of people, but now I keep moving around and around. No one for me to help…no one to help me.*

For other women, however, friends were central to the management of their health. Eileen described the community support given to a friend who had recently died at home:

> *She didn't go into hospital, everybody was there… We looked after one another, then we decided we would be each other's advocates and we would be there for one another…and we have been.*

While many women were sustained by a sense of community support, others were overwhelmed by their own loneliness and that observed among their acquaintances, which the medical community often "treated" with anti-depressant medications. The descriptions of depression and extensive prescribing of anti-depressants was notable in some of the group discussions. Margaret spoke about a sense of malaise and disconnection among her peers:

> *I think depression is rampant; maybe it's just an attitude toward life.*

While Margaret regarded the treatment of depression with pharmaceuticals as useful in certain circumstances, social isolation in general is increasingly being medicalized. The needs voiced by the participants in this study echo Michael Ignatieff's (1984) notion of "the human gestures money cannot buy" (p. 13); these needs extend beyond the medicalized interpretations of isolation. Our "society of strangers" (Ignatieff, p. 18) simply cannot meet the needs of many older women (or indeed others).

Access to health care. Many of the women seemed to lack knowledge about how to access services (where to go, whom to ask, how to navigate the system, how to avoid long waits in the emergency room, etc.), as well as specific health information. This lack of access was compounded by poverty issues and environmental factors. For example, many of the Ismaili women did not know that a public health nurse was available in their apartment building. Other than their friends, they had no one to call if they had health questions or concerns, and therefore either went to the emergency room or kept their illness to themselves. The situation described by Kassa, an Ismaili participant, seemed to be a common one:

> *Mostly I don't talk to anybody because somebody said we are sick too much, so I don't tell anybody that I am sick.*

Two issues, transportation and reliance on family and cultural groups, serve to illustrate the lack of information, support, and access. One of the Ismaili women summarized the transportation issue:

> *If I am sick and know in advance I can book the handicap system, but what happens if you are sick just this very minute and need the transportation? Then we have to go in our own private taxi or car and pay for that…some people don't go because they can't afford it.*

For many of the participants, family and cultural groups were their means of accessing health services. While dependent on such support, these women may also, paradoxically, have been silenced by it, in that health-care providers might have assumed that because they had apparent support they knew how to access whatever health services they needed.

The reliance on family members/cultural groups as translators and the institutional practice of allocating cultural groups as "support" instead of providing real access to services (Brotman, 2003) were particularly notable among the Ismaili and First Nations women. For example, Sunara was accompanied to her regular physician's appointments by her daughter, a working mother. The families of hospitalized immigrant women were immediately called by health-care professionals to serve as interpreters and to assist with care. The lack of access was closely linked to the poverty experienced by many of the participants. In addition, according to Das Gupta (1999), systemic racism places many immigrant women in the role of "victim" (p. 167), due to their lack of cultural and language skills in the new environment.

Advocacy is essential for many older women attempting to navigate the health-care system. Some of the participants had family or friends interceding for them, but others had to advocate on their own behalf, seek out the specific resources they needed, or do without appropriate care (Boyle, 2003). For example, Soshan was sent home from hospital after surgery even though she was unable to look after herself; if her daughter had not stayed with her, she would have been on her own.

The Supportive Role of Faith, Religion, and Tradition

The women consistently reported faith and religious affiliation as central to their health. Josephine described her support system:

> *It's the F's — not a bad word at all — it's your family, friends, and faith, and not necessarily in that order.*

Many participants reflected on the significance of faith and religion in the management of their health. Shirley said:

> *Doggone it, you know, sometimes you have to believe that a prayer has made a difference.*

The women placed a remarkable degree of emphasis on their faith in times of sickness and adversity. Patricia commented on the comfort she received from her faith during her husband's illness:

> *My family and friends would come. I am Christian so I also have faith in God, who is able and comforting and ever present, and I have friends who would come and pray with me, so the peace of God was there even though the pain was unbearable.*

Religion and community were found to be mutually strengthening for the women in the study. McIntosh, Sykes, and Kubena (2002) similarly affirm that "religious ties of the elderly may strengthen community links and attachments" (p. 110).

The participants reported that in times of need "prayer letters came from all over," or "it's the traditions, the incense I turn to." Those from the First Nations community relied on traditional remedies. Some First Nations women consulted with elders concerning their health. Helen confided:

> *For a long time I just stayed home…then I met with the elders and advisors and it's been help for me to go to meetings and start making myself get a living, to start again.*

Jennie, also a member of the First Nations community, described her use of prayer:

> *Praying is good [as a source of support in managing one's health]. I always pray in the morning and at night. That's it. And we pray together — that's the most important.*

Jean, from another group, said:

> *I care for my parents and husband, but no one looks after me…only God…otherwise it is me alone.*

The participants also spoke of traditional cultural values (e.g., respect for elders, self-reliance) that had been instilled in them during childhood and through traumatic experiences such as living through war or in residential schools or internment camps. First Nations women cited health concerns such as poverty and the politics of poverty. In the face of their health challenges, they turned to the traditions (gendered and neutral) of persevering, coping, and surviving. They also discussed the experience of collectively and consciously passing on cultural expressions, healing traditions, and traditional health practices. Florence commented:

> *Our health changed in the residential school. Now I take seven pills, for diabetes, hypertension, and arthritis… We never used to take pills. We used Indian medicine.*

The rituals of the Ismaili participants were clearly a means of traditional collective support (evident even during the group interview, in the form of food-sharing). In times of need these women relied on their mosque, their family, and their friends.

The participants' faith and traditional values both sustained and supported them in managing their health care, but at the same time may have obscured the needs of older women from the health-care system. Church, philanthropic, and social organizations, both formal and informal, offer stopgaps for the health needs of older women. While these human connections broke through the loneliness, they may have also served to keep the real needs of older women from reaching the radar of decision-makers (see Lauder, Sharkey, & Mummery, 2004).

Abuse and Power

Three subthemes of abuse and power were identified: historical tensions; unspeakable stories; and lack of understanding, poverty, and the politics of poverty.

Historical tensions. Underlying currents of tension were evident at the beginning of some of the conversations. We were aware of the historical and cultural nature of distrust of outsiders and attributed the tension to the fact that we were the outsiders. However, as the women became more comfortable with our presence, the tension decreased and the topic of abuse and misuse of power emerged.

The First Nations and Japanese-Canadian participants spoke about historical abuses matter-of-factly, explaining that traditional knowledge and practices had helped them to persevere and overcome injustices of the last century. Women's poverty of access to health care was manifested in a broadly experienced form of abuse that many of the participants had endured most of their lives.

The residential schooling endured by many First Nations children took a toll on the physical and mental health of the three First Nations participants. The removal of children from Aboriginal families and their placement in residential schools at seven and eight years of age by the Canadian government is well documented (Wasekeesikaw, 2003). The women retained memories of their ill treatment well into their later years (for example, they were forbidden to speak their native Cree language, were required to wear hand-me-down "white" clothing, and were allowed to bathe, in a communal tub, only once a week). Florence speculated about what had made her health change:

> *I think that what makes it change is the residential school. That's what changed us. I was nine years in the school.*

With reference to her arthritis and sore feet, she recalled:

> *We never wore our own moccasins. We wore those old ragged running shoes to church. Sometimes that hurts me nowadays.*

Dietary impositions were also a factor. In place of their customary "eating off the land" and herbal drinks, they were given "white man's food," and were not allowed to visit their parents, who might have fed them their usual diet.

The four Japanese-Canadian women endured discrimination and upheaval during the Second World War when their families were forcibly removed from coastal areas (this "evacuation" is well documented; see Ichikawa, 1994; Kobayashi, 1992). Betty said:

> *There are still people who have the effects of that in their life and haven't learned to get over it. I think everybody knows people who did not.*

The four participants had overcome the mental burden of their past through education, family relationships, gardening, reiki, and social activities.

Unspeakable stories. The follow-up interview requested by one group revealed new but related data on abuse and power. This was the first time these five women had shared such "personal" information. The first author's intention for that follow-up meeting was twofold: to present the data collected so far, and to conceive of new directions for the principal investigator's program of research into the health of older women. However, the 2-hour meeting, held at a seniors' centre, unfolded in unforeseen ways. It began as somewhat of a continuation of the research interview, with a discussion of some of the findings. The participants described changes in their lives since the research interview. The dam seems to have burst, as each of the five women shared information about herself that she had never shared with anyone. The women reported having felt guilty and full of shame for many years over secrets long-held — about unspeakable stories.

The secrets they had kept from each other were startling to them but not surprising given the vast literature on the abuse of women (Johnson, 1998; Thomlinson, 2003). One by one, the women spoke about verbal and emotional abuse during long-term marriages to men considered good husbands and good neighbours. The topic arose during a discussion about the deaths of their husbands and their having to adjust to a new lifestyle. One woman said that although the adjustment had been difficult she found her new, solitary life quite fulfilling. The admissions evolved after the facilitator commented tentatively that many women feel guilty admitting that they experienced relief after their husband's death. Marta looked around at the other women and warned that what she was about to say would shock. She admitted that she had felt stronger and more independent since her husband's death, even though she had loved him and still missed him at times. The other women then contributed stories of powerlessness and submission during their marriages.

These findings are consistent with Johnson's (1998) reported effects of abuse to older women and the many barriers to help/support-seeking. Johnson reports that older women in a support group saw religious views on marriage as a barrier to speaking out against their spouse. Extreme shame and habitual secrecy, as well as the invisibility of older women in Western culture, made it difficult for the women to take their own needs seriously. Like the participants in the present study, they reported depression and consequent prescribing of medications. Also consistent with the present study, the support group had a positive impact. The participants in the present study had little distance to travel, however, while some of the women in that study drove100 kilometres to attend the weekly meetings. Johnson stresses the importance of support groups to older women in abusive relationships and the need for them to speak out. The present results confirm the need for such supportive interventions. All of the participants in the follow-up discussion indicated that they wished to meet again.

Lack of understanding, poverty, and the politics of poverty. In addition to the institutionalized reliance on social and cultural groups to support elders, in the dominant medical culture women are often pressured into participating in research or complying with health practices that they do not fully understand (Butler & Collins, 1995). Butler and Collins share the results of a round-table discussion during which a group of geriatricians expressed concern about the medical dominance of older women's health care.

The issue of being treated differently arose in all groups. The Ismaili participants struggled the most in their pursuit of health services. They were hesitant to criticize what they perceived as a flawed system. Many managed to obtain the information they needed by consulting their pharmacists, who apparently played an important role by translating information for them. When their needs were still not being met, many of the women waited until their condition worsened. One woman's comment suggests ageist, cultural, and gendered marginalization: "We are women; we are not allowed to complain." Another expressed the view that some younger physicians

> *do not listen at all; they don't want to hear…[what I say] because [of] what's in their book, it's in their book.*

Some women believed that they had not received the proper treatment because they had not asked, or been asked, the right questions.

Discussion

The participants in this study managed their health care privately, with the support of family, friends, and voluntary organizations (primarily faith-based, cultural, or accessed over the Internet). Paradoxically, the very means they used to access health services kept their issues out of the public and political consciousness. The story of older women's management of their health is one of poverty (in the broadest sense) and neglect. The politics of poverty was particularly evident in the case of the First Nations women. However, the politics of access to information and services, although unnamed, also applied to the Ismaili women. Some of the more educated women with resources and initiative sought information from television, the Internet, and wellness centres in shopping malls (which they highly recommended), but the Ismaili and First Nations women had no such points of reference.

There is a clear distinction between the haves and have-nots, not only in terms of access but also in terms of information. In a study by Grundy and Sloggett (2003), poor health in older populations in the United Kingdom was consistently associated with poor personal capital, social resources, and socio-economic circumstances; childhood experiences were also considered important, particularly with regard to current socio-economic status (p. 942), while exclusion from political/community life and decision-making was a significant marker of poverty, especially for women. These indicators reflect poverty of autonomy in decision-making in ways that traditional indicators of poverty, such as income and social assistance, do not (Fukuda-Parr, 1999; O'Reilly, 2002). Poverty and poverty of participation and access are increasing health concerns for all marginalized people (Grundy & Sloggett).

Not only are issues of poverty and access largely overlooked in the planning of elder care, but many of them are institutionalized. Butler and Collins (1995) report on a round-table discussion that revealed gender gaps in elder medical care in the United States; geriatricians expressed concern about the neglect of women in medical education, gender bias in health insurance and in quality of treatment, and preventive care, particularly in the area of domestic violence. In the present study, several of the women recalled not being listened to, being patronized, and being ignored until their health condition became very serious. Publicizing of the traditionally "private" concerns of older women will help to bring this growing population out of the margins.

Implications for Nursing

Registered nurses are uniquely positioned to care for, educate, and counsel patients regarding their physical, emotional, and spiritual health. They are often sought out by members of the public for information and advice. Relationships of trust develop as nurses relate to patients during assessment and care, often resulting in the disclosure of information that is relevant to safe and appropriate care. Nurses may be compelled by the results of the present study to ask older women more specific questions during assessment and ongoing interventions, and to advocate more fully for *and with* older women. This should result in more collaborative relationships between nurses and their older female clients. Such collaboration is critical if older women's voices are to be heard and their health-care needs met.

The method of data collection used in this study holds much promise for a pathway outside of the margins for older women. Group-interview and storytelling methods of data collection have been demonstrated to be useful for both research and intervention. As Banks-Wallace (1998) found in her group interviews with African-American women, "group storytelling can create an environment that supports evaluation of experience and promotes problem solving" (p. 17). The participants in the present study consistently commented that meeting in this way was a new and powerful experience for them. Rola said:

> *We've been meeting for a long time now, but we don't really talk about these personal things usually. It's been real nice…just the little things we're sharing back and forth, and I'm wondering if there are groups of people who get together like this.*

Future plans are to work with older women to devise strategies for them to take control of their lives, their health, and their health care by becoming active in the political arena.

Implications for Future Research

Health-care planning for older women has been absent from the public and political agendas (Rosser, 1994; Weitz & Estes, 2001). Weitz and Estes propose an agenda in which the complex needs of older women are addressed and include collaboration by all health-care providers interested in both older women's health and issues of ageing. Further research might involve collaborative groups of older women with representation from nursing, other health-care disciplines, social-welfare groups, and gerontologists. The depth and richness of the women's experiences, and the insights and suggestions they offer, should prove valuable in the development of health policies and health planning for all women.

Dialogue among nurses, clinicians, researchers, educators, and older women is crucial in developing strategies to meet the health and social needs of this unique and diverse population. Innovative ideas for prevention and intervention, such as inviting older women to sit on planning committees for new primary-care clinics and to play a collaborative role in all phases of development, should be explored and tested. Partnerships between older women and nurses or other health-care providers could set the scene for appropriate, effective, and sensitive health-care planning, policy development, and interventions.

The next step in this program of research is to meet with the participants in each of the five groups to present a summary of the results. We hope that some of the women will agree to participate in a further study that we would develop together as a participatory action project, in order to set a research/activist agenda that will shift the margins that have constrained the growing population of older women. Through sharing, learning, and becoming more aware of their health and health-care issues, older women themselves might spearhead important changes to the way the health-care system addresses their needs. They will have the opportunity to become activists in their own right, leading the way to health-care policy and health-care reform related to older women and men. Their voices will be raised in concert and will be heard.

Arundhati Roy (2003), in a reference to other activist movements, speaks of a gentle giant who has been silent for too long: "Another world is not only possible, she is on her way. On a quiet day, I can hear her breathing" (p. 4).

References

Banister, E., Tate, B., Wright, N., Rinzema, S., & Flato, L. (2002). Data collection strategies for accessing adolescent women's worlds. *Health Care for Women International, 23,* 267–280.

Banks-Wallace, J. (1998). Emancipatory potential of storytelling in a group. *Image: Journal of Nursing Scholarship, 30*(1), 17–22.

Baslow, S. (2000). Gender dynamics in the classroom. In J. C. Chrisler, C. Golden, & P. D. Rozee (Eds.), *Lectures on the psychology of women* (2nd ed.) (pp. 37–46). Boston: McGraw-Hill.

Blow, F. C., & Barry, K. L. (2002). Use and misuse of alcohol among older women. *Alcohol Research and Health, 26*(4), 308–315.

Boyle, I. (2003). The consumer movement. In M. McIntyre & E. Thomlinson (Eds.), *Realities of Canadian nursing: Professional, practice, and power issues* (pp. 375–390). Philadelphia: Lippincott/Williams & Wilkins.

Bradley, N., & Poppen, W. (2003). Assistive technology, computers and Internet may decrease sense of isolation for homebound elderly and disabled persons. *Technology and Disability, 1,* 19–25.

Brotman, S. (2003). The limits of multiculturalism in elder care services. *Journal of Aging Studies, 17,* 209–229.

Butler, R. N., & Collins, K. S. (1995). Older women's health: "Taking the pulse" reveals gender gap in medical care. *Geriatrics, 50*(5), 39–46.

Campbell, J. C., & Bunting, S. (1991). Voices and paradigms: Perspectives on critical and feminist theory in nursing. *Advances in Nursing Science, 13*(3), 1–15.

Chinn, P. L. (1989). Nursing patterns of knowing and feminist thought. *Nursing and Health Care, 10*(2), 71–75.

Chinn, P. (1995). *Peace and power: Building communities for the future* (4th ed.). New York: National League for Nursing Press.

Das Gupta, T. (1999). Multiculturalism policy: A terrain of struggle for immigrant women. In N. Amin, F. Beer, K. McPherson, A. Medovarski, A. Miles, & G. Rezai-Rashti (Eds.), *Canadian woman studies: An introductory reader* (pp. 167–171). Toronto: Inanna.

Fukuda-Parr, S. (1999). What does feminization of poverty mean? It isn't just lack of income. *Feminist Economics, 5*(2), 99–103.

Gonyea, J. G. (1994). The paradox of the advantaged elder and the feminization of poverty. *Social Work, 39*(1), 35–41.

Grundy, E., & Sloggett, A. (2003). Health inequalities in the older population: The role of personal capital, social resources and socio-economic circumstances. *Social Science and Medicine, 56,* 935–947.

Gustafson, D. L. (2000). Introduction: Health care reform and its impact on women. In D. L. Gustafson (Ed.), *Care and consequences: The impact of health care reform* (pp. 15–24). Halifax: Fernwood.

Harman, L. D. (1999). The feminization of poverty: An old problem with a new name. In N. Amin, F. Beer, K. McPherson, A. Medovarski, A. Miles, & G. Rezai-Rashti (Eds.), *Canadian woman studies: An introductory reader* (pp. 128–133). Toronto: Inanna.

Hedin, B. A., & Duffy, M. E. (1991). Researching: Designing research from a feminist method. In R. M. Neil & R. Watts (Eds.), *Caring and nursing: Explorations in feminist perspectives* (pp. 227–235). New York: National League for Nursing Press.

Hekman, S. (1999). Backgrounds and riverbeds: Feminist reflections. In S. Hekman, *The future of differences: Truth and method in feminist theory* (pp. 120–149). Cambridge: Polity Press.

Hunt, S. M. (2001). The subjective health of older women: Measuring outcomes in relation to prevention. *Quality of Life Research, 9,* 709–719.

Ichikawa, A. (1994). A test of tolerance: Canadian government and Jodo Shinshu Buddhism during the Pacific war. *Canadian Ethnic Studies, 26*(2), 46–70.

Ignatieff, M. (1984). *The needs of strangers*. New York: Picador.

Johnson, D. F. (1998). Older women rise up to find themselves. *Herizons, 12*(3), 9–10.

Kinch, J. L. K. (1997). *Older women's stories about health care.* Unpublished manuscript, School of Nursing, Health Sciences Center, University of Colorado.

Kinch, J. L. K. (1999). *Voices of lesbian women living longer.* Unpublished doctoral dissertation, Health Sciences Center, University of Colorado.

Kobayashi, A. (1992). The Japanese-Canadian redress settlement and its implications for "race relations." *Canadian Ethnic Studies, 24*(1), 1–20.

Krueger, R. A. (1994). *Focus groups: A practical guide for applied research* (2nd ed.). Thousand Oaks, CA: Sage.

Lauder, W., Sharkey, S., & Mummery, K. (2004). A community survey of loneliness. *Journal of Advanced Nursing, 46*(1), 88–94.

McCormick, K. M. (2002). Application of feminist theory in nursing research: The case of women and cardiovascular disease. *Health Care for Women International, 23,* 820–834.

McIntosh, W. A., Sykes, D., & Kubena, K. S. (2002). Religion and community among the elderly: The relationships between the religious and secular characteristics of their social networks. *Review of Religious Research, 44*(2), 109–125.

Mohanty, C. T. (1995). Interpreting gender. In *The play of reason: From the modern to the postmodern* (pp. 68–86). Cambridge: Cambridge University Press.

Morse, J. M. (2000). Determining sample size. *Qualitative Health Research, 10*(1), 3–5.

Munhall, P. L. (1994). *Revisioning phenomenology: Nursing and health science research.* New York: National League for Nursing Press.

O'Reilly, D. (2002). Standard indicators of deprivation: Do they disadvantage older people? *Age and Ageing, 31,* 197–202.

Ratcliff, K. S. (2002). *Women and health: Power, technology, inequality, and conflict in a gendered world.* Boston: Allyn & Bacon.

Reinharz, S. (1992). *Feminist methods in social research*. New York: Oxford University Press.

Rosser, S. V. (1994). *Women's health – missing from U.S. medicine.* Bloomington and Indianapolis: Indiana University Press.

Roy, A. (2003). *Confronting empire.* Speech from January 27, 2003, Porto Alegre, Brazil. Reprinted in *ZNet.* http://www.zmag.org/content/showarticle.cfm?SectionID=51&ItemID=2919

Sharpe, P. A. (1995). Older women and health services: Moving from ageism toward empowerment. *Women and Health, 22*(3), 9–26.

Smith, D. E. (1999). Introduction. In In N. Amin, F. Beer, K. McPherson, A. Medovarski, A. Miles, & G. Rezai-Rashti (Eds.), *Canadian woman studies: An introductory reader* (pp. 1–6). Toronto: Inanna.

Statistics Canada. (2003). *General social survey cycle 16: Caring for an aging society.* Retrieved October 18, 2004, from http://www.statcan.ca/english/freepub/89-582-XIE/pdf/89-582-XIE03001.pdf

Thomlinson, E. (2003). Violence and abuse: Ending the silence. In M. McIntyre & E. Thomlinson (Eds.), *Realities of Canadian nursing: Professional, practice, and power issues* (pp. 391–408). Philadelphia: Lippincott/Williams & Wilkins.

Trypuc, J. M. (1994). Gender based mortality and morbidity patterns and health risks. In B. S. Bolaria & R. Bolaria (Eds.), *Women, medicine and health.* Halifax: Fernwood.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy.* New York: State University of New York Press.

Wasekeesikaw, F. H. (2003). Challenges for the new millennium: Nursing in First Nations communities. In M. McIntyre & E. Thomlinson (Eds.), *Realities of Canadian nursing: Professional, practice, and power issues* (pp. 447–469). Philadelphia: Lippincott/Williams & Wilkins.

Weitz, T., & Estes, C. L. (2001). Adding aging and gender to the women's health agenda. *Journal of Women and Aging, 13*(2), 3–20.

Worcester, N., & Whatley, M. H. (2000). *Women's health: Readings on social, economic, and political issues* (3rd ed.). Dubuque, IA: Kendall/Hunt.

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Résumé

Croyances autochtones et dons d'organes : Points de vue de certains Salish du littoral

Anita E. Molzahn, Rosalie Starzomski,
Michael McDonald et Chloe O'Loughlin

De très nombreux autochtones sont en attente d'une transplantation et l'on a constaté chez les peuples autochtones une réticence à accepter le prélèvement d'organe. Cette étude explore les valeurs et les croyances liées au don d'organes chez les Salish du littoral qui vivent en Colombie-Britannique, au Canada. Des entrevues ont été menées auprès de 14 personnes (8 femmes et 6 hommes) dont l'âge variait de 25 à 63 ans. Les sujets contextuels abordés étaient : le manque de confiance, la vie dans les communautés autochtones et les tensions entre les positions contemporaines et traditionnelles. Les sujets relatifs à la mort étaient : l'acceptation du destin, les habitudes et rituels liés à la mort et la plénitude du corps. Les sujets relatifs au don d'organes étaient : l'attitude voulant que « l'on n'en parle pas », le voyage de l'esprit, et l'entraide. Il y avait une grande diversité de croyances parmi les participants, ce qui montre que les croyances d'un Autochtone ne reflètent pas nécessairement celles d'une communauté autochtone en particulier.

Mots clés : don d'organe, transplantation, croyances ethnoculturelles, culture

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Aboriginal Beliefs About Organ Donation: Some Coast Salish Viewpoints

Anita E. Molzahn, Rosalie Starzomski, Michael McDonald, and Chloe O'Loughlin

A large number of Aboriginal people await transplantation, and reluctance to donate organs has been noted among Aboriginal people. The purpose of this study was to explore the values and beliefs regarding organ donation of Coast Salish people living in British Columbia, Canada. Interviews were held with 14 people (8 women and 6 men) ranging in age from 25 to 63 years. Contextual themes were: lack of trust, life in Aboriginal communities, and tension between contemporary and traditional perspectives. Themes pertaining to death and dying were: acceptance of fate, death routines/rituals, and body wholeness. Themes pertaining to organ donation were: "we don't talk about it," transfer of spirit, and helping others. There was considerable diversity in beliefs among participants, which suggests that the beliefs held by an individual Aboriginal person should not be assumed to reflect those of any specific Aboriginal community.

Keywords: organ donation, transplantation, ethnocultural beliefs, culture

While transplantation is not always viewed positively, and some people have concerns about disproportionate allocation of scarce health-care resources to the procedure, research shows that transplantation improves the quality of life of many individuals with end-stage organ failure (Molzahn, 1991). A shortage of organs means that many people die waiting for transplantation and that many people wait a number of years while using costly and less effective medical therapies such as dialysis.

Members of Aboriginal and other non-white ethnocultural communities tend to wait significantly longer for transplants than their white counterparts. Some of the difference in waiting times has been attributed to biological differences in tissue types and blood groups that make it more difficult to find a suitable donor in some ethnic groups than in others (Plawecki, Freiberg, & Plawecki, 1989; Verble et al., 2002). A scarcity of donors from Aboriginal communities contributes to longer waiting times for this population.

In Canada, approximately 4% of the population is identified as Aboriginal; nearly one million people in Canada self-identified with one or more Aboriginal groups in the 2001 Census (Statistics Canada, 2004).

Aboriginal communities are quite diverse. Because of the different traditions and spiritual beliefs among various Native groups, we decided to focus on one First Nation, the Coast Salish people who inhabit the southern part of Vancouver Island and the west coast of the Lower Mainland.

The Coast Salish Nation is geographically located in western British Columbia, Canada, and the northwestern United States. The term Coast Salish is used to describe a number of peoples, including Klahoose, Homalco, Sliammon, Sechelth, Squamish, Halq'emeylem, Ostlq'emeylem, Hul'qumi'num, Pentlatch, and Straits. Each of these communities consists of several bands (Ellerby, McKenzie, McKay, Gariepy, & Kaufert, 2000).

Although there have been some American and British studies on ethnocultural barriers to organ donation, there has been no Canadian research in this area. It is an area that is particularly important for nurses, who are frequently in a position to discuss the possibility of organ donation with families. Knowledge of values and beliefs regarding organ donation can be helpful to nurses and physicians in raising the topic with families in culturally appropriate ways.

The objective of this study was to explore the values and beliefs of Coast Salish people regarding organ donation.

Literature Review

The number of organs available for transplantation falls far short of the demand. Numerous reasons have been proposed for the limited number of organ donations from deceased persons, including fewer accidental deaths, public perceptions regarding organ donation, professional attitudes, the knowledge of health professionals regarding organ donation, donor identification and request processes, lack of family consent for organ donation, and ethnocultural considerations (Molzahn, Starzomski, & McCormick, 2003).

Numerous studies have been conducted to examine the factors that influence decisions regarding organ donation. Some of the research pertains to demographic correlates such as age, gender, class, and level of education. Specifically, it has been found that people who sign organ-donor cards tend to be relatively affluent, educated, and young (the 35–44-year-old age group is more likely to donate than both younger and older age groups) (Cleveland & Johnson, 1970; Frauman & Miles, 1987; Gallup Poll, 1993).

Ethnocultural Beliefs About Organ Donation

Most of the literature on organ donation in ethnocultural communities encompasses diverse people who may or may not share values, beliefs, practices, or traditions. However, there has been little research that captures the diversity of perspectives within and between communities.

Considerable attention has been given to organ donation in the African-American population in the United States (Callender et al., 1991; Callender, Burston, Yeager, & Miles, 1997). A lack of public awareness about transplantation in the black population, distrust of health providers, and religious beliefs have been found to be barriers to organ donation (Plawecki et al., 1989).

There is some reluctance to donate organs upon death in Chinese communities (Evers, Lewis, & Schaeffer, 1999). In Hong Kong, 37% to 83% of respondents to a survey (using hypothetical cases) indicated willingness to donate (Yong, Cheng, & Ho, 2000). Among nurses working in a teaching hospital in Hong Kong, more than half were undecided about their commitment to organ donation (Boey, 2001). Greater receptiveness was found among younger and better-educated respondents (Yong et al.). Younger and unmarried nurses were more likely to commit to posthumous organ donation than older and single nurses (Boey). Individuals were more willing to donate their own kidneys than to allow the organs of a deceased relative to be donated. Half of the Hong Kong respondents over 60 years of age were opposed to donating organs of next of kin (Yong et al.).

Similarly, Lam and McCulloch (2000), in a US study with 122 Chinese-American church attendees, found that only 23% of the participants would be willing to sign an organ donor card and only 4.9% currently carried organ donor cards. While 45.1% said they would donate their organs to strangers, 84.4% would donate to a distant relative and 95.9% would donate to a close relative.

Wheeler, O'Friel, and Cheung (1994) examined barriers to organ donation among Asian Americans. They used focus groups to collect data from Japanese, Chinese, and Filipino participants in Hawaii. Participants expressed the view that a body should remain intact to the grave, as it would reunite with the spirit in the afterlife. Chinese participants believed that the dead should be buried in their finest clothing and jewellery, and that no part of the body should be missing. Filipinos viewed both cremation and organ donation as destruction of the corpse, which was contrary to their cultural beliefs. These Asian Americans were concerned about lack of respect during handling of the body after death, and did not wish to be party to the desecration of a family member's remains (Wheeler & Cheung, 1996).

Religion and Organ Donation

In addition to the cultural influences on beliefs about organ donation, religion may also have an influence. Although leaders of most organized religions support organ donation (United Network for Organ Sharing [UNOS], 1995), surveys of general populations have found that one in six people report that, for them, religion is a barrier to organ donation (Environics Research Group, 2001). Buddhists, Muslims, and Hindus are not prohibited from donating organs and most believe that organ donation is a personal decision (UNOS).

Recent studies in the United Kingdom with people of South Asian origin have found that culture and religion play a much smaller part in decisions about organ donation than originally thought. Randhawa (1998) conducted focus groups and individual interviews, and found that participants expressed a desire to be aware of the religious stances so as to make a more informed decision. Similarly, Exley, Sim, Reid, Jackson, and West (1996) found that barriers to transplantation in the Sikh community seemed to have more to do with lack of knowledge about organ donation than with cultural or religious factors.

Organ Donation in Aboriginal Communities

Aboriginal people in Canada show a disproportionately high incidence of end-stage renal disease, with an eight-fold increase in the number of people on dialysis between 1980 and 2000 (Dyck, 2001). Data are not routinely collected regarding the number of Aboriginal people on dialysis or awaiting transplantation, but with the rising prevalence of diabetes and its complications among Aboriginal people the need for transplantation will only continue to increase. Tonelli et al. (2004) found that Aboriginal patients from Alberta, Saskatchewan, and Manitoba were less than half as likely as other patients to receive a renal transplant after commencing dialysis, even after adjustment for diabetes, other comorbid conditions, residence location, and socio-economic status. The reasons for this discrepancy are not clear. While anecdotal reports from Canadian organ-donation programs/transplant services suggest that the rates of organ donation are very low in Canadian Aboriginal populations, further exploration is warranted.

In relation to Aboriginal perceptions about organ donation, Wheeler and Cheung (1996) report that Native American attitudes towards organ donation are generally positive. However, the rate of organ donation is low. Lee (1996) reports that Native Americans donate 10.5 organs per million population, compared to 27.5 for Caucasians. Blagg et al. (1992) found that less than 50% of Northwest Native Americans would consent to organ donation without a clear directive from the deceased. Several reasons were given for reluctance to donate organs, including: never thought about it, didn't know, had concern about donating unhealthy organs, and wanted to maintain the body intact. It was important to members of this group that family be involved in decisions about organ retrieval (Blagg et al.). As with other groups, Native Americans without a high-school education were less willing to consent to donation than those with a high-school education.

In these communities there may be less concern about living kidney donation than donation from deceased persons. In a study with 846 Native Americans (Danielson, Lapree, Odland, & Steffans, 1998), 81% of respondents indicated that they would be willing to be live kidney donors for family members. The factors influencing their willingness to do so included knowing someone with diabetes, belief that a transplant could offer a normal life, and comfort in donating to someone of their own culture. In contrast, only 54% of respondents indicated that they would be willing to donate upon their death.

In summary, there has been little research pertaining to ethnocultural beliefs about organ donation and no previous Canadian research addressing the perceptions of Aboriginal people pertaining to organ donation. In this study, we undertook to develop some understanding of the values and beliefs of Coast Salish people related to organ donation, in order to generate more questions and eventually equip nurses to provide more appropriate care.

Method/Design

The approach for the study was naturalistic inquiry (Lincoln & Guba, 1985), which is based on an underlying belief that there are multiple perceptions of reality and that individuals construct understandings of reality in interaction with others. Naturalistic inquiry takes place in naturally occurring environments, with no manipulation of individuals or situations.

The research process, including identification of participants, data collection, and data analysis, was guided by the input of an Aboriginal advisory committee consisting of three Aboriginal leaders familiar with research issues. They included a former Coast Salish chief with graduate education, an Aboriginal physician practising in the region, and a scholar in Native studies. They advised on matters such as selection of participants, appropriateness of the questions, strategies for eliciting the maximum amount of information, data analysis, and validation of the findings.

Sample

Purposive sampling was used to obtain a sample. The sample consisted of adults who were identified as willing and able to express their values and beliefs about organ donation, able to speak English, and willing to participate in the study. Snowball sampling, whereby one participant or contact person is asked to identify others who have an understanding of or interest in the topic, was also used. The research team received suggestions from members of the advisory committee regarding potential informants. The coordinator then approached these individuals and also asked them about other people knowledgable about the topic. The coordinator also used his contacts in the Aboriginal community to locate participants.

A total of 14 individuals participated. Approximately five other people who were asked to participate declined because they did not wish to discuss the topic. Eight of the participants were women and six were men. They ranged in age from 25 to 63 years, with a mean age of 39.1 years. Six of the participants lived off-reserve. A variety of occupations and socio-economic levels were represented. One person was disabled. In terms of occupation, they ranged from students to lawyers to band leaders. Participants came from at least seven different Coast Salish bands.

Data Collection

The individual interviews were conducted at a time and location convenient for the participant and for the research coordinator. The research coordinator was a male Aboriginal graduate student. He conducted all the interviews and participated in data analysis. Each participant was interviewed at least once. The interviews lasted approximately 60 to 90 minutes. They began with broad general questions regarding experience with the health-care system and then became more focused (see Table 1 for guiding questions). This approach was taken because organ donation was deemed to be a sensitive topic and we wanted to start with a neutral question. All interviews were audiotaped and transcribed. Follow-up interviews were held with two participants, who reviewed the transcripts and themes that emerged from the data.

Data Analysis

A constant comparative method of data analysis was used (Glaser & Strauss, 1967), with each piece of data being compared with every other piece in a search for similarities and differences. Since the approach used was naturalistic inquiry (rather than grounded theory), no attempt was made to develop a theory or relate themes to one another. The data from each interview were reviewed and the investigators examined the data for themes or categories. Saturation was reached after approximately 10 interviews.

Coding of transcripts and data analysis were facilitated by use of the N5 software package. All co-investigators and the research coordinator participated in the data analysis. Summaries of findings were reviewed with members of the advisory committee and minor clarifications made

Table 1 *Guiding Questions*
Can you tell me a bit about some of your experiences interacting with health-care professionals and the health-care system?
Do you or have you known anyone waiting for an organ transplant?
Can you tell me about your general reaction to transplantation?
Are there any traditional/spiritual/cultural beliefs in the Coast Salish culture about organ donation? Can you tell me about them?
What beliefs or values do most people of your culture hold about organ donation?
Can you tell me how decisions about health-care issues get made in your family?
If a family member indicated that they wanted to be an organ donor, how would you respond? Can you tell me why you have that opinion?
How do you think your beliefs and values about organ donation and transplantation compare to other people in your culture?
Have you ever considered becoming an organ donor? Why or why not?

as a result. As well, themes were reviewed by two participants, who agreed that the findings represented their perceptions. Other participants were not available to review the findings within the time frame requested.

Rigour

The criteria for rigour in qualitative research have been discussed in various ways, using language different from that used in quantitative research. *Credibility* refers to measures that increase the likelihood that credible findings will be produced. In this study, credibility was established by having participants review parts of the data analysis during the research process; two participants and members of the advisory group reviewed and commented on the analysis. *Confirmability* refers to the process of determining the extent to which the description and/or interpretation will serve to illuminate the issue being studied. In this study, participants were asked whether they considered the research analysis to be a true representation of their perceptions and experiences; the participants and advisory committee members agreed that it did. *Auditability* is another hallmark of rigour. In this study, an audit trail (Guba & Lincoln, 1994) was maintained to record the context and background of the study, the rationale for all methodologic decisions, the evolution of the findings, and the researchers' orientation to the problem.

Ethical Considerations

Participation was voluntary and no remuneration was offered. Approval for the study was obtained from the unversity's Research Ethics Review Committee. Each participant signed a consent form that outlined the purpose of the study and procedures to be used and also assured confidentiality; the participants were told that no individual names would be used in any report on the study and codes would be used as identifiers in the transcripts. Approval was not sought from any band, community, or nation, because we were interested in the perspectives of individual Aboriginal people rather than the official position of any specific community.

Findings

A number of themes emerged relating to two broad categories: importance of context, and values and beliefs.

Importance of Context

Importance of context included life in Aboriginal communities, contemporary and traditional perspectives, and lack of trust. These are each described below.

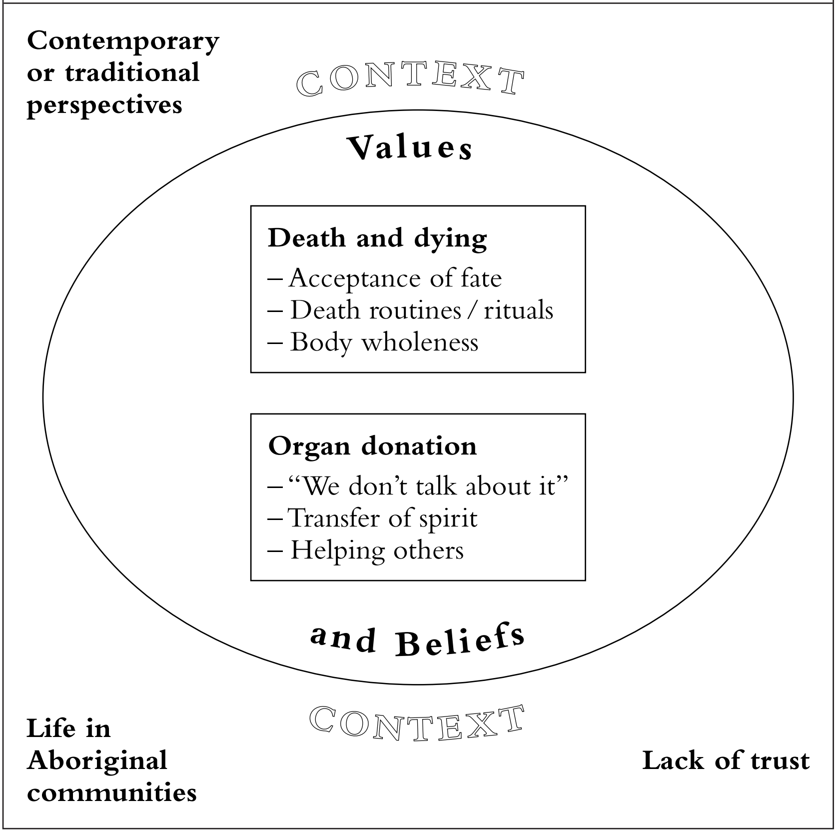
Life in Aboriginal communities. Many participants discussed the context of life in Aboriginal communities in Canada as a backdrop for their responses. For example, one woman who was very supportive of organ donation said:

> *I think at this point in our lives, in our Native communities, our spirits are in pretty bad shape… You know, if you don't have a good spirit, your body's going to react, you know, your mind and your body reacts to what you're feeling inside.*

Frustration with issues pertaining to the jurisdiction over health care between provincial, federal, and First Nations governments was evident. The participants said it was often difficult to obtain necessary medications or other treatment. There were numerous concerns raised about the quality of health services, and numerous examples given of discrimination and racism experienced in the course of accessing health care.

The participants explained that the Coast Salish Nation comprises many communities and perspectives: "each one of our bands, their teachings are different." A woman who had lived in several different communities noted that "in the Chilliwack area," in contrast to other Coast Salish communities, "it's seen as, yeah, if you can help someone out you can do it, and it would be accepted." Similarly, it was reported that means of communicating about organ donation would vary from one commu-

Figure 1 *Themes Arising from Research*



nity to the next. It was also noted that family routines or protocols contributed significantly to values and beliefs. One participant said: "Family law…that's the basis of everything…that's traditional law." Hence, the context for the findings was not only structural and political issues in Canada but also specific differences among Coast Salish communities and families.

As a relatively new technology, organ donation and transplantation had not received a great deal of attention by the participants. None were familiar with British Columbia's organ donor registry. One participant noted that the communities were not accustomed to considering complex scientific issues such as organ donation and transplantation. Nevertheless, there may have been more awareness about it in the region where the study was undertaken than in other Aboriginal communities, because a Coast Salish athlete had developed lymphoma requiring a bone marrow transplant. This had resulted in numerous community meetings and much media attention. The case of this young man, who subsequently died, certainly raised awareness about the need for bone marrow, and possibly transplantation more generally.

Contemporary and traditional perspectives. While most of the participants spoke of organ donation as a matter of personal choice, some framed the issue in terms of contemporary as opposed to traditional thinking. The participants frequently commented that young adults were likely to feel positively about organ donation but elderly people would "still have some difficulty with it." One person said: "Every generation seems to be getting more laid back about our ways and stuff." Another characterized the different views of organ donation as "contemporary," "traditional," and "contemporary traditional":

> *I think that for someone who's a traditionalist, no, it wouldn't be a dilemma [to donate an organ] because it's, no, this is the way it is and that's what I do. For someone who's a contemporary, they would probably have different values and beliefs…they grow outside the culture, not learning the values and beliefs… I think the individual that would have the problem would be someone who's more a traditionalist contemporary, contemporary traditionalist, they would have more of a dilemma as to what they wanted to do.*

Lack of trust. The data show an evident lack of trust regarding health-care professionals and the health-care system. One person said: "There's definitely trust issues and, basically, I see my people as empiricists. They don't believe it until they see it." Another noted: "I might not be ready to die and they take it anyways. There's no trust there." A person who indicated a willingness to be a living donor said:

> *But there's just some fear, some anger somewhere. And I don't know if it's rational. I would…feel much better knowing who it [the organ recipient] was than just a general thing, because I don't think I trust the system enough.*

There was also some evidence of a lack of trust in government. For example, in relation to the establishment of an organ donor registry, one person said that the registry should have "Aboriginal people in charge of it…cause it couldn't be the Department of Indian Affairs."

Values and Beliefs

The participants discussed a number of values related to death and dying. These included: acceptance of fate, death routines/rituals, and body wholeness. In relation to organ donation, a number of values and beliefs emerged, including "we don't talk about it," transfer of spirit, and helping others.

Acceptance of fate. A number of participants expressed the view that medical interventions should be limited:

> *The elders are saying no, the culture that they grew up with…you die when the Creator thinks it's time for you to die, not to extend a person's life simply because of their age, or, you know, because there is a chance to do so.*
>
> *Then there's another part of just thinking how much medical intervention is necessary before you accept what your challenges are.*

The thinking with regard to organ donation must surely be influenced by such beliefs about death and the need for transplantation.

Death routines/rituals. Some of the participants spoke of the protocols and procedures that were observed following death:

> *Spiritually, after someone is gone, then our people would say it would be really wrong to touch that person after, after death I guess. So if someone was approached that way, we need a part of your relative that's gone, that would be a real no-no I guess.*

It appeared that each family had its own traditional death ritual. While many of the participants did not discuss specific rituals, because they considered these private and specific to their family, one participant stated:

> *Basically when, for example, a relative passes away, his family has to go through a traditional ritual, put on a kerchief, wearing sunglasses and having somebody look after them and protect them. Because they have to follow a set protocol and this may be different for different families, but I'm speaking in general terms…picking out the similarities that usually exist… And when that body is in the longhouse, they have somebody looking after the body. And there's…a spiritual, cyclical content, and after 4 days the funeral happens. And with that in mind, 4 is…very sacred in context. You know, after 4 days you have to be going for baths for days, spiritual bathing. And taking away from that kind of tradition by wanting to put the body elsewhere or use it for something else…that kind of infringes on those people's beliefs and values.*

Other participants similarly noted that there were "routines" to be followed before and after death and that the organ-donation process could interfere with these.

Body wholeness. The concept of preserving body wholeness was emphasized by most participants. One participant summarized the importance of body wholeness in light of the spiritual journey to the afterworld:

> *But when it comes to a burial, our people would like to have a whole body, organs intact. Everything. So that a person has a complete soul, body, when they go to, you know, travel on to the rest of their journey. And when they are buried in the cemetery their journey is complete. Their bodies full. There is nothing missing. If they want to be buried and their eyes are missing or their ears are missing or something, it will disturb their journey. And it will bring a lot of hardship to the family or a lot of hardship to the community. It will bring bad things for a while, until the spirits are satisfied that what we did, they sort of have been satisfied that we have sort of paid a price for bringing bad spirits into a place that is very sacred. So it's kind of a rough-doing, organ donation.*

"We don't talk about it." There was no question that people did not normally talk about organ donation. One person said: "That is something that, you know, we never talk about with elders." Some of the participants were reluctant to share their beliefs about organ donation. One person explained:

> *It's sort of too complex to, to really sort of even get into during an interview. And, you know, even…if I were to share an aspect of it with you, you'd be missing the other pieces that went with it so you'd only get, you know, a part of the story.*

Others felt they had no right to discuss the subject:

> *And for some things it's not appropriate for me to be talking about because…it's not my right to talk about them… Someone who has that gift, it's more appropriate for them to be talking about it.*

A third reason for not sharing information was that "it's not appropriate to be sharing outside the culture and it's also not appropriate to share outside the family, some of the teachings." The participants were assured that they did not have to respond to the questions and could withdraw at any time. None chose to withdraw but it appeared that several chose not to share this personal information.

Transfer of spirit. Some participants seemed to be concerned that the spirit of one person might be transferred to another during the course of transplantation. One participant said:

> *It's like we're vessels. Like we're vessels of our spirit, our body is our vessel. So, would I be bringing someone else's spirit to the body part that I have in me?*

Some of those who were supportive of organ donation noted that it might be appropriate to do a cleansing ceremony to address this concern.

Helping others. While most of the participants had concerns about organ donation and transplantation, a few were very supportive, primarily because they viewed it as a way to help family members and community members. One person stated, "We always help our own people." Another said:

> *I think that if you can save someone's life, then I would support anyone making that decision. I personally would make the decision, although I would respect also my family's wishes.*

Some of the participants indicated that they would feel more comfortable donating an organ if they knew the recipient. Certainly, there was a willingness to make a living donation in the case of a family member. However, it was suggested that even then some "psychological/spiritual preparation" might be required.

Discussion

Family and community were important elements of the context for this study. It was evident that extended families were important to the participants and that family members were consulted on all significant decisions. Although some of the participants regarded organ donation as a personal decision, talking over such issues with family members was emphasized as a cultural practice throughout the interviews. In Coast Salish culture, families are intimately involved in routines and rituals relating to death. Miller and Pylypa (1995) point out that Coast Salish families act collectively in the provision of child and elder care as well as in ceremonial functions. Family members provide one another with food, equipment, financial assistance, transportation, and advice. On the other hand, there was also a sense that the family and community would respect the decisions of individuals on personal matters such as organ donation.

The lack of trust found in this study has been noted previously (Miller & Pylypa, 1995; Royal Commission on Aboriginal Peoples, 1996). "The problem of gaining the trust of community members is repeatedly cited in the Swinomish project's publication…and Lewis noted that among Coast Salish peoples, there is a prevalent distrust of all who are not close kin" (Miller & Pylypa, p. 22). Lack of trust in health professionals in particular and mainstream society in general likely influences attitudes about organ donation. Lack of trust has been associated with the structural barriers to access to care, such as language barriers and lack of cultural competence on the part of health-care providers.

Individual as well as systemic discrimination have been found in healthcare institutions (Ellerby et al., 2000). Although these structural factors were not the focus of the present study, they certainly influence life in Aboriginal communities and have relevance for the lack of trust cited by the participants.

While some of the participants supported organ donation, it was apparent that they had little information on the procedure for doing so. None of the participants was familiar with the current organ-donor registration system in British Columbia; a registry established in 1997 is the only legally recognized way to register for organ donation (British Columbia Transplant Society, 2004). Of the 4 million people in the province, only about 475,000 have registered, so the lack of awareness goes beyond the Coast Salish community. However, the participants showed greater awareness of the bone marrow registry. This suggests that it may be beneficial to link public education about organ donation to the specific transplantation needs of the Aboriginal community.

It was apparent that many of the values and beliefs of the participants were congruent with traditional Aboriginal values and beliefs. The participants' discussions of body wholeness reflect Kan's (1989) observation, with regard to the Tlinglit culture, that "human remains had to be maintained whole so as to ensure proper rebirth and well-being of the deceased's new incarnation" (p. 127). On the other hand, they also conveyed a sense that the family and community would respect the decisions of individuals on such personal matters.

While the participants displayed a lack of awareness about organ donation, many of their comments indicated that they were cautious about the concept. It was apparent that those holding traditional values would have serious concerns about organ donation. According to traditional Aboriginal beliefs, for one to enter the spirit world after death, one's body must remain whole (Danielson et al., 1998; Evers et al., 1999). Some participants viewed organ transplantation as the transference of one person's spirit to another person (Danielson et al.). Such beliefs are inconsistent with the process of organ donation. A significant subset of participants spoke about the importance of helping others, particularly members of their own community. There appeared to be a contradiction between traditional beliefs about body wholeness and transfer of spirit on the one hand, and the notion of doing good on the other. Participants who were supportive of organ donation suggested cleansing ceremonies to address certain concerns. However, this would likely be insufficient to allay serious concerns. The participants exhibited a wide range of perspectives on the subject, and the beliefs of elders and traditional members of the community may differ from those of young people and individuals with a contemporary outlook.

The attitudes and beliefs of Coast Salish individuals may vary significantly from the position, formal or informal, of the Coast Salish community to which they belong. The participants who were supportive of organ donation cited the importance of helping members of their community. This might be a point to emphasize in community health educational programs. Also, the targeting of organ donation *within* the Aboriginal community might serve to reduce suspicion. However, the ethical implications of such a strategy would have to be considered.

Implications for Nursing Practice, Education, and Research

Nurses can play a key role both in educating patients and families and in respecting their beliefs and wishes regarding organ donation. The purpose of this study was not to alter values and beliefs but, rather, to better understand them in order to influence the organ-donation process so as to make it more culturally sensitive and ensure that people who are interested and willing to donate organs have the opportunity to do so. An attempt should be made to accommodate rituals and cultural practices pertaining to the death of organ donors. These practices are likely to be different for each family. Concerns about body wholeness and transfer of spirit must be respected. Nurses who are knowledgeable about these values and beliefs will be in a better position to respect patients' wishes and address their concerns about organ donation.

In terms of educating the Aboriginal community about organ donation, the results of this study suggest that Aboriginal leaders should be made aware, in meaningful and sensitive ways, of the shortage of organs for Aboriginal people. Given the many challenges facing Aboriginal communities, the issue may not become a priority until a community member develops end-stage organ failure.

Future research might include participatory action approaches whereby researchers and community members work in partnership to address mutual research objectives. It would also be interesting to explore the possibility of involving Aboriginal nurses in education about organ donation and in the donor-request process. This strategy has been effective in the African-American community. Ethnographic studies with Aboriginal families facing organ donation could elicit further details about values and beliefs with regard to organ donation, but ethnography is an intrusive method and is often viewed with suspicion by Aboriginal communities; it would therefore need to be conducted in a participatory manner.

The views of the participants in this study do not necessarily represent the views of Coast Salish people in general or, indeed, those of their own Coast Salish communities. Hence, the findings are not generalizable to other Coast Salish people or to Aboriginal peoples elsewhere. Given the sensitive nature of the subject and the reluctance of some of the participants to fully disclose their cultural beliefs, it is unlikely that the findings are comprehensive and complete. Furthermore, decisions regarding organ donation are influenced by many factors — in addition to ethnocultural beliefs — all of which may not have been elicited in this study.

Conclusions

This study has shown that people with traditional Aboriginal beliefs stress body wholeness and are apprehensive about the transfer of the spirit from the organ donor to the recipient. However, it has also shown that Aboriginal people are concerned with doing good for others. While the participants expressed a range of opinions about organ donation, they indicated considerable lack of knowledge about the organ-donation process. These findings raise issues that nurses should consider when requesting organ donation and when planning public education programs around organ donation.

References

Blagg, C. R., Helgerson, S. D., Warren, C. W., Keendenton, K., Seely, M., Peterson, L., et al. (1992). Awareness and attitudes of Northwest Native Americans regarding organ donation and transplantation. *Clinical Transplantation, 46,* 436–442.

Boey, K.W. (2001). A cross-validation study of nurses' attitudes and commitment to organ donation in Hong Kong. *International Journal of Nursing Studies, 39,* 95–104.

British Columbia Transplant Society. (2004). *Organ donor registry.* Retrieved April 5, 2004, from http://www.transplant.bc.ca/

Callender, C., Burston, B., Yeager, C., & Miles, P. (1997). A national minority transplant program for increasing donation rates. *Transplantation Proceedings, 29,* 1482–1483.

Callender, C. O., Hall, L. E., Yeager, C. L., Barber, J. B., Dunston, G. M., & Pinn-Wiggins, V. W. (1991). Organ donation and blacks: A critical frontier. *New England Journal of Medicine, 325,* 442–444.

Cleveland, S. E., & Johnson, D. L. (1970). Motivation and readiness of potential human tissue donors and nondonors. *Psychosomatic Medicine, 32,* 225–231.

Danielson, B. L., Lapree, A. J., Odland, M. D., & Steffans, E. K. (1998). Attitudes and beliefs concerning organ donation among Native Americans in the upper Midwest. *Journal of Transplant Coordination, 8,* 153–156.

Dyck, R. F. (2001). Mechanisms of renal disease in indigenous populations: Influences at work in Canadian indigenous peoples. *Nephrology, 6,* 3–7.

Ellerby, J. H., McKenzie, J., McKay, S., Gariepy, G. J., & Kaufert, J. M. (2000). Bioethics for clinicians: Aboriginal cultures. *Canadian Medical Association Journal, 163,* 845–850.

Environics Research Group. (2001). *Organ and tissue donations: Canadian public awareness, knowledge and attitudes.* Toronto: Author.

Evers, K. A., Lewis, D. D., & Schaeffer, M. J. (1999). Cultural diversity: Sociological and cultural factors affecting consent for organ donation. *Critical Care Nurse, 19*(4), 57–61.

Exley, C., Sim, J., Reid, N., Jackson, S., & West, N. (1996). Attitudes and beliefs within the Sikh community regarding organ donation: A pilot study. *Social Science and Medicine, 43,* 23–28.

Frauman, A. C., & Miles, M. S. (1987). Parental willingness to donate the organs of a child. *American Nephrology Nurses Association Journal, 14,* 401–404.

Gallup Poll. (1993). *Attitudes and opinions of the American public toward organ transplants/organ donation*. Princeton, NJ: Gallup Organization.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory.* Chicago: Aldine.

Guba, E., & Lincoln, Y. (1994). Competing paradigms in qualitative research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–118). Thousand Oaks, CA: Sage.

Kan, S. (1989). *Symbolic immortality: The Tlinglit potlatch of the 19th century*. Washington: Smithsonian Institution Press.

Lam, W. A., & McCullough, L. B. (2000). Influence of religious and spiritual values on the willingness of Chinese-Americans to donate organs for transplantation. *Clinical Transplantation, 14,* 449–456.

Lee, S. M. K. (1996). End-stage renal disease in Asian-Americans. *Nephrology News and Issues, 6,* 13–14.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.

Miller, B. G., & Pylypa, J. (1995). The dilemma of mental health paraprofessionals at home. *American Indian and Alaska Native Mental Health Research, 6*(2), 13–33.

Molzahn, A. E. (1991). Quality of life after organ transplantation. *Journal of Advanced Nursing, 16,* 1042–1047.

Molzahn, A. E., Starzomski, R., & McCormick, J. (2003). The supply of organs for transplantation: Issues and challenges. *Nephrology Nursing Journal, 30,* 17–26.

Plawecki, H. M., Freiberg, G., & Plawecki, J. A. (1989). Increasing organ donation in the black community. *American Nephrology Nurses Association Journal, 16,* 321–324.

Randhawa, G. (1998). An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton, UK. *Nephrology Dialysis Transplantation, 13,* 1949–1954.

Royal Commission on Aboriginal Peoples. (1996). *People to people, Nation to nation*: *Report of the Royal Commission on Aboriginal Peoples.* Ottawa: Author.

Statistics Canada. (2004). *Population and demography.* Retrieved November 9, 2004, from http://www.statcan.ca/english/Pgdb/popula.htm#firnat.

Tonelli, M., Hemmelgarn, B., Manns, B., Pylypchuk, G., Bohm, C., Yeates, K., et al. (2004). Death and renal transplantation among Aboriginal people undergoing dialysis. *Canadian Medical Association Journal, 171,* 577–582.

United Network for Organ Sharing. (1995). Organ *and tissue donation: A reference guide for clergy*. Richmond, VA: Author.

Verble, M., Bowen, G. R., Kay, N., Mitoff, J., Shafer, T. J., & Worth, J. (2002). A multiethnic study of the relationship between fears and concerns and organ donation rates. *Progress in Transplantation, 12,* 185–190.

Wheeler, M. S., & Cheung, A. H. S. (1996). Minority attitudes toward organ donation. *Critical Care Nurse, 16*(1), 30–35.

Wheeler, M. S., O'Friel, M., & Cheung, A. H. S. (1994). Cultural beliefs of Americans as barriers to organ donation. *Journal of Transplant Coordination, 4,* 146–150.

Yong, B. H., Cheng, B., & Ho, S. (2000). Refusal of consent for organ donation: From survey to bedside. *Transplantation Proceedings, 32,* 1563.

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Résumé

Le recours à l'altérité dans la pratique infirmière en milieux psychiatriques médico-légaux et correctionnels : une exploration

Cindy Peternelj-Taylor

En milieux médico-légaux et correctionnels, il n'est pas rare de voir les infirmières, les infirmiers et autres professionnels de la santé dépersonnaliser leurs patients et leurs clients en faisant usage de certains termes. Par exemple, non seulement l'utilisation de mots comme « détenus », « prisonniers », « psychopathes », « schizophrènes » ou « monstres » pour parler des patients évoque-t-elle des images stéréotypées mais elle projette surtout l'individu dans le rôle de l'autre. L'utilisation de l'altérité est généralement vue comme une forme négative d'engagement et contraire à une pratique infirmière respectueuse de la déontologie. Par le biais d'une exploration de facteurs relationnels et contextuels contribuant à ce phénomène, l'auteure argue que le recours à l'altérité est une question morale contemporaine qui nécessite un dialogue continu au sein des communautés infirmières des milieux médico-légaux et correctionnels.

Mots clés : recours à l'altérité, pratique infirmière en milieux psychiatriques médico-légaux et correctionnels, question morale

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An Exploration of Othering in Forensic Psychiatric and Correctional Nursing

Cindy Peternelj-Taylor

In forensic and correctional environments, it is not uncommon for nurses and other health-care practitioners to depersonalize their patients and clients through their use of language. For example, referring to patients as "inmates," "cons," "psychopaths," "schizophrenics," or "monsters" not only evokes stereotypical images, but, more importantly, casts the individual in the role of the other. Othering is generally viewed as a negative form of engagement, one that is contrary to ethical nursing practice. Through the exploration of relational and contextual factors contributing to this phenomenon, the author argues that othering is a contemporary ethical issue that requires ongoing dialogue within the forensic and correctional nursing communities.

Keywords: othering, forensic psychiatric and correctional nursing, ethical issues in practice

I became interested in "othering" a long time ago. I didn't know what othering was, but I certainly lived with its consequences in my day-to-day practice as a forensic psychiatric nurse. I could feel the hatred in the words of those who engaged in othering. I was mocked and laughed at when I referred to the individuals I was working with as patients. I was new, I wanted to fit in, but I could not adopt the derogatory language of my peers — many of them nurses. How could I form therapeutic relationships with my patients if I thought so little of them as individuals, as fellow human beings? And I remember the correctional supervisor who, with a raised, clenched fist, walked off the unit declaring he was going to go and do some "therapy."

Forensic and correctional institutions are among the most extreme and stressful environments known to contemporary society. Sadly, for a variety of reasons and life circumstances, such environments have become health-care "havens" for a large portion of vulnerable and at-risk populations. Accepting the challenge to provide nursing care in environments where health-care delivery is not the primary goal is fraught with moral dilemmas not often encountered in more traditional health-care settings. The profession's obligations to caring, often touted as the essence of nursing, should not be affected by the fact that those seeking care have been charged with, or convicted of, criminal acts. As Drake (1998) asserts, "whatever the setting, the provision of optimum holistic health care is the raison d'être for professional nurses" (p. 52).

However simple this edict, the development of therapeutic relationships, the foundation of health-care provision, is tenuous at best, and can be particularly difficult if the patient has committed a grievous or heinous crime (Chaloner, 2000). In practice, it is not uncommon for forensic psychiatric and correctional nurses to use language that depersonalizes their patients and clients. For example, referring to those in their care as "inmates," "cons," "psychopaths," "schizophrenics," or "monsters" not only evokes stereotypical images but, more importantly, casts the individual in the role of other. The process of engaging others — those who are perceived as different from self — is referred to as othering in the contemporary health-care literature (Canales, 2000; MacCallum, 2002; Myhrvold, 2003). Considering the hierarchical power structure in forensic and correctional environments, othering is perhaps inevitable: those who are hospitalized and/or incarcerated are at risk for eliciting this response from those who work with them (Corley & Goren, 1998).

Although othering is usually seen as a negative or exclusionary form of engagement, one that leads to stereotyping, labelling, and marginalization (Canales, 2000; Corley & Goren, 1998; MacCallum, 2002), connecting with the other can be an empowering and transformative experience, one that promotes inclusion over exclusion (Bunkers, 2003; Canales; Zerwekh, 2000). By exploring the relational and contextual factors that contribute to the enactment of this phenomenon, it is argued that othering reflects a contemporary practice issue of moral significance — one that addresses the provision of competent and ethical nursing care and one that requires ongoing dialogue within the forensic and correctional nursing community.

Defining Other and Othering

The New Oxford Dictionary of English defines other as a noun, "used to refer to a person or thing that is different or distinct from one already mentioned or known about," and as a pronoun, "that which is distinct from, different from, or opposite to oneself" (Pearsall, 1998, p. 1314). Canales (2000) defines othering as engaging "with those perceived to be different from self — the Other" (p. 16). In philosophical writings, reports Myhrvold (2003), the other is someone who falls outside of the "established support system" (p. 41). The apparent clarity of these definitions conceals the fact that designating the other and engaging in othering are complex, multifaceted phenomena revealed only within a relationship of power (Canales; Carabine, 1996).

In its broadest sense, othering has its roots in feminist discourse, postcolonialism, critical theory, and symbolic interactionist theory (Canales, 2000; Kirkham, 2003; Kitzinger & Wilkinson, 1996; Varcoe, 2004). Accordingly, individuals may be designated other on the basis of their skin colour, gender, sexual identity, and social class; whether they are homeless, illegal immigrants, refugees, addicted to drugs or alcohol, experience a disability, are HIV-positive, have a diagnosis of tuberculosis or mental illness, or are a prisoner (Bunkers, 2003; Canales; Doyle, 1998; Kirkham; MacCallum, 2002; Reaume, 2002; Stevens, 1998; Strickland, 2001). The same individuals generally considered vulnerable by society and the health-care community (Flaskerud & Winslow, 1998; Myhrvold, 2003) are those at risk of being labelled other and subjected to othering by those charged with meeting their health-care needs. And, as with vulnerability, those who might be labelled other at any given point in time is not a constant factor but is continually evolving (Kirkham; Myhrvold). Canales outlines several questions that are critical to any discussion of othering: "Who is designated as Other? By whom? How? Under what conditions? And with what consequences?" (p. 18).

The prevailing sentiment regarding othering is typically negative or exclusionary. Othering occurs in relationships between the powerful and the powerless, where vulnerabilities are exploited and where domination and subordination prevail (Canales, 2000; Carabine, 1996; Kitzinger & Wilkinson, 1996). Therefore, othering as a form of engagement is not restricted to individuals but is manifested on multiple levels: personal, professional, institutional/organizational, and societal (Canales; Corley & Goren, 1998; Zerwekh, 2000). The consequences of othering include alienation, marginalization, stigmatization, oppression, internalized oppression, and decreased social and political opportunities (Bunkers, 2003; Canales; MacCallum, 2002). From a health-care perspective, these consequences impede the development and maintenance of therapeutic relationships and ultimately affect every aspect of health care, including health promotion, health maintenance, and health restoration (Canales; Evans, 2000).

Kitzinger and Wilkinson (1996) provide a concise summary of othering that is relevant to this exploration:

> A key aspect of the various theoretical approaches to Othering (albeit differently treated by each), is the observation that the notion of who and what Others are (what they are like, the attributes assigned to them, the sorts of lives they are supposed to lead) is intimately related to "our" notion of who and what "we" are. That is, "we" use the Other to define ourselves: "we" understand ourselves in relation to what "we" are not. (p. 8)

Factors Impacting on Othering in the Forensic and Correctional Milieu

This exploration of othering centres on the nature of forensic psychiatric and correctional nursing. Forensic psychiatric and correctional facilities are controversial; they elicit strong reactions from various sectors who debate their proper place in society. As public-sector institutions, they provide the community with both social necessities and social goods. Social necessities are, by definition, essential to a community's existence. Social goods, on the other hand, are perceived as a kindness; although not essential, they do benefit the community. However, the distinction between a forensic psychiatric facility and a correctional facility is not a clear one. Both fulfil their social-necessity mandate through the social control of their populations; the protection of the community is perceived to be a direct consequence of the confinement and control they provide. Forensic psychiatric hospitals and correctional facilities also fulfil a social-goods mandate, in that they provide health care to those who are confined. In essence, nurses are faced with the dilemma of providing a social good (health care) but within institutions dedicated to the provision of a social necessity (confinement) (Osborne, 1995; Peternelj-Taylor, 1999; Peternelj-Taylor & Johnson, 1995). The moral climate of forensic psychiatric and correctional settings is shaped as the competing demands of custody (social necessity) and caring (social good) are embraced by health-care professionals (Austin, 2001).

The impact of the environment on nursing practice cannot be ignored, as nurses are clearly influenced by the organizational context in which they work. There exists a continuum of controlled or secure environments, operated as part of the health-care system, the criminal-justice system, or, in some jurisdictions, jointly operated. Although the ideological priorities of the correctional system centre on confinement and security, while forensic psychiatric facilities function as hospitals within the ethos of the health-care system, power, control, and authority are manifested in the physical and interpersonal environments of both settings and can run counter to the achievement of health-care goals (Blair, 2000; Droes, 1994; Holmes & Federman, 2003; Maeve, 1997; Weinberger & Screenivasan, 1994). It is no wonder that Osborne (1995) declares, "There is a blurring of the mission of corrections and mental health facilities" (p. 5).

The Power of Language

Adshead (2000) observes that the ethical dilemmas encountered in forensic settings often reflect the nature of the patient population. As a highly stigmatized and stereotyped group, this population is frequently "deemed as *valueless* by the rest of society" (p. 304). Questions such as "Why would you want to work *there*?" "How can you stand working with those *mentally ill criminals*?" "Aren't you afraid of getting hurt?" are all too familiar to nurses practising in forensic psychiatric and correctional settings. Scheela (1999), a nurse therapist who works with sex offenders, adds her own list of questions, such as "Why would anyone want to work with *them*?" and "What's the matter with *you*?" (p. 25). Such questions indicate that individuals receiving care in forensic and correctional settings are also cast in the role of other by outsiders, whose fear and ignorance also breed contempt for health-care professionals, as they too are stigmatized and rendered suspect (Chaloner, 2000; Doyle, 2001; Martin, 2001; Peternelj-Taylor & Johnson, 1995; Scheela).

Kitzinger and Wilkinson (1996) observe that "Others are *constructed* — by those who do Othering, by those who reflect upon that Othering, and by the Others' own representations of themselves" (p. 15). Individuals who seek health care within forensic and correctional settings are frequently portrayed by correctional staff (and sometimes by health-care staff) as inherently manipulative, conniving con artists even when their health concerns are legitimate (Doyle, 1999; Maeve, 1997; Martin, 2001). Regardless of what othering labels are applied in these settings, they all have a similar, distressing tone. Not only do they elicit strong emotions, stigmatize, and stereotype, but they all construct the person as something other than a person, in many cases as a "monster" (Evans, 2000; Holmes & Federman, 2003; Scheela, 1999).

Even use of the term "inmate"[1] is not without problems, although it is officially sanctioned in correctional facilities. In some institutions, policy dictates that nurses refer to their patients as inmates — for example, "Inmate Smith" — while in other institutions individuals are referred to by their institutional number — for example, "Inmate 47329." So even though inmate is a legitimate term, it can have derogatory implications. It places the nurse in the role of professional keeper; nurses work with patients and clients, correctional staff work with inmates. In the nurse-inmate scenario the helping, therapeutic role of the nurse is lost, replaced by a custodial role.

Drake (1998) reports that when conducting research with incarcerated women she would ask them directly if they found it insulting to be referred to as inmates. To her surprise, the women said that it depended on who was using the term and how it was being used. Clearly, the term can be used in a way that maintains the power differential between those who are institutionalized and those who are free, between those who

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[1] Defined in *The New Oxford Dictionary of English* simply as "a person living in an institution such as a prison or a hospital" (Pearsall, 1998, p. 941).

exert power and those who are oppressed. When nurses refer to individuals as inmates instead of as patients or clients, a punitive atmosphere prevails, with the nurse being cast in the role of custodian rather than that of caregiver.

Even terms that have a quasi-legitimate place in health care — for example, "psychopath," "schizophrenic," or "borderline" — are problematic, even though they can generally be found in the professional literature. The significance lies in the meaning of the label and how it is used (Corley & Goren, 1998). Does "borderline," for example, imply that one is unworthy or has brought one's problems upon oneself? (Nehls, 1999). Does "psychopath" suggest that one is incurable and therefore unworthy of treatment? (Horsfall, 1999). Individuals who are mentally ill are subjected to a number of derogatory, stigmatizing labels — for example, "spinner," "psycho," "schizo," "loon" (Doyle, 1999; Reaume, 2002); those who have been diagnosed with schizophrenia are not individuals but "schizophrenics," or, to use Reaume's words, "the dreaded other" (p. 424). Othering practices find their principal focus not in person-as-a-person (MacMurray, 1961) but in person-as-an-illness (Swinton & Boyd, 2000).

Any label associated with mental illness can be problematic in correctional settings. Some individuals incarcerated for violent crimes even resist the label "patient," as it may imply that they are mentally ill and thus subject to abuse by their peers. Being identified as a "bug," a "goof," or a "spinner" invites ostracism and victimization by one's peers and, to a lesser degree, by correctional staff (Doyle, 2001; Peternelj-Taylor & Johnson, 1995). Holmes and Federman (2003) conclude that all such derogatory labels "are superimposed on the nurse's common theoretical representation that a patient is a person for whom care is provided" (p. 945.) When a patient's behaviour is interpreted solely as manipulative, caregivers will respond negatively to that patient's needs. Labelling someone as manipulative only serves to perpetuate othering, such that strategies for exploring and effectively dealing with the "manipulative behaviours" are lost to the psychotherapeutic relationship (Weinberger & Screenivasan, 1994).

Language is exceedingly powerful and "shapes how nurses define their presence with clients" (Mitchell, Ferguson-Paré, & Richards, 2003, p. 49). Negative labelling conveys an attitude of disrespect and contributes to powerlessness. Language can be accusatory and dismissive, and can be non-conducive to the establishment of a trusting relationship (Horsfall, 1999). Particularly derogatory labelling prevails in forensic and correctional settings. It includes terms that on the surface appear innocuous (e.g., patient, inmate) as well as terms that are used to describe individuals who are criminals or those who are mentally ill, some of which are too crude to include in this discussion. The negative labelling that occurs in verbal discourse is further perpetuated and reinforced in the written word. For instance, Mohr (1999) observes that othering is revealed in nurses' charting and documentation in patients' medical records, through implicit preconceptions, assumptions, and stereotypes as the self of the nurse is exposed through his or her relationship with the othered. For example, the lack of documentation on the therapeutic relationship, mutual definition of problems, or inability to explore solutions (Martin & Street, 2003) may reflect the nurse's fears or inadequacies, or the nurse's unwillingness to engage forensic patients therapeutically. In essence, othering may be reflected in what is not documented.

One thing is clear. When the person who is othered is a forensic psychiatric patient or an individual who has been charged with or convicted of a criminal act, the consequences of othering are significant. The enacting of othering through language often reflects the informal culture of the organization, by separating "them" from "us" — those who are "kept" from those who are the "keepers" (Corley & Goren, 1998).

The Power of the Interpersonal Climate

Othering, whether on the part of health-care professionals or correctional staff, does not occur in a vacuum (Corley & Goren, 1998; Myrhold, 2003). Understanding the referent groups within institutions, and the power they wield, is critical. Even though there may be a clash of cultural and professional values, the power exercised within correctional institutions often influences how othering is enacted, tolerated, and sanctioned by peers. In many settings a nurse's peer group is made up not of nurses, or even health-care professionals, but custodial or correctional staff. Clearly, the ideological priorities of the correctional system are contrary to nursing's caring mandate (Blair, 2000; Corley & Goren; Mitchell, 2001). Nurses employed by correctional systems are often at odds with policies and personnel as they struggle to fulfil their professional obligations within the confines of the correctional mandate. Blair reports that when nurses are faced with dilemmas in their practice they often choose not to intervene or not to advocate on their patients' behalf for fear of disturbing the status quo, resulting in conflict among health-care staff or between nurses and correctional staff. Stohr, Hemmens, Kifer, and Sholer (2000) acknowledge that "doing the right thing" is not always easy and in many situations impossible. Weinberger and Screenivasan (1994) conclude that as correctional psychologists they often feel that their role is simply one of "window dressing." It is not uncommon for correctional staff to undermine the power of health-care professionals by ignoring their clinical decisions, often under the guise of serving the greater good of the institution (Blair; Droes, 1994; Peternelj-Taylor & Johnson, 1995).

Holmes and Federman (2003) found that nurses working in a correctional psychiatric unit reported changes in the way they provided care for their patients over the course of their employment, learning to conform to the facility's norms and correctional mandate. Doyle (1999), Maeve (1997), and Maeve and Vaughn (2001) caution nurses to be wary of being co-opted by the correctional mandate and abandoning their nursing ideals. In addition, although doing the right thing may be possible (Stohr et al., 2000), it is not always an easy choice, especially if it means not getting along with others. Fisher (1995) reports that when one's clients have a known history of violence getting along with colleagues takes precedence over speaking up and doing what might be perceived as the right thing, as staff may depend on one another for their personal safety. Thus, nurses quickly learn the "right way" of behaving, even if such behaviour is not illustrative of the right thing to do (Corley & Goren, 1998; Fisher; Stohr et al.).

Doyle (1998) affirms that forensic and correctional nurses face unique clinical challenges as they strive to meet the idiosyncratic needs of their patients and clients while balancing the issues that arise from their professional coexistence with custodial staff "who function as powerful others over nurses" (Maeve, 1997, p. 506). In the final analysis, forensic psychiatric and correctional nurses must articulate their professional authority and responsibility in order to maintain their professional integrity (Lindeke & Block, 1998).

Implications for Ethical Nursing Practice

Othering as it is articulated in forensic and correctional nursing clearly demands further ethical reflection. A nurse who adopts othering behaviours as embodied in both the written and the spoken word fails to see the "person-as-a-person" (MacMurray, 1961). Othering represents an attempt to separate "them," those who are othered, from "us," those who do the othering. In essence, when nurses engage in othering they are forced to look at themselves, as they come to know themselves through their relationships with others (Bunkers, 2003; Canales, 2000; Kitzinger & Wilkinson, 1996).

Forensic psychiatric and correctional nurses care for a client population that is frequently stigmatized, stereotyped, and subjected to othering, often at the hands of those charged with their care. The personal experiences of nurses may well colour their worldview, and ultimately their therapeutic response to their patients and clients. It may well be that not all nurses will be able to embrace non-judgemental behaviours with all patients and clients in all situations, but they should be encouraged to "build a bridge" (Liaschenko, 1994) and approach their work in a noncondemnatory manner. Martin (2001) concludes that "it would be naïve for nurses to ignore the impact of patients' offending on the personal beliefs of the nurse, and subsequently on the nurse-patient relationship" (p. 28). Clearly, some patients and clients possess characteristics that could easily provoke negative responses in their caregivers. Not all patients are likeable, easy to care for, and appreciative of nurses' efforts to provide care (Maeve, 1997; Maeve, & Vaughn, 2001). The potential for manipulation is very real in forensic and correctional nursing. Some individuals in correctional facilities may attempt to manipulate health-care services for some secondary gain (e.g., medication, escape from the facility, social diversion), and issues pertaining to safety cannot be ignored (Brewer & Nelms, 2000; Flanagan & Flanagan, 2002).

Patients and clients may also be disrespectful towards nurses and engage in their own othering activities. For instance, they may view nurses as part of a much-hated system and refer to them using derogatory terms that are usually reserved for correctional officers, such as "screw" or "bull." Worse yet, serial offenders may other the nurse as their next victim, in which case the nurse may engage in intentional othering for self-protective purposes. And, similar to the use of aberrant humour in stressful clinical situations, othering might be used as a means of coping with the accumulation of fear, pain, or horror resulting from exposure to difficult clinical situations. Finally, othering may be a call for help, particularly if enacted by a nurse who is usually seen as a patient advocate (Sayre, 2001).

Impact of Othering on the Therapeutic Relationship

Othering can have an enormous impact on the therapeutic relationship and ultimately on the quality of care received by patients and clients. It has a direct impact on the creation and maintenance of the therapeutic relationship (Evans, 2000; Peternelj-Taylor & Johnson, 1995). It may result in care that is not individualized, that is less than optimally supportive, or that does not take the patient or client's psychosocial needs into account (Corley & Goren, 1998). It may also result in care providers being "under-involved" (Peternelj-Taylor, 2002) or may lead to misrepresentation of individuals through oppression (MacCallum, 2002). When the forces of othering are at play, nurses are less likely to explore concerns that have been raised or to take the time to conduct the thorough assessments that are necessary before appropriate interventions can be administered (Blair, 2000).

Engaging the Other

In Holmes and Federman's (2003) study with nurses working in a correctional psychiatric unit, the nurses began to question whether they were still practising nursing, as they believed they had surrendered their professional ideals to those of the institution. As a way of coping with this realization, some nurses "reconstructed" their care, treating their clients as individuals in need of care rather than as "monsters." The authors found, however, that this care was, in general, provided without the tacit knowledge or sanction of nursing peers or correctional staff. In exercising their professional identity and relating to patients as fellow human beings, nurses may excite the wrath of other nurses or, more likely, the correctional staff, who might see such attempts at engaging the other empathically as their downfall (Maeve, 1997). Even though such practices as treating people like human beings may be adopted for the noblest of reasons, if carried out in isolation they can cause great consternation among team members and contribute to division within the team, as well as invite excessive scrutiny of one's nursing practice. Moreover, practising in isolation from the team is dangerous and can lead to boundary transgressions. The creation and maintenance of treatment boundaries is critical to safe and effective clinical interventions. Communication among nurses and other team members (including security staff in the case of correctional settings) is vital to safe and professional practice. Clinical work can be particularly demanding and challenging, and nurses need to be able to rely on the support and strength of the team (Peternelj-Taylor, 2002; Peternelj-Taylor & Yonge, 2003).

In her work with incarcerated women, Maeve (1997) concluded that ethical care was achieved through a process of identifying with the women relationally. To gain such an appreciation for the other, nurses must "learn to think about difference in relation to self and Other" (Canales, 2000, p. 29). Similarly, Gadow (1999) states that "the valuing of persons requires special perception of each one's uniqueness, and perception involves engagement" (p. 63).

Othering is grounded in relationship. In nursing we can no longer ignore othering, believing we are immune to its consequences simply because we are nurses. Canales (2000) states that in order to avoid the negative consequences of othering nurses must be able to assume the role of the other and view the world from the other's perspective. Bunkers (2003) suggests that by "acting with a spirit of hospitality" (p. 308) nurses can come to comprehend the other's experiences without judging or labelling. This notion of role-taking, or engaging the other in a spirit of hospitality, is a tall order for forensic and correctional nurses, especially considering that many of their patients have committed horrid, grievous crimes. Can a nurse empathize with a person who has committed a violent sexual offence, or a person who has invaded the home of an innocent family and robbed them of their sense of security, let alone their worldly possessions? Maeve (1997) reports that nurses often try to make sense of their role by acknowledging their own vulnerabilities, as reflected in their personal disclosures: "At another time in my life this could have been me, or someone I love" (p. 505). Through role-taking, "persons can come to know and understand the Other and interact based on these understandings" (Canales, p. 26).

To understand the other is to understand the failure of multiple systems to address issues of poverty, interpersonal violence, substance abuse, criminalization of the mentally ill, and lack of access to adequate health care (Peternelj-Taylor, 2003). To understand the other, nurses must be politically astute, capable of influencing social policies and effecting social change (Canales, 2000).

Emerging Recommendations

How nurses relate to those in their care is fundamental to their ability to establish therapeutic relationships and to resist the temptation to engage in othering behaviours. Nurses should advocate for the consistent use of professional language in their interactions with individuals seeking health care, and, when working with persons with mental illness, refer to them as individuals and avoid the use of pejorative labels. The advocacy role in forensic and correctional environments is tenuous at best. It should be endorsed not only by individual nurses but also by the administrative structure of the facility. Lützen and Schreiber (1998) conclude that when nurses lack the support they need to function as patient advocates, the very nature of patient care is compromised. Nurses need to adopt a philosophical stance that views health-care recipients not as problems, or as criminals in the case of forensic or incarcerated patients, but as persons, and they need to seek ways of discovering who they are as individuals (Evans, 2000).

The work of forensic psychiatric and correctional nurses requires careful attention to clinical supervision, education, and training. Their clientele can test even the seasoned veteran; clearly, knowledge and clinical judgement are necessary ingredients for working through clients' challenging behaviours in the context of the therapeutic relationship. Kitzinger and Wilkinson (1996) emphasize the need to listen to others and to create the conditions "under which it is possible to hear the voices of Others 'talking back': to 'us,' over 'us,' regardless of 'us,' to each other, or to other Others" (p. 17). Bunkers (2003) reiterates this point of listening, as manifested in what she calls "true presence" — "how we language our care, our concern, and our honoring of others by the way we move and are still, by the way we speak and are silent" (p. 308).

Concluding Remarks

Othering in forensic and correctional nursing is an ethical concern that faces all nurses working in such settings. Despite the concern that forensic and psychiatric environments are rife with moral and ethical dilemmas, nurses have been more or less silent on matters pertaining to exclusionary othering in their professional roles. Conversely, engaging in inclusionary othering provides opportunities for nurses to understand the other's story (Bunkers, 2003) and to learn about themselves. It is through such engagement that othering can lead to empowering and transformative experiences.

Although this analysis of othering represents only a glimpse of how nurses work and care for individuals in forensic and correctional environments, it may challenge nurses to situate themselves within this dialogue as they reflect upon, relate to, and refute othering, and in so doing be better positioned to work in a competent and ethical manner with individuals who have come into conflict with the law.

Because this exploration of othering is still in its infancy, fundamental questions remain unanswered. Does othering, as described herein, unequivocally have a negative impact on the quality of care provided to patients and clients? Does language in essence construct reality? Do nurses and other health-care professionals blame correctional staff for their othering behaviours, thereby negating the need to look at themselves and their professional and ethical responsibilities? Can the suggested strategies for engaging the other be applied in forensic and correctional settings, given the nature of the clientele and given the interpersonal climate? Does othering lead to moral distress for nurses? What impact does the nurse's philosophy regarding crime and punishment have on nursing care within forensic and correctional settings? Will nurses' attempts at inclusionary othering be thwarted by administrators and correctional staff and be perceived as over-involvements and boundary violations?

Nurses represent the largest group of health-care professionals working in forensic psychiatric and correctional settings. Clearly, they have a significant role to play in influencing the health and well-being of those in their care, by providing health care in a competent and ethical manner. In the final analysis, nurses who practise from a position of ethical integrity "see human possibilities where others see no hope. Thus power is born when caring others value another and believe in human potential" (Zerwekh, 2000, p. 60).

I have long contemplated issues that affect the development of therapeutic relationships in nursing practice, regardless of the practice setting or the presenting problems of those seeking care. Forensic psychiatric and correctional settings may be considered hotbeds of othering, and it may well be that othering needs to be explored as a form of countertransference. Nonetheless, when I am being completely honest with myself I know that I too am guilty of othering in aspects of my personal and professional life. It is through such personal revelations that I humbly engage in personal character building. Moreover, it is in such moments that my personal vulnerabilities and frailties prevail — for I too am the other.

References

Adshead, G. (2000). Care or custody? Ethical dilemmas in forensic psychiatry. *Journal of Medical Ethics, 26,* 302–304.

Austin, W. (2001). Relational ethics in forensic psychiatric settings. *Journal of Psychosocial Nursing, 39*(9), 12–17.

Blair, P. (2000). Improving nursing practice in correctional settings. *Journal of Nursing Law, 7*(2), 19–30.

Brewer, M. K., & Nelms, T. P. (2000). A Heideggerian hermeneutic study of correctional nurses' experience of caregiving. *International Journal for Human Caring, 4*(1), 23–29.

Bunkers, S. S. (2003). Understanding the stranger. *Nursing Science Quarterly, 16*(4), 305–309.

Canales, M. K. (2000). Othering: Toward an understanding of difference. *Advances in Nursing Science, 22*(4), 16–31.

Carabine, J. (1996). Questioning representing the other. In S. Wilkinson & C. Kitzinger (Eds.), *Representing the other: A feminism and psychology reader* (pp. 165–169). London: Sage.

Chaloner, C. (2000). Ethics and morality. In C. Chaloner & M. Coffey (Eds.), *Forensic mental health nursing: Current approaches* (pp. 269–287). Oxford: Blackwell Science.

Corley, M. C., & Goren, S. (1998). The dark side of nursing: Impact of stigmatizing responses on patients. *Scholarly Inquiry for Nursing Practice: An International Journal, 12*(2), 99–118.

Doyle, J. (1998). Prisoners as patients: The experience of delivering mental health nursing care in an Australian prison. *Journal of Psychosocial Nursing and Mental Health Services, 36*(12), 25–29.

Doyle, J. (1999). A qualitative study of factors influencing psychiatric nursing practice in Australian prisons. *Perspectives in Psychiatric Care, 35*(1), 29–35.

Doyle, J. (2001). Forensic nursing: A review of the literature. *Australian Journal of Advanced Nursing, 18*(3), 32–39.

Drake, V. K. (1998). Process, perils, and pitfalls of research in prison. *Issues in Mental Health Nursing, 19,* 41–52.

Droes, N. S. (1994). Correctional nursing practice. *Journal of Community Health Nursing, 11*(4), 201–210.

Evans, M. (2000). The significance of ethical sophistication. *Journal of Psychosocial Nursing and Mental Health Services, 38*(4), 8–13.

Fisher, A. (1995). The ethical problems encountered in psychiatric nursing practice with dangerous mentally ill persons. *Scholarly Inquiry for Nursing Practice: An International Journal, 9*(2), 193–208.

Flanagan, N. A., & Flanagan, T. J. (2002). An analysis of the relationship between job satisfaction and job stress in correctional nurses. *Research in Nursing and Health, 25,* 282–294.

Flaskerud, J. H., & Winslow, B. J. (1998). Conceptualizing vulnerable populations' health-related research. *Nursing Research, 47*(2), 69–78.

Gadow, S. (1999). Relational narrative: The postmodern turn in nursing. *Scholarly Inquiry for Nursing Practice, 13*(1), 57–70.

Holmes, D., & Federman, D. (2003). Constructing monsters: Correctional discourse and nursing practice. *International Journal of Psychiatric Nursing, 8*(1), 942–962.

Horsfall, J. (1999). Towards understanding some complex borderline behaviors. *Journal of Psychiatric and Mental Health Nursing, 6*(6), 425–432.

Kirkham, S. R. (2003). The politics of belonging and intercultural health care. *Western Journal of Nursing Research, 25*(7), 762–780.

Kitzinger, C., & Wilkinson, S. (1996). Theorizing representing the other. In S. Wilkinson & C. Kitzinger (Eds.), *Representing the other: A feminism and psychology reader* (pp. 1–32). London: Sage.

Liaschenko, J. (1994). Making a bridge: The moral work with patients we do not like. *Journal of Palliative Care, 10*(3), 83–89.

Lindeke, L. L., & Block, D. E. (1998). Maintaining professional integrity in the midst of interdisciplinary collaboration. *Nursing Outlook, 46*(5), 213–218.

Lützen, K., & Schreiber, R. (1998). Moral survival in a non-therapeutic environment. *Issues in Mental Health Nursing, 19*(4), 303–315.

MacCallum, E. J. (2002). Othering and psychiatric nursing. *Journal of Psychiatric and Mental Health Nursing, 9*, 87–94.

MacMurray, J. (1961). *Persons in relation.* London: Faber & Faber.

Maeve, M. K. (1997). Nursing practice with incarcerated women: Caring within mandated (sic) alienation. *Issues in Mental Health Nursing, 18,* 495–519.

Maeve, M. K., & Vaughn, M. S. (2001). Nursing with prisoners: The practice of caring, forensic nursing or penal harm nursing? *Advances in Nursing Science, 24*(2), 47–64.

Martin, T. (2001). Something special: Forensic psychiatric nursing. *Journal of Psychiatric and Mental Health Nursing, 8,* 25–32.

Martin, T., & Street, A. F. (2003). Exploring evidence of a therapeutic relationship in forensic psychiatric nursing. *Journal of Psychiatric and Mental Health Nursing, 10*(5), 543–541.

Mitchell, G. J. (2001). Policy, procedure, and routine: Matters of moral influence. *Nursing Science Quarterly, 14*(2), 109–114.

Mitchell, G. J., Feguson-Paré, M., & Richards, J. (2003). Exploring an alternative metaphor for nursing: Relinquishing military images and language. *Canadian Journal of Nursing Leadership, 16*(1), 48–60.

Mohr, W. (1999). Deconstructing the language of psychiatric hospitalization. *Journal of Advanced Nursing, 29*(5), 1052–1059.

Myhrvold, T. (2003). The exclusion of other: Challenges to the ethics of closeness. *Nursing Philosophy, 4,* 33–43.

Nehls, N. (1999). Borderline personality disorder: The voice of patients. *Research in Nursing and Health, 22,* 285–293.

Osborne, O. (1995). Public sector psychosocial nursing. *Journal of Psychosocial Nursing and Mental Health Services, 33*(8), 4–6.

Pearsall, J. (1998). *The new Oxford dictionary of English*. Oxford: Oxford University Press.

Peternelj-Taylor, C. (1999). Forensic psychiatric nursing: The paradox of custody and caring. *Journal of Psychosocial Nursing and Mental Health Services, 37*(9), 9–11.

Peternelj-Taylor, C. (2002). Professional boundaries: A matter of therapeutic integrity. *Journal of Psychosocial Nursing and Mental Health Services, 40*(4), 22–29.

Peternelj-Taylor, C. (2003). Incarceration of vulnerable populations. *Journal of Psychosocial Nursing, 41*(9), 405.

Peternelj-Taylor, C., & Johnson, R. (1995). Serving time: Psychiatric mental health nursing in corrections. *Journal of Psychosocial Nursing and Mental Health Services, 33*(8), 12–19.

Peternelj-Taylor, C., & Yonge, O. (2003). Exploring boundaries in the nurse-client relationship: Professional roles and responsibilities. *Perspectives in Psychiatric Care, 39*(2), 55–56.

Reaume, G. (2002). Lunatic to patient to person: Nomenclature in psychiatric history and the influence of patients' activism in North America. *International Journal of Law and Psychiatry, 25,* 405–426.

Sayre, J. (2001). The use of aberrant medical humor by psychiatric unit staff. *Issues in Mental Health Nursing, 22,* 669–689.

Scheela, R. A. (1999). A nurse's experiences working with sex offenders. *Journal of Psychosocial Nursing and Mental Health Services, 37*(9), 25–31.

Stevens, P. E. (1998). Response to "The dark side of nursing: Impact of stigmatizing responses on patients." *Scholarly Inquiry for Nursing Practice: An International Journal, 12*(2), 119–122.

Stohr, M. K., Hemmens, C., Kifer, M., & Schoeler, M. (2000). We know it, we just have to do it: Perceptions of ethical work in prisons and jails. *Prison Journal, 80*(2), 126–150.

Strickland, B. R. (2001). Including the other in psychology. *Ethics and Behavior, 11*(4), 365–373.

Swinton, J., & Boyd, J. (2000). Autonomy and personhood: The forensic nurse as a moral agent. In D. Robinson & A. Kettles (Eds.), *Forensic nursing and multidisciplinary care of the mentally disordered offender* (pp. 128–141). London: Jessica Kingsley.

Varcoe, C. (2004). Widening the scope of ethical theory, practice and policy: Violence against women as an illustration. In J. L. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (pp. 414–432). Toronto: Pearson/Prentice-Hall.

Weinberger, L. E., & Screenivasan, S. (1994). Ethical and professional conflicts in correctional psychology. *Professional Psychology: Research and Practice, 25*(2), 161–167.

Zerwekh, J.V. (2000). Caring on the ragged edge: Nursing persons who are disenfranchised. *Advances in Nursing Science, 22*(4), 47–61.

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Résumé

Les soins spirituels à la jonction de la religion, la culture et l'État

**Sheryl Reimer Kirkham, Barbara Pesut,
Heather Meyerhoff et Rick Sawatzky**

En réponse à une diversité sociale croissante parmi les bénéficiaires de soins de santé, les infirmier(ière)s-chercheur(euse)s ont tourné leur attention vers l'élaboration de fondements théoriques qui permettront de mettre en place des pratiques infirmières respectueuses des croyances spirituelles. Toutefois, malgré la possibilité d'harmoniser ces deux volets, il existe peu de recherches portant sur les intersections potentielles entre culture et spiritualité. Les auteur(e)s présentent les résultats d'une étude pilote axée sur la description interprétative qui a pour objectif l'examen des contextes dans lesquels a lieu la prestation de soins spirituels interculturels, selon la perspective des infirmières, des infirmiers et des aumôniers. Les résultats révèlent des besoins qui invitent les professionnels de la santé à cultiver un espace intérieur à partir duquel ils peuvent dispenser des soins spirituels et rechercher des points spirituels communs en présence de diverses croyances et traditions culturelles. Les environnements de pratique actuels et le milieu social inhérent à un État pluraliste et séculier façonnent les dynamiques entourant les soins spirituels. Les résultats indiquent la nécessité de mener une analyse critique postcoloniale des conceptions contemporaines de la spiritualité et des soins spirituels, et de remettre en question la tendance à éliminer l'importance des *credos* dans la quête d'une expérience spirituelle universelle.

Mots clés : spiritualité, soins spirituels, religion, culture, ethnique, diversité, postcoloniale, description interprétative

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Spiritual Caregiving at the Juncture of Religion, Culture, and State

**Sheryl Reimer Kirkham, Barbara Pesut,
Heather Meyerhoff, and Rick Sawatzky**

In response to the increasing social diversity of health-care recipients, nurse scholars have turned their attention to developing theoretical foundations for culturally responsive and spiritually sensitive nursing practice. However, despite the potential overlap between these 2 areas, there has been little exploration of the intersections between culture and spirituality. The authors present the findings of an interpretive descriptive pilot study that examined the contexts of intercultural spiritual caregiving from the perspectives of nurses and chaplains. The findings point to the need for health-care professionals to cultivate an internal space in which to provide spiritual care and to seek spiritual points of connection amidst diverse faith and cultural traditions. The contexts of current practice environments, as well as the social setting of a pluralistic and secular state, shape the dynamics of spiritual caregiving. The findings invite postcolonial, critical analyses of contemporary conceptions of spirituality and spiritual caregiving, and call for a rethinking of the trend towards de-emphasizing creedal religions in the quest for a universal spiritual experience.

Keywords: spirituality, spiritual caregiving, religion, culture, ethnicity, diversity, postcolonialism, interpretive description

As our societies become increasingly diverse, the nursing profession is faced with new challenges across its practice and scholarship domains. To support nurses in the provision of care across a breadth of ethnic, religious, gender, class, and sexual orientation diversity, significant attention has been directed to the areas of culture and spirituality over the past decade or two. Building on the ground-breaking work of Madeleine Leininger, and more recent theoretical influences in critical traditions such as postcolonialism and feminism, a rich body of nursing scholarship has developed to address culture, race, and ethnicity in health care. At the same time, the nursing profession has renewed its commitment to the integration of spirituality and spiritual caregiving, with a burgeoning scholarship base demonstrating a desire for a more universal approach to things spiritual. Yet despite these two growing fields addressing diversity within health care, there has been relatively little substantive exploration of the intersections between these areas of scholarship. In this paper, drawing on a pilot study examining the contexts of intercultural spiritual caregiving, we focus on the borderlands between spirituality, religion, culture, and ethnicity.

Background

The purpose of this study was to explore the moral dilemmas faced by nurses and chaplains in the context of intercultural spiritual caregiving and to increase our understanding of how these encounters are shaped by social context. To set the background for the study, we present the demographic diversity of Canadian society. We then discuss two theoretical trends in nursing that have emerged in response to that diversity: that of replacing religion with a more generic and universal spirituality, and that of conflating religion with culture and ethnicity.

Demographic Profile of Canadian Society

With the rise in global migration, cities around the world are becoming increasingly pluralistic. In the geographic area of this study, for instance, recent census data reveal over 80 language groups (Statistics Canada, 2001). As in other Canadian centres, more people reported a language other than English or French as their mother tongue than did in the previous census (1996), yet more citizens referred to themselves as "Canadian," challenging the longstanding construction of Canada as white and English- or French-speaking. In the province where this study was conducted, visible minorities account for 22% (a number rising to 37% in the urban setting of the study) of the total population, although this is well above the national average. Adding to the diversity of Canada's population, the Aboriginal population is also expanding, accounting for 3.3% of the nation's population in 2001 (up 22% from 1996).

Along with this broadening ethnocultural diversity comes a shift in religious affiliation. Although 7 out of 10 Canadians still identify themselves, in recent census data, as Roman Catholic or Protestant, the number of Canadians who report religions such as Islam, Hinduism, Sikhism, and Buddhism has increased substantially. Statistics Canada (2003) explains that "much of the shift in the nation's religious makeup during the past several decades is the result of changing sources of immigrants, which has created a more diverse religious profile." Whereas earlier immigrants came predominantly from Europe, today's immigrants are most likely to come from Asia. Additionally, more Canadians (16%) report that they have no religious affiliation. Bibby (1993), a Canadian sociologist of religion, suggests that while association with formalized religion may be declining, a more personalized spirituality is flourishing. Canadians are also becoming increasingly concerned about religion as a potential source of social conflict (Montgomery, 2004).

Distinguishing Between Religion and Spirituality

Over the past several decades there has been a trend within nursing theory to separate religion from spirituality and to make spirituality the legitimate focus of nursing care. In 1987 Lane explored care of the human spirit and suggested there were two types of care, one that was dependent upon the beliefs and needs of the patient, typically those associated with religious affiliation, and one that applied to all patients. This second form transcended particular belief systems to encompass universal acts of care. These acts were typically sacrificial and characterized by "inward turning, surrendering, committing and struggling" (Lane, 1987, p. 334). Building on this line of differentiation, scholars such as Burkhardt (1989) and Emblen (1992) concluded that religion and spirituality are distinct yet related concepts. They characterized religion as a rational belief system with certain worship practices, whereas they characterized spirituality in terms of mysteriousness, transcendence, and connectedness. At the same time, Reed (1992) was making an argument for a broad understanding of spirituality as part of the foundational ontology of nursing. She claimed that nursing was moving beyond the positivistic, materialistic worldview to embrace the dimensions of humanity related to connectedness, transcendence, and meaning — the characteristics of spirituality. Over the past decade a number of other analyses have treated spirituality and religion as either discrete or hierarchal concepts whereby religion becomes an optional element of spirituality (e.g., Dyson, Cobb, & Forman, 1997; Goddard, 1995; Long, 1997; McSherry & Draper, 1998).

This separation of religion from spirituality in nursing discourse may be related to the changing role of religion in society. Pre-modern societies were based primarily in religion, which provided both legitimacy and meaning to existence. Modernity saw primary legitimacy move from religion to science (Armstrong, 1993; Henery, 2003). This change was clearly reflected in nursing theory, where little was written about the religious dimension of care. Postmodernism has challenged the worldviews of both theism and science, creating a worldview characterized by pluralism and relativism. Within this worldview, spirituality is in large part considered intensely personal and based upon the assumption that all spiritualities are equally valid and true (Salladay, 2000). This perspective promises benefits for nursing practice by offering a conceptual lens through which to provide spiritual care within a context of diversity.

Emerging definitions of spirituality have not been without criticism. Dawson (1997), in reaction to Goddard's (1995) definition of spirituality as integrative energy, argues that this definition has stripped spirituality of its social and historical context, removing much of its meaning.

Henery (2003) views the trend of trying to separate religion from spirituality as one that reconstructs spirituality as religious or scientific discourse. He illustrates that many of the emerging definitions remain highly value laden and create a new religion that lacks the moral and conceptual substance of traditional theologies.

Given such controversy, key questions remain regarding the implementation of this conceptual separation. Does separating religion from spirituality and universalizing the concept of spirituality make spiritual nursing care easier to implement, particularly in the face of diversity? Are current definitions of spirituality congruent with how patients and caregivers define their spirituality? Most importantly in the context of this study, how would this separation be viewed from various cultural perspectives? Would it be seen as a worthy distinction, or simply as a dichotomous product of Western, secularized society? Wright (2002) raises the question of whether spiritual care is transferable across cultures and faiths. Certainly, our constructions of spirituality and religion have the potential to influence that transferability.

Subsuming Religion Under Culture and Ethnicity

Nursing scholarship, influenced by anthropological and sociological perspectives, has tended to subsume religion under the umbrella of culture. From this stance, all cultures are seen to have important religious aspects, and, therefore, to understand ethnic or cultural identity, one must take into account religious identity. Davidhizar, Bechtel, and Cosey (2000), for example, state that "religious practices are usually rooted in culture, and each culture typically has a set of beliefs that define health and the behaviours that prevent or treat illness" (p. 24). Informed by such anthropological views, nursing literature has tended towards descriptions of circumscribed cultural-religious practices, often at the expense of critical analyses of the social, historical, economic, and political contexts in which spiritual and/or religious beliefs are held.

Along with critiques of predominantly culturalist theorizing in nursing (see, for instance, Culley, 1996), several specific concerns arise from the conflation of religion and culture. Close linkages between culture and religion result in essentialist tendencies in which assumptions are made such that ethnocultural affiliation determines religious orientation. Although certain ethnocultural groups tend to affiliate with particular religions, there are always exceptions (e.g., not all Arabic people are Islamic). Moreover, significant variations in beliefs and practices exist within each religious group. Identity politics are such that one's affiliation with any particular group, whether ethnic or religious, shifts over time and context. A broad brush that subsumes religion as a dimension of culture tends not to differentiate specific spiritual care issues, and may leave nurses bereft of direction in situations of spiritual need. This is particularly the case in liberal-democratic states such as Canada that have secularized public life so that the role of religion/spirituality in public life has been de-emphasized. Conversely, cultural meanings may be lost or attributed to religious affiliation. For example, Narayanasamy and Andrews (2000) recount a situation in which a focus on the religious needs of Muslims overlooks cultural aspects of care that can be of equal importance. Undoubtedly, considerable overlap exists between culture and both religion and spirituality. Our intention here is not to deny this relationship but, rather, to call for more careful conceptual unpacking of this intersection in order to reach a clearer understanding of the implications of conflating one with the other.

The critical traditions of postcolonialism and cultural studies, offering analytic mileage in uncovering damaging effects of race in everyday health care and accounting for intersecting and historical oppressions, serve as more recent theoretical influences on nursing scholarship (Anderson, 2000, 2002; Browne & Smye, 2002; Reimer Kirkham & Anderson, 2002). However, postcolonialism has tended to write out religion, naming it as an instrument of colonialism but offering little analysis of the confluences of religion, state, and ethnicity. A notable exception is the work of Stuart Hall, who provides a postcolonial commentary on religion, citing its political influence:

> In one historical-social formation after another, religion has been bound up in particular ways, wired up very directly as the cultural and ideological underpinning of a particular structure of power. …religion is not free-floating. It exists historically in a particular formation, anchored very directly in a number of different forces… Its meaning — political and ideological — comes precisely from its position within a formation…these are not inevitable articulations.…They can potentially be transformed, so that religion can be articulated in more than one way. (cited in Morley & Chen, 1996, p. 142)

Hall recognizes the contradictory nature of religion within colonial contexts, using the example of missionaries helping the same Jamaicans whose enslavement the church previously sanctioned. Such work signals that a postcolonial reading may offer important insights into the realm of spirituality and health care. Overall, the lack of critical conversation at the intersections of religion, spirituality, culture, and ethnicity has resulted in a dearth of theoretical work to draw upon in the examination of intercultural spiritual caregiving. Yet real practice dilemmas face nurses and other health-care workers as they seek to meet the spiritual needs of patients from a range of ethnocultural backgrounds.

Clinical issues at the intersection of religion and culture became visible in an earlier critical ethnography exploring the social organization of intergroup health-care provision (Reimer Kirkham, 2000, 2003) in which nurses told of distressing situations related to spiritual and religious matters, especially in the realm of care at death (e.g., facilitating grieving, death rituals). This finding raised the question of intercultural spiritual caregiving and prompted an extensive literature search. A growing body of prescriptive literature was retrieved, with less empirical evidence pertaining to intercultural spiritual caregiving. McSherry and Ross (2002) explicate the dilemmas inherent in spiritual assessment. Various barriers have been identified. These include demanding workloads that prohibit spiritual caregiving, the perception of spiritual caregiving as low priority, insufficient education in spiritual caregiving, lack of confidence, differences in faith between patient and nurse, and confusion over the distinction between proselytizing and providing spiritual care (Narayanasamy & Owens, 2001; Vance, 2001; Van Dover & Bacon, 2001). The diversity of Canadian society and the trends within nursing to separate religion from spirituality and to subsume religion under culture and ethnicity formed the background for this study. We were particularly interested in how the intersection of these important concepts played out in intercultural encounters within health care.

The Study

The purpose of the study was to explore moral dilemmas faced by nurses and chaplains in intercultural spiritual caregiving, and how these moral dilemmas are shaped by social context. The research questions were: *How do nurses and chaplains describe spirituality and spiritual care? How do they provide spiritual care in intercultural situations? How do they provide spiritual care to someone who does not share their spiritual and/or religious beliefs? What contextual factors influence intercultural spiritual caregiving?*

As a pilot study, this project forms the basis of a larger ethnographic study examining religious plurality in health care. The interpretive descriptive method developed by Thorne, Reimer Kirkham, and MacDonald-Emes (1997) was employed. The base of interpretive description is the smaller-scale qualitative investigation of a clinical phenomenon of interest to the discipline of nursing. The method provides "direction in the creation of an interpretive account that is generated on the basis of informed questioning, using techniques of reflective, critical examination, and which will ultimately guide and inform disciplinary thought in some manner" (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004, p. 6).

Persons were invited to participate on the basis of their known expertise and/or commitment to spiritual caregiving. Four nurses (three female, one male) and two chaplains (one male, one female) were interviewed. Although representing various denominations (e.g., Catholicism and mainstream and evangelical Protestantism), all of the participants self-identified as holding to the broader Christian tradition. The participants were all English-speaking Canadians but reported various cultural heritages. Following approval by the Institutional Review Board, informed consent was obtained from each participant. Interviews were conducted by the principal investigator in various locations identified as "convenient" by the participants (e.g., cafés, homes, workplaces). These interviews were guided by broad open-ended questions such as "How do you understand spiritual care?" "How do you provide spiritual care in intercultural situations?" All interviews were audiotaped and transcribed. A follow-up focus-group interview with the same participants was used to validate meanings and extend the discussion. Each investigator coded the transcripts using a mutually agreed upon code book, and main themes emerging from the data were synthesized into a thematic framework representing the whole.

Strategies for ensuring trustworthiness of the data-collection and analysis processes involved triangulation of theoretical schemes (Lather, 1991), reflexivity (enhanced through field notes), and member checking in which emerging analytical structures were discussed in a follow-up focus-group meeting with participants. Construct validity (Lather) was sought through repeated immersion in the data while grounding analyses in the above-mentioned theoretical perspectives, thus maintaining a dialectic between theory and research. Detailed notes recorded during group analysis served as an auditable decision trail.

Limitations of the study include those intrinsic to self-report and a small non-representative sample. We also acknowledge dangers stemming from our position as researchers, particularly as our Christian affiliations lent to a reading of data from the perspective of a shared lens. To counter these limitations, we engaged in reflexive application of various theoretical perspectives, including those of postcolonialism, philosophy, and theology. This reflexivity prompted us to continuously evaluate our interpretations through these various theoretical lenses. Postcolonialism, for example, alerted us to the possibility that our analysis might be inscribed by dominant Western interpretations of spirituality.

Findings

The central question of this study — What are the moral dilemmas faced by nurses engaged in intercultural spiritual caregiving? — served as the basis for our initial analysis. As the study progressed, however, the theme of moral dilemma became less central as we struggled to understand how culture, spirituality, and spiritual caregiving are constructed, and what contextual factors and philosophical positions influence these constructions. Indeed, this illustrates how challenging it can be to construct spirituality and culture or to differentiate these concepts from religion except in a purely theoretical sense. Although we present our findings using personal, interpersonal, institutional, and sociopolitical levels as the organizing framework, we seek an integrated understanding of how everyday person-to-person encounters are shaped by larger social processes.

Personal Context: Cultivating an Internal Space for Spiritual Caregiving

All of the participants identified the importance of the internal space of the caregiver to the effectiveness of spiritual caregiving encounters. This internal space had certain characteristics such as a posture of learning, a willingness to connect, and a level of comfort with things spiritual. However, creating this space was often portrayed as challenging, risky work in which caregivers were forced to confront their own conflicting beliefs and agendas.

Participants spoke of an evolving level of comfort with what they referred to as spiritual issues. One participant recounted an experience she had had as a new graduate that opened the door to the possibility of spiritual caregiving and enabled her to feel more confident with this sensitive topic:

> *There was a young boy who was 17 and he was dying of leukemia. One night he just couldn't sleep. We sat down and we were talking about death, dying, and heaven and what his beliefs were. And it was a really, really wonderful, wonderful night.*

Thus, there needed to be a determination that spiritual caregiving was a legitimate part of the nursing role. Once that decision was made, nurses needed to make it a part of their routine consideration. Several participants spoke of the importance of keeping spiritual caregiving foremost in their minds as they went about their day. When spiritual caregiving was understood as integrated into the day-to-day care of the patient, as one participant pointed out, careful listening to cues would often provide an opportunity for further exploration of spiritual matters:

> *As a nurse, I think the first step has to be something at the forefront of your mind. So if you're coming in to look after a patient, it is not so much about asking but being aware in yourself. So that when those kinds of things come up in conversation, whether a feeling of anxiety about something or not feeling support, these are windows of opportunity.*

This comment reflects the importance of the nurse's own positioning and self-awareness as a precondition to reading the cues a patient might provide.

Beyond the holding of the consciousness of spirituality, participants spoke of cultivating an attitude that allowed them to enter what one referred to as the "god space":

> *In many different ways I am a healer, and I'm not up here looking down on you who's weak and in the bed, and you have nothing to offer me. But it's now I'm a healer and if I'm open, and I'm honest, and I'm vulnerable to you, then that will again create sort of a god space. We're two human beings and we're struggling in different ways. But I have something in common with you. To realize that in fact…they were becoming a healer for me.*

This statement reveals that a caregiver's openness, vulnerability, and desire to genuinely understand the beliefs of another facilitate connection and exchange. Overall, it meant being comfortable with things spiritual, shaped by one's own sense of meaning, experiences of transcendence, and/or religious beliefs. Interestingly, one participant eloquently expressed the belief that this level of comfort could also be achieved through education.

One theme that emerged was that of addressing personal fears, agendas, and motivations. To engage with others, one had to be willing to take risks, such as being seen as interfering or as imposing one's views. Personal agendas were particularly challenging from the perspective of the evangelical worldview. Participants reflected on how they came to terms with the larger evangelical agenda of proselytizing (e.g., "sharing the good news") and their awareness of this as crossing professional boundaries. Caregivers spoke of considering the potential of harming the patient. They imagined themselves in a vulnerable position in a society where different beliefs prevailed and wondered how they might feel. For some, this fear was so strong that they had avoided the subject of spirituality altogether with their patients. One participant thoughtfully reflected on her longstanding relationship with a Thai family:

> *I'm so careful about not transgressing professional boundaries. Since she hadn't brought it up, I hadn't. The way I approached it is if I can build enough trust that they'll bring it up, then I'm happy to talk about it and encourage them to talk about it. But I'm not going to bring it up. I've been too paralyzed by these fears of imposing my religion. …being so respectful that you avoid the subject.*

This participant realized, however, that because of her guarded approach she was missing an entire dimension of her patients' lives. When she tactfully brought up the topic, the client "opened like a flower; she wanted to talk about it." A rich spiritual relationship ensued. Thus, while the fear of imposition represented a moral dilemma for the participant, by reframing her understanding of spirituality and spiritual caregiving she came to a place where she had the freedom to address spirituality in client-sensitive ways.

Another participant spoke of redefining spiritual care, from talking about God and the Bible to being an authentic "listening presence" of god for the person; she found it hard work to remain conscious of that:

> *The challenge and the discipline of that was to go in and leave my own self outside the door, just walk in, available…it's discipline and hard work to really be in tune. You leave the room realizing if you believed your traditional things, I didn't provide spiritual care because we didn't talk about God, read any Bible verses, and I didn't even pray with him. So how did I provide spiritual care? Well, I was aware of his spirituality. I was present for him.*

For this particular caregiver, internal reframing entailed cultivating an awareness that God was at work beyond her ability, and that work was often mysterious and surprising.

In summary, participants described a conscious internal context, characterized by connectedness, learning, and an ease with things spiritual. The development of this context required one to confront personal agendas and motivations and come to terms with how they fit into the context of a pluralistic society.

Interpersonal Encounters: Narratives of Connection

Spiritual caregiving as essentially relational in nature was another theme, one that is in keeping with a construction of spiritual caregiving as primarily a matter of "being" rather than "doing." While specific actions (e.g., facilitating prayer, listening to music with the patient, making referrals to chaplaincy or other spiritual providers) were identified as examples of spiritual caregiving, the data more often revealed spiritual caregiving as a combination of being present, reading cues provided by the patient/family, and creating spaces for spiritual expression. As participants described their evolution through the "work" of valuing and gaining comfort in tending to the spiritual, many of their narratives suggested the centrality of human connectedness in intercultural spiritual caregiving.

Participants emphasized trusting relationships as foundational to spiritual caregiving. One nurse commented: "I don't think I could go into a room and start talking about religion with someone I didn't know. I feel more comfortable doing that with my primary…patients." Another nurse observed: "I don't believe we'll get anywhere near enough to a person to talk about spirituality…because that is probably pretty core for them…unless we build a relationship." Inherent in the need for a pre-existing relationship, then, was the conviction that spirituality can be an intensely private or personal aspect of a person, one that cannot be tapped into without trust and caring. Other participants, particularly chaplains, recounted situations in which they did not have an opportunity to develop a relationship with the patient and had to "go in cold." In such situations, they paid close attention to the patient's cues and sought to follow the patient's agenda or expectations.

Participants told powerful stories of connecting with clients through the dimension of spirituality. The theme of seeking common ground was evident in a range of situations. In the context of caring for patients with chemical dependencies ("drug abusers, alcoholics"), one participant spoke to the importance of "finding that common ground." Another nurse, reflecting on her relationship with a Thai family, observed that "true spirituality cuts across all these barriers." She understood spirituality as a point of connection with her patients, regardless of their religious or spiritual affiliations. This connection is aptly reflected in her description of a visit to the home of a Sikh woman:

> *I feel I have a spiritual bond with many of the Sikh and Punjabi patients — they are so devout. When I come to a woman's house and I know that she has had a prayer shawl over her head and then she comes and beckons me, I feel like I'm almost walking on holy ground. And I feel an immediate bond. So I don't feel, oh, you're from a different religion. I admire her devotion and so it's a bond for me. Not such a barrier.*

Such a propensity to seek connections in the face of what might be constructed as a considerable religious difference (between a Sikh and a Christian) reveals a high level of regard for others and an understanding of spirituality as at the core of each person. This same participant had visited various religious/spiritual sites (Sikh temple, First Nations longhouse) at the invitation of clients, which again suggests openness to a range of spiritual traditions.

Connections were facilitated through "presencing," or what one chaplain referred to as the "ministry of presence." As an aspect of presencing, participants described how they created sacred spaces through subtle but intentional movement towards a discussion of things spiritual. A simple question such as "Did the priest come today?" or "It looks like your representative from the Sikh faith was here" could be used as an opportunity to explore a patient's spiritual concerns. The participants also cited the importance of establishing a physical environment conducive to meditation, prayer, or spiritual reflection. One nurse explained: "I'll hear chanting and I'll know it's 7 o'clock — that's prayer time, so I don't disturb them…or you close the curtain so that they have more privacy, that sort of climate."

Participants recognized the challenges, however, in seeking spiritual connection in the face of differences in religious affiliation, language, and cultural identity. As with other dimensions of intercultural care, the issue of language was raised in the context of spiritual caregiving:

> *My experience has been that the faith group they belong to often involves a language barrier and therein is the problem. It is not so much that I wouldn't be there for the person who is experiencing, say, the Baha'i faith, or they are Hindu, or Muslim…. That's not the problem. The problem is frequently the language link.*

Moral dilemmas arose for participants when patients/families held divergent worldviews that resulted in disagreement over treatment options. One participant reflected on a case in which active oncological treatment, including bone marrow transplantation, was withdrawn when the patient, a young man with leukemia, "failed his treatment; his disease came back":

> *His family wanted us to do everything, but we couldn't do that because we have policies laid out. In order to have a bone marrow transplant, you have to go through all of this criteria. It was very difficult. There was a lot of argument. There was a lot of anger and resentment. They would say, "You don't understand." It certainly caused a lot of stress for the nursing staff. Actually, initially we didn't understand why they were acting like this and we had to be told that this was part of the religion that they certainly didn't give up on life.*

This story demonstrates the need for the clear communication of basic values between families and caregivers, and the tension that stems from discrepant values and beliefs. It also speaks to the breadth of knowledge regarding religious and cultural practices required of nurses in today's diverse societies.

Another participant mused about the challenges of providing spiritual care to someone with vastly different beliefs:

> *It would be very difficult if a person, nurse X, has, for the sake of discussion, a fairly conservative Christian position…. This nurse is going to have some real personal struggles if they find out that the patient is Wiccan; the patient says, "I'm a Wiccan, I'm a witch." This witch lying in the bed is dying and is struggling with some issues. What on earth does that nurse do with those sets of values? How do you be there to respect that person when every fibre of your religious orientation says that is what I live in opposition to?*

Participants in this study, then, spoke to the importance of building spiritual connections across worldviews and belief systems, but also recognized the difficulties inherent in such efforts.

Health-Care Context: Workloads, Professional (De)Valuing, and Curative Agendas

Not surprisingly, current practice environments were described as barriers to addressing spiritual matters. Maintaining an awareness of the spiritual dimension was particularly challenging because of the heavy workloads of the nurse caregivers, and the invisibility of the spiritual domain within biomedical agendas and secular culture.

Participants spoke of the amount of time and energy it takes to perform basic physical care and the sheer fatigue that could prevent them from engaging with the often emotionally demanding spiritual dimension. One nurse described the priorities embedded within patterns of caregiving:

> *You've got this hideous morning rush that starts at 7 a.m. and doesn't end until 10ish. It is the magical 3 hours during which all nurses, according to the good little books — I'm being sarcastic here — are supposed to have done all of the nice things, the bed baths, make the beds, get them up, get them dressed. Now, in the larger scheme of things, if I don't get three of the patients up and bathed by 10:30 because I've spent some time with the patient meeting spiritual needs, for me that's not a problem. However, one of the problems we have within the context of nursing is that my colleagues might look at me with more than a little disgust. "What the blank blank blank is he doing? I just saw him sitting talking to a patient. Well, doesn't he know we have work to do?"*

As revealed in this comment, nurses might be made to feel irresponsible for engaging in a "non-essential" aspect of care. Nurses and chaplains alike experienced a marginalization of spiritual care. In the words of one participant:

> *It doesn't have that validation stamp, that societal validation stamp. Right now, society, thank goodness, is just now, in the last 5 years, starting to say, yeah, there's a whole area of mental health that is just as legitimate as the broken arm, cut hand. What we have yet to do is take that societal step and say there is a whole spiritual crisis that is just as legitimate as the psychological/physical.*

To counter this devaluing of spiritual matters, participants recommended stronger endorsement of spiritual caregiving by the profession's leaders. This same participant asked, "How many nurses feel [they have] permission from their supervisor, the hospital administration, their own professional association, to pursue spiritual issues with their patients?" Administrative decisions were seen as vital in the valuing or devaluing of spiritual care. For example, the provision of chaplaincy services (delivered by paid or unpaid hospital staff), as evidenced during interdisciplinary rounds, was seen as communicating a valuing of spiritual matters. On the other hand, hospitals that did not have paid chaplaincy but relied on volunteers from the pastoral community were perceived as placing less value on spiritual care.

Participants posited that the spiritual dimension was more visible and attended to in non-acute settings such as the community or palliative care, citing as barriers the overarching curative agenda of biomedicine and the fiscal priorities of today's health-care management. One participant commented on the curative focus of the unit she worked on:

> *You would think spiritual care would be really important on an oncology unit, but surprisingly it's not.... We're so acute, the focus is cure, cure, cure. We're constantly boosting, boosting, boosting. Then, when we have to deal with palliation, we have to change gears quickly... It's weird to sit down and talk.*

This "changing of gears" raises the question of how spirituality is integrated into acute settings, and how spiritual caregiving issues are addressed within curative agendas. Another participant reflected on the potential incongruence between contemporary emphases on evidence-based practice and spiritual caregiving: "The whole realm of faith issues, by their nature, are not always evidence-based. By definition, spiritual matters are intrinsically internal."

A subtext of moral dilemma, sometimes in the form of guilt, was evident as participants reflected on how practice environments mitigated their attending to things of a spiritual nature. Although they were committed to integrating spirituality into their practice, they were constrained by heavy workloads (driven by fiscal agendas), curative foci, and widespread devaluing of the spiritual, leaving them dissatisfied.

Sociopolitical Context: Negotiating Secularism, Pluralism, and Relativism

While significantly shaped by the commitment of each caregiver at the personal level, by the degree of interpersonal connection achieved, and by the demands and agendas of the health-care environment, spiritual caregiving is also influenced by sociopolitical context. In particular, the confluence between secularism and pluralism at the level of state polity entered into the dialogue of this study. Several participants commented on Canada's official position of secularism, noting that this policy prohibits proselytization, or "missionary work," in health-care settings while at the same time fostering pluralistic spiritual/religious expression. One chaplain explained: "It's a public institution. If that man wants the witch doctor, get him the witch doctor. You cannot control a public environment from a specific religious point of view." However, in a pluralistic environment, especially under an official state policy of secularism, the tendency is towards what one participant referred to as "relativizing" religions:

> *There is a tendency in Canada that toleration becomes relativism, that people aren't allowed to be specific people. That is dangerous. What do you do with the Sikh? The Hindu? And with a Jew? You want to relativize them? Make no mistake. You look just at what happens in the world today. There's no way you can relativize religions. You have to respect the particularity of the people you're working with.*

Such comments alert us to the challenges inherent in a society that professes cultural and religious plurality. It may be that in some situations, secularism, rather than opening up space for dialogue, actually constrains open expression of religious/spiritual beliefs. Further, the secularism of Western society may be interpreted as an instrument of assimilation, whereby the role of religion is downplayed and religious distinctions are quietly erased or "relativized."

The exclusion of religion from the state, characteristic of secular societies such as Canada, also intimates that spiritual matters fall within the domain of the personal and therefore may have less relevance in the public administration of health care. Several participants raised the notion of the spiritual as private and, in turn, spiritual caregiving as potentially intrusive. Yet others recognized the political nature of religion:

> *What if a committed Catholic nurse working in Emerg in Dublin [sic] finds herself having to treat an Orangeman who's just come in from a riot? The Orangeman opens his eyes, recognizes he's likely to die shortly. Now this deeply Catholic nurse has to be there spiritually for the person who has just killed her family members or friends. What do we do with that?*

This participant is astutely observing the dangers of assuming an apolitical interpretation of spirituality and religion.

The findings also suggest a pervasive conflation of religion and ethnicity, with the associated tendency towards essentialism and exoticizing of "foreign" beliefs. While the participants acknowledged the range of diversity within the Christian tradition, they made generalizing assumptions about religious groups, such as that all people of Punjabi heritage would be devout believers in the Sikh faith, or that followers of Eastern religions are "more devout." A participant who worked closely with Aboriginal communities observed that although public discourse makes much of indigenous "spiritist" beliefs, this picture may not fit all

Aboriginal peoples. She quoted an Aboriginal woman as asserting, "Christianity is a strong part of our tradition; there's this thought that it is foreign, but as far back as I can remember our family…are Christians." This example highlights the need for a more careful approach to the matter of religious affiliation, and illustrates the non-static, political nature of religious/spiritual affiliations as played out in particular sociohistorical contexts.

Overall, the findings of this study suggest that nurses and health-care providers are caught in the currents of social change as they respond to the diverse spiritual and religious needs of those they care for. The curative emphases of biomedicine and science; the postmodern reawakening of the spiritual; Western ideologies of individualism and secularism; increased global migration; and the inevitable managerialism occurring in the large health-care organizations of our free-market societies all enter into contemporary constructions of spirituality and spiritual caregiving.

Discussion: Constructing Spirituality, Operationalizing Spiritual Caregiving

The issues raised by this study have implications for how we theorize spirituality and operationalize spiritual caregiving within health care. As portrayed in this study, spiritual caregiving, when founded on the belief that all humans are spiritual beings, is capable of crossing boundaries of faith and tradition, serving as a vehicle for intercultural connection in a broader sense. We concur with Wright (2002), who observes that while we must recognize the inherent dangers in ascribing a Western concept of spirituality to other cultures or religions, we ought also to acknowledge the capacity of human beings to make contact with each other through humanitarian gestures such as being present, listening, respecting, and loving. Herein lies considerable potential for interfaith, intercultural community in a pluralistic society. Yet, perhaps more fundamentally, this study raises questions regarding our theorizing of spirituality and religion.

Much is said in the nursing literature about the need to clarify the rather elusive concept of spirituality. With this study, we add our voices to this call for conceptual clarity. At a rudimentary level, the findings echo current tensions in both nursing scholarship and nursing practice: Is spirituality a constituting energy, resulting in a view of spiritual caregiving as integrated into all of what one does as a nurse, or is it a discrete aspect of a larger whole, in which case spiritual caregiving might well be compartmentalized (as is the case when relegated to chaplains, the "spiritual care specialists"). This tension was evident in many of the transcripts.

As researchers, we also found ourselves struggling with such a dichotomy, initially coding specific actions as spiritual caregiving and looking for antecedents and consequences of spiritual caregiving in the data. We soon found this coding structure constraining and difficult to apply, and therefore moved to a broader understanding of spirituality and spiritual caregiving, as integrated into the very essence of all nursing care. Both positions carry implications that require further analysis.

Where one's construction of spirituality falls on this discrete/integrated continuum is influenced in part by the objectivist, material emphases of science that continue to dominate biomedicine. Offering a countering tone to these strong social forces is the postmodern worldview with its criticism of the hegemonic hold of modernism's totalizing discourses. Contemporary nursing scholarship relies substantially on New Age spiritualities associated with postmodernism (see, for example, Watson, 2004) and views spirituality, on paper at least, as an integrated phenomenon. Yet in nursing, as in many other arenas, the gap between theory and practice is such that while spirituality and spiritual caregiving are carefully described in the literature, nurses continue to view spiritual caregiving as a discrete "add on," perhaps the responsibility of a spiritual expert and likely not a priority in the face of the endless demands characteristic of today's practice environments. Thus, a continuum of valuing or (de)valuing spirituality and spiritual caregiving can be roughly traced in conjunction with the integrated/discrete continuum, both of which are shaped by health-care contexts that privilege the scientific agendas of biomedicine and the fiscal constraints characteristic of today's pervasive managerialism.

The findings speaking to the tension between constructions of spirituality as personal/apolitical or public/political also have important ramifications. Nursing scholarship, in emphasizing spirituality as a universal phenomenon with its myriad individual expressions, rather than religion with its formalized institutions, attempts to transcend ideological and theological differences among religious groups, thereby establishing a common ground for discussion. But where the lens of spirituality in our theorizing has succeeded in opening a space for the re-entry of the immaterial — the spiritual — into our discourse, we run into danger when it closes the door on a whole range of religious expressions. It could be argued that nursing's turn towards spirituality as a universal phenomenon and its de-emphasis on religion has the inadvertent, paradoxical effect of writing out groups of people, many of them from non-Western, non-English-speaking backgrounds, who see their spirituality as integrally linked to creedal religion. With both Christianity and Islam growing quickly in developing countries, more migrants coming to Canada carry strong religious affiliations. Religion, as a fundamentally social phenomenon, is intensely political, rooted in long histories of conquest, domination, and diaspora. These histories continue to penetrate the religious/spiritual experiences of many. While some leave behind institutionalized religion on account of these histories and seek spirituality outside of religion, others hold to their faith traditions. To move our theory exclusively towards spirituality is to risk being profoundly apolitical, in essence failing to understand people's lives contextually at a time when religion is deeply political, and increasingly racialized. If we agree with spiritual leaders such as Rabbi Michael Lerner (2002) and Matthew Fox (2000), that spirituality is experienced within and outside of religion, then we need to situate our theorizing across this grid of religious influence, not solely outside the realm of religion.

Assumptions about a secular society and the erasure of creedal religions from much of our nursing theorizing on spirituality may be "read" as a form of imposition by affiliates of such religions. However, this distancing from religion is only partial, in that religious traditions, particularly Christian ones, continue to deeply influence how spirituality is constructed. A review of our interview data and our analytic notes reveals that participants, in describing spiritual caregiving, relied heavily on Christian images. This dominant reference point raises further questions about how nurses interpret cues to spiritual need. Similarly, accounts such as that of the Christian nurse who connected with the Sikh woman in her prayer shawl illustrate an ambiguous position of openness to shared spirituality (ecumenism) while reproducing Western discourses of spirituality/religion as primarily personal and within the realm of the private. Our call, then, is for a re-evaluation of current nursing scholarship with an eye to unpacking the inscription of Western constructions of religion and spirituality onto spiritual experiences, while continuing to acknowledge the very real and often political role that, for many, religion plays in the everyday experiences of spirituality.

A handful of scholars offer similar cautions. Markham (1998) observes that all multifaith traditions may not identify with the term or share the same definition of spirituality, noting that the manner in which spirituality is being developed within health care is a secular version of Judeo-Christian spirituality, thereby running the risk of offending. Wright (2002) explains that Western definitions of personhood construct the person as individualized, intentional, the locus of thought, action, and belief. These ideas resonate with the notions that spirituality is about seeing the individual as a unique person, discovering the purpose of one's life, internal values, and a religious set of beliefs. In contrast, Eastern pantheist traditions view the spirit as non-local, timeless, spaceless, and immortal, and the world as a single interconnected entity with spirituality being synonymous with the forces of nature (Greenstreet, 1999).

Thus, while we have expanded our conceptions of spirituality to extend beyond religion, we question whether nursing scholarship has remained firmly rooted in Western thought, and whether it is at risk of failing to resonate with today's pluralistic society and further inscribing imperialist histories of Western domination.

We have drawn attention to shortcomings in current constructions of spirituality and spiritual care that are exposed in an investigation of the contexts of spiritual caregiving. Our caution is not to abandon development of the concept of spirituality, but rather to theorize spirituality in conjunction with careful analyses of related issues such as dynamics of power, opportunities for social support and identification, and political affiliations associated with religion. The intersection of ethnicity, culture, religion, and spirituality needs to be probed for the sake of conceptual clarity and direction for practice. The results of this study, then, raise questions for future research and underline the need for alternative analytic lenses, including those offered by postcolonial studies and philosophical inquiry, in order to understand the complex terrain at the juncture of religion, spirituality, culture, state, and health care.

References

Anderson, J. (2000). Gender, "race," poverty, health and discourses of health reform in the context of globalization: A postcolonial feminist perspective in policy research. *Nursing Inquiry, 7,* 220–229.

Anderson, J. (2002). Toward a post-colonial feminist methodology in nursing research: Exploring the convergence of post-colonial and black feminist scholarship. *Nurse Researcher: International Journal of Research Methodology in Nursing and Health Care, 9*(3), 7–27.

Armstrong, K. (1993). *A history of God: The 4,000 year quest of Judaism, Christianity and Islam.* New York: Ballantine.

Bibby, R. W. (1993). *Unknown gods: The ongoing story of religion in Canada.* Toronto: Stoddart.

Browne, A. J., & Smye, V. (2002). A postcolonial analysis of health care discourses addressing aboriginal women. *Nurse Researcher, 9*(3), 28–41.

Burkhardt, M. (1989). Spirituality: An analysis of the concept. *Holistic Nursing Practice, 3*(3), 69–77.

Culley, L. (1996). A critique of multiculturalism in health care: The challenge for nurse education. *Journal of Advanced Nursing, 23,* 564–570.

Davidhizar, R., Bechtel, G. A., & Cosey, E. J. (2000). Hospital extra: The spiritual needs of hospitalized patients. *American Journal of Nursing, 100*(7), 24C–D.

Dawson, P. J. (1997). A reply to Goddard's "spirituality as integrative energy." *Journal of Advanced Nursing, 25,* 282–289.

Dyson, J., Cobb, M., & Forman, D. (1997). The meaning of spirituality: A literature review. *Journal of Advanced Nursing, 26,* 1183–1188.

Emblen, J. (1992). Religion and spirituality defined according to current use in nursing literature. *Journal of Professional Nursing, 8*(1), 41–47.

Fox, M. (2000). *One river, many wells: Wisdom springing from global faiths.* New York: Penguin/Putnam.

Goddard, N. C. (1995). Spirituality as integrative energy: A philosophical analysis as requisite precursor to holistic nursing practice. *Journal of Advanced Nursing, 22,* 808–815.

Greenstreet, W. M. (1999). Teaching spirituality in nursing: A literature review. *Nurse Education Today, 19*(8), 649–658.

Henery, N. (2003). Constructions of spirituality in contemporary nursing theory. *Journal of Advanced Nursing, 42*(6), 550–557.

Lane, J. A. (1987). The care of the human spirit. *Journal of Professional Nursing,* November–December, 332–337.

Lather, P. (1991). *Getting smart: Feminist research and pedagogy with/in the postmodern.* New York: Routledge.

Lerner, M. (2002). The state of the spirit. *Tikkum, 17*(3). Available: http://www.tikkun.org/magazine/index.cfm/action/contents/issue/tik0205.html

Long, A. (1997). Nursing: A spiritual perspective. *Nursing Ethics, 4*(6), 496–510.

Markham, I. (1998). Spirituality and world faiths. In M. Cobb & V. Robshaw (Eds.), *The spiritual challenge of health care* (pp. 73–88). Edinburgh: Churchill Livingstone.

McSherry, W., & Draper, P. (1998). The debates emerging from the literature surrounding the concept of spirituality as applied to nursing. *Journal of Advanced Nursing, 27,* 683–691.

McSherry, W., & Ross, L. (2002). Dilemmas of spiritual assessment: Considerations for nursing practice. *Journal of Advanced Nursing, 38*(5), 479–488.

Montgomery, S. (2004, May 8). Religion replaces language as Canadians' sore spot. *Vancouver Sun,* p. A7.

Morley, D., & Chen, K. (1996). *Stuart Hall: Critical dialogues in cultural studies.* London: Routledge.

Narayanasamy, A., & Andrews, A. (2000). The cultural impact of Islam on nursing education. *Nurse Education Today, 7,* 57–64.

Narayanasamy, A., & Owens, J. (2001). A critical incident study of nurses' responses to the spiritual needs of their patients. *Journal of Advanced Nursing, 33*(4), 446–455.

Reed, P. G. (1992). An emerging paradigm for the investigation of spirituality in nursing. *Research in Nursing and Health, 15,* 349–357.

Reimer Kirkham, S. (2000). *"Making sense of difference": Intergroup relations in health care provision.* Unpublished doctoral dissertation, University of British Columbia.

Reimer Kirkham, S. (2003). The politics of belonging and intercultural health care provision. *Western Journal of Nursing Research, 25*(7), 762–780.

Reimer Kirkham, S., & Anderson, J. M. (2002). Postcolonial nursing scholarship: From epistemology to method. *Advances in Nursing Science, 25*(1), 1–17.

Salladay, S. A. (2000). Healing is believing: Postmodernism impacts nursing. *Scientific Review of Alternative Medicine, 4*(1), 39–47.

Statistics Canada. (2001). *Recent immigrants by country of last residence.* Retrieved September 10, 2003, from http://www.statcan.ca/english/PGdb/People/Population

Statistics Canada. (2003). *Overview: Canada still predominantly Roman Catholic and Protestant.* Retrieved September 10, 2003, from http://www12.statcan.ca/english/census01/Products/Analytic/companion/rel/canada.cfm

Thorne, S., Reimer Kirkham, S., & MacDonald-Emes. J. (1997). Interpretive description: A non-categorical alternative for developing nursing knowledge. *Research in Nursing and Health, 20,* 169–177.

Thorne, S., Reimer Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods, 3*(1). Available: http://www.ualberta.ca/~ijqm/english/engframeset.html

Vance, D. (2001). Nurses' attitudes towards spirituality and patient care. *MEDSURG Nursing, 10*(5), 264–168.

Van Dover, L., & Bacon, J. (2001). Spiritual care in nursing practice: A close-up view. *Nursing Forum, 36*(3), 18–30.

Watson, J. (2004). *Caring science as sacred science.* Philadelphia: F. A. Davis.

Wright, M. (2002). The essence of spiritual care: A phenomenological enquiry. *Palliative Medicine, 16,* 125–132.

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Résumé

Homophobie et hétérosexisme dans la prestation des soins contre le cancer : l'expérience des lesbiennes

Christina Sinding, Lisa Barnoff et Pamela Grassau

Cette étude participative et qualitative examine la particularité de l'expérience des lesbiennes en ce qui concerne le cancer et la prestation des soins contre le cancer. On a interviewé 26 lesbiennes sur leur expérience en matière de dépistage du cancer, de traitement et de l'aide qu'elle ont reçue ainsi que sur leurs sentiments et perceptions à propos des changements survenus dans leur identité, leur corps, leur sexualité et leurs relations. Le document montre de quelle façon la manière dont l'homophobie et l'hétérosexisme, dans la pratique actuelle des soins infirmiers et comme élément historique du système de soins de santé, façonnent le vécu des lesbiennes atteintes de cancer. Un petit nombre de participantes a été ciblé, s'est vu refuser des soins courants, ou estime que l'on a pas tenu compte d'aspects de leur identité et de leur contexte social importants pour la prestation des soins contre le cancer. La majorité a souligné que les réalités lesbiennes étaient peu prises en compte dans l'aide psychosociale. Un hétérosexisme résiduel semble déclencher des efforts stratégiques pour éviter l'homophobie et donne lieu à de la gratitude lorsque des soins équitables sont fournis. Les infirmières enseignantes, les médecins praticiens et les décisionnaires ont tous un rôle crucial à jouer en matière d'accessibilité aux soins contre le cancer.

Mots clés : lesbienne, cancer, discrimination, accessibilité aux services de santé

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Homophobia and Heterosexism in Cancer Care: The Experiences of Lesbians

Christina Sinding, Lisa Barnoff, and Pamela Grassau

This participatory, qualitative study examines "what is lesbian" about lesbians' experiences of cancer and cancer care. Twenty-six lesbians were interviewed about their experiences of cancer diagnosis, treatment, and support, and their feelings and perceptions about shifts in identity, body, sexuality, and relationships. This paper highlights how homophobia and heterosexism, in contemporary nursing practice and as historical features of the health-care system, shape the experiences of lesbians with cancer. A minority of participants were targeted, denied standard care, or had aspects of their identity and social context relevant to cancer care dismissed. The majority commented on the lack of attention to lesbian realities in psychosocial support. A legacy of heterosexism appears to prompt strategic efforts to avoid homophobia and also appears to foster gratitude for equitable care. Nurse educators, practitioners, and policy-makers have critical roles to play in the accessibility of cancer care.

Keywords: lesbian, cancer, discrimination, health-services accessibility

Literature Review

Lesbians' risk of cancer is a subject of debate and confusion among health researchers and within lesbian communities. A recent examination of data from the Women's Health Initiative (WHI), a cluster of studies designed to investigate disease outcomes in older women (Matthews et al., 1997), confirms what has long been suspected — lesbian and bisexual women have higher rates of breast cancer than heterosexual women (Valanis et al., 2000).

Valanis and colleagues (2000) link this finding with other data from the WHI, which suggests that lesbians and bisexual women have somewhat higher rates of "risky" health behaviours than heterosexual women (smoking, alcohol use), consume fewer fruits and vegetables, and are more likely to be overweight. Lesbians' lower likelihood of ever having been pregnant is also cited.

Yet the prevalence of cancer among lesbians reported in this study is less than what had been previously suggested, with 5.8% of the "lifetime lesbians" and 7% of the "adult lesbians" reporting having had breast cancer, as compared with 4.9% of the heterosexual women.[1] As well, critics point out that a risk-factor approach often confuses health behaviour (eating vegetables) with identity (being a lesbian) (Yadlon, 1997) and tends to individualize what are essentially social phenomena (Link & Phelan, 1995). Fish and Wilkinson (2003) note that the paucity of research on lesbian health overall makes ascribing socially undesirable characteristics to lesbians as a group problematic.

While studies that link lesbian identity with cancer risk continue to require careful qualification, both the perception of heightened vulnerability to the disease and this new finding of increased prevalence affect lesbians and lesbian communities. Yet there is virtually no research on lesbians' *experiences* of cancer or cancer care (Matthews, Peterman, Delaney, Menard, & Brandenburg, 2002). Our literature review to date has not generated a single published Canadian study.

In a US study, Fobair and colleagues (2001) compared heterosexual and lesbian women's psychosocial responses to a breast-cancer diagnosis. The picture that emerged was "mixed in terms of strengths and vulnerabilities" (p. 47). The lesbians in the study tended not to struggle with body image to the same degree as heterosexual women. They tended not to have the same degree of social support from given families, yet often had broad networks of relationships, "chosen families," from which to draw practical and emotional support.

Importantly, Fobair and colleagues (2001) report that lesbian breast-cancer patients were less satisfied than heterosexual patients with their physicians' care and the inclusion of their partner in discussions about medical treatment. Similarly, Matthews and colleagues (2002), in exploring similarities and differences in lesbian and heterosexual breast-cancer survivors, note that lesbians reported lower satisfaction with care received from physicians, and describe a trend towards lower satisfaction with the availability of emotional support from health-care providers. These findings are consistent with those of several other studies that highlight lesbians' difficult health-care experiences and their worries about interactions with health professionals. In a Health Canada survey of client satisfaction with care received, lesbians reported dissatisfaction across health disciplines (Jalbert, 1999; Ryan, Brotman, & Rowe, 2000). A 1995 province-wide survey of the health and social service needs of sexual minorities in Ontario (Mulé, 1999) highlighted the importance of hospital staff being comfortable in acknowledging a patient's sexual orientation, yet 44% of the respondents who had been hospitalized in the

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[1] The media used the results of a study that mapped lesbians' reported health behaviours onto known cancer risks (Haynes, 1992) to claim that lesbians' lifetime risk for breast cancer was one in three — three times that of women overall.

5 preceding years were uncomfortable being open about their identity. Specifically in relation to nursing, a literature review (Brogan, 1997) concluded that significant numbers of nurses are uncomfortable providing care for lesbians, some even refusing to do so.

The Lesbians and Breast Cancer Research Project (LBCRP) was designed to redress gaps in knowledge in cancer care and clinical literature, and to break the silence in lesbian communities about lesbians' experiences with cancer and cancer care.

Methods

The methodology used in the LBCRP reflected a Participatory Action Research (PAR) model. PAR is "systematic inquiry, with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or affecting social change" (Green et al., 1995). It emphasizes the goal of "liberating oppressed groups through research as praxis" (Gatenby & Humphries, 2000, p. 89) as well as dialogue and collaboration; researchers are positioned not as "separate, neutral academics theorizing about others, but [as] co-researchers or collaborators with people working towards social equality" (Gatenby & Humphries, p. 90).

The LBCRP was undertaken by a Project Team, made up of lesbians directly affected by cancer, along with staff and volunteers at agencies in the cancer, queer, and women's health communities. Members of the Project Team were actively involved in every aspect of the research process.

While the focus of the study was lesbians' experiences of breast cancer, the Project Team speculated early on that lesbians with gynecological cancers might face very similar issues. Both for this reason and to increase the number of potential participants, we recruited lesbians with breast or gynecological cancer. In promotional material, we defined lesbians as women whose primary emotional and sexual relationships were with women.

The study was promoted across Ontario by staff and members of the Project Team (and, eventually, also by the research participants). Posters advertising the study were mailed to key contacts, including agencies listed in a province-wide directory of lesbian and gay resources. E-mail notices were circulated to service and advocacy agencies in the women's health, feminist, queer, and cancer communities. We also asked our personal and professional contacts to transmit the information through their networks. The project attracted media attention across the province, including print, radio, and television. Potential participants were asked to contact the Research Facilitator, either by phone or e-mail, for further information.

Recognizing the diversity that exists among lesbians and aiming to ensure that the study reflected this diversity, the Project Team developed a set of goals that specified the multiple groups of women we hoped to attract as participants. Our intention was to recruit a diversity of women with regard to age, time since diagnosis, geographic location, socio-economic status, race/ethnicity, health status, ability, and family status. To support our diversity goal the Project Team developed specific promotional materials for specific communities (e.g., for lesbians of colour and for lesbians with disabilities).

Interview topics were developed in consultation with the Project Team. Participants were asked about their treatment, their cancer-care and support experiences, and their feelings about any changes in identity, body, sexuality, and relationships. To offer participants a role in defining the scope and the focus of the research, we included the following question in the interview guide: "If you had planned this study, what questions would you have wanted to ask?" Responses to this question largely confirmed our approach, yet where participants suggested new directions (encouraging, for instance, an increased focus on the impact of cancer on partners and children), these were incorporated in subsequent interviews.

Interviews (approximately 90 minutes in length) were audiotaped and transcribed. Face-to-face interviews (17) were conducted at a time and place convenient for participants, either in their homes or in our research unit. Telephone interviews (9) were conducted with participants living at a distance from our research unit in Toronto, at a time convenient to them and when they were in settings where the conversation could happen comfortably and confidentially. A $30 honorarium was provided.

Twenty-six lesbians diagnosed with cancer (22 with breast cancer, three with gynecological cancer, and one with both forms of cancer) were interviewed over an 8-month period. Demographic information can be found in Table 1.

Analysis

Once five interviews had been completed, each member of the Project Team reviewed three transcripts. Based on our conversation about these transcripts, and review by the research team of an additional seven transcripts, the research team created a coding framework. Transcripts were coded using the qualitative software program *NVivo* (Bazeley & Richards, 2000). Further interviews were coded as they were completed and new codes were added by the Research Facilitator in consultation with the team. Both to adhere to principles of qualitative analysis (Seale,

Table 1 ***Demographic Characteristics of Participants***

Age	Average 50, range = 36–72
Time since diagnosis	Three years or more 13, less than three years 13
Place of birth	Canada 20, United States 2, England 1, Philippines 1, Jamaica 1, Hong Kong 1
First language	English 24, Cree 1, Dutch 1
Race / ethnicity (self-defined)[a]	Caucasian/white 7, British 6, Canadian 2, Jewish 2, Indigenous/Native 2, Métis-Ukrainian 1, Euro-Canadian 1, Polish Canadian 1, Italian 1, Asian 1
Total annual household income ($)[b]	100,000 + – 6 90–99,000 – 1 80–89,000 – 1 70–79,000 – 2 60–69,000 – 3 50–59,000 – 4 40–49,000 – 1 30–39,000 – 4 20–29,000 – 2 Less than 20,000 – 1[c]
Education	University degree 19, college diploma 6, secondary school diploma 1
Disability / health problems aside from cancer	Hearing impaired 1, heart problems / arthritis / psychiatric survivor 1, depression (in past) / fibromyalgia 1, endometriosis 1
Urban / rural (at time of treatment)	Urban 20, semi-urban 2, rural 4
Family status (at diagnosis)	Partnered 17, single 9; adult children 5, young children 1, trying to have children 2
Sexual identity	Lesbian 22, gay 2, dyke 1, bisexual 1
Family doctor knew of sexual identity	Yes 23, no 2, not sure 1

[a] One woman said the question was impossible to answer as her ethnicity was "too mixed"; one did not respond.

[b] One woman did not respond.

[c] Actual income was $8,000.

1999) and to minimize the risk of stereotyping lesbians, we deliberately read for and coded negative cases (instances where participants' experiences or commentary departed from or challenged an emerging theme).

A draft research report was written describing lesbians' experiences in each of the key thematic areas outlined in the interview guide. In keeping with our participatory research framework, we asked eight interviewees to join the Project Team for two half-day meetings, in order to review this draft and comment on the emerging analysis. These eight participants were selected on the basis of some of our diversity aims (for example, we specifically invited women who were from outside of Toronto, and we invited one participant who identified as "poor," since women from low socio-economic groups were not well represented in the study).

Feedback from this meeting led to substantial revision of the research report. While the first draft described lesbians experiences' with cancer in a general way, the second draft focused on "the lesbian parts" of the women's experiences with cancer. We took this direction because it was advocated by the participants and members of the Project Team and because it supported one of the mandates of the project, which was to challenge the invisibility of lesbians as cancer survivors and in cancer care. The consequences of our analytic and representational choices are discussed towards the end of the paper.

In this paper we highlight one of the research themes: lesbians' experiences of cancer care. A community report summarizing the additional research themes (including support, fallout from treatment, partnerships and dating, families, and finances) is available at http://dawn.thot.net/lbcp

Findings

Homophobia and Heterosexism in Cancer Care

The majority of lesbians interviewed said they had not encountered discrimination in their cancer care. While transferability of the findings may be limited (participants were, in the main, well educated and economically privileged), this is an encouraging finding — yet one that requires contextualizing.

In this section we describe lesbians' difficult experiences with health professionals. We draw on definitions of homophobia (fear of, aversion to, or discomfort with homosexual people; irrational hatred of homosexual people) and heterosexism (a belief that heterosexuality is the only form of sexuality, the only acceptable form of sexuality, or a superior form of sexuality) adapted from Mihalik (1991) and Mullaly (2002).

Homophobia: lesbians targeted or denied standard care. In detailing her cancer treatment, Paddy[2] noted that she had a cardiac condition that prevented her from receiving a general anesthetic. As the surgeon performed a lumpectomy, Paddy found the local anesthetic insufficient. "I told him that he was beneath the level of the freezing," she recalled, "and he told me that I was a dyke, therefore I should be able to tolerate pain." Theresa said that the nurses in the hospital seemed unable to comprehend her identity as a lesbian:

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[2] Names associated with quotes were chosen by the participants themselves.

> *I found a lot of the nurses just couldn't get their head around it and were saying, "You're a nice-looking girl, you can find someone…" So it was very hard. And they would pull faces and all different kinds of stuff.*

Kate described an interaction with the physician with whom she discussed her unusual vaginal bleeding. The physician pulled herself back in her chair in the middle of a Pap test and posed her first (and only) question to Kate: when had she last had a sexual relationship with a man? Kate responded that it had been about 20 years. The physician then told Kate that she thought there was "something wrong" and that she could either finish the test or refer Kate to a specialist:

> *I was pretty clear at that point that she was making me uncomfortable. And I was making her uncomfortable. And I don't know which was worse. But at that point I didn't want her to finish the exam, because I felt like she had disappeared on me, because of her anxiety about the fact that — first of all I guess because it wasn't a normal Pap. And secondly the fact that I was a lesbian and I don't think she knew how to handle even talking to me about cervical health… I'm sure everything she's been taught has been about heterosexual women, and if somebody had cervical dysplasia you ask them about their relationships with men.*

When a physician who had just learned Lillian was a lesbian examined Lillian's breast, "she stood about as far away as a person could — you know, like she was moving a computer mouse from across the room."

In the situations described, lesbians seeking health care were treated as if they were somehow contagious or so far outside a framework of "normal" that health professionals were unable to act in a professional way (indeed entitled to act in entirely unprofessional ways, expressing disgust and justifying inattention to pain). As well, as a consequence of the history of heterosexism in medicine, Kate's physician did not know how to take an adequate history from a lesbian with cervical changes. The Pap test, which might have provided Kate with more information about her condition, could not reasonably proceed; the physician's discomfort and lack of knowledge were so apparent that continuing would have only made things worse. In the encounter she describes, Kate was essentially denied care. We might also hypothesize that Lillian's breast exam "from across the room" was less than adequate.

Mary Lou spoke about the uniqueness of being a lesbian with cancer, the fear that cancer generates, and the importance to her of having a medical team that would not be unsettled by fear — of cancer or of her. "If my lesbianism is going to provoke fear on their part, that's at my expense," she said.

It was apparent in the interviews that the poor care the women received was sometimes linked to economic class as well as their identity as lesbians. At home with a drain after surgery, Glenda needed nursing care but did not receive it. "Welfare wouldn't pay for it; welfare said Community Care Access should send me somebody…all they did was argue." Later in her treatment, Glenda called to see if she could get a ride to the cancer centre. The agency told her that welfare should pay for her cab. The welfare worker told her that the cancer agency provided the service free to other people, so refused to pay. Glenda ended up walking, every day, for 28 radiation treatments. These incidents demonstrate that lesbians' difficult experiences of cancer care are related to more than their identity as lesbians; other systems of privilege operate in concert with heterosexism to restrict access to care and services.

Heterosexism: lesbian identity and social context ignored or dismissed. It became clear that aspects of lesbian identity and social contexts directly relevant to cancer care can be dismissed or overlooked by health professionals. A series of encounters experienced by Sarah highlights this point. Sarah spoke, for example, of drawing on her courage to raise the question of a double mastectomy with her surgeon:

> *And he said, "Oh, well, we'll just cut them off; you'll be fine. If you want to do it, call me in a couple of weeks." And he left. And I just, I just, I just, I crumbled…and then he came back in and he goes… "If breasts are important to you and your husband we can always do implants and we can talk about reconstructive surgery after you do that." And he left. And I remember sitting there thinking, he forgot who I was, you know, and he left, and I just thought, oh my God, I'm never going back to see that guy ever again.*

In failing to acknowledge Sarah as a person and as a lesbian, this physician jeopardized her cancer care. Sarah cancelled her next appointment and seriously considered not going back at all. As she put it, "If I have to battle this one emotionally, I'd rather die physically." Other studies have concluded that lesbians sometimes avoid routine health care, or delay seeking care for health problems, because of worries about homophobia and heterosexism (Trippet & Bain, 1992). Sarah's case illustrates that heterosexism can affect a woman's capacity to *continue* with care. When the care is treatment for cancer, heterosexism can threaten survival. As an additional consequence of this interaction, Sarah's connection with an important nursing support, a nurse navigator, was lost: "I haven't called her. I couldn't call her. I know she has left messages on my phone, but I can't call her, because I'm so angry and I'm so lost."

A genetic counsellor sought Sarah's permission to contact her older sister for testing, to see if she had the genetic mutation associated with hereditary breast cancer. When Sarah refused, the counsellor pressed the point:

> *I finally broke down and said, "I'm lesbian and my RC [Roman Catholic] family makes it difficult for me to be that person, you know..." She didn't get it; she fought me on that one for a half hour and I finally stood up and said, "I'm leaving," and I walked out.*

The counsellor essentially forced Sarah to come out, and then failed to appreciate (or even to learn about) the salience to the situation of being a lesbian in a homophobic family. The reality of a heterosexist social context was central to this cancer-care situation, and yet it was dismissed. Clearly, the care — and the woman — suffered for this.

Heterosexism: lack of lesbian-positive psychosocial support. Considering the blatant homophobia in cancer care, one might think that the lack of lesbian-specific support services, or explicitly lesbian-positive services, would be less of an issue. Yet it became clear that the lack of attention to lesbian realities in psychosocial oncology can have the same consequences: the exclusion of lesbians and the denial of standard care.

Jessica's social worker had told her about a support group at the hospital and asked if she would like to join. The social worker posed the question casually, as if it were an easy decision. But it was not an easy decision. Jessica was fairly certain she would be the youngest woman in the group, as well as the only lesbian. She spoke specifically about her reluctance to be part of a group where she might encounter homophobia:

> *You have enough on your plate to deal with, with your diagnosis or your treatment, that you don't want to deal with [homophobia]... And you sort of feel, like, a bit of camaraderie with other women who are going through the same thing and you don't want to be shunned away from the only place that you can go... You know what I mean? Like, what if you got into a support group, came out [as a lesbian], and then had to deal with homophobia on top of everything else? Then you'd be left with no place to go. So it's almost better to go and hide, or not go at all, than deal with the stigma.*

Jessica made the point that joining a support group and encountering homophobia may be more difficult than doing without the support. She spoke of a longing for connection and "safe space" with other women experiencing cancer and suggested that homophobia, in severing that connection, could negate the benefit of the group.

Joining a cancer support group can be a difficult step for any woman. Jessica's comments point to the need for cancer-care professionals to appreciate what it takes for a lesbian to join a support group or service. Lesbians, like marginalized women generally, face particular risks, and the decision to join a group is often more complicated than health professionals might suspect.

Experiences reported by two other participants, Paddy and Theresa, showed that Jessica's worries about coming out and having to endure painful reactions within a support group were well founded. Even when responses were not blatantly negative, the feeling of being "not quite part of it," not quite "there" in the group, was common. Anticipating such experiences, some of the women never made an attempt to access existing services.

In a few instances the participants attempted to have their needs as lesbians met within mainstream support services. After a session in which members of Theresa's group had reacted negatively to her coming out, Theresa asked the facilitator to speak to them about the importance of relationships — including lesbian partnerships — to one's ability to cope with cancer.

> *[The facilitator said], "Well, it's really not my mandate…it's for the group to talk on its own and for me to give guidance." And I go, "So, what you're saying is, you're not willing to help me integrate into the group, right?"*

The "not our mandate" comment was reported by more than one of the lesbians with cancer. It conveys the idea that providing care and support to lesbians is above and beyond what the service does. The "not our mandate" line was heard in relation to additional dimensions of lesbians' lives and social realities:

> *[The health professional] said to me, "I can only work with you and your cancer; you've got too many things going on." I was too poor, I was too busy figuring out what I was going to eat.* [Glenda]

The notion that lesbians and poor women are "not our mandate" clarifies the position of many psychosocial support services: they do not intentionally exclude anyone, but, lacking a critical perspective on their own mandate, they do end up excluding lesbians and other marginalized women. This process of exclusion is much more subtle than outright homophobia. Service providers can easily claim that lesbians are welcome, and some can even claim that lesbians participate in their services. Yet it is the realities of heterosexual, middle-class, white, able-boded women that define the scope and landscape of many cancer care and support programs.

Lesbian-Positive Care in a Context of Homophobia and Heterosexism

Although the majority of lesbians said they had not encountered homophobia in cancer care, they had clearly put a significant amount of effort into avoiding homophobia. Comments about positive experiences with cancer services can say as much about a history of disentitlement to equitable health care as about lesbian-positive services.

Screening for homophobia. "Early detection strategies" took on new meaning as the participants sought to detect homophobia in cancer care, and to avoid it. For instance, when Maureen went for her first appointment with the primary nurse assigned to her care, she asked about the nurse's values:

> *I just said, "You know, my partner's a woman — do you have a problem with that?" And she said, "Absolutely not." So it was okay. Because if she had said [she had a problem], then I would say, "Send someone else in," because I don't have time to have this be an issue at all.*

As Maureen and others pointed out, a strategy that includes coming out usually assumes that lesbians have other options for care. Of course, this is not always the case.

Mary Lou's family physician tried to ensure that specialists to whom she referred Mary Lou were lesbian-positive. Mary Lou appreciated her physician's efforts, believing that this kind of commitment by a health professional represents progress. Yet the fact that a health professional perceives the need to protect a patient from the homophobia of colleagues reveals the salience of homophobia to health-care interactions.

Being out and not being out. It became clear that both coming out and remaining closeted are strategies lesbians use to influence the quality of their health care. Sarah, for example, came out to a nurse and explained what her breasts meant to her as a lesbian, indicating just how difficult it would be for her to lose them. She felt it would be impossible for the nurse to adequately support her without understanding this. Coming out was often described by the participants as a deliberate effort on the part of lesbians with cancer to communicate with oncology professionals about what, for them, constituted "good care."

On the other hand, several of the women deliberately remained closeted in order to avoid having to deal with homophobia in cancer care. Laura, for instance, kept her sexuality to herself over the course of her cancer treatment. She was out to her family physician, but that physician was based elsewhere, in a city. "Had I come out here, in my town, I don't think it would have gone over so well."

A few participants explained that the cancer-care system was one of the few places where they were *not* out as lesbians. This was partly because they feared it would compromise their care. However, they also spoke about how draining it was to deal with heterosexism, to come out over and over, to anticipate and deal with awkward or homophobic reactions, to explain what it means to be a lesbian. Because dealing with cancer is itself extremely energy-depleting, lesbians with cancer may not be willing or able to risk expending further energy battling homophobia.

Both Glenda and Kate made the point that to be safe in the cancer-care system, women may conform to norms and expectations, not only around sexuality but also around class, gender, and "patienthood." "Of course, I didn't say I was lesbian," said Glenda. "I was just an aging, nice lady — not a woman, a lady. I did all I was supposed to do, didn't raise any questions or whatever." Kate spoke about masking her working-class background when interacting with health professionals, being sure to "talk the talk...act in a certain way to get what you need, which is stressful due to the situation."

The efforts of the lesbians with cancer to get good care and avoid bad care were often strategic, creative, and defiant. The fact that lesbians feel the need for such behaviour calls attention to the legacy and reality of homophobia and heterosexism in cancer care.

Gratitude for receiving equitable care/readiness to fight for equitable care. Several participants spoke warmly about health-care workers and support staff who had accepted and related to their partners. Paula B.'s surgeon could have spoken first with her mother or father but instead chose her partner:

> *It made such a difference to me that she went to [my partner] first. Just that, in legitimatization of who we are, because she would have for sure gone to my husband if I were married, right? It just normalizes it, and you've got so much to deal with emotionally.*

The physician clearly acted in a lesbian-positive way, and Paula B.'s appreciation was genuine. Yet as Paula B. herself suggests, a heterosexual woman would not even have to think about the possibility of a physician overlooking her spouse. What is normal treatment for heterosexual women was something that the lesbians remarked on and even praised.

The narratives reveal that legacies of homophobia and heterosexism leave lesbians in the position of being grateful for things that heterosexual people take for granted. And if gratitude for equal treatment is a consequence of marginalization, so too are anticipation of problems and readiness to fight for care. Rosalie said, "I always felt respected as a woman and a lesbian… And I always felt that [my partner]'s position as my partner was respected. *I think she would've clobbered anyone that didn't.*"

Lesbian-Positive Cancer Care

A few of the women had felt very well supported as lesbians by oncology professionals and by their family physicians. In speaking about these instances, and also in articulating what was missing in their interactions with health professionals, they defined some of the features of lesbian-positive cancer care. One participant, Teagan, received "incredible" support from her primary nurse:

> *She knew of my relationship, and when I would do my chemo it would be her and I in an isolated area, and we would be talking about how the situation is playing at home, you know, how comfortable is Mom that [participant's partner] is there sleeping with you every night…those kinds of things. So she was awesome. Awesome, awesome.*

More commonly, however, lesbian-positive care was articulated in terms of the absence of homophobia, in some ways from a position of disentitlement to equitable care. Marcia's comment captures the tension inherent in this position:

> *There was no glitches, there was no hiccups, there was…certainly no…I mean they were very nice about it… I don't think there was an awkward moment ever when I said, "This is [my partner] and she will be here." It was, "Oh, of course." [pause] But I will also still tell you, I felt extremely invisible…it's a sense that you're always alone.*

This comment, and the form it takes, echoes those of other participants. Kate, for instance, had to use a dilator several times a week after receiving internal radiation for cervical cancer. Her physician and primary nurse offered her a pamphlet, and nothing more:

> *[They] said nothing to me. Said nothing in the whole experience about how I deal with my sexual life, said nothing about the effects this might have on my life. Absolutely zero, nothing about that… I don't know if she would have said more if I was heterosexual… It's not like [the nurse] didn't answer my phone calls if I had to call and I had a problem here and there. But there was absolutely no real patient-focused care or contact that allowed me to talk about my life at all. And she really was the point person. So if your point person can do that for you, you can…deal with a lot of other things. That didn't happen.*

As Kate and others noted, it was sometimes difficult to discern whether less-than-satisfactory health-care experiences were the result of usual health-care practices or stemmed from health professionals' discomfort with lesbians. Yet the more general points are clear: while both Kate and Marcia were at pains to state that health professionals had not discriminated against them as lesbians, they also perceived that health professionals had failed to engage meaningfully with their lesbian selves and realities. Marcia said, "I never got beyond 'How are you doing?'"

Recent research by Dibble and Roberts (2002) comparing the diagnosis and treatment of lesbian and heterosexual women generated an unexpected finding: lesbians reported more side effects from chemotherapy than heterosexual women. In considering explanations for this finding, the researchers note that informal talk — often about husbands and (heterosexual) families — is a feature of cancer care and commonly results in a bond between patients and nurses administering chemotherapy (Jarrett & Payne, 2000), and that such talk may be awkward or nonexistent between lesbians and health professionals. They speculate that lesbians may be reluctant to report problems, and that nurses may block patients from divulging worries and concerns when communication is problematic. Comments made by participants in the present study certainly show that nurses' engagement with lesbian identities and social contexts can facilitate a valued bond, and that lack of such engagement can undermine or preclude such a connection. This finding takes on particular relevance in light of Dibble and Roberts' suggestion that the quality of the relationship between women with cancer and nurses may mediate — for better and for worse — women's experiences of treatment side effects.

Discussion

A persistent tension in the literature on the illness experiences of women in particular social locations, with particular identities, is the extent to which identity is the centre of analysis and representation. In this study, one of the consequences of focusing on "what is lesbian" about lesbians' cancer experiences is that those lesbians for whom "lesbian" was less at the fore in terms of identity and social life tended to be less well represented. As well, highlighting aspects of the cancer experience linked to lesbian identity means that other aspects of having cancer — aspects that might in fact be important to an individual lesbian's experience — receive less attention. For instance, one participant said that people who focus on hair loss as the most difficult aspect of chemotherapy "just don't know about all the other stuff — mouth sores...all the other stuff that comes with it…all the suffering that goes on." In this paper, as in other reports of findings from this research, we have indeed overlooked some of the suffering that was endured, and we have missed some of the joys that lesbians discovered after the cancer experience — the positive life changes they underwent. Yet we trust that the bases of our analytic and representational decisions are clear: the persistence of homophobia and heterosexism in cancer care calls for focused attention to lesbians' experiences "as lesbians" with cancer.

While the majority of participants said they had not encountered discrimination, a minority had been targeted or had been denied standard care; in a few cases, aspects of lesbian identity and social context directly relevant to cancer care had been ignored or dismissed. The participants also commented on the lack of attention to lesbian realities in psychosocial support. However, the historical failure of health professionals to respect lesbians or grant legitimacy to lesbian relationships means that lesbians with cancer sometimes do not *expect* that they or their partners will be offered equitable care. This was the context in which gratitude, readiness to fight, and steps to identify and avoid homophobia occurred.

Nurse policy-makers, educators, and practitioners have critical roles to play in determining the extent to which cancer care and support are accessible to lesbians. Elsewhere (Barnoff, Sinding, & Grassau, submitted), we consider recommendations for new programs and services that emerged from this study (for instance, support and wellness groups that enable connections between lesbians with cancer and their partners and families; resource materials that integrate lesbian realities). Further discussion of lesbians' access to health care can be found in Hudspith and Bastedo (2001), McNair (2003), and Peterkin and Risdon (2003).

In relation to treatment settings, lesbians who took part in this study called for oncology professionals to actively create welcoming space for all of their identities. Specific suggestions for change included:

- intake procedures that make it clear that all identities are welcome; use of the word "lesbian" so that lesbians do not have to come out in order to access appropriate services. *Suggested wording: "In order for us to best support you, I'm going to ask a few questions. Some of the questions won't relate to you, but I want to make sure I'm connecting you with all the services and resources that make sense." Then ask: "Do you identify with a particular ethnic or cultural group, are you a lesbian or bisexual or trans-woman, do you have a disability, do you have financial needs, what is your housing situation, your age…"*
- forms that allow for self-identification as a lesbian. *When a woman identifies as a lesbian, discussion about the meaning of her identity in relation to cancer and cancer care; and choices offered about how and with whom the information is shared.*
- "positive space" campaigns, *including, for instance, stickers on doors or nametags indicating that this professional is lesbian-positive; beyond the value of the actual sticker, this practice promotes dialogue in the setting. Could also include specific sections in patient resource centres identifying lesbian material, and having the word "lesbian" or a rainbow symbol on the Web site.*

- intentional support for lesbian partnerships and lesbian families
- lesbian and gay health professionals coming out *(recognizing that this requires workplace support)*

At the broadest level, the institutionalization of positive change for lesbian patients requires policy development: specifically, a commitment to equitable treatment for lesbians should appear in organizational mission statements, providing strategic direction for ongoing efforts to increase accessibility, and anti-discrimination policies should specifically prohibit heterosexism. As with all "living" policies, lines of accountability for implementation and processes to address instances of discrimination should be clear.

Nurses at all levels have an opportunity to forge partnerships with lesbian community agencies, actively supporting processes by which lesbians articulate their own health-care concerns and needs and have a role in shaping health-care services. Participants in this study advocated such partnerships, encouraging lesbian community organizations to attend more actively to cancer and urging cancer-care agencies to attend more actively to the realities of lesbians' lives. The latter is facilitated when lesbians are represented (and thus safely "out") at all organizational levels and in all nursing sectors.

Education and training are obvious and critical means of intervention. It is important that nurses be aware of the range of ways that lesbian identity may be relevant to cancer and cancer care. Yet, as Beagan (2003) points out, a "difference perspective" — learning about how "others" experience a particular health condition — is inadequate and risks stereotyping. Educational strategies, then, should focus on challenging the assumption that all service users are heterosexual; on unpacking assumptions, myths, and stereotypes about lesbians; and on exposing the ways in which heterosexism affects lesbian health. Securing these understandings among nurses working at all levels should result in the commitment upon which every other effort at change ultimately rests. Ultimately, however, nurses must understand that nursing care can itself be complicated and compromised by systemic oppression, and must be prepared to examine their own complicity in — and to challenge — homophobia and hetereosexism.

References

Barnoff, L., Sinding, C., & Grassau, P. (submitted). *Lesbians diagnosed with cancer: Experiences of cancer support services and recommendations for change.*

Bazeley, P., & Richards, L. (2000). NVivo *qualitative project book.* London: Sage.

Beagan, B. L. (2003). Teaching social and cultural awareness to medical students: "It's all very nice to talk about it in theory, but ultimately it makes no difference." *Academic Medicine, 78*(6), 605–614.

Brogan, M. (1997). Healthcare for lesbians: Attitudes and experiences. *Nursing Standard, 11*(45), 39–42.

Dibble, S. L., & Roberts, S. A. (2002). A comparison of breast cancer diagnosis and treatment between lesbian and heterosexual women. *Journal of the Gay and Lesbian Medical Association, 6*(1), 9–17.

Fish, J., & Wilkinson, S. (2003). Understanding lesbians' healthcare behaviour: The case of breast self-examination. *Social Science and Medicine, 56*(2), 235–245.

Fobair, P., O'Hanlan, K., Koopman, C., Classen, C., Dimiceli, S., Drooker, N., et al. (2001). Comparison of lesbian and heterosexual women's response to newly diagnosed breast cancer. *Psychooncology, 10*(1), 40–51.

Gatenby, B., & Humphries, M. (2000). Feminist participatory action research: Methodological and ethical issues. *Women's Studies International Forum, 23*(1), 89–105.

Green, L. W., George, M. A., Daniel, M., Frankish, C. J., Herbert, C. J., Bowie, W. R., et al. (1995). *Study of participatory research in health promotion: Review and recommendations for the development of participatory research in health promotion in Canada*. Vancouver: Institute of Health Promotion Research, University of British Columbia, and B.C. Consortium for Health Promotion Research.

Haynes, S. (1992, July 12–18). *Are lesbians at high risk of breast cancer?* Paper presented at the 14th National Gay and Lesbian Health Foundation Conference, Los Angeles, California.

Hudspith, M., & Bastedo, S. (2001). *Caring for lesbian health: A resource for Canadian health care providers, policy makers, planners.* Ottawa: Health Canada.

Jalbert, Y. (1999). *Gay health: Current knowledge and future actions.* Montreal: Coalition des organismes communautaires québécois de lutte contre le sida.

Jarrett, N. J., & Payne, S. A. (2000). Creating and maintaining "optimism" in cancer care communication. *International Journal of Nursing Studies, 37*(1), 81–90.

Link, B. G., & Phelan, J. (1995). Social conditions as fundamental causes of disease. *Journal of Health and Social Behavior,* (38) 80–94.

Matthews, A. K., Peterman, A. H., Delaney, P., Menard, L., & Brandenburg, D. (2002). A qualitative exploration of the experiences of lesbian and heterosexual patients with breast cancer. *Oncology Nursing Forum, 29*(10), 1455–1462.

Matthews, K. A., Shumaker, S. A., Bowen, D. J., Langer, R. D., Hunt, J. R., Kaplan, R. M., et al. (1997). Women's health initiative. Why now? What is it? What's new? *American Psychologist, 52*(2), 101–116.

McNair, R. P. (2003). Lesbian health inequalities: A cultural minority issue for health professionals. *Medical Journal of Australia, 178*(12), 643–645.

Mihalik, G. J. (1991). Homosexuality, stigma and bicultural evolution. *Journal of Gay and Lesbian Psychotherapy, 1*, 15–29.

Mulé, N. (1999). Social work and the provision of health care and social services to sexual minority populations. *Canadian Social Work, 1*(1), 39–55.

Mullaly, B. (2002). *Challenging oppression: A critical social work approach.* Don Mills, ON: Oxford University Press.

Peterkin, A., & Risdon, C. (2003). *Caring for lesbian and gay people: A clinical guide.* Toronto: University of Toronto Press.

Ryan, B., Brotman, S., & Rowe, B. (2000). *Access to care: Exploring the health and well-being of gay, lesbian, bisexual and two-spirit people in Canada.* Montreal: McGill Centre for Applied Family Studies.

Seale, C. (1999). *The quality of qualitative research.* London: Sage.

Trippet, S., & Bain, J. (1992). Reasons American lesbians fail to seek traditional health care. *Health Care for Women International, 13*(2), 145–153.

Valanis, B. G., Bowen, D. J., Bassford, T., Whitlock, E., Charney, P., & Carter, R. A. (2000). Sexual orientation and health: Comparisons in the Women's Health Initiative sample. *Archives of Family Medicine, 9*(9), 843–853.

Yadlon, S. (1997). Skinny women and good mothers: The rhetoric of risk, control, and culpability in the production of knowledge about breast cancer. *Feminist Studies, 23*(3), 645–677.

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Designer's Corner

Photovoice: Picturing the Health of Aboriginal Women in a Remote Northern Community

Pertice Moffitt and Ardene Robinson Vollman

The purpose of this paper, part of an evolving ethnographic doctoral study, is to describe the use of photovoice in exploring the health beliefs and health promotion practices of pregnant Tlicho women in Canada's Northwest Territories. It is but a preliminary look at the method and its use in a remote community.

What research methods are culturally appropriate for working with Aboriginal people? Photovoice, a technique based on participation, empowerment, and self-documentation, is a culturally appropriate method for conducting rural and remote health research. It is a way of capturing images of one's everyday life experiences using a camera, then describing the images in the context of one's life, thus allowing others to gain an insider's view of everyday life in one's community. In this paper we will describe how photovoice is being used as part of an ethnographic study, provide examples of its use, and describe lessons we have learned and challenges we have encountered.

It has been said that a picture is worth a thousand words, but it is more than that. A picture is a way of gaining insight into the "humanness that surrounds us" (Collier & Collier, 1986, p. 1). In fact, Bach (1998) describes photographs as "mini-narratives." It is this aspect of photography that drew our attention to the possibility of exploring its use as part of a research project with pregnant Tlicho women from a remote community in the Northwest Territories.

The Tlicho (Dogrib) Nation is the largest Dene tribe in the Northwest Territories. The women who participated in the study were from the largest Tlicho community, which has a population of 1,864 (NWT Bureau of Statistics, 2001) and year-round road access to the city of Yellowknife.

Meleis (1996) suggests that a true understanding of the health and illness status of a group can result only from the group's own knowledge concerning its values, priorities, responses to life's disruptions, perceptions of health, help-seeking behaviours, and contexts in which people live. We agree that an understanding of the health beliefs and health promotion practices of pregnant Tlicho women can come only from knowledge provided by the women themselves.

Photovoice

Photovoice Defined

Photovoice (originally termed *photo novella*) has been referred to as a concept, an approach, an educational tool, a participatory action research method, a participatory action tool, a participatory health promotion strategy, and a process (Wang, 1999; Wang & Burris, 1994, 1997; Wang, Yi, Tao, & Carovano, 1998). The varied language used to describe photovoice suggests its adaptability to many goals, an assortment of groups and communities, and a variety of public health issues. Wang and Burris (1997) define photovoice as "a process by which people can identify, represent, and enhance their community through a specific photographic technique" (p. 369).

With this technique, people capture images of their everyday life experiences in their communities through the use of a camera. By telling the story behind a photograph, they describe life in their communities and thus convey to others the context of their lives from their personal points of view. Lykes, Blanche, and Hamber (2003) characterize photovoice as a means of self-representation.

Photovoice Research

Photovoice has been used by village women to assess rural reproductive health needs in China (Wang, 1999; Wang, Burris, & Xiang, 1996); by homeless children, men, and women to capture the essence of their everyday lives (Hubbard, 1991; Wang, Cash, & Powers, 2000); by community members to reach policy-makers (Wang & Redwood-Jones, 2001); by research participants to evaluate the impact of social reform in New York City neighbourhoods (New York State Scholar Practitioner Team, 2002); by Mayan women in post-war Guatemala to reconcile differences and promote community change (Lykes et al., 2003); by African-American women to establish intergenerational connections between young homeless women and elderly housed women (Killon & Wang, 2000); and by elderly women to describe their everyday lives in the first 6 to 8 weeks post-hospital discharge (LeClerc, Wells, Craig, & Wilson, 2002). When photovoice was used with groups of women to assess and evaluate policy and public health issues, the participants increased their knowledge by creating a record of their own realities.

Photovoice Foundations

The theoretical underpinnings of the photovoice technique lie in empowerment education, feminist theory, and documentary photography (Wang, 1999; Wang & Burris, 1994, 1997), which Wang and Burris (1994, 1997) connect, in turn, to health policy and health promotion principles.

The empowerment and critical consciousness literature is described as originating with Friere (1970) and affirmed by photovoice through health-education methods described by Wallerstein and Bernstein (1988). Friere proposed the building up of social equity through a process of educational empowerment and consciousness-raising among ordinary people, compelling them to be agents of policy change by using photography to reflect the realities of community life. Wang and Burris (1994) build on Friere's work by having the local people themselves take the photographs about which stories will be told. Photography, critical reflection, and dialogue can serve to reveal significant social and political issues.

Feminist theory advocates that women become emancipated and made visible by acting instead of being the objects of action; feminists have objected to research methods that keep women in passive roles (Wang & Burris, 1994). Williams (1996), in discussing the politics of feminist ethnography, suggests that research consider the complexities of women's lives through the eyes of both the researcher and the researched in a manner that explores differences and acknowledges similarities. Photovoice addresses power inequalities by placing cameras not in the hands of the researchers but in those of the research participants, thus investing them with authority and responsibility (Wang & Burris, 1997).

Photovoice also has foundations in documentary photography, where visual images are used as an impetus for social change by revealing the concerns and issues of specific individuals or groups. As described by Wang and Burris (1994, 1997), photographs are used in a similar manner, to generate a story that legitimizes the contextual reality of the research participants.

Use of Photovoice with Pregnant Tlicho Women

Photovoice has three goals: "to enable people to record and reflect community strengths and concerns; to promote critical dialogue and knowledge about personal and community issues; and to reach policymakers" (Wang & Burris, 1997, p. 369). Considering that the ethnographer's concern is "to discover and describe complex patterns of behaviour" (Agar & Hobbs, 1980, p. 1), and considering that in the present study photovoice is being used as a data-collection technique within an ethnographic design, our objective is to achieve the first two of these goals. The third goal is beyond the scope of this exploratory study, although the participants may later choose to display their photographs for the benefit of local policy-makers and community members.

We used photovoice with pregnant Tlicho women in order to better see, hear, and understand their everyday lives and to promote dialogue on their health beliefs and health promotion practices. Following the approach of Killon and Wang (2000), three questions were posed to the women in order to focus their photography: *What do you do to stay well or feel good during pregnancy? What do you believe creates, influences, and prevents being well in pregnancy? What are your health concerns during pregnancy?*

The first step in the photovoice technique is recruitment of participants. Posters were placed in strategic locations throughout the community and letters were distributed to pregnant women by the staff of the community health centre advising of a meeting about photovoice.

Since the women were at different stages in their pregnancies, assembling a group of participants proved to be a challenge. Some were near delivery while others were in their first trimester. To build trust, rapport, and respect, we accepted all pregnant women who volunteered regardless of gestational dates. At the time of writing, data collection is ongoing and all 13 participants have disposable cameras. Women who were in the first trimester on entering the study will have used up as many as three cameras to detail their experiences, one in each trimester.

We held an initial meeting with the women to discuss the cameras, ethics, and power, and to obtain their informed consent (Wang et al., 2000). As data collection progressed and more women entered the study, the approach became individualized. We introduced photovoice technique, method, and goals, and obtained informed consent. Then each woman was given a disposable camera with instructions on its use, including how to approach people, obtain consent before taking a photograph, and inform subjects that they would receive copies of photographs in which they appear.

The women returned the cameras to the researcher when they had used up all the film. The film was developed and the photographs and negatives returned to the women. The researcher kept a CD-ROM copy of all photographs. To facilitate storytelling, the photographs were loaded onto a laptop computer for use with a multimedia projector and projected onto a screen for group discussion. The CDs will be given to the women once the project is complete; no photograph will be published without the woman's consent. The researcher meets with the participants weekly at prenatal classes and individually as the photographs are developed and stories recorded.

Participatory analysis begins with the participants selecting photographs to discuss. The women share their stories individually and then as a group, articulating their health beliefs and health promotion practices. Wang et al. (1998) suggest a storytelling approach adapted from Wallerstein and Bernstein (1988) using questions related to "the acronym SHOWeD: what do you See here; what's really Happening here; how does this relate to Our lives; why does this problem or strength exist; what can we Do about this?" (p. 80).

In the photovoice technique, data collection and analysis do not occur in isolation. Participant observation and interviewing take place concurrently, as these methods are integrated into the ethnographic design. For example, the researcher has attended prenatal nutrition classes with the participants, been present as an observer during prenatal visits, and attended the births of participants' babies.

Use of Photovoice Within Ethnography

Ethnography has been described as a way of learning *about* people *from* people (Fetterman, 1998; LeCompte & Schensul, 1999; Roper & Shapira, 2000; Spradley, 1979). Photovoice is a natural fit with ethnography because it is a way for people to tell others about themselves through the use of pictures. Brink (2000) describes ethnography as the original "mixed method," and in this respect photovoice, participant observation, and interviewing are the tools of the method. In ethnography, data collection and analysis develop concurrently as the story unfolds and new depths of understanding are reached. This process is also true of photovoice, as the photographs are selected and analyzed by means of dialogue and reflection. The issues, themes, and theories interpreted from photovoice are juxtaposed against the other data sources (triangulation) and integrated into the written ethnography.

Although photovoice is a unique method, photography has long been used by ethnographers engaged in fieldwork (Denzin & Lincoln, 2000; Fetterman, 1998; Morse & Field, 1995; Spradley, 1979). Fetterman suggests that the camera has several benefits in the field: it serves as a "can opener" for entry to the community, records transitions in behaviour, documents the contextual reality, assists with memory of events, and assists with interpretation. Photography has also been described as a medium for learning about people in nursing research and practice (Savedra & Highley, 1988).

Denzin and Lincoln (2000) describe photography as "the mirror with a memory" (p. 635) and go on to explain that, from a positivist paradigm, anthropologists and sociologists originally used photographs as a form of evidence. Today, researchers are questioning how photographs are used and are exploring photography in a social constructivist way, considering the power invoked by the camera, the perspective of the person taking the photograph, and the individual meaning evoked by the photograph (Harper, 2000).

Suitability of Photovoice for a Population

Wang and Burris (1994, 1997) describe photovoice as a participatory method that can be used in the context of a variety of public health issues. The health beliefs and practices of pregnant Tlicho women fall into this category, since nurses and other health professionals are concerned with the health of pregnant women and with health promotion practices. Central to photovoice is the perspective of those involved in the process and the stories they tell. The histories of Aboriginal people and the stories that reveal those histories are the bases of good Aboriginal research (Kenny, 2002; Smith, 2001).

Photovoice has been used with vulnerable groups as a means of empowerment (Wang & Burris, 1994). The power of pregnant Tlicho women has been particularly eroded through travel away from their community for birth, a practice that has been the norm for decades (O'Neil, 1988; Paulette, 1990). According to Wang and Burris (1994), empowerment "includes at least four kinds of access: access to knowledge, access to decisions, access to networks and access to resources" (p. 180). By engaging in photovoice, pregnant Tlicho women may experience improvement in all four kinds of access. They may together learn about their collective experiences in a way that provides them with the knowledge necessary to improve their health during pregnancy. By discussing health beliefs and health promotion practices among themselves, the women learn from each other, a process that can be emancipatory in and of itself. Through their pictures and their stories, they make their voices heard. For all of these reasons, the process has been an appealing one for the Tlicho women in the study.

The women are given their photographs, the negatives, and an album as a keepsake. They enjoy taking and receiving photographs and have said that this is a benefit of participating in the study. The anthropological literature contains photographs of Tlicho people; Helm (2000) includes photographs of Tlicho people taken during her fieldwork in the 1950s and 1960s. As well, photovoice has been used with Native American youths (Hubbard, 1994) and photography has been suggested as a useful tool for community-based research with Native Americans (Guyette, 1983).

Participatory research methods are considered to be culturally appropriate (Clarke, 1997; Grenier, 1998; Ryan, 1995). Through participation with local people, traditional or indigenous knowledge is recognized, respected, and utilized in decision-making processes (Grenier). The participatory nature of the photovoice technique suggests the engagement of participants, such as the Tlicho women in the present study, as members of the research team, with the camera as the primary data-collection tool. The participants are also involved in the analysis, by articulating the meaning of their photographs with stories. If photovoice is used as the sole participatory action method, the research question should be generated by the participants themselves. This is not the case in our focused ethnographic study, but the use of photovoice may generate questions for future studies.

Findings from other studies suggest that photovoice contributes to health promotion by stimulating knowledge-generating personal and community action, and by increasing power through participation, leading to self-awareness and the attainment of a voice within the community (Wang et al., 2000). These advantages apply to Tlicho women, who, along with other Aboriginal people in Canada, have been described as victims of colonization and loss of power (Adams, 1994; Alfred, 1999; Battiste, 2000; Berger, 1991; Brown & Smye, 2002; Carter, 1999; Fumoleau, 1975; Moffitt, 2004; O'Neil, 1988; Smith, 2001; Steckley & Cummins, 2001).

A Photograph Generated Through the Photovoice Technique

The photograph shown here and its accompanying story illustrate the richness that photovoice brings to the research process. Barthes (1981) states that "the photograph possesses an evidential force…its testimony bears not on the object but on time, from a phenomenological viewpoint…the power of authentication exceeds the power of representation" (p. 88). Although this single photo authenticates and represents only a sliver of the complexity that surrounds Tlicho women's health beliefs and health promotion practices, and the context from which they arise, it makes the utility of photovoice obvious. As well as adding an aesthetic dimension to knowledge transmission, it may enhance the identity and visibility of past traditions. The process may facilitate the reclamation of indigenous knowledge, which, as Battiste (2000) states, is a critical component of health and healing for indigenous people.

One of the Tlicho women described the practice of infant packing that has been passed down from one generation to the next: "Some elders used to tell me back in those days they used to carry a baby up front and…all this caribou meat in the back and have a canoe on their forehead." Nurses have observed the practice of infant packing today, and one can also read past accounts of infant packing by Tlicho women, as described by this participant. Infant packing has been and is still today a way for women to do their work efficiently in the community.

Lessons and Challenges

Privacy and Confidentiality

Wang and Redwood-Jones (2001) discuss four kinds of invasion of privacy that may occur when the camera is used as a research tool. The first kind is intrusion into a person's private space; although in Canada we photograph freely in public, attaching a story or meaning to a photo of someone can be morally problematic. The second is disclosure of embarrassing facts about someone; people are apt to become angry when shown in a bad light in the name of social change, and this could ultimately affect the cohesiveness of an entire community. The third kind of invasion of privacy is twisting the truth, such as by using a photograph out of context to make a point or tell a story. The fourth kind is publishing a photograph in order to make money. These kinds of invasion of privacy are dealt with in several ways.

We held a group discussion about the use of cameras and issues of power and ethics as suggested by Wang and Redwood-Jones (2001). To date, most of the participants' photographs have been taken in the context of home and family; those taken outside the home setting have been in the context of the general community environment, without the inclusion of people or particular objects so that identification has not been an issue. Although this was not articulated as an ethical response during the initial meetings, the women's collective action appears to confirm it as their approach. Duplicates are made when films are developed so that participants can give copies to people they have photographed.

Representation Issues

Wang and Redwood-Jones (2001) identify several concerns around the issue of representation. Each disposable camera used in our study takes up to 27 photographs. The women were asked to choose two photographs to discuss from among the hundreds that formed the data pool. The choice of photographs to display, and who makes that choice, can pose a dilemma. This point is not always addressed in the literature; in most published studies it was the researcher who decided which photographs and stories would be highlighted. Our concern was to balance the needs of the researcher with those of the participants and the community. We approached this challenge through dialogue and consensus, with the goal of selecting photographs that all participants agree are representative of the experiences and viewpoints of the group.

Koche and Herrington's (1998) response to questions of representation is reflexive research, described as "ongoing self-critique and self-appraisal…shaped by the politics of location and positioning" (p. 888). The researcher is engaged with and responding to the researched at the same time as the researched are engaged with and responding to the researcher, creating multiple truths so that representation can be explained only through the contextual meaning that the researcher and the researched negotiate and create together.

The other challenge posed by the photovoice technique is representing the community and its members in a balanced and fair way. The following questions concerning photographic ethics, as suggested by Wang et al. (2000), were posed in a group discussion with participants: "What is an acceptable way to approach someone to take their picture? Should someone take pictures of other people without their knowledge? What kind of responsibility does carrying a camera give? What would you not want to be photographed doing?" (p. 83)

Informed Consent

Wang and Redwood-Jones (2001) recommend the use of three separate consent forms: one for consent to participate in the study, one for use by the participants to solicit permission to photograph people, and one for consent by the photographer and the subject to publish the photograph. Informed consent is obtained from each person who agrees to take part in the research. To address the specific photovoice issues identified by Wang and Redwood-Jones, the recommendations of these authors were included on the consent forms.

Although 90% of the residents of the study community speak English (NWT Bureau of Statistics, 2001), their first language is Tlicho and that is the language the participants use to communicate with each other. The consent form was translated into written Tlicho, which is a relatively new representation of the language, the Tlicho dictionary being published only in 1996. Very few of the women can read their own language. However, they have all expressed delight that the consent form has been translated and we believe it is a respectful gesture that fosters a sense of trust. The Tlicho language is steeped in a history of oral transmission. Because of this, coupled with the fact that interaction with white health professionals is often in writing — frequently through the use of author-itative forms — the women are uncomfortable using a form when asking people if they can take their picture; they prefer to obtain oral consent.

The Camera as Research Tool

Since all the participants are not pregnant at the same time, they enter the study at different times and begin to use a camera at different times. This has required the development of a camera-tracking system. As well, the cameras are labelled so that a camera being used for the study does not get mistaken for a personal camera. The participants in this study are busy mothers, some with as many as five children. For this reason, cameras sometimes get shelved while the women deal with matters of more immediate concern. Also, cameras are sometimes misplaced or damaged, which can have implications for the project's budget. The photovoice process is time-intensive; it requires patience and diligence on the part of the researcher, to enable the women to return films, record stories, and attend meetings.

Conclusion

The camera is a valuable tool for gaining entry to a community and for engaging participants in the research process. Photovoice has been an incentive for Tlicho women to participate in the present study and has been a source of pride for those whose photographs are chosen for discussion. Kenny (2002) proposes that policies be developed locally through discourse with local women, so that the women are the policymakers. The photovoice technique has enabled Tlicho women to talk about and reflect on their health beliefs and health promotion practices in the context of their individual and collective lives in their community. This in turn may generate the insight and empowerment necessary to promote policy change.

References

Adams, H. (1994). *A tortured people: The politics of colonization.* Penticton, BC: Theytus.

Agar, M., & Hobbs, J. R. (1980). *Interpreting discourse: Coherence and the analysis of ethnographic interviews.* Menlo Park, CA: SRI International.

Alfred, T. (1999). *Peace, power, righteousness: An indigenous manifesto.* New York: Oxford University Press.

Bach, H. (1998). *A visual narrative concerning curriculum, girls, photography etc.* Edmonton: Qual Institute Press.

Barthes, R. (1981). *Camera lucida: Reflections on photography.* New York: Hill & Wang.

Battiste, M. (Ed.). (2000). *Reclaiming indigenous voice and vision.* Vancouver: University of British Columbia Press.

Berger, T. R. (1991). *A long and terrible shadow.* Toronto: Douglas & McIntyre.

Brink, P. (2000). Series editor's foreword. In J. M. Roper & J. Shipira, *Ethnography in nursing research.* Thousand Oaks, CA: Sage.

Brown, A., & Smye, V. (2002). A post-colonial analysis of healthcare discourses addressing Aboriginal women. *Nurse Researcher, 9*(3), 28–41.

Carter, S. (1999). *Aboriginal people and colonizers of western Canada to 1900.* Toronto: University of Toronto Press.

Clarke, H. E. (1997). Research in nursing and cultural diversity: Working with First Nations peoples. *Canadian Journal of Nursing Research, 29*(2), 11–25.

Collier, J., & Collier, M. (1986). *Visual anthropology: Photography as a research method.* Albuquerque: University of New Mexico Press.

Denzin, N. K., & Lincoln, Y. S. (Eds.). (2000). *Handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.

Fetterman, D. M. (1998). *Ethnography: Step by step* (2nd ed.). Thousand Oaks: CA: Sage.

Friere, P. (1970). *Pedagogy of the oppressed.* New York: Seabury.

Fumoleau, R. (1975). *As long as this land shall last: A history of Treaty 8 and Treaty 11 1870–1939.* Toronto: McClelland & Stewart.

Grenier, L. (1998). *Working with indigenous knowledge: A guide for researchers.* Ottawa: International Development Research Centre.

Guyette, S. (1983). *Community-based research: A handbook for Native Americans.* Los Angeles: Regents of the University of California.

Harper, D. (2000). Reimaging visual methods: Galileo to Neuromancer. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.

Helm, J. (2000). *The people of Denendeh: Ethnohistoy of the Indians of Canada's Northwest Territories.* Montreal: McGill-Queen's University Press.

Hubbard, J. (1991). *Shooting back: A photographic view of life by homeless children.* San Francisco: Chronicle.

Hubbard, J. (1994). *Shooting back from the reservation.* New York: New Press.

Kenny, C. (2002). *North American Indian, Métis and Inuit women speak about culture, education and work.* Ottawa: Status of Women Canada.

Killon, C. M., & Wang, C. C. (2000). Linking African American mothers across life stage and station through photovoice. *Journal of Health Care for the Poor and Underserved, 11*(3), 310–325.

Koche, T., & Herrington, A. (1998). Reconceptualizing rigour: The case for reflexivity. *Journal of Advanced Nursing, 28*(4), 882–890.

LeClerc, C. M., Wells, D. L., Craig, D., & Wilson, J. L. (2002). Falling short of the mark: Tales of life after hospital discharge. *Clinical Nursing Research, 11*(3), 242–263.

LeCompte, M. D., & Schensul, J. J. (1999). *Designing and conducting ethnographic research: Ethnographer's toolkit.* London: AltaMira.

Lykes, B., Blanche, M. T., & Hamber, B. (2003). Narrating survival and change in Guatemala and South Africa: The politics of representation and a liberatory community psychology. *American Journal of Community Psychology, 31*(1/2), 79–90.

Meleis, A. I. (1996). Culturally competent scholarship: Substance and rigour. *Advanced Nursing Science, 19*(2), 1–16.

Moffitt, P. (2004). Colonialization: A health determinant for pregnant Dogrib women. *Journal of Transcultural Nursing, 15,* 323–330.

Morse, J. M., & Field, P. A. (1995). *Qualitative research methods for health professionals* (2nd ed.). Thousand Oaks, CA: Sage.

New York State Scholar Practitioner Team. (2002). *Visions and voice: Representations of welfare reform.* Retrieved June 2, 2003, from http://web.gc.cuny.edu/Anthropology/field_photovoice.html

NWT Bureau of Statistics. (2001). *Population statistics.* Retrieved June 6, 2003, from http://www.stats.gov.nt.ca/statinfo.html

O'Neil, J. (1988). Self-determination, medical ideology and health services in Inuit communities. In G. Dacks & K. Coates (Eds.), *Northern communities: The prospects for empowerment* (pp. 33–48). Edmonton: Boreal Institute for Northern Studies.

Paulette, L. (1990). The changing experience of childbirth in the Western N.W.T. In J. D. O'Neil & P. Gilbert (Eds.), *Childbirth in the Canadian North: Epidemiological, clinical and cultural perspectives* (pp. 45–50). Winnipeg: Northern Health Research Unit, University of Manitoba.

Roper, J. M., & Shapira, J. (2000). *Ethnography in nursing research.* Thousand Oaks, CA: Sage.

Ryan, J. (1995). *Doing things the right way: Dene traditional justice in Lac La Marte NWT.* Calgary: University of Calgary Press.

Savedra, M. C., & Highley, B. L. (1988). Photography: Is it useful in learning how adolescents view hospitalization? *Journal of Adolescent Health Care, 9,* 219–224.

Smith, D. (2003). Maternal-child health care in Aboriginal communities. *Canadian Journal of Nursing Research, 35*(2), 143–152.

Smith, L. T. (2001). *Decolonizing methodologies: Research and indigenous peoples.* New York: Zed.

Spradley, J. P. (1979). *The ethnographic interview.* Toronto: Holt, Rinehart & Winston.

Steckley, J. L., & Cummins, B. D. (2001). *Full circle: Canada's First Nations.* Toronto: Prentice-Hall.

Wallerstein, N., & Bernstein, E. (1988). Empowerment education: Friere's ideas adapted to health education. *Health Education Quarterly, 15*(4), 379–394.

Wang, C. (1999). *Photovoice.* Retrieved June 2, 2003, from http://www.photovoice.com/method/index_con.html

Wang, C., & Burris, M. A. (1994). Empowerment through photo novella: Portraits of participation. *Health Education Quarterly, 21*(2), 171–186.

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education and Behavior, 24*(3), 369–387.

Wang, C., Burris, M. A., & Xiang, Y. P. (1996). Chinese village women as visual anthropologists: A participatory approach to reaching policymakers. *Social Science and Medicine, 42*(10), 1391–1400.

Wang, C., Cash, J. L., & Powers, L. S. (2000). Who knows the streets as well as the homeless? Promoting personal and community action through photovoice. *Health Promotion Practice, 1*(1), 81–89.

Wang, C., & Redwood-Jones, Y. A. (2001). Photovoice ethics: Perspectives from Flint Photovoice. *Health Education and Behavior, 23*(5), 560–572.

Wang, C. C., Yi, W. K., Tao, Z. W., & Carovano, K. (1998). Photovoice as a participatory health promotion strategy. *Health Promotion International, 13*(1), 75–86.

Williams, A. (1996). The politics of feminist ethnography. *Canadian Journal of Nursing Research, 28*(1), 87–94.

Authors' Note

[The following comments are those of the first author.] I would like to thank all of the Tlicho women who shared their photographs and stories. Without their participation this method could not have been used. It is my sincere hope that this paper demonstrates a self-representation they can be proud of. I am also grateful to my committee members: Dr. Ardene Robinson Vollman and Dr. Sandra Reilly (co-supervisors), Dr. Lynn Meadows, and the late Dr. Elizabeth (Betty) Thomlinson.

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Happenings

CHNET-Works! A Networking Infrastructure for Community Health Nurse Researchers and Decision-Makers

Nancy Edwards and Anita Kothari

Community health nurse researchers, practitioners, and decision-makers in Canada are about to be introduced to CHNET-Works!, a networking infrastructure. The purposes of the network are to increase the responsiveness of the research community to emerging issues in the community health policy and practice fields, and to support use of the latest research evidence by those in the decision-making and practice communities. The network will promote community health nursing leadership, foster multisite and multidisciplinary research, and facilitate evidence-based policy and program development. It will provide a suite of networking tools and support activities such as links to searchable databases and face-to-face interactions among community health decision-makers, practitioners, and researchers. Our mission is to encourage formal partnerships between nurse researchers and decision-makers. It is expected that these partnerships will lead to high-quality applied health services research and to more timely use of research findings.

Although strategic and efficient networking is an important strategy for all nurse researcher and decision-making partners, it is particularly germane to the community health field. The design of evidence-based community health programs and policy initiatives is a complex undertaking (Bryant, 2002; Campbell et al., 2000; Edwards, Mill, & Kothari, 2004) and must be guided by an array of theoretical and empirical evidence (Krieger, 2001). Accessing this broad range of information could be better supported via a network. Furthermore, due to the complex designs of community health and public health programs, mixed methods are often required to address research questions about effective program delivery. A strong network can support access to the specialized areas of methodology expertise required in this field (Baum, 1995; Glasgow, Vogt, & Boles, 1999; Russell et al., 2004).

Decision-makers spend much time and effort assessing and prioritizing community needs, identifying an effective range of services, and allocating human resources to deliver these services. A network will provide a means to more readily access relevant data and research, including health-status profiles (e.g., regional and provincial "report cards" on health status) (Fulop & McKee, 1996), systematic reviews (e.g., Public Health reviews, Cochrane reviews, Campbell reviews), policy and legislative data (e.g., tobacco legislation database assembled by researchers funded through the Tobacco Demand Reduction Strategy of Health Canada), policy and management research, health surveillance information (e.g., Perinatal and Injury Databases), and health human resource data and research findings). Access to this type of information is essential for the design of responsive, needs-based programs by decision-makers.

The network will also be relevant for nursing practice. The nature of community health practice and program delivery is such that many nurses are working in geographically disparate settings, isolated from researchers and key decision-making partners. A virtual network provides an essential means to identify important and researchable health service delivery issues arising in rural and remote areas of Canada.

Why a Network?

Our preliminary needs assessment (through focus-group discussions, a national workshop, and interviews) highlighted the need for a network to link nurses in practice settings with decision-makers and researchers in order to advance the public and community health agendas. Interviewees also expressed the need for a network to support nursing leadership while building broad public and community health initiatives and collaborating with other disciplines, sectors, and stakeholders. Thus, while CHNET-Works! will have a nursing disciplinary focus, it will also encourage an interdisciplinary approach to community health.

The literature on networks spans a range of disciplines. Hill (2002) provides a comprehensive overview of the literature, with a focus on population health issues. The literature defines a network as three or more autonomous organizations coming together for a common purpose in which participation is voluntary and no member is superior or subordinate to another (horizontal organization) (Hill). It is collaborative, membership-driven, and ongoing/continuous (not a one-time collaboration). It takes time to develop, must be nurtured, and requires clear goals. It is more likely to be successful if it has a clear vision and mission, and a modest number of broad objectives accompanied by clear steps for action (Roussos & Fawcett, 2000). Leadership needs to be developed and supported; different leadership skills are important at different stages of the network (Roussos & Fawcett). Trust-building, facilitated through frequent and open communication, is important and can take years (Hill).

To summarize, the literature argues that networks are a way to resolve complex problems (Hill, 2002). A network can facilitate the sharing of resources, access to expertise, and the adoption of technologies, not to mention mobilizing political power within the health-care community (Hill).

What CHNET-Works! Will Look Like

The purpose of CHNET-Works! is to enhance communication, collaboration, and cooperation among community health nurse decision-makers, practitioners, and researchers. The network will bring together the creators of knowledge and the users of knowledge; foster cross-community learning and instil a culture of collaboration; facilitate the movement of evidence-based research into community health policies, programs, and practice; and broker the sharing by decision-makers of how they access and use research findings for decision-making in the field of community health.

During the next phase of this initiative, a set of networking tools will be designed and pilot-tested. Examples of tools under consideration include *commentaries* on emerging issues from those in the evaluation and policy fields, *debating panels* on hot issues with opinion leaders, *E-share* where program design tools such as logic models can be exchanged, *flash polls* where nurses can express their opinions on hot issues, and *dialogue from the front lines* where nurses can discuss the innovations that are emerging in the practice field.

Initially, the network will have two main tracks. The aim of Track 1 will be timely responsiveness to current critical issues and opportunities; these would have a short-term focus and would shift over time in response to changes in the community health environment. Examples of topics that might be featured in this track include communicable disease outbreaks such as SARS or West Nile virus, imminent legislation impacting on health such as changes in tobacco taxation, or critical budgetary decisions impacting on the delivery of public health services. Track 2, in contrast, will focus on building a networking infrastructure for issues requiring a longer-term vision for change. Potential areas of strategic interest are the prevention of chronic disease or the addressing of health inequities. Through Track 2 we hope to develop meaningful depth around an issue — that is, cultivate lasting linkages that require practice-based knowledge, research knowledge, and decision-maker commitment.

The network is being governed by an Interim Steering Committee. This committee will be in place for approximately 6 months with the mandate of launching the network, guiding the formation of subsequent Working Groups, and forming a post-launch Advisory Group. An evaluation of the network structure and outcomes is being planned concurrently with prototype development.

Development of this network is timely, as it coincides with provincial and national initiatives to identify public health competencies, the dissemination of community health standards, the establishment of an active coalition for public health in the 21st century, and the creation of the Ministry of State for Public Health. Although the network is at an early phase in its development, it is expected to provide a venue to forge productive interactions among those who are attempting to build a stronger infrastructure of cost-effective community health services across the country.

References

Baum, F. (1995). Researching public health: Behind the qualitative-quantitative methodological debate. *Social Science and Medicine, 40*(4), 459–468.

Bryant, T. (2002). Role of knowledge in public health and health promotion policy change. *Health Promotion International, 17*(1), 89–98.

Campbell, M., Fitzpatrick, R., Haines, A., Kinmonth, A. L., Sandercock, P., Spiegelhalter, D., et al. (2000). Framework for design and evaluation of complex interventions to improve health. *British Medical Journal, 321*(7262), 694–696.

Edwards, N., Mill, J., & Kothari, A. (2004). Multiple intervention research programs in community health. *CJNR, 36*(1), 40–54.

Fulop, N., & McKee, M. (1996). What impact do annual public health reports have? *Public Health, 110*(5), 307–311.

Glasgow, R. E., Vogt, T. M., & Boles, S. M. (1999). Evaluating the public health impact of health promotion interventions: The RE-AIM Framework. *American Journal of Public Health, 89*(9), 1322–1327.

Hill, C. (2002). *Network literature review: Conceptualizing and evaluating networks.* Unpublished paper prepared for the Southern Alberta Child and Youth Health Network.

Krieger, N. (2001). Theories for social epidemiology in the 21st century: An ecosocial perspective. *International Journal of Epidemiology, 30*(4), 668–677.

Roussos, S. T., & Fawcett, S. B. (2000). A review of collaborative partnerships as a strategy for improving community health. *Annual Review of Public Health, 21*(1), 369–402.

Russell, J., Greenhalgh, T., Boynton, P., & Rigby, M. (2004). Soft networks for bridging the gap between research and practice: Illuminative evaluation of CHAIN. *British Medical Journal (International Edition), 328*(7449), 1169–1174.

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To obtain more information on CHNET-Works!, readers are invited to contact Nancy Edwards at nedwards@uottawa.ca or Anita Kothari at akothari@uwo.ca

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Book Review

Cultural Diversity in Health and Illness (6th ed.)

Rachel E. Spector
Upper Saddle River, NJ: Pearson Education. 375 pp.
ISBN 0-13-049379-1

Reviewed by Joan Gillie

Cultural Diversity in Health and Illness focuses on the myriad dimensions of providing health care to diverse populations in a culturally competent way. The preface to this 6th edition outlines the new requirement in the United States for health-care providers to be culturally competent, reflective of the policies of the Joint Commission of Hospital Accreditation and the Centers for Medicare and Medicaid Services. This edition features complementary resources such as a companion Web site (www.prenhall.com/spector), an online course management system, and cultural competency guidelines.

This US-focused publication is organized into three units, Cultural Foundations, Health Domains, and Health and Illness Panoramas. Unit 1 focuses on three elements: heritage and culture, population diversity based on 2000 US Census data, and health and illness. Unit 2 outlines health, healing, and familial health traditions as well as health-care delivery. Unit 3 provides examples of health and illness scenarios from the American Indian and Alaska Native, Asian, Black, Hispanic, and White populations. A comprehensive set of appendices includes a sample course outline, suggested activities, networking resources, glossary, bibliography, and index.

There is no doubt as to the thoroughness and dedication with which this information has been compiled, and Spector provides impressively detailed and interesting information about a variety of approaches to health and illness. However, she focuses primarily on culture as ethnicity in her analyses and in doing so conflates culture with ethnicity. This focus obscures the important intersectional and socially constructed realities of culture that are reflected in health-care experiences informed by gender, class, age, sexual orientation, ability, history, immigration, and so on. The result is a treatment of culture that does not take fully into account the complex interplay between the sociocultural determinants of health that influence differential health experiences of individuals and groups. Further, Spector does not draw upon more recent social science and health literatures that consider health perspectives informed by feminist, critical social, humanist, phenomenological, and postcolonial theories.

In order to develop cultural competence in the context of a multi-levelled holistic "cultural care" model, Spector recommends developing awareness of both self and other. However, she approaches self and other mostly uncritically, with the focus less on health-care providers acknowledging themselves as bearers of culture, both personally and professionally, than on "others" as the bearers of culture. While Spector states that the health-care provider must "explore his or her own cultural identity and heritage and confront biases and stereotypes" (p. 301), she offers no concomitant critical analysis of the power relations informing why most health-care providers do not acknowledge their location within the dominant biomedical culture. Thus, despite the recommendation above, Spector's analysis remains in the more (implicitly) passive realm of cultural sensitivity rather than moving towards the transformation of health-care systems as culturally safe places requiring the active engagement of health-care professionals in critical reflection about their roles and locations.

Spector describes culture as a medium for relationships and as encompassing learned behaviours (p. 10). However, she presents historic sociocultural events as influencing the health experiences of individuals and health providers "in the United States and the world" (pp. 19–20) without paying sufficient attention to how culture is co-created or socially constructed and experienced by individuals affected by historic, economic, or social processes. Further, she does not discuss the power relations that inform these processes. A critical analysis of power relations in health-care interactions, from the micro level of individual experience through to meso and macro levels of health-care policy implementation, would explicate the differential locations of individual and group access to health care. Without an understanding of the culturally embedded nature of inequities in relation to self and other, constructive transformation of health experiences will not occur.

In the past 15 years, writers of culture and health across disciplines have theorized beyond the view of culture as ethnicity as seen in transcultural nursing theory and cultural sensitivity models (see Leininger, 1970, 1978). This more recent work considers culture and the social determinants of health in broader theoretical contexts (see Bhabha, 1994; Corbett, 1994; Gandhi, 1998; Gilroy, 2000; Nicholls, 1997; Stephenson, 1999; Wendell, 1996). Nursing has contributed a wealth of resources, particularly the development of the concept of cultural safety (see Anderson & Reimer Kirkham, 1999; Canales, 2000; Polaschek, 1998; Ramsden, 1993, 2000; Smye & Browne, 2002). This book would have benefited from consideration of these broader ideas.

Detailed charts of birth and death rites organized by nation of origin or religion will be useful to health professionals as a guide, but without adequate critical reflection on a health provider's own social location(s) within the culture(s) of health care and beyond, such charts may perpetuate stereotyping and labelling. For example, in chapter 8, Health and Illness in the American Indian and Alaska Native Population, the opportunity arises, in a discussion of fetal alcohol syndrome, to contextualize FAS in relation to colonization, dominance, and internalized oppression resulting from unequal power relations in the historic development of the United States. It is important for health professionals to understand this, so that challenges arising from FAS are not essentialized or reduced to the individual or to culture, resulting in "blaming the victim" or blaming Native "culture." FAS needs to be discussed in the wider context of cultural expropriation and obfuscation of choice. While Spector states that "the story of colonization and settlement of the United States is being retold with a different emphasis" (p. 108), she does not describe this new emphasis in enough detail, or explain why it is important. Although Spector cites Native medicine person Hawk Littlejohn regarding how loss of choice by American Indians has contributed to FAS (p. 199), she does not explain in detail how this loss of choice is a result of the dynamics of colonization and genocide. In the absence of such an explanation, many readers may not be fully aware of the connections between FAS, individual lived experiences of health, and power dynamics in the wider society. Nor does Spector say how American Indians will "return to a sense of identification within themselves," which Littlejohn proposes (p. 199). Without such explanation, it is unclear that health-care providers either can have a role in facilitating a return to a sense of self-identification or can perpetuate present inequities.

Spector offers little critical examination of the intersections and simultaneities of human health experiences varying from conventional heteronormative models of the family, nor does she consider (dis)ability, or other "isms," as she calls them, in much depth. By focusing primarily on culture as ethnicity, Spector overlooks the profoundly important intersections among ethnicity, gender, poverty, race, class, immigration, citizenship, ability, size, and sexual orientation, all of which contribute to culture. The "isms" are summarized in a short section on Cultural Conflict (pp. 21–22) and portrayed as problems that occur "when cultures clash" (p. 22).

Finally, Spector has missed an opportunity to endorse health-promoting practice, especially in relation to recent research exploring the possibilities for cultural safety. She does not adequately emphasize the importance of understanding how difference has been problematized in health-care interactions through dominant power relations in biomedicine and in society. Consequently, health professionals using this resource uncritically may unwittingly perpetuate "othering" and marginalizing relationships.

The value of *Cultural Diversity in Health and Illness* is the fascinating and detailed information it provides on diverse health traditions as well as current US demographic data. This book clearly promotes cultural sensitivity, and any effort to foster better health relationships is laudable. Learners and teachers in the health professions will find much of interest in this book. However, my endorsement is tempered by a recommendation for critical reflection, particularly to consider the data on health statuses in relation to the powerful influences of colonization and to consider the recent literature on cultural safety.

References

Anderson, J., & Reimer Kirkham, S. (1999). Discourses on health: A critical perspective. In H. Coward & P. Ratanakul (Eds.), *A cross-cultural dialogue on health care ethics* (pp. 47–67). Waterloo, ON: Wilfrid Laurier University Press.

Bhabha, H. (1994). *The location of culture*. London: Routledge.

Canales, M. K. (2000). Othering: Toward an understanding of difference. *Advances in Nursing Science, 22*(4), 16–31.

Corbett, J. (1994). A proud label: Exploring the relationship between disability politics and gay pride. *Disability and Society, 93,* 343–357.

Gandhi, L. (1998). *Postcolonial theory: A critical introduction.* New York: Columbia University Press.

Gilroy, P. (2000). *Against race: Imagining political culture beyond the color line.* Cambridge, MA: Belknap.

Leininger, M. (1970). *Nursing and anthropology: Two worlds to blend.* New York: John Wiley.

Leininger, M. (1978). *Transcultural nursing: Concepts, theories, and practices.* New York: John Wiley.

Nicholls, N. (1997). Disability as difference. In P. Angelini (Ed.), *Our society: Human diversity in Canada*. Scarborough, ON: ITP Nelson.

Polaschek, N. R. (1998). Cultural safety: A new concept in nursing people of different ethnicities. *Journal of Advanced Nursing, 27,* 452–457.

Ramsden, I. (1993). Kawa whakaruruhau cultural safety in nursing education in Aotearoa (New Zealand). *Nursing Praxis in New Zealand, 8*(3), 4–10.

Ramsden, I. (2000).Cultural safety/kawa whakaruruhau ten years on: A personal overview. *Nursing Praxis in New Zealand, 15*(1), 4–12.

Smye, V., & Browne, A. J. (2002). Cultural safety and the analysis of health policy affecting Aboriginal people. *Nurse Researcher, 9*(3), 42–56.

Stephenson, P. (1999). Expanding notions of culture for cross-cultural ethics in health and medicine. In. H. Coward and P. Ratanakul (Eds.), *A cross-cultural dialogue on health care ethics* (pp. 68–91). Waterloo, ON: Wilfrid Laurier University Press.

Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability.* New York: Routledge.

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