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GUEST EDITORIAL

Towards Understanding Women's Health through a Social Determinants Lens

Judith Wuest

Women's health is a compelling, complex, and prodigious domain for nursing research. Our ways of thinking about and studying the health of women have been influenced by shifting models of health, from absence of disease, to personal responsibility through lifestyle choices, to, finally, social determination. The strength of a social determinants perspective for understanding women's health is its acknowledgement of the influence of social context, at macro and micro levels (Moss, 2002), not only on health outcomes but also on patterns of promoting, maintaining, and regaining health. Neither biology nor personal responsibility are ignored, but rather they are understood within the context of social, economic, environmental, and political contexts at the societal, familial, and individual levels. Health Canada's 1999 *Women's Health Strategy* provides an excellent background to the complexity of a social determinants perspective.

While nurses recognize the importance of a social determinants model for understanding the intricacy of women's health, rarely do they explicitly situate their research studies in this framework. More often, the social determinants perspective is introduced after the fact. If a social determinants model guides the research, frequently the focus is on one or two determinants or solely at an individual level. To some extent, this relates to the complicated nature of the social determinants perspective. Making sense of women's health in a way that accounts for multiple determinants at both macro and micro levels requires advanced research skills and a complex research plan, whether the approach is rooted in traditional science or in naturalism. Another deterrent is the fact that research situated in a social determinants framework may be less identifiable as "health" or "nursing" research, especially if the implications focus on policy or structural changes outside the realm of what is traditionally considered health or nursing. While lip service is given to the notion of healthy public policy, editors of health-research journals often have difficulty seeing findings with implications for the justice, housing, employment, or immigration sectors as relevant to health research.

Despite these challenges, in my judgement findings from research with a social determinants orientation offer us the best chance for understanding the tangled patterns of women's health within a family, social, cultural, political, and economic context. Such knowledge is essential for informing the construction, evaluation, and promotion of nursing interventions that promote equity and well-being. Hence, the call for papers for this issue invited theoretical and research-based manuscripts that addressed the cumulative and interactive effects of multiple social determinants at various levels (individual, family, community, organizations, services, policy, laws). The response was overwhelming, with almost 40 papers submitted. Finding almost 80 scholars to review these submissions in midsummer, not just for scholarly merit but also for relevance to the issue, was no mean feat! My heartfelt thanks to those of you who did reviews. They were thoughtful, substantive, and encouraging for authors; indeed, some authors have indicated that these reviews were exemplary and provided extraordinary direction for strengthening future submissions.

The manuscripts submitted reflect the fact that authors considered their studies to be relevant to a social determinants perspective, regardless of whether they had explicitly used a social determinants model. Some manuscripts targeted named social determinants such as income, gender, social support, culture, employment, or environment. In other manuscripts the connection to social determinants was tenuous, almost an afterthought. Many of the studies addressed single determinants at an individual level; the cumulative and interactive effects at macro and micro levels were less well addressed.

This collection of six scholarly papers reflects the current state of health research with respect to the social determination of women's health. Issues addressed are wide-ranging, with social determinants situated diversely as foreground or background. I am heartened that several of the papers are reports of doctoral research, suggesting that new scholars recognize the importance of a social determinants perspective. The first paper focuses on cardiac disease, a growing concern for women. Kathryn King and her colleagues have drawn on their extensive program of research exploring the complexities of ethnocultural affiliation, gender, and management of cardiac risk factors to present an analysis of the gender-based challenges of older Sikh immigrant women when facing and responding to the risk of coronary artery disease. The analysis reveals the effects of multiple health determinants at individual, familial, and community levels and offers suggestions for more targeted intervention. The next paper is a noteworthy report of Carol MacDonald's doctoral exploration of the experience of lesbian disclosure. These findings help us to shift our assumptions and illuminate sexual orientation as a determinant of health. Mental health among single mothers is the focus of the third paper, contributed by Joan Samuels-Dennis, a doctoral student who has embraced the social determinants perspective. Samuels-

Dennis makes a contribution to the untangling of relationships among employment status, stressors, and symptoms of clinical depression. Another important issue for women is screening for breast and cervical cancers. Tam Truong Donnelly reports the findings of her doctoral research in her exploratory study of the influence of cultural knowledge and values on Vietnamese women's decisions with regard to cancer screening. These findings tap the intersection of the determinants of culture and health services. The fifth paper in our collection addresses the health of First Nations women. Helen Vallianatos and her colleagues explored weight gain and weight loss related to pregnancy among First Nations women, elucidating not only the effects of cultural beliefs, but also the influences of community and environmental constraints. The final paper is an exploration of dementia care by daughters from the perspectives of the mothers receiving care. Catherine Ward-Griffin and her colleagues demonstrate at a family level how social support is enacted in this vulnerable population.

Our collection is augmented by several invited papers. Joan Anderson provides a thought-provoking Discourse, exploring our progress in understanding women's health as socially determined and, through a critical examination of racialization, demonstrating the depth and detail of analysis necessary to understand social determination. In Happenings, Shirley Solberg offers a splendid discussion of the findings related to women's health from a major collaborative research initiative to understand how reduced fish stocks and subsequent loss of the fisheries interacted with social changes to affect human and environmental health and well-being in Newfoundland coastal communities. Finally, Marilyn Ford-Gilboe and her colleagues, in Translating Research, discuss the development of an intervention model to improve the health and well-being of women in the aftermath of leaving an abusive partner. The proposed intervention model is informed by their previous qualitative and quantitative findings from research studies situated in a social determinants perspective.

Finally, my thanks to Laurie Gottlieb and Joanna Toti for their guidance over the past months. I have gained an appreciation of the dedication, time, and determination needed to produce an issue of a scholarly journal. My thanks to all editors who do this important yet difficult work month after month, thus providing scholars a venue for sharing their work.

Judith Wuest, RN, PhD, is Professor and Canadian Institutes of Health Research/University of New Brunswick Investigator, Faculty of Nursing, University of New Brunswick, Fredericton, Canada.

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Discourse

Reflections on the Social Determinants of Women's Health

Exploring Intersections: Does Racialization Matter?

Joan M. Anderson

Introduction

It is an honour to be invited to write the Discourse for this issue devoted to a social determinants perspective on women's health. It is especially gratifying to reread the call for papers and to see determinants conceptualized as inclusive of gender and culture. For me, the mention of culture as a determinant immediately raises a question: How/why is culture a determinant of health, and, if we examine culture as a determinant, what else should we include? I will return to this question later. Suffice it to say that writing this essay has given me an opportunity to reflect on the trends and funding support over the past 10 years that have contributed to our understanding of the social determinants of women's health. *CJNR* has provided ample opportunity for us to engage in a substantive dialogue. For example, in 1994 and 2001 it published issues devoted to Women's Health (Vol. 26, N° 4, and Vol. 33, N° 3). Other focus issues pertinent to the topic include Culture and Gender, in 1996 and 2003 (Vol. 28, N° 1, and Vol. 35, N° 2), and Diversity and Health, in 2004 (Vol. 36, N° 4). This is a good time to revisit some of the ideas that were highlighted over a decade ago as well as to pose some further questions: To what extent have these earlier discussions informed our understanding/conceptualization of social determinants? How far have we come? Where are we going?

Connecting Past Dialogues with a Social Determinants Perspective

Ellen Hodnett, in her guest editorial in the Winter 1994 issue of *CJNR* devoted to Women's Health, states, "I was an active participant at the local and national levels in the recent restructuring of the Medical Research

Council, and I remain optimistic that Canada's largest health research granting agency will one day fulfil its legislated mandate" (Hodnett, 1994, p. 8).

The launch of the Canadian Institutes of Health Research (CIHR) in 2000, with its broad, inclusive, transformative mandate, has been a watershed in Canadian health research, opening up opportunities for research on the social determinants of women's health. The CIHR is committed to four research themes (biomedical, clinical, health systems and services, and population and public health), all of which are reflected in its 13 institutes. This commitment has provided an enormous boost to research on women's health and on emerging conceptualizations of gender and health research. Miriam Stewart and her colleagues (Stewart, Kushner, & Spitzer, 2001) set out the research priorities conceptualized by the CIHR's Institute of Gender and Health, pointing the way to the inclusion of gender analysis across a wide spectrum of health research.

The discipline of nursing has benefited from new funding opportunities and new synergies in health research. Many nurse scholars, at different stages in their careers, have received CIHR awards and research grants. Yet, while we have good reason to celebrate our achievements, as we look to new horizons many questions remain, in terms of not only how to ensure stable funding for new generations of nurse researchers, but also how to address new questions and how to translate knowledge into policy and practice. How have the new opportunities in research funding affected the everyday lives of women and provided new insights into the determinants of their health?

Pat McKeever, in the Winter 1994 issue of *CJNR*, states, "I believe that women currently are bearing a disproportionate share of the costs that are associated with chronic illness and disability" (McKeever, 1994, p. 15). How far have we come since 1994? Are women still bearing a disproportionate share of the costs associated with chronic illness and disability? With all of the changes in health-care delivery systems over the past decade, one might argue that an even larger proportion of the cost of caring is being passed on to women (and men), who are the caretakers despite the resources being put into home-care management. Lynam and her colleagues (2003) argue, for example, that "In enacting the reform agenda, the importance of the home as a site for illness care has increased." There are consequences, most likely, for women's caretaking role in the home.

A cogent argument could be made for naming the allocation of resources to health-care delivery systems a social determinant of women's health, since it shapes women's lives in significant ways. One is struck by the complexity of the determinants, the multiplicity of intersecting factors, and the shallowness of our understanding of the issues. For example, impoverished women seem more vulnerable than affluent women when they have to assume a caretaker role, as caregiving can drain their scarce resources. But can one leave it at that? One might argue that the support networks of some poor women mitigate their lack of economic resources. What are some of the sociopolitical conditions that condemn women to a life of poverty or to a life of social isolation? Are some women positioned in such a way that they are "at greater risk" for a life of poverty or social isolation? In mulling over these questions, I have found it necessary to sift through the many concepts that have been making their way into the health-care literature over the past decade or so. It is to these concepts that I now turn.

Exploring Emerging Directions in the Social Determinants of Women's Health

In 1996 I was invited to serve as guest editor of the *CJNR* focus issue on Culture and Gender. In reviewing the papers that were to be published in that issue, I observed that one of them provided "the lenses through which we might begin to grasp the simultaneity of oppressions at the intersectionality of gender, class, and race relations" (Anderson, 1996, p. 18). How and to what extent should these concepts be woven into the social determinants of women's health? I would argue that if we name culture as a determinant of health, we must, of necessity, include other concepts that have become conflated with culture. It is only by grappling with these complexities that we will be able to pursue a meaningful and insightful analysis.

In reflecting on how far we have come in our understanding of the "simultaneity of oppressions" since I wrote that editorial in 1996, I have thought about my own struggles with the complexity of this kind of analysis and some of the concepts that have been surfacing in my own research and that of my colleagues. Many scholars in Canada and elsewhere are conducting research into women's health and are exploring various intersections in their work, including the intersections of gender, race, class, and other social relations. But despite the work that is being done, I believe, much remains to be unmasked; we have to make transparent the complexities of these intersections and how they are *played out in everyday life to determine women's health.* We might assume we know what "race" means, but how can we use the concept as an analytic category in trying to comprehend the social determinants of women's health? What are the *processes* by which *race* is played out in everyday life that makes it worthy of mention, and how do these processes intersect with class and gender? I suspect that there is no single way to tackle these questions — our paradigms of inquiry will, to some extent, organize how such questions are approached — but I want to reflect on one tack we might take as we analyze these complex issues as social determinants of women's health.

In her groundbreaking doctoral dissertation research (for which she won the Governor General's Gold Medal at the University of British Columbia), Sheryl Reimer Kirkham (2000) offers a convincing analysis of racialization in health-care settings. It is to this concept that I now turn. Before discussing some of Reimer Kirkham's insights, I would like to direct the reader to a definition of *racialization.* Although not as widely used as *race*, the word racialization could offer a handle on how we might begin to unpack the concept of race in our research. Ahmad (1994) tells us that "racialization assumes that 'race' is the primary, natural and neutral means of categorization, and that the groups are distinct also in behavioural characteristics, which result from their 'race'" (p. 18). I take it that Ahmad is drawing our attention to the assumptions we make about people based on the racial categories we put them in. He goes on to tell us that "a major issue in the racialization of health research is that it is assumed that the populations can only be meaningfully divided into 'ethnic' or 'racial' groups, taking these as primary categories and using these categories for explanatory purposes" (p. 19). The problem with this, Ahmad warns, is that "issues of institutional and individual racism as determinants of health status or health care become peripheral at best" (p. 19).

For me, Ahmad's observation raises many questions about the conduct of health research and the conundrum that faces the health researcher. For example, I am mindful of the ways in which the very research we do to address inequities in women's health might reinforce the inequities, since we assign people to "ethnic" categories that could carry connotations about people's behaviour. Such research, though well-intentioned, could eventually feed into racialized categories. For this reason, I believe, the concept of racialization *as process,* as opposed to race *as category,* may hold promise as an analytic strategy: instead of categorizing people by race, we would be examining how racial categories are constructed and how the *constructions are used* in everyday social encounters to *categorize* people in order to interpret what they do and say.

What is compelling about Reimer Kirhkam's (2000) work is that she draws our attention to *how racialization operates,* showing us how the nurses of colour in her study experienced racialization. Reimer Kirkham explicates how *processes actually worked in day-to-day interactions to construct people in particular ways.* As she point out, "While much health care literature focuses on encounters between White health care providers and recipients of Colour, there are a whole range of other relations, often along various intersecting axes of power differentials, that illustrate the nefarious and shifting ways in which *race* is constructed and negotiated in health care settings" (p. 203). What is implicit here is that constructions of race (*racializing processes)* are not neutral; they have implications for people's lives. I am reminded of an incident from one of our research studies. A nurse, a woman of colour, related her experience of working with a patient who had undergone eye surgery. Before the patient's eye patches were removed — before he could see the nurse — the conversation was cordial. Once he could see her, his tone changed. The nurse felt that she could no longer do anything right; her competence was questioned. Such racialized assumptions about competence are historically located and socially reproduced in everyday interactions, sometimes in ways that are "hidden." They make up the substratum of the taken for granted and often go unquestioned and unchallenged.

Let me be swift in pointing out that it is not only people of colour who are racialized. The processes of racialization apply to everyone. For example, we might assume that white middle-class people are able to "manage" without home-care services because they have the resources to care for themselves; we related such a case in one of our research papers (Anderson et al., 2003). Or we might assume that people from some "ethnic groups" will go home from hospital to an extended-family situation when, in fact, they may have no one to help them out at home. Although racializing processes can affect anyone, they are most detrimental in situations of unequal power relations, when people from some racialized categories are constructed as *inferior, therefore lacking in authority and unable to fulfil some roles, or when people from some groups are constructed as needy or as expecting too much from the "system,"* as some of the findings from our individual research projects (which form the basis for a knowledge translation study) are now showing.[1] These racialized assumptions, when acted upon, can put people at a disadvantage, with dire consequences for their health and their lives. In such instances, "race" can play out as a determinant of health.

Reimer Kirkham (2003) takes up this point when she argues that "there is mounting evidence of inequities in both health outcomes and health care experiences that fall along lines of race, class and gender.... The health discrepancies experienced by women and those who are impoverished are further complicated by the intersectionality of disadvantages" (p. 2).

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[1] Cultural Safety and Knowledge Uptake in Clinical Settings: A Model for Practice in Culturally Diverse Populations (J. Anderson, A. Browne, J. Lynam, S. Reimer Kirkham, P. Rodney, P. Semeniuk, and others — 2005–08). RFA funded by the Canadian Institutes of Health Research. (A knowledge translation project in the Culture, Gender, and Health Research Unit.)

What we might take from all of this is that the determinant of health is not race as a fixed or biological category but, rather, *the social process of racialization, how people are constructed based on assumptions about race.* That I am brown is not the issue — the issue is how brownness is constructed. *These are the constructions that intersect with relations of power to disadvantage some groups and to ultimately determine and maintain class position.* It is this complex interaction between racialization, gender, and class relations that we need to explore if we are to get a handle on the determinants of women's health that are inclusive of all women who make up the Canadian mosaic. We have a rich research literature on ethnic inequalities and how ethnicity positions people in terms of occupational opportunities and income (see, for example, Li, 1988). In order to determine the mental and physical health of women (and men), we need to understand and further analyze the processes (e.g., racialization) and various intersections with gender and other social relations that operate in everyday interactions.

Earlier, I asked how and why "culture" is a determinant of health and, if we examine "culture" as a determinant, what else we need to include in the discourse. I would suggest that, first of all, we must be clear about what we mean by culture and how it becomes a determinant of health. To what extent might we unwittingly conflate "culture" with "racialized categories"? As Ahmad (1994) tells us, "Racialization takes place in terms of notions of cultures being static and homogeneous and having a biological basis" (p. 19). While, for analytic purposes, the concept of culture needs to be threaded through the discourse on social determinants, we need to monitor our use of the term — is it being used as a static concept or as a fluid, dynamic concept, constructed within highly charged socio-economic-political contexts?

As we unmask the complex processes and intersections that form the social determinants of health, I would like to turn to one further issue. If our analysis is gendered, can we continue to focus our attention solely on women's health? I raise this question not to shift the spotlight from the concerns of women but, rather, in the spirit of analysis. I contend that we can understand women's issues only through rigorous gender analysis, examining the socio-economic-political-historical-racialized contexts of women's lives and comparing them to the lives of men in similar contexts. It is comparison, I argue, that strengthens our analyses, as it is only through comparison that some inequalities can be understood. By comparing the lives of poor women with those of affluent women, for example, and the lives of white women with these of women of colour, we can see how racialization serves to position women in different ways. We need to remain cognizant of the fact that all women do not share the same social reality and the fact that "privilege" operates along different, socially determined, axes of power. We need to tease out the various social and historical locations in order to understand how they function as social determinants of health.

Concluding Comments

When one looks towards the health research of the future and its conceptualizations of the social determinants of health, the opportunities for pushing the boundaries of theorizing seem greater than ever — and the complexities that confront us more daunting than ever. We now have a national funding body that makes it possible for us to do innovative research. Nurse researchers are positioned as never before to engage in research that can influence practice as well as health and social policy. Nurse researchers are in positions of influence. But it is not only the availability of research funding that will make possible the kind of analysis I am suggesting. Nurses have a social and moral responsibility to conduct research that is inclusive of all of Canada's populations. However, we must conduct this research in ways that do not reproduce racialized categories but that, instead, challenge the categories and assumptions that result in the demeaning of people. We need to question the taken for granted and expose the processes through which social reality is constructed and maintained. This issue is not just a theoretical one. It is also a moral issue, with implications for people's lives. It seems reasonable to argue that being demeaned and disempowered is a potent determinant of one's mental and physical health. Nurses should be aware of the processes through which a climate of despair is created. The choice is ours to make. Will we take up the challenge of conducting research that pushes us to a new level in understanding the social determinants of health? Such research may well provide new insights into how we might work towards a more just society.

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Author's Note

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Comments or queries may be directed to Dr. Joan M. Anderson, School of Nursing, University of British Columbia, T201 – 2211 Wesbrook Mall, Vancouver, British Columbia V6T 2B5 Canada. Telephone: 604-822-7455. E-mail: anderson@nursing.ubc.ca

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Joan M. Anderson is Health Research Coordinator, Office of the Vice President Research, University of British Columbia, Vancouver, Canada.

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Résumé

Les défis sexospécifiques auxquels font face les immigrantes sikh âgées : reconnaître les risques de maladie coronarienne et agir

Kathryn M. King, Pam LeBlanc,
Julianne Sanguins et Charles Mather

Le sexe et l'appartenance à un groupe ethnoculturel peuvent avoir une incidence sur les croyances des gens en matière de santé et leur capacité à modifier leur comportement de manière à réduire les risques. Les auteurs ont entrepris une série d'études théoriques à base empirique visant à décrire et expliquer comment la sexospécificité et l'appartenance à un groupe ethnoculturel influent sur le processus dans lequel s'engagent les personnes qui doivent modifier leurs habitudes de vie pour réduire les risques de maladie coronarienne. Ils décrivent comment les différences sexuelles ont une incidence sur la manière de gérer les risques de maladie coronarienne à partir d'un petit échantillon de femmes sikh âgées ayant immigré au Canada. Les données ont été recueillies dans le cadre d'entrevues semi-structurées, avec l'aide d'un interprète lorsque nécessaire. Les entrevues ont été enregistrées sur bandes audio afin de permettre la vérification de l'interprétation et la transcription. On a utilisé la méthode d'analyse des données par comparaison continue. La principale variable qui est ressortie de la série d'études était « relever le défi ». Le processus de gestion des risques de maladie coronarienne incluait le pré-diagnostic ou l'événement, la liminalité ou les changements, et vivre avec une maladie coronarienne. Les facteurs intra-, inter-, et extrapersonnels ainsi que les caractéristiques sociodémographiques influaient sur la capacité des participantes à relever le défi de la gestion du risque de maladie coronarienne. Les fournisseurs de soins de santé et les décideurs doivent travailler avec les communautés ethnoculturelles pour 1) améliorer la capacité des fournisseurs de soins de santé à donner des soins en tenant compte de l'appartenance ethnoculturelle et 2) développer des ressources appropriées sur le plan ethnoculturel pour promouvoir la santé et prévenir les maladies. L'objectif ultime étant d'améliorer l'état de santé des immigrantes sikh considérées comme des membres vulnérables de la société.

Mots-clés : Sikh, immigrantes, femmes, maladie coronarienne

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Gender-Based Challenges Faced by Older Sikh Women as Immigrants: Recognizing and Acting on the Risk of Coronary Artery Disease

**Kathryn M. King, Pam LeBlanc,
Julianne Sanguins, and Charles Mather**

Gender and ethnocultural affiliation can influence people's health beliefs and their ability to make behavioural changes associated with risk reduction. The authors undertook a series of grounded theory studies aimed at describing and explaining how gender and ethnocultural affiliation influence the process that people undergo when faced with the need to make behavioural changes to reduce the risk of coronary artery disease (CAD). Here, they describe the gender-based influences associated with managing CAD risk in a small sample of older Sikh immigrants to Canada. Data were collected through semi-structured interviews, using an interpreter when necessary. Interviews were audiotaped to enable verification of interpretation and transcription. Data were analyzed using constant comparative methods. The core variable that emerged in the series of studies was "meeting the challenge." The process of managing CAD risk included pre-diagnosis or event, liminal or changing self, and living with CAD. Intra-, inter-, and extrapersonal factors as well as sociodemographic characteristics influenced the participants' ability to meet the challenge of managing CAD risk. Health-care providers and policy-makers have a responsibility to work with ethnocultural communities in order to (1) enhance the ability of health-care providers to provide ethnoculturally sensitive care, and (2) develop ethnoculturally relevant resources to enable health promotion and disease prevention. The ultimate aim is to improve health outcomes for Sikh immigrants as vulnerable members of society.

Keywords: Sikh, immigrant, women, coronary artery disease, secondary prevention

Introduction

Canada is an ethnic[1] and cultural[2] mosaic, with more than 18% of the population being first-generation migrants from another country. South

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[1] Ethnicity: the common and/or inherited traits and characteristics of people from the same race, ancestry, background, and/or actual or assumed culture (Canadian Ethnocultural Council, 2000; Giger & Davidhizar, 1991; Waxler-Morrison, Anderson, & Richardson, 1990).

[2] Culture: the "values, norms, beliefs and practices of a particular group that are learned and shared and that guide thinking, decisions, and actions in a patterned way" that are

Asians (i.e., people indigenous to India, Pakistan, Bangladesh, and Sri Lanka) are one of Canada's major non-European immigrant groups; currently, Canada has more than 700,000 residents of South Asian origin (Statistics Canada, 2001).

Coronary artery disease (CAD) is a "global health problem" with common risk factors. However, patterns of CAD risk as well as morbidity and mortality differ among ethnic groups (Yusuf, Reddy, Ounpuu, & Anand, 2001). The landmark INTERHEART Study reveals that modifiable risk factors (i.e., smoking, dyslipidemia, diabetes, abdominal obesity, stress, poor diet, regular alcohol consumption, and lack of physical activity) account for most of the CAD risk (as manifested by myocardial infarction) in both sexes worldwide (Yusuf et al., 2004). When residing in their home country, and particularly in rural environments, South Asians exhibit less hypertension, smoking, and dyslipidemias than their North American counterparts (Yusuf et al., 2001), but when they adopt an urban lifestyle or immigrate to a developed country their rates of impaired glucose tolerance, diabetes, central obesity, and dyslipidemias increase exponentially and their rates of CAD become similar to those of people of European origin (Sheth, Nair, Nargundkar, Anand, & Yusuf, 1999; Yusuf et al., 2001).

Rates of CAD morbidity in South Asians while in their home countries are low relative to those of many other ethnic groups. Yet the Study of Health Assessment and Risk in Ethnic Groups (SHARE) revealed that South Asians residing in Canada had the highest prevalence of cardiovascular disease of all the ethnic groups studied (Anand et al., 2000). When South Asians immigrate to developed countries such as Canada they have 1.5 to 4.0 times greater CAD mortality than the indigenous groups (Enas, Yusuf, & Mehta, 1992).

In earlier work (King, Mather, & Sanguins, 2005; King, Thomlinson, Sanguins, & LeBlanc, 2006), we contended that gender[3] and ethnocultural[4] affiliation influence people's beliefs and understanding about health and disease risks, access to health-management resources, and ultimately their behavioural choices concerning change associated with disease risk.

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often associated with one's ethnicity but are also associated with the social environment in which one is reared and lives (Canadian Ethnocultural Council, 2000; King et al., 2006; Waxler-Morrison et al., 1990).

[3] Gender refers to distinctions between the social and culturally embedded roles that men and women play, as opposed to biological distinctions of males and females (King & Arthur, 2003).

[4] Ethnocultural: the ethnic and cultural group(s) to which a person belongs but that do not necessarily describe a person's citizenship (Canadian Ethnocultural Council, 2000; Waxler-Morrison et al., 1990).

Given that South Asians are at exponentially greater risk for developing CAD upon immigrating to Canada, it is imperative that more understanding be developed about the influence of gender and ethnocultural affiliation on making behavioural change associated with CAD risk.

Context and Objectives

We have undertaken a series of studies examining the influence of gender and ethnocultural (i.e., urban- and rural-dwelling Euro-Celtic, French, Aboriginal, South Asian, and Chinese) affiliation on the process that people undergo when faced with the need to make lifestyle choices associated with CAD risk (King et al., 2005; King et al., 2006). South Asian advisors to our work identified South Asians as a much less homogeneous group than the other ethnocultural groups included in the series of studies. South Asians, we were told, comprise a variety of religious subgroups (i.e., Sikh, Muslim, Hindu) with characteristics that could influence their choices concerning CAD risk management (Dr. R. Indira, personal communication, September 13, 2003). Thus, only one subgroup of South Asians, those of the Sikh religion, were included in this study. Nearly 300,000 people practise the Sikh religion in Canada (Statistics Canada, 2001).

In this article, we will describe and explain the influence of gender, from women's perspectives, on the process that older South Asian (Sikh) immigrants undergo when managing CAD risk. To appropriately describe the experience of these older Sikh women, we will distinguish their experience from those of Sikh men, the Sikh community in general, and some of the other ethnocultural groups we have studied.

Methodology

Qualitative methods are well suited to research in which the investigators aim to understand culture "as a context that circumscribes humans' daily lives" (Im, Page, Lin, Tsai, & Cheng, 2004, p. 891). The goal of grounded theory, the qualitative method used in this work, is to describe and explain processes of human behaviour (Field & Morse, 1985; Morse & Field, 1995). Grounded theory is rooted in symbolic interactionism; thus its use in research can serve to illuminate the "shared meanings, the foundation of culture" (Milliken & Schreiber, 2001, p. 178) formed by groups of people about particular phenomena (Milliken & Schreiber; Morse, 2001). Use of grounded theory enabled us to undertake an inductive investigation of the process that Sikh women and men undergo when faced with the need to manage their CAD risk.

Sample

Sampling began following the securing of approval from the local Health Research Ethics Board. Our aim was to gain a deep understanding of the gender and ethnoculturally bound issues that may face Sikh immigrants to Canada. Thus, we first sought participants who were deeply embedded in the Sikh community. We thought these people would best exemplify the ethnocultural affiliation of interest.

We learned that there were two Gurdwaras (the Sikh place of worship) in the city in which the study was conducted, with some important differences between the two congregations. Gurdwara A was, on the whole, attended by people who were more recent immigrants or were more fundamentalist in their approach to Sikhism, whereas Gurdwara B was attended by people who had been in Canada for some time and were deemed more "progressive" in their approach to Sikhism. First, we recruited participants through seniors' groups who met at Gurdwara A. Later, we purposively recruited participants, who varied in age, time since CAD diagnosis, and time since immigration to Canada, from both Gurdwaras. Gender-specific presentations were made to female and male seniors' groups by the principal investigator (KMK) at Gurdwara A. Thereafter, a Punjabi-speaking social worker who worked with the community assisted with recruitment. A member of Gurdwara B (who also undertook the translation verification that will be described below) made a presentation about the study during a religious service. Investigators were available after the service to speak with potential participants. Later, some of the participants were able to refer us to other potential participants; this snowball technique was effective.

In order to meet the inclusion criteria, the participants had to (1) self-identify as having heart disease (this was confirmed during a screening phone call); (2) be first-generation immigrants from India (that is, born in India, emigrating as an adult); (3) declare themselves members of the Sikh religion; (4) agree to participate in at least two audiotaped interviews, (5) be able to express themselves in either English or Punjabi; and (6) be able to provide informed consent. Sampling continued until no new data were found; redundancy was achieved.

We needed to appropriately contextualize the experience of the older Sikh participants. In grounded theory studies, the researcher often seeks data sources beyond the individuals who have had the experience of interest, in order to enrich and further contextualize the data collected from participants (Morse & Johnson, 1991). In this study, such additional sources included secondary informants; social workers who were not of the Sikh faith but practised in the Sikh community; and other Sikh people, of various ages, who did not have heart disease. We had many opportunities to observe members of the Sikh community, such as by frequenting Sikh businesses, attending Sikh Awareness Week at the University of Calgary, and attending (by invitation) various celebrations in Sikh homes and at the Gurdwaras.

Data Collection and Analysis

In grounded theory research, data collection and analysis are essentially simultaneous processes (Schreiber, 2001). All interviews were conducted in person and were audiotaped. For participants who did not speak English, the interview was conducted using a Punjabi-speaking interpreter. The interpreter assisted 12 of the 18 participants (7 women and 5 men) in sharing their experiences. The majority of women chose to be interviewed in their own home, while the majority of men preferred to be interviewed outside the family home.

First, sociodemographic data were collected. Then, questions based on Kleinman's (1980) health sectors and using Spradley's (1979) format for ethnographic interviewing were posed. Use of Kleinman's health-sector model as a basis for questioning enabled us to conduct a thorough investigation of the ethnoculturally embedded factors that could influence the participants' understanding and management of their CAD risk. "Grand tour" questions included the following: *I understand that you have had some difficulty with your heart. Can you tell me about that?* and *Once people have been told they have heart disease, they are often asked to take a close look at their lives and make some changes. Can you tell me about that? What have you been asked to do? Who asked you to do it? Has this affected some people around you? If so, how?* "Mini tour" questions included the following: *What are all the things/changes that have been suggested to you by your…* [people in the popular, folk, and professional sectors as described by Kleinman] *to help your heart?* and *What all did you take into account when making choices about changing some things that you might do every day?* and *Can you tell me all about the impact that making/not making these changes had on you/your spouse/family/other significant people?* Interviews generally lasted 1 hour.

To ensure that the interpretation of interviews was accurate and that no systematic mechanism was in place to shine a particular light on the participants, we enlisted a second Punjabi-speaking (and Sikh) person to verify the interpretations. This person, a recent university graduate raised in Canada, was knowledgeable about the research process and aware of the ethical imperative for confidentiality. Also, before beginning any translation we determined that the informant was not known by the translator. Indeed obtaining these second translations was very useful for the process. We gained much deeper insights into the nuances of what the participants were trying to convey.

Audiotaped interviews, the extensive notes produced by the second translator, interviewers' field notes, and documentation on the analytic process (i.e., memos) were transcribed into a format compatible with NVivo. From the outset of data collection, members of the research team engaged in data analysis using constant comparative methods. New data were compared to those previously collected, emerging concepts and their linkages were identified, and plans were made for further sampling and data generation (Schreiber, 2001; Strauss & Corbin, 1990).

First-level coding (sometimes called substantive or open coding [Strauss & Corbin, 1990]) involved line-by-line analysis of the text. Pieces of the text that represented common concepts were identified and coded (given a label or name). As many codes as possible were identified; one piece of data could have multiple codes. This work contributed to the process of developing mutually exclusive criteria for categorization of these concepts.

Memoing (literally, writing notes to oneself) was undertaken. This is a process of recording the research team's ideas, insights, thoughts, and feelings about the codings, category development, and emerging category relationships (Schreiber, 2001). Memoing is central to the analytical process of grounded theory methodology, and it allowed us to produce documentation (i.e., an audit trail) on decision-making.

Selective or axial coding was then undertaken. This process involved the categorizing, re-categorizing, and condensing of first-level codes. First-level codes were clustered based on (dis)similarity of the content. Each category was named and mutually exclusive rules for inclusion were generated. Substantive categories were thus inductively generated from the data and attributes were well defined. During the coding of specific statements for categorical assignment, they were compared with other statements in the same and different categories. During this process as well, memoing on potential linkages of these categories generated ideas about the merging theory.

The questions posed about linkages or relationships of categories helped us to identify a core category or variable around which the theory was developed (Strauss & Corbin, 1990). The core category or variable is "the process that (a) is central and is related to as many other categories as possible, (b) continuously occurs in the data, and (c) accounts for the most variation" (Morse & Johnson, 1991, p. 5).

Findings

The participants were women and men of the Sikh religion who resided in a large city (see Table 1). Most of the participants had immigrated to Canada at the age of 50 to 60 years. On average, the time since immi-

Table 1 ***Characteristics of Participants***

Gender		**Female (*n* = 8)**	**Male (*n* = 10)**
Age	Mean (years)	67	70.5
	Range (years)	56–78	54–86
Time elapsed since immigration	Mean (years)	14.9	25.5
Marital status	Married	7	8
	Separated	1	0
	Widowed	0	2
Habitation	Alone	1	0
	With spouse	1	3
	With spouse and unmarried children/grandchildren	3	3
	With spouse and son's family	3	2
	With son's family	0	2
Education	None	4	3
	Elementary school	1	3
	Junior high school	0	1
	High school	2	1
	College/university/graduate studies	1	2
Household income[a]	Lower middle income	1	0
	Middle income	3	0
	Upper middle income	0	4
	Highest income	1	3
	Did not know	3	3
Occupational role	Returned to full-time work	1	2
	Returned to reduced work	0	2
	Remains retired	0	6
	Returned to homemaking	7	0
Event(s)/treatment(s)[b]	Myocardial infarction	5	7
	Percutaneous coronary intervention (PCI)	2	4
	Surgery: coronary artery bypass graft (CABG)/valve	4	6
	Medical intervention only	3	1

[a] According to the household income scale used by the Heart and Stroke Foundation of Canada (http://www.statcan.ca/english/freepub/82F0076XIE/free.htm)

[b] Participants may have had multiple events/treatments.

gration was 14.9 years for women and 25.5 years for men. The majority of participants were married and lived with family members (i.e., unmarried children, a married son and his family). More than half of the participants had no formal elementary education. More men (*n* = 5) than women (*n* = 1) spoke English. The participants who resided with their son's family were rarely aware of the household (i.e., family) income. Typically, the women were homemakers and the men were working reduced hours or retired. Most participants reported having had a previous myocardial infarction and having undergone an intervention (i.e., percutaneous coronary intervention or surgery).

Core Variable

As identified in an earlier publication (King et al., 2006), "meeting the challenge" was the core variable that emerged from our series of studies. A number of factors, pervasively influenced by ethnocultural affiliation and gender, impacted and shaped the South Asian (Sikh) participants' ability to meet the challenge of managing their CAD risk. These factors were intrapersonal (e.g., personal beliefs as well as understandings about heart disease); interpersonal (e.g., interactions with family members, within social networks, with people in the health-care system who might provide social, informational, or instrumental support); extrapersonal (e.g., system and environmental influences beyond the participant's control such as access to health and transportation resources, place of residence, and weather); and sociodemographic (e.g., education, ability to speak English, household income, habitation). These factors could directly or indirectly (mediated by their knowledge of heart disease) influence the participants' ability to meet the challenge of managing their CAD risk.

The Process of Managing CAD Risk

Through our research with various ethnocultural groups, we have identified three phases of managing CAD risk: pre-diagnosis or event, the liminal[5] or changing self, and living with CAD (see also King et al., 2006). The major finding of our studies with older Sikh immigrants was that they are limited, relative to members of other groups, in their ability to move through the process of managing CAD risk.

Pre-diagnosis or event. The period before a diagnosis or cardiac event was critical to situating how the participants would meet the challenge of managing their CAD risk. Indeed, the belief system and understanding about heart disease (intrapersonal factors) played a pivotal role. Participants

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[5] Liminal: describing a threshold, neither here nor there; betwixt and between; a period of ambiguity in one's social identity; a hinterland between recognized states (Turner, 1969).

in this study had a limited appreciation of "heart disease" as a preventable or chronic illness. Though the Punjabi language includes words for heart disease *(dil dee bimari or dil da roag)* and heart attack *(dil da doara),* a secondary informant suggested that the Sikh people are more receptive to attending to the acute phase of a heart attack than attending to the chronicity of heart disease. This secondary informant said, "Sikhs tend not to be too concerned with a condition until it becomes a problem. [Thus] the term heart attack has a greater effect than heart disease. So, in short, while…the term heart disease does exist in the Punjabi language, it does not really exist in the minds of Sikhs."

We learned that the Sikh community on the whole tends to have a great affinity for socializing. Though the Sikh community is extremely interconnected, it is somewhat isolated from the population at large. Thus interpersonal connections can be limited to immediate family members and others of the Sikh religion. This is particularly so for those who are not employed outside the home, those whose English-language skills are limited, and those who immigrated to Canada later in life. Despite the affinity for socializing, the Sikh community's cultural norms are such that members are very cognizant of "putting on the best face." On the whole, members of this community were extremely reluctant to share personal details with each other — particularly if there were some difficulties. One of the women said:

> *When I go to…Sikh temple every day for prayer…I do my prayers and come back. There is no, um, interaction as such. Even when there may be opportunity, women are just so happy to get together and talk, talk, talk that they are not talking of problems.*

The participants' ability to share their "problems" with each other as a means of seeking support (social, informational, or functional) was extremely limited.

Upon immigrating as older adults, the participants often experienced a change in their social status. We learned that, in their home communities, older family members (i.e., parents) tend to be very well positioned, having financial security and accorded respect based on their senior status in the family and community. Importantly, children tend to yield to the judgement of their parents and more senior family members. However, the dynamics of this relationship change when older people who immigrate to Canada are sponsored by children who have immigrated before them. Rather than being the respected head of the family, the more senior members must yield to the judgement of the son (usually) who acted as their sponsor. The parents are no longer self-supporting and in fact rely on the son and/or other children for support until they become eligible for public pensions.

Extrapersonal factors also played a role in limiting the participants' ability to maintain a healthy lifestyle, as well as their access to information and care during this phase and throughout the process. The change in lifestyle experienced by the participants upon moving to a Canadian city was profound. In their home country, we were told, Sikh women typically walk to the shops daily (often twice daily) for groceries and men walk to central locations to meet. In the new environment, the opportunities for even this amount of exercise were limited because of the location of shops and often the weather. One participant told us, "Here…because of the cold weather, we are so much homebound, can't go anywhere." Further, the types of foods (particularly desserts) served at social gatherings are often laden with fat and sugar. Though CAD is clearly an important health issue for Sikh people (and for South Asians as a whole), there are no widespread mechanisms in place to communicate this information to community members or to help them to modify their diets (such as by avoiding foods high in fat and sugar). Moreover, older Sikh people with heart disease may have limited access to healthcare resources. They may have responsibilities associated with child care and may be reliant on their children (who often face restrictions on their time due to the nature of their employment) for transportation.

Sociodemographic factors, particularly English-language skills, play a critical role in the ability of Sikh immigrants to access information and to appreciate the fact that they may be at risk for CAD. The participants with less than a junior high school education were often illiterate even in their own language. Moreover, many of the participants did not speak English. For those who were illiterate and spoke no English, the difficulty in obtaining information rose exponentially, as their only means of accessing information was family or community members. One participant said, "I had difficulty with language in the hospital to explain things, and I can't read anyway — I'm not literate." This served to perpetuate their lack of understanding about CAD risk, as well as their isolation within and reliance on their own community.

Liminal phase. Following the cardiac diagnosis or event, the participants experienced the liminal (or changing) self, which was associated with their first perceptions of "the challenge." For most of the ethnocultural groups in this series of studies, the diagnosis or event served as a motivator for behavioural change. For many of the Sikh participants, however, it caused profound confusion. While those from the other ethnocultural groups asked "why me?" during this phase, for the Sikh participants the questioning was especially profound and intense — having CAD or a cardiac event was not within their frame of reference. One of the participants told us, "I had not a clue that this is heart problem, no, nothing, nothing, absolutely nothing." Another said, "I had never heard, never seen, anybody like this [having a heart attack]… I had never heard about it."

On an intrapersonal level, the participants' identity was further challenged; they were even more vulnerable. Further, they had little appreciation or understanding of CAD as an illness that would require attention over the long term. Those participants who had had a myocardial infarction viewed it as an isolated event that should have resulted in death. "They said, 'You are not going home because you had serious heart attack'," one participant recalled. "And I said, 'If it was so serious why didn't I die?'" Faith played a role in their refraining from questioning God's plan. As confirmed by our secondary informants, the participants had a strong sense of destiny and fatalism. This belief system seemed to support the idea that having and managing an illness such as CAD was out of their control. "It is what God has written in your fate," said one participant. "Whether you are male or female, cared for or not, it all depends on your fate."

Relationships with family members as well as with health-care providers who could provide social, informational, or instrumental support were more strained during this phase. Attending to or advocating for the ill person was often a challenge for family members, largely due to their failure to grasp the impact of the illness as well as employment- or family-related time constraints. Health-care providers often relied on family members to act as interpreters for the participant. Yet family members' understanding and translating of the information often resulted in inaccuracies, misinterpretations, and a watering down of the message. "Information was given to son," recounted one participant, "so I don't know what information was given to my son."

The lack of understanding about heart disease in the community as a whole served to reduce the appreciation of those who were receiving information about the importance of and instructions for maintaining health. During this phase, Euro-Celtic participants spoke well of in-hospital education classes, abundant written instructions, and availability of cardiac rehabilitation programs (King et al., 2006). This was not the case for the Sikh participants in this study. "The doctor had then taken lots of tests and he gave the medicines," said one participant. "He didn't say anything in particular about how to take care of heart; he just gave the medicines." Many of the participants returned home isolated and without detailed instructions, to frustrated families who did not understand.

The previously described extrapersonal influences (i.e., availability of information) continued to affect the participants' ability to move forward in their appreciation and management of their CAD risk. These influences consistently limited their ability to access additional care and resources. Our secondary informants suggested that the participants may have been perceived as being non-compliant. In fact, there were practical barriers, beyond their control, that limited the participants' ability to attend to their health.

Sociodemographic factors continued to influence the participants' ability to attend to their CAD risk. Our secondary informants explained that older immigrants usually must wait several years before they are eligible for public health insurance or pensions. Thus the participants' families had to bear the financial burden of expensive prescription drugs such as cholesterol-reducing medications. As we have indicated, the participants' English-language skills immensely impacted their ability to obtain accurate information.

Living with CAD. Over time, the participants seemed to settle into living with CAD, how ever they had come to understand what this meant to them and their families. The common lack of understanding about the CAD process and a faith-based belief in destiny (intrapersonal factors) were the foundations of why the participants did not take up many health-promoting, disease-preventing activities. The participants aimed to accept what had happened and return to life as they knew it, as opposed to engaging in activities that might prevent further illness or another event. One participant said, "From the beginning I just have no interest in it [preventative action]. I just want to help people or get the work done, help my daughter, my son, help everybody. I don't take any interest in it." These beliefs and behaviours were much more pronounced in Sikh participants than in members of the other ethnocultural groups studied.

Having a diagnosis of heart disease posed many interpersonal challenges for the participants. Given the ethnoculturally bound nature of "keeping up appearances," it is unlikely that the participants or their burdened families would publicly acknowledge a problem and ask for support, whether social, instrumental, or functional. Occasionally the participants and their families were greatly challenged to manage the illness, particularly if the participant did not make a quick or complete recovery and was unable to return fully to his or her previous role (i.e., as child caregiver) in the home. The participants were predominantly satisfied with their physicians and compliant with their medication regimens, yet they rarely had an understanding of what the medications would do:

> *I know how to take medicine, what time and how many. Doctor has given me good instructions… He's a good doctor. He looks after me like my son. Very big major portion of my good health I attribute to my doctor because*

> *he's a very good doctor. I will never change…I will never change my doctor.*

Adherence to a medication regimen did not affect the participant's return to his or her role in the family. Within the household, the participants were not in a position to make decisions about managing their CAD risk; they were not in charge of determining how money would be spent or grocery shopping for the family. One woman said, "I couldn't go out for a walk due to weather. I wanted a treadmill but my husband would not take the initiative to buy one."

There were extrapersonal factors associated with the participants' access to health care and health information and thus their ability to make heart-healthy choices. It was difficult for the women to adhere to a heart-healthy diet while participating in their religious-based (and virtually only) social network. The culture of eating when at the Gurdwara (which was their meeting place) and their consumption of the traditional foods (particularly desserts) inevitably placed them at risk. They had very little access to culturally appropriate (and language-appropriate) information about a heart-healthy diet and had no access to mechanisms for reinforcement. Many of the women revealed that they did not recognize Western foods and had no way of knowing how their own foods might rate in terms of their health.

Sociodemographic characteristics continued to play an important role in the participants' ability to live with CAD. As found in the earlier studies in the series, these characteristics influenced the participants' ability to access care and to become informed about their disease process. "There isn't information," one woman said. "I like to read but my husband brings books in English for him to read. He doesn't bring any Punjabi books from library for me to read."

Gender-Based Elements

The older Sikh women who participated in the study were for the most part deeply entrenched in their cultural community. They therefore faced particular ethnoculturally bound challenges to the management of their CAD risk. These challenges stemmed from: (1) extraordinary isolation within the Sikh community and from the population at large, (2) lack of autonomy associated with women's role in Sikh social networks, (3) their vulnerability, and (4) obstacles to and perceived consequences of integration.

Isolation. While recruiting participants for this study, members of the research team were frequently told by various immigrant Sikh women that they felt extraordinarily isolated even within their own community. One of the participants compared, through an interpreter, the lot of women in her community with that of men: "Women don't have support and men have lots of support." Another participant said, "Men tell about their problems, women do not."

Socializing at the Gurdwara and at community celebrations was an extremely important part of the participants' lives. However, due to the culturally embedded value of projecting an image of "doing well" and "having a good family," they often remained "alone"; they could not genuinely share their troubles with those with whom they socialized. One woman described socializing in her community as "all lies, no truth." Another said, "I came to [live with] my in-laws and was living in a very large family. Only I know how hard my life was, but I never complained." A third woman stated, "I never complained about my husband's treatment or behaviour to my brothers or to my father because I did not want them not to respect my husband." Any health or family problems had to be kept within the family.

The women who participated in this study could also be bound to the home by child care, lack of means of transport, or their own poor health, and thus have few opportunities to socialize within the Sikh community or to become acquainted with the population at large. One woman said, "The support during the operation, after surgery and everything....who supported me? ...only God." This isolation was exemplified when, following a meeting of the research team with a group of Sikh women at one of the Gurdwaras, a few women asked (through an interpreter) if they could touch the skin of the principal investigator (KMK) to see if white skin felt different from their own. These women had never touched white skin, yet the mean time since immigration to Canada for the female participants was nearly 15 years. They were out of touch with the larger society into which they had immigrated.

Yet the women participants were curious and excited about having a white woman come to their home for an interview. The researchers were welcomed into the home, introduced to family members, and offered refreshments. These participants reported feeling a sense of importance, being cared for (or about), and being respected when they were asked to share their stories with someone from outside their community. They were more comfortable sharing intimate details of their lives with an outsider than with members of their own community. The women who participated in the study did so in the hope that they would be helping other Sikh women with heart disease and that they would be heard and understood. One woman said, "We just want to be loved and respected."

Lack of autonomy. The Sikh women who we encountered described their societal roles as highly prescribed by the males (and mothers-in-law) in their community. Many of the women from the other ethnocultural groups we studied reported feeling constrained by their traditional roles. This was particularly so for the immigrant Sikh women. One interpreter said, on behalf of the participant: "He doesn't like her going [out]…because he thinks that she will learn something from outside which is contrary to his beliefs." Another participant elaborated (through an interpreter):

> *Men want their women in our society to remain illiterate. They don't want them to get knowledge and anything around them…probably because of insecurity within themselves. But they [the women] don't take any steps. By keeping them suppressed and illiterate, they have to keep on taking a lot of the burden of the family and burden of husband. And because she's not literate, she doesn't know how to go, where to go, whom to ask, what to ask, so she's further subjected to the stress.*

The participants were often prevented from making independent decisions about their lives. Since girlhood, the women had never been in a position to do so. Many of the immigrant women with whom we spoke shared stories of their arranged marriages. Some had been married as young as 5 years of age, with the young bride moving in with her husband's family and adopting the customs of that household. Typically, before immigration it was the husband's will that predominated in marital, household, and family decisions, while following immigration the sponsoring son (and his wife) assumed the dominant role. Ultimately, the female participants remained in their prescribed, less influential role, unaccustomed to questioning the status quo or engaging in forward thinking. An interpreter described the social norms under which one participant had grown up:

> *The times have changed. In the times when she grew up, for women it was very hard, for they were not allowed to go and get out of the house, talk to anybody, [or] take any bold steps. A lot of stress was built in, within, because of all the stresses from society and family and culture. Nowadays [younger] women are free. They are able to do a lot of things on their own. They can just take off, no restrictions, and even if there are restrictions they are not going to necessarily obey the way she obeyed.*

Often, the women did not have the means to make health-related decisions or to take a proactive stance with regard to their health. The husband of one participant objected to her remaining in hospital: "My husband say no, no, no. I don't want care for her. I want her to come home. Her mother is there. Her children are there. No." Also, the participants, even as the senior women in their homes, did not control the household budget and therefore could not make the decision to purchase the more expensive heart-healthy foods. Moreover, most of the participants were not in a position to influence the family diet; they yielded to the wishes of the head of the household. The participants resumed their usual role, which was to keep the peace and uphold the status quo.

The participants acknowledged, however, that "times are changing." One participant recalled that "they used to think that if we educated girls they would leave home…so it was better not to educate." The older Sikh women appreciated the vigour of the younger women in their community. The participants expressed the hope that these young women would be able to take steps towards achieving autonomy and would not suffer the personal costs of challenging the status quo — being accused of shaming their families and being shunned by family and community members.

Vulnerability. Many of the participants' cultural norms and belief systems kept them powerless to effect change for themselves or their families; this was a situation the older immigrant Sikh women learned to live with. The lack of understanding of the association between heart disease and heart attack, as well as the belief systems regarding destiny and fatalism, were such that the participants remained vulnerable to heart disease.

As we have indicated, many of the more recent immigrants were financially dependent on their sponsoring family. As a result, the immigrant husbands often suffered psychologically from the loss of their elevated status in the family and community. An interpreter explained on behalf of a participant:

> *He was saying he had very good job. He was admired. He was praised. Then he was gone out of that job where he had power. He said, "If I am in that chair, that chair is the one which is giving me power." I say to him [the participant] that the power is within him, and he is not seeing that. Theoretically he is seeing that, but it is very difficult for him to agree in real life that, yes, the power is within him. So he says his power is gone. It probably has something to do with…the other family members letting him know…that he is not worth[y] any more.*

It was apparent, in conversations with members of Sikh men's groups and during the study interviews, that excessive alcohol consumption is not uncommon among immigrant Sikh men. Some Sikh women revealed (to members of the research team, as outsiders) that their partners' excessive alcohol use increased their emotional and (occasionally) physical abuse. "As far as care is concerned, there is no care or thinking," one participant said of her husband. "I'm not at all ever a priority to him." An interpreter stated the following on behalf of another participant:

> *In fact when she had this, all this episode of the heart attack, admitting, with ambulance in the hospital like that, it took a long time in the hospital to get the bed, like 2:30 in the morning. He [the husband] said, "I'm getting in a taxi. I'm going home." He just went home. The son said to father, "Anything could happen to her! There are so many people they stay with their spouses when they're having heart attack. How could you just leave her there and go home?" But she's quite used to this kind of nature. But she never complained to anybody else that he is like that.*

For some women, the abuse began early in their lives. An interpreter said the following for a participant:

> *When she got married [at a very young age] and he took her to his family, she was subjected to abuse. She should have inherited enormous amounts of wealth from her father but unfortunately she never had the comfort of a single penny. Her husband forged the signatures, got the money transferred on his name, sold property and everything… She got nothing.*

During a heart-health presentation to a group of immigrant Sikh women, one woman asked, "Do white women's hearts break when their husbands hurt them?" This question serves to illustrate not only the vulnerability of immigrant Sikh women to mistreatment by their husbands, but also their understanding of heart disease. The Sikh women in the group were only beginning to become aware of the societal intolerance for any kind of abuse and of the resources available in the city where they now lived. Yet publicizing this information within their community would doubtless have serious consequences for their place in the Sikh social network. One woman shared her story of leaving her abusive husband:

> *How could they [the children] know [that I had wanted to have more control over my life]? Because their father said, "Your mother shamed us because she is living alone." For my children, I have guilty feelings, because I went to live alone [to stop the abuse].*

Obstacles to and perceived consequences of integration. Immigrant Sikh women can face tremendous obstacles to reaping the benefits of Canadian health care. Many immigrant women are uneducated, illiterate, and lacking in English-language skills. This greatly hinders their ability to obtain information about their well-being in general, their CAD, and how to take secondary prevention initiatives. When immigrant Sikh women must rely on others who read or speak English, their isolation and the cultural belief system surrounding heart disease is perpetuated.

The immigrant Sikh community is very interconnected. We learned that there is a continuum of assimilation into Canadian society that produces both advantages and disadvantages. The Sikh women who were able to assimilate into the dominant culture tended to have immigrated early in life, to have married men who had also immigrated early in life, and to be employed, along with their husbands, outside the home in professional or paraprofessional positions. These women were able to reap benefits such as acceptance into the dominant culture and access to health information and resources:

> *We [our family members] are very independent, all of us. We are a very different family from the typical East Indian families… That's why we…laugh about it. We think that other East Indians, they get intimidated by us, because they think we are very open-minded, and too opened.*

There are strong mechanisms hindering the assimilation of Sikh women who are less educated, who do not speak English, or who immigrated later in life. Members of this community are connected by their way of "being" — through religion, language, food, and socialization. The people who choose to extend their lives beyond the Sikh community can risk being stigmatized for failing to observe Sikh religious customs or for being somehow impure, which can lead to their being mistrusted by the more fundamentalist members of the community. People who begin to move beyond the boundaries of the Sikh community and religion often do so through their employment. The immigrant Sikh women in this study were unlikely to have such an opportunity. There are various strong mechanisms within the community limiting the ability of new immigrants to integrate into Canadian society.

Discussion

There is a continuum of integration of Sikh immigrants into Canadian society. We set out to describe the gender and ethnocultural factors that influence the ability of older immigrant Sikh women and men to attend to their CAD risk. To do so, we focused on describing the experiences of Sikh people who have not integrated into Canadian society and who suffer from CAD. Though the findings of this study do not represent the experience of all Sikh immigrants to Canada, they open a window to the experience of a vast number of Sikh immigrants who remain hidden and silent in our cities.

We have identified several salient issues that threaten the ability of immigrant Sikh women and men to meet the challenge of managing their CAD risk. These include a lack of understanding and appreciation of heart disease, stressors that may increase the risk, and the lack of integration into Canadian society. We have focused on these issues from the gender-based perspective of women.

Understanding of Heart Disease

Generally speaking, health-behaviour models hypothesize that health-related action is linked to the perception of risk/vulnerability to a threat (Lefler, 2004). We learned from our participants as well as from our secondary informants that among Sikh immigrants there is a limited understanding and appreciation of the meaning of heart disease. Rankin and Bhopal (2001) surveyed a small sample of South Asian residents of the United Kingdom who were of Pakistani, Indian, and Bangladeshi ethnic origin (n = 334, aged 16–74 years). Overall, 35% of those surveyed did not understand the meaning of "heart disease." Those who had immigrated to the United Kingdom were less likely than those born there to understand the term. Further, 14% of respondents could not identify a cause (or risk factor) and 17% could not identify a preventative measure for heart disease. Studies of mainly Punjabi people living in the United Kingdom report similar findings; 24% to more than 33% of survey respondents were unable to identify one risk factor for heart disease (Bhopal, 1986; Datta, 1985). Though there are no directly comparable Canadian data, the Canadian Heart Health Survey reports that 41% of surveyed Canadians aged 55 to 74 years named smoking as a risk factor for heart disease (Kirkland et al., 1999). Clearly, there is a need for ethnoculturally sensitive means of improving understanding and appreciation of CAD risk.

Stressors

Sikh immigrants face particular psychological stressors that may place them at increased risk for CAD and prevent them from attending to their CAD. Many of the older immigrant Sikh women in this study reported stressors such as isolation, lack of autonomy, and change in social status. Stress has psychological and physiological sequelae that increase the risk for CAD. Recent studies provide clear and consistent evidence that psychosocial stressors contribute greatly to the pathogenesis and manifestations of CAD (Rozanski, Blumenthal, & Kaplan, 1999). The increased risk caused by psychosocial stressors is of similar order to the more traditional risk factors that account for between 58% and 75% of cases of CAD (Beaglehole & Magnus, 2002).

In a British study comparing 173 men and women of South Asian origin with members of the general population, Williams, Bhopal, and Hunt (1994) concluded that CAD rates in South Asians were likely a result of a complex interaction of risk factors, including stress and socioeconomic deprivation. For example, South Asians were significantly more likely than members of the general population to report feeling sad or depressed, to perceive low social support, to live in overcrowded homes, and to endure extraordinarily long (≥75-hour) work weeks.

The presence of high levels of social support is known to promote psychological and physical well-being, whereas low levels of social support have been identified as health risks (Stewart & Tilden, 1995). Mookadam and Arthur (2004) found low levels of social support to be associated with increased (two to three times more) morbidity and mortality in post-myocardial infarction patients — that is, independent of other known predictors such as hypertension, reduced cardiac function, smoking, previous myocardial infarction, age, and female sex.

Sikh women live in a patriarchal system. Parents and then husbands make decisions for girls and women regarding their education, whether they will work outside the home, and so on. "As a result…women develop a tendency to depend upon men. They…start depending on men for all their personal and family decisions" (Bal, 1997, p. 103). When the men on whom Sikh women depend become abusive, the women have access to very few psychological or social resources. Cochrane and Bal (1990) conducted a study with 800 men of Sikh, Hindu, Muslim, and white ethnocultural background living in the United Kingdom. Sikh men were more likely than the others to drink every day and alone. Moreover, they were more likely to drink to excess if they were married or were first-generation immigrants and as they aged. Though no reliable data are available on the rates of reported abuse in the Sikh community, Bal reports "high rates" of mental and physical abuse in Sikh women in Canada. These additional stressors not only can contribute to the women's risk for CAD but can receive higher priority than attending to one's health.

Integration

The older participants in this study were tightly connected to the Sikh community. Chadney (1980) asserts that maintaining cultural (religious) identity is of paramount importance to the Sikh community: "Retention of traditional family values, attitudes, and patterns of behaviour has been extremely influential in the maintenance of a distinct ethnic identity" (p. 31). The criteria under which women are admitted to a country as immigrants can play an important role in the process of integration. In 1962, Canadian immigration policy became based on a point system that included education, training, and skills. Under this system, it was virtually impossible for many women to be accepted as independent immigrants (Bal, 1997). Many of the older Sikh participants in the present study had been brought to Canada as dependants to reunite the family. Women who enter as dependants and have little education are particularly likely to experience difficulty integrating in their new country (Dion & Dion, 2001). Chadney contends that these people maintain a stronger Sikh identity than professionals, who develop and maintain a professional identity (through language, dress, and their interactions within the dominant society). Yet, as we have seen, there are costs to this lack of integration.

Recommendations

There are tremendous opportunities to improve the ability of older Sikh immigrants to manage their CAD risk. It is imperative that the message about the risk of heart disease get to the often isolated members of the Sikh community. A variety of mechanisms can be used to communicate the message despite the language, literacy, and ethnocultural barriers. Since many older Sikh immigrants (particularly women) lack literacy skills, there is a need for alternative media, particularly those that are verbal and pictorial. The American Heart Association's Search Your Heart program (www.americanheart.org), a church-based educational initiative aimed at African and Latino Americans, might be a viable model for implementation in the Sikh community. Given that the Gurdwara is the chief meeting place for those at risk for CAD and their families, it may be the ideal place to reach the Sikh people. Many communities have Punjabi television networks that could offer heart-health programming. Useful, culturally relevant (not merely translated) materials for Sikh people could be produced with the collaboration of Punjabi-speaking health-care providers (i.e., dietitians, physiotherapists, nurses, physicians). A variety of successful cardiac-rehabilitation and other programs could be extended to Sikh communities with the cooperation of interpreters. Though the Sikh community comprises second- and third-generation Canadians as well as recent immigrants, people from outside the community can and should play a role in implementing these initiatives.

Conclusion

In order to develop appropriate strategies and health policy aimed at improving people's ability to address CAD risk through lifestyle changes, one must first understand the process they undergo when making decisions about such changes. Health-care providers and policy-makers have a responsibility to assist new immigrants by working with ethnocultural communities to (1) enhance the ability of health-care providers to provide ethnoculturally sensitive care, and (2) develop ethnoculturally relevant resources to enable health promotion and disease prevention activities. The ultimate aim is to improve the health outcomes of these vulnerable members of Canadian society.

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Comments or queries may be directed to Kathryn M. King, Faculty of Nursing and Department of Community Health Sciences, University of Calgary, 2500 University Drive NW, Calgary, Alberta T2N 1N4 Canada. Telephone: 403-220-4643. Fax: 403-284-4803. E-mail: kingk@ucalgary.ca

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Kathryn M. King, RN, PhD, is Associate Professor and Heritage Population Health Investigator, Faculty of Nursing and Department of Community Health Sciences, University of Calgary, Alberta, Canada. Pam LeBlanc is Research Associate, Faculty of Nursing, University of Calgary. Julianne Sanguins, RN, is a doctoral student in the Faculty of Nursing, University of Calgary. Charles Mather, PhD, is Assistant Professor, Medical Anthropology, Department of Anthropology, University of Calgary.

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Résumé

La divulgation du lesbianisme : le bousculement des a priori

Carol McDonald

Le but de cette enquête interprétative est de favoriser la compréhension de l'expérience que vivent les lesbiennes qui divulguent leur orientation sexuelle. L'étude, fondée sur l'herméneutique gadamérienne et la pensée philosophique féministe, s'inscrit au créneau de la santé des femmes. Selon la perspective féministe de la santé des femmes, l'expérience de la santé est indissociable des expériences quotidiennes de la vie sous toutes ses facettes et est composée des réalités que vit chaque femme sur le plan social, matériel et discursif. L'étude a été réalisée à partir de conversations auxquelles ont participé 15 femmes qui se sont identifiées comme lesbiennes pour les fins de l'enquête, ainsi qu'à partir de témoignages portant sur les femmes dans les médias, et le journal de réflexion de la chercheuse. Les résultats nous font voir de nouveaux points de vue concernant les multiples significations du mot « lesbienne ». Ils invitent vivement le personnel infirmier à considérer les catégories binaires de l'homosexualité et l'hétérosexualité comme des signifiants qui décrivent inadéquatement les réalités vécues par les femmes, à tenir compte des composantes particulières de la vie de chaque femme et à délaisser les a priori hétérosexistes dans le but de réduire l'impact néfaste de l'exclusion sociale, l'isolement, la discrimination et la stigmatisation comme déterminants de la santé.

Mots clés : lesbienne, divulgation, herméneutique, féministe

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Lesbian Disclosure: Disrupting the Taken for Granted

Carol McDonald

The purpose of this interpretive inquiry was to generate understandings about the experience of lesbian disclosure. The inquiry relied on Gadamerian hermeneutic and feminist philosophical thought and was situated in women's health. In a feminist understanding of women's health, experiences of health are inseparable from the everyday experiences of an embodied life and are constituted within each woman's social, material, and discursive realities. The study was informed by conversations with 15 women who self-identified as lesbian for the purpose of the inquiry, accounts of women in the media, and the researcher's reflective journals. The findings move us towards new understandings about the multiple meanings of "lesbian." They challenge nurses to consider the binary categories of homosexual and heterosexual as inadequate signifiers for the reality of women's lives, to consider the particular arrangements of each woman's life, and to disrupt assumptions of heterosexism in order to reduce the negative impact of social exclusion, isolation, discrimination, and stigmatization as social determinants of health.

Keywords: lesbian, disclosure, heteronormativity, hermeneutics, heterosexism, feminist

Introduction

"The health of a nation, physically and emotionally, can only be as good as the health of its most vulnerable and stigmatized citizens. While culture, class and religion are known to affect how illness may appear and be understood, sexual orientation has been less well researched or understood as a mediator of health and illness." (Forstein, 2003)

In this paper I will report on a study that was intended to open to question our understandings of the interrelationship of lesbian life, the process of disclosure, and experiences of health. In this study the experience of disclosure was understood as central to lesbian life and disclosure was understood as an ongoing process through which a woman makes her lesbian orientation known to herself and to others. The process of disclosure might include overt verbal disclosure, covert or taken-for-granted disclosure, public disclosure, disclosure in relationships, and the decision to withhold disclosure. The breadth of this understanding of disclosure is beyond a temporally located "coming out" event.

The inquiry was based on an understanding of health that goes beyond a biomedical definition, to the emotional, social, interpersonal, mental, and spiritual realms. Experience of health is not merely the experience of disease or absence of disease from our bodies or our minds. It is increasingly accepted that the social and economic conditions of a person's life influence not only access to health care but the experience of health and illness (Wilkinson & Marmot, 2003). The social determinants of health as identified by the World Health Organization include social and economic realities that construct the environment or context in which a life, including a lesbian life, is lived. Several of these social determinants are particularly important when one considers that the lives of lesbian women are lived in ways that do not conform to the heterosexist social norm. In particular the World Health Organization states that "continuing anxiety, insecurity, low self-esteem, social isolation and lack of control over work and home life have powerful effects on health" (Wilkinson & Marmot, p. 12) and that "social exclusion" resulting from "discrimination and stigmatization" has a deleterious effect on health (p. 16). These threats to health and well-being, constituted in social environments, are particularly significant for the lives of lesbian women as they negotiate their way through a heterosexually determined landscape and face daily decisions regarding the disclosure of their sexual orientation. In addition to the social determinants of health that make up our material world — such as housing, employment, economic realities, social relationships, addiction, means of transport, and circumstances in early life — the experience of health is constituted through the influences of dominant discourses in society that attribute meaning to our lived experiences. The meanings attached to being a lesbian woman in a particular historical context influence the way in which a woman lives her life and the ways in which she and others view her life. It is perhaps these discursive realities that most profoundly affect decisions surrounding disclosure and influence the experience of health and wellness. This conceptualization of social determinants of health — both material and discursive realities — leads one to wonder what it is like for lesbian women to live their lives as a marginalized population in a heterosexist society (Hall, Stevens, & Meleis, 1994; Hitchcock & Wilson, 1992; Misner, Sowell, Phillips, & Harris, 1997; Radonsky & Borders, 1995; Robertson, 1992; Stevens, 1995).

Purpose of the Study

The purpose of the study was to create space for conversations that might generate new understandings of lesbian life as it is lived in a heterosexist society. Disclosure is assumed to be a central and ongoing experience in lesbian life, mediating lesbian identity and dominant heteronormative discourses. It is through disclosure of lesbian orientation that the voice and visibility of lesbian existence come into being. The research question was, then, *What is the experience of disclosure of lesbian orientation in a heteronormative society?*

Self-disclosure of a lesbian orientation is the acquisition of self-knowledge that changes irrevocably how one is situated in the world. This assumption is intended not to support an essentialist belief in a lesbian experience of self-disclosure, but to say that disclosing a lesbian orientation, even to oneself, locates a woman outside of the dominant societal assumptions of heterosexuality.

This experience of being situated outside of heteronormativity raises concerns about the health experiences of lesbian women. The present study was built upon a belief that health is constituted in our experiences of a life lived in a body and in our interpretations of those experiences. Health is constructed as we live our lives in interpersonal relationships, in couples, in communities, and in families. It is enmeshed in our sense of self, our sense of worth, and our sense of belonging; it is embedded in and constituted through our everyday experiences. The experience of living outside of a dominant cultural norm has the potential to affect both one's health and the health care that one receives. It is my assumption that nurses in practice, in education, and in research, as well as other health-care providers, have a limited understanding of the lives of lesbian women and that this lack of understanding compromises the health care that is provided to these women (Mathieson, 1998; Stevens, 1994a, 1994b, 1995).

Background

"All gay people, to one degree or another, travel down the road of coming out to themselves and others about their sexual orientation. The journey lasts a lifetime and is profoundly affected by societal inculcated homophobia." (Scasta, 1998, p. 87)

Disclosure Constructed as Health

The practice literature that addresses lesbian self-disclosure overwhelmingly correlates disclosure with health. Articles that report on research studies (Jordan & Deluty, 1998; Kahn, 1991; Morrow, 1996; Radonsky & Borders, 1995), theoretical articles (Deevey, 1993; Saddul, 1996; Scasta, 1998), and articles that review studies (Taylor, 1999) describe self-disclosure as positively associated with psychological and emotional health and authenticity in relationships. Radonsky and Borders, for example, state unequivocally that "coming out to friends and family…is crucial for self-esteem and self-acceptance" (p. 19). The harmful effects of non-disclosure can include feelings of shame and anxiety, depression, and disrupted interpersonal relationships (Jordan & Deluty). This picture of disclosure as constitutive of health and well-being is by no means straightforward or uncomplicated. It could be argued that the correlation of disclosure with self-esteem and self-acceptance contributes to a view of non-disclosure as pathological. This is a contentious implication given that the risks of disclosure in a heterosexist society include threats to personal safety, loss of relationships, discrimination in housing, employment, and health care, and irrevocably disrupted family functioning (Gramling, Carr, & McCain, 2000; Radonsky & Borders; Saddul; Stevens & Hall, 1988). And so, while self-acceptance and self-esteem are desirable, they are not unconditionally the result of high levels of self-disclosure. The decision whether to disclose is meaningful and understandable in the context of the lives of lesbians, and may even play a role in their mental health. Closely related to this issue is the fact that disclosure has become valorized among some groups of lesbians as exemplifying gay pride and defiance of heteronormative assumptions. This politicization of disclosure, though a reality of lesbian life, is seldom addressed in the literature. The essentializing of disclosure as always the "right thing to do," whether in the name of health or in the name of political ideology, negates the circumstances and experiences of each lesbian life and divests the woman of the opportunity to exercise agency in her own life.

Assumption of Heterosexuality

One cannot understand the experience of disclosure without considering the sociocultural context in which each lesbian life is lived. Heterosexism, which is grounded in the belief that heterosexuality is representative of sexual orientation, fuels the assumption that all women either are or wish to be in sexual/intimate relationships with men. It is a process of oppression through which heterosexual persons are given a privileged position and non-heterosexual persons are considered "other" (Gray et al., 1996).

From a review of the literature it is apparent that there is a pervasive assumption of heterosexuality underlying the health-care structure; the lesbian population is frequently an invisible minority in the health-care system (Hitchcock & Wilson, 1992; Radonsky & Borders, 1995; Robertson, 1992; Stevens, 1995). The assumption of heteronormativity is problematic for women in general and for lesbian women in particular, leaving little space in health care for the reality of lesbian life. The norm of heterosexuality is reflected in sexual and reproductive health-care practices, in demographic forms and interviews, and in the posters and pamphlets found on the walls and on the desks of health services. In research studies published over the past 20 years, lesbian participants report instances of neglect, discrimination, and abuse by health-care providers (Stevens, 1994a, 1994b, 1995) and report that their life experience appears to be poorly understood by those who deliver care (Mathieson, 1998). The experience of being poorly understood is constructed within the dominant discourse of our health-care culture and our society, which presumes heteronormativity.

The work of Stevens and others over the course of a decade indicates that the decision whether to disclose is more complex than the metaphor of being in or out of the closet suggests, and that it must be guided by the particular lived lives of lesbian women. Most recently, Stevens, Tatum, and White (1996) conclude that health-care practices directed towards women should move beyond unexamined categories of identity to consider the particular behaviours that influence the health of each woman.

Methodology

This inquiry relied on Gadamerian hermeneutics and feminist philosophical thought (Butler, 1990, 1991, 1999). Hermeneutics compels us to think about what is at work in our world. Feminist thought creates the space to problematize and historicize gender categories in a way that the male-dominated hermeneutic tradition has not (Butler, 1991; Scott, 1999). Feminist conceptualities thus extend the hermeneutic project of disrupting the taken for granted and opening up possibilities for how we might interpret and understand our world. According to Gadamerian hermeneutics, as we encounter a world and consider how it came to be, we develop an understanding of it and of ourselves as situated in it. Instead of following a set of methodological procedures to capture understandings, we are guided by Gadamerian hermeneutics to "clarify the conditions in which understanding takes place" (Gadamer, 1998, p. 295). "Understanding the lived experience is about understanding the structures and relationships that construct our lived realities, the meanings we create from the context in which we find ourselves" (Ceci, 2000, p. 68).

In hermeneutic inquiry, text is interpreted in such a way that new understandings are generated. The inquiry rests on gathering and accumulating the texts that will inform the interpretation. In the present inquiry, the texts were generated through research conversations with lesbian women, accounts by women in the media, and reflective journaling by the researcher, and the notion of the interview was replaced by that of conversation, as a means of both gathering data and beginning the process of interpretation.

Written informed consent for participation and for audiotaping the conversations was obtained from each participant. The primary texts for the study were generated through conversations between the researcher and the participants. Through conversation, each woman was invited to explore her experience of disclosure of lesbian orientation in order to uncover and generate meanings that the experience held in her life. The purpose of questioning in this hermeneutic inquiry was to stimulate reflection and deeper exploration of the experience. The in-depth exploration produced the meanings and the understandings of a particular experience. In the conversations the women moved beyond describing their experiences, to reflect on the meaning of them (Bergum, 1989), thereby opening up space for new understandings and interpretations of the experience.

The audiotapes of the conversations were transcribed verbatim. The transcripts became the primary data for the study and were used alongside the media accounts of lesbian life and my own reflective journaling. Unlike other approaches to qualitative research, hermeneutic inquiry does not prescribe a procedural, step-by-step method for analysis (Gadamer, 1998). Rather, the researcher "dwells with" the research data, moving between the parts and the whole. This perpetual movement, referred to as the hermeneutic circle, is central to the process of interpretation and understanding. Gadamer defines Heidegger's explication of this reflection or movement between the parts and the whole as an account of the way in which understanding is achieved. Interpretation means following the relationship between particular, shared, experiences and the contexts in which the meanings of these experiences were generated. In the present analysis, the intention was not to recite the experiences of the 15 participants, nor to provide the reader with a set of themes that consistently emerged in the conversations. The interpretations do not stand in for the story of lesbian disclosure, although each interpretation has something to say about that story. Rather, the findings consist of interpretations of what could be transpiring for any lesbian woman and the possible implications of this for her experience of health.

Participants

Conversations were held with 15 women who responded to advertisements for the study posted in women's centres and bookstores and on a university campus in western Canada. Of the participants, some chose to name themselves lesbian and some spoke of being lesbian as central to their identity, giving direction to the journey "a way to have a life." Nine of the participants were in a committed monogamous relationship with another woman; for several of those participants, this was their first lesbian relationship. Six of the participants were not currently partnered. Of the 15 participating women, many had previously been in sexual relationships with men, including having been married to men, and six became mothers during those heterosexual relationships. One woman had previously lived as a man and become a father. One woman became a mother with her female partner. All of the participants had repeatedly faced decisions about disclosure of their orientation.

The participants had, during their lives, spent varying lengths of time in intimate relationships with women. Isis had been out to herself for 29 years. Alex was 49 years old when she sought out a sexual encounter with a woman. Taylor was married to a man for 23 years before she and her two daughters all identified themselves as gay. Jade and Tracey came out to themselves as young women.

The women's ages spanned four decades, ranging from 26 to 56 years. There were no participants in their teens or early twenties. One woman identified her home country as located in Central America; the remainder of the participants identified themselves as of European extraction. Most of the women were employed. Eight had been to university and three were currently students. One woman was a stay-at-home mother. One woman was being supported by social assistance.

Each of the participants had created a life for herself in which intimate/sexual/affectionate relationships with women were valued if not central to the way in which she lived her life. All of the women had passed "under the sign of lesbian" (Butler, 1991, p. 14) and some had chosen to stay and "establish residency there." When one embarks on such a journey, questions of naming and of telling are inevitable. The person has inhabited the terrain.

Findings

The horizons of the study were expanded immediately by the diversity of the women who responded to the call for participants "under the sign of lesbian." A decision was made to include any person who called herself lesbian. I have become familiar, in our culture, with the taken-for-granted meaning of lesbian as a category of sexuality — that is, a woman's object of desire is another woman. Female homosexuality is defined as the manifestation of sexual desire towards a member of one's own sex (*Webster's New Collegiate Dictionary,* 1980). Although all of the women responded to the call for participants as "lesbians," they practised being a lesbian in notably different ways. Many of them had had previous sexual relationships with men and several did not rule out the possibility of relationships with men in the future. Half of the participants were currently in a relationship with a woman and half were not in a relationship.

Several had never had a sexual relationship with a woman. One woman who identified herself as lesbian could also be named transgendered, having previously lived as a man. This group of people standing together as lesbians disrupts the stability of the category. If a lesbian is no longer a woman who manifests sexual desire towards another woman, then what does it mean to say, "I am a lesbian"?

The experiences of women in the world give us some indication of how we might understand disclosure. The possibilities are many, not only for how disclosure might be taken up by different women, but also for how it might be taken up by the same woman. The participants generated multiple meanings of disclosure. They saw disclosure as truth telling, as activist naming, as constituting the self, and as creating lesbian space.

Disclosure as Truth Telling

In the conversations with the women about disclosure to self and to others, there emerged an epistemological discourse of truth. Some women had come to believe or to act as if there were an indisputable truth to be discovered about their sexuality, the confirmation of which placed them under pressure to "tell the truth." One participant, Clara, wanted to tell her mother that she considered herself a lesbian, that she was attracted to women, even though she knew this would jeopardize both her son's and her own relationship with her mother. For Clara, "honesty is the most important thing." Jade said, "To actually put the truth out there is an incredible journey." Jade had lost her family and her job; she had moved across the country to make a new start; her mental health was precarious. Rose said, "I can't raise a daughter who is true to herself when as a mother I am not true to myself." Rose's male partner had accused her of being an unfit mother and vowed to reduce her to poverty. Rose went to jail to defend her truth. Judith spoke of having plunged her family into a crisis with her disclosure and of their disbelief over her truth; her mother had said, "I raised you and I would know if you were a lesbian — you've just had bad marriages." What is the effect of a mother's denying the identity of her daughter? Does it undermine the daughter's sense of herself, particularly in view of her discovery of having, even joyously, found a way to make a life for herself, to make sense of the life that she lives?

This incitation to confess assumes that "there is such a thing as a literal account, the final truth of the matter, stripped of connection with other matters, told without metaphor" (Gadow, 1995, p. 213). Lives as they are lived clearly illuminate "truths" as constructed in relationships, as inseparable from the social, material, and discursive realties in which those lives are lived.

In the practice literature, disclosure is positively associated with psychological and emotional health and authenticity in relationships (Deevey, 1993; Jordan & Deluty, 1998; Kahn, 1991; Morrow, 1996; Radonsky & Borders, 1995; Saddul, 1996; Scasta, 1998; Taylor, 1999). The conversations with the women in the present study, as well as McWhorter's (1999) reading of Foucault, complicate this correlation of health and disclosure. In fact, McWhorter is wary of the findings in the practice literature: "What we're always told, of course, is that knowledge is the first step towards health, happiness, and freedom, because the opposite of knowledge is repression." She suggests instead: "Knowledge is the first step toward discrimination" (p. 13). This point is made not to support the notion that discrimination will always follow on the heels of disclosure, but, rather, to speak to the assumption that interpersonal relationships should be grounded in an authenticity that derives from honest interaction and the belief that living with a secret impinges on authentic interpersonal engagement (Yalom, 1985).

There is no doubt about the broad compliance to the incitation to confess the "truth" of one's sexuality, particularly to those whose understanding or acceptance the woman especially values. Paradoxically, it may be within the relationships in which a woman has the greatest emotional investment and thus the most to lose that she feels compelled to disclose the "truth" of her membership in a particular historically and socially constructed category.

To suggest that a woman is "living a lie" or that her relationships are less than authentic if she does not always and everywhere disclose her sexuality is to reify a narrow understanding of truth. Like categories of sexuality, truth itself can be considered an epistemological construction. Instead of deriving the "truth" of sexuality from an internal identity, we could understand the truth of a woman's sexuality as historically constructed in her particular social, material, and discursive world. Depending on a woman's situatedness, it may be more constitutive of her health to construct the truth as "I am living with a woman," or even as "I love a woman," than as "I am a lesbian."

Disclosure as Constituting Self

Some of the participants spoke about disclosure as a way of being in the world, as the means by which they intentionally and inadvertently presented themselves to others "under the sign of lesbian." While disclosure can be seen as a manifestation of wishing another to know (presumably, the "truth"), it can also serve to remind a woman of who she is. In the study, reminding or reconstituting of self was presented most clearly in the non-verbal lesbian disclosure. Tattooing the sign of lesbian on one's body, wearing the rainbow colours, or wearing jewellery constructed of two female symbols was meant not only to disclose to others but also to remind the woman herself of her identification with the sign of lesbian. Disclosure through wearing a lesbian symbol, acting demonstratively with another woman in public, or verbally telling are ways of practising/being lesbian. Repetition of disclosure re-enacts lesbian. Jade wore her lesbianism tattooed on her body, literally and figuratively:

> *I have incredibly short hair — it's a buzz. I dress in jeans and shirts. I don't wear the rainbow necklace for everyone to see that I'm a lesbian. I don't have the tattoo for everyone to see that I'm a lesbian. I have it for myself. It's difficult to explain. I went through a lot of crises because of my lesbianism, and I deserve to be able to say, yeah, I'm a dyke and I'm very proud of that. I've earned the right… It's about every single day; you have to fight to say I'm okay to be here. There's nothing abnormal about me. I'm just me, you know... I don't care what you think about me because I'm a great person, and it's your loss if you don't want to get to know me…but every day I still struggle with that.*

Disclosure as Active(ist) Naming

Some women practise lesbian disclosure as an obligation. The participants spoke of their responsibility to not only raise the lesbian flag but to stand under it, to claim allegiance as a way of disrupting taken-for-granted heteronormativity. There is a belief that heteronormativity would topple and discrimination against homosexuals plummet if people discovered that their mother/teacher/sister/friend/neighbour/professor/aunt/roommate/minister was a lesbian. There is a desire to counteract the image of lesbians as evil or pathological and to demonstrate to non-lesbian people that lesbians are similar to them in many respects. Judith, a university professor, described her activist role of using every available opportunity to educate others:

> *It's part of my feminist perspective. It's part of my convictions as a psychologist about our larger responsibility to society. I see it as a part of my work to educate, and my sexual orientation has become a part of my work…and what I see as my career goals or what I integrate into my role as a psychologist…educating people and encouraging more open understanding.*

Disclosure as Creating Lesbian Space

"Lesbian space" is a place or places where lesbian women experience respect, acceptance, and safety. Within such a space, heterosexual dominance recedes and, at least temporally, the power of heteronormativity is contested. Lesbian space can be manifested in diverse places and mediums: an office door in a nursing faculty or a hospital unit where a "positive space" rainbow decal promises respect for sexual diversity, literature in which lesbian realities are accurately portrayed, formal and informal gatherings during which lesbians play and dance and celebrate their lives. The participants spoke repeatedly of belonging, joining, visiting spaces where they felt fully accepted as lesbian women. They also spoke about ways in which their own disclosure had opened discursive and social lesbian spaces.

The creation of these spaces in our society is seldom happenstance; it is more likely to result from deliberate, strategic effort. And while it would be remiss to not acknowledge the contribution of non-lesbian women to the production of lesbian spaces, lesbian disclosure is one of the strategic practices through which safe and respectful spaces are created for lesbian women.

After 21 years in a heterosexual marriage, Alex left to live her life as a lesbian. She spoke of a life that no longer served her: "I could not stay in my life. I could not pretend any more. I felt really wonderful because I felt like I truly found myself and wouldn't everybody be so happy for me?" Instead, however, Alex experienced rejection by family members and friends: "I was ostracized…a lot of people I have never heard from since." Yet Alex was committed to her own disclosure and to providing a space in which she and other women could celebrate their lives:

> *I am very open in disclosing still. I felt that this was important enough to me to always continue to be open, which I have always been, in every situation… Okay, no matter how much I had felt hurt…this is my life. I have nothing to be ashamed of. I'm proud to be a lesbian. I feel like this: I've waited all my life to know who I am, and so, you know, I mean, I've done nothing wrong and I'm a good person. What do I have to hide? I have nothing to hide.*

Nursing Situatedness

In writing about difference as a feature of the world of nursing, Ceci (2003) reminds us of nurses' position of access to the lives of others: "As nurses, we encounter people in their most vulnerable moments and so have the opportunity to cause harm by unthinking adherence to the false and damaging beliefs and assumptions often contained in categories and labels" (p. 428). The unexamined beliefs of health-care providers, often imbued with erroneous voices from the past, contribute to our complicity in maintaining authoritative and inaccurate discourses. The willingness of care providers to question our own assumptions about difference instigates the disruption of taken-for-granted categories and labels.

Nurses might also view themselves as in a position to engage in strategic practices to destabilize heteronormativity and the unthinking use of categories of sexuality in the health-care environment. Nurses' knowledge of and place in the power structures of the health-care system positions them to effectively participate in destabilizing practices.

Implications for Nursing

The results of this study may be useful to nurses involved in direct patient care, in education, and in research endeavours, by disrupting the norm of heterosexuality in nursing discourse and questioning the adequacy of categories of sexuality to speak to the realities of women's lives. We are challenged to consider the possibility that any given woman may be living a life outside of the dominant norm of heterosexuality, and to engage with this reality as we encounter women as colleagues, patients, students, and research participants.

As nurses come to understand heteronormativity and the effects of categorization, our complicity in maintaining these discourses is challenged and new possibilities for practice are generated. Disruption of the assumptions of heterosexism is a means for nurses to reduce the deleterious impact of social exclusion, isolation, discrimination, and stigmatization as social determinants of health (Wilkinson & Marmot, 2003). How would health-care practices be altered if space were created to consider the differences in women's lives and experiences of health? Posters, pamphlets, and films would reflect women partnered with women, women partnered with men, men partnered with men, people not partnered, people with and without children; medical history forms would have a space for significant relationships, family practice would include all families, and the health-care system would ensure equal rights and privileges for every type of partner. Health-care providers would have conversations with all women about the alternatives available for having children, and all women would receive accurate information and intervention about their sexual health, based on their past and current sexual practices. Relationships with health-care providers would be a safe place for lesbians to talk about their relationships with lovers, friends, and family. Domestic violence in women's relationships would be addressed as seriously as other forms of violence against women. Women who name themselves lesbian would feel safe and supported in their relationships with health-care providers.

Nurses who engage in interpretive practice consider the multiple meanings that may be at play in a woman's life. We are challenged to question the assumptions that are attached to labels and categories and to become vigilant as to the ways in which received language misrepresents the lives of women. The results of the present inquiry point to an understanding of all women's lives as constructed of multiple and complex realities: realities constituted under social, material, and discursive influences. We cannot escape history. Categories of classification and scientification are our inheritance; they are alive in our world. We are not, however, destined to dutifully, unquestioningly accept our inheritances. Rather, we are invited to unpack the categories, to disrupt the taken-for-granted meanings that have been handed to us from the past and to remain open to the future as it unfolds.

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Comments or queries may be directed to Carol McDonald, Assistant Professor, School of Nursing, University of Victoria, PO Box 1700, Victoria, British Columbia V8W 2Y2 Canada. E-mail: carolmcd@uvic.ca

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Carol McDonald, RN, PhD, is Assistant Professor, School of Nursing, University of Victoria, British Columbia, Canada.

Résumé

Les liens entre la situation par rapport à l'emploi, les événements de vie stressants et la dépression chez les mères monoparentales

Joan Samuels-Dennis

Cette étude vise à comprendre davantage le rôle de la situation de l'emploi comme déterminant social de la détresse psychologique chez les mères monoparentales. Une enquête transversale étudiant les événements de vie stressants et la dépression a été réalisée auprès de 96 mères monoparentales (48 détenaient un emploi et 48 étaient bénéficiaires d'aide sociale [AS]), de novembre 2003 à mars 2004. La prévalence de symptômes de dépression était significativement supérieure chez les bénéficiaires d'AS. Des symptômes légers, modérés et graves ont été rapportés chez respectivement 2 %, 23 % et 67 % des bénéficiaires d'AS. Le taux d'événements stressants était nettement plus élevé chez les assistées sociales. De plus, ces dernières ont signalé la présence d'un plus grand nombre d'agents stresseurs liés au logement, à la santé, aux interactions sociales et à l'argent. Une analyse de régression a indiqué que 40,6 % de la variation relative aux symptômes de dépression chez les mères monoparentales étaient liés à la situation de l'emploi et aux événements stressants. Les résultats indiquent que la situation par rapport à l'emploi exerce un impact important sur le bien-être psychologique des femmes. L'auteure identifie les implications concernant la pratique infirmière, l'élaboration de politiques et la future recherche, et discute de ces éléments.

Mots clés : dépression, stress, mères monoparentales, aide sociale

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Relationship among Employment Status, Stressful Life Events, and Depression in Single Mothers

Joan Samuels-Dennis

This purpose of this study was to extend our understanding of employment status as a social determinant of psychological distress among single mothers. A cross-sectional survey assessing stressful life events and depression was completed with 96 single mothers (48 employed and 48 social assistance [SA] recipients) between November 2003 and March 2004. The prevalence of depressive symptoms was significantly higher for the SA recipients. Mild, moderate, and severe depressive symptoms were reported by 2%, 23%, and 67%, respectively, of SA recipients. Total stressful events were markedly greater for SA recipients. In addition, SA recipients reported larger numbers of housing, health, social, and financial stressors. Regression analysis indicated that 40.6% of the variation in depressive symptoms among single mothers was explained by their employment status and stressful events. The findings suggest that women's employment status significantly impacts on their psychological well-being. Implications for nursing practice, policy development, and future research are identified and discussed.

Keywords: determinant of health, depression, stress, single mothers, welfare

Introduction

Among the many social and economic factors that influence and shape the health of Canadians, income has been identified as the single most important determinant of health (Raphael, 2004). For the 12.7% of Canadian families headed by single mothers (Statistics Canada, 2001), poverty is a particular challenge to psychological well-being (Avison, 2002). Single mothers, when compared to the general population, have almost double the 12-month prevalence rates of depression (15.4% vs. 7.9–8.6%) (Cairney, Thorpe, Rietschlin, & Avison, 1999).

Single mothers receiving social assistance (SA) are at particularly high risk for psychological distress because of established relationships between mental illness and family structure (Avison, 2002), poverty (Belle, 1990; Bryne & Brown, 1998; Gyamfi, Brooks-Gunn, & Jackson, 2001), and life adversities (Davies, Avison, & MacAlpine, 1997; Ford-Gilboe, Berman, Laschinger, & Laforet-Fliesser, 2000; Tolman & Rosen, 2001). The chronic strains that accompany single motherhood, including economic hardship, parental stress, and role strain, have been credited with much of the responsibility for the disproportionate burden of mental illness experienced by this population (Avison).

Having identified single-parent families as vulnerable to increased risk for poor health, the National Children's Agenda has, over the past three decades, launched national and provincial health promotion programs (i.e., Healthy Babies Healthy Children, Ontario Early Years Initiatives, and Community Action for Children) directed at improving the health status of at-risk families with children under 6 years of age (Ministry of Health and Long-Term Care, 2002; National Children's Agenda, 2005). Historically, nursing interventions offered by such programs have focused on enhancing the social competencies or personal resilience of single parents and have often failed to address the socio-economic factors that contribute to the heightened risk for health disparities among single-parent families.

This article highlights the findings of an exploratory study examining the influence of the socio-economic context of single mothers' lives on their psychological well-being. A premise of the study was that family structure alone is not a risk factor for poor health. It is acknowledged, however, that single mothers are a heterogeneous group with significant differences in level of education, employment and socio-economic status, access to resources, and life experiences (Ford-Gilboe et al., 2000). Given that these differences may affect one's vulnerability to psychological distress, it is essential for the development of group-specific nursing interventions that nurse researchers identify those subgroups of single mothers in which mental health disparities are most pronounced.

Literature Review

The Stress Process Model (Pearlin, 1989, 1999, 2002) provided the theoretical framework for the study. According to this model, stress is a dynamic and evolving process that incorporates three core elements: stressors, stress moderators, and stress outcomes.

Stressors

In general, stressors are tension-producing stimuli or forces — problems, hardships, or threats — whose reduced impact requires the mobilization of cognitive and behavioural efforts (Pearlin, 1999, 2002; Wheaton, 1999). Pearlin (1999, 2002) and Wheaton identify three primary categories of social stressor: life events, chronic stressors, and trauma. Life events are significant life changes that are discrete and observable, have a relatively clear onset, and have a well-defined set of sub-events that progress from stressor initiation to stressor termination. In contrast to life events, chronic stressors or strains arise insidiously and may either surface repeatedly or maintain a presence over a considerable period of time. Chronic stressors represent the enduring problems, conflicts, and threats that individuals face in their daily lives and that may arise from systems of inequality such as class, institutionalized social roles, social networks, neighbourhoods and communities, or households (Pearlin, 1999, 2002; Wheaton). Traumatic events are typically more severe than normal stressful events; they occur both as isolated events and as long-term chronic events, and, because of their level of severity, their impact is long-lasting (Pearlin, 1999, 2002; Wheaton). Traumas include a potentially wide range of severe situations and events, including war, natural disasters, sexual abuse during childhood or adulthood, and physical violence and abuse.

A key feature of the Stress Process Model is what Pearlin (2002) calls *stress proliferation*. This refers to the human reality that individuals are frequently exposed to multiple stressors that may negatively impact on their well-being (Pearlin, 2002). According to the Stress Process Model, exposure to one set of stressors eventually leads to other stressors (Pearlin, 2002). Job loss, for example, is a precursor to chronic financial strain, which increases single mothers' risk for insufficient food, housing insecurity, and psychological distress or depression.

In addition to socio-economic disadvantages, a wide range of life adversities in both early and adult life have been identified as significant contributors to higher rates of psychological distress among single mothers (Avison, 2002; Davies et al., 1997; Ford-Gilboe et al., 2000). McLanahan (1983) examined the relationship between family headship (single-mother and two-parent families) and three types of stressor: chronic life strains (demographic characteristics — race, income, age); major life strains (events that lead to a disruption of social networks or life patterns); and the absence of social and psychological support. That study revealed that single-mother families were more likely than other families to experience chronic strains commonly associated with poverty, being black, and being less educated. Income change, change in household composition, and residence change were identified as the major life events most frequently experienced by single mothers. In other studies (Scarini, Ames, & Brantley, 1999; Wagner & Menke, 1991) with low-income single mothers, the most common stressful life events reported were related to intra-family strains, finance, work-family transitions, health status of individuals and family, and change in social activities.

An important life adversity endemic to single-parent families, particularly those receiving SA, is intimate partner violence (IPV). Tolman and Rosen (2001) used data from a random sample of women from welfare caseloads in Michigan County, in the United States, to investigate the prevalence of domestic violence and its association with mental health, physical health, and economic well-being. They found 12-month and lifetime prevalence rates of IPV to be 25% and 62.8%, respectively. Ford-Gilboe et al. (2000), in a community sample of 236 single mothers, found that 86%, 78%, 65%, and 52% had experienced emotional, verbal, physical, and sexual abuse, respectively, during their lifetime. Compared to women who had never experienced intimate partner abuse, recent victims had markedly higher rates of five psychiatric disorders: depression, generalized anxiety disorder, post-traumatic stress disorder, drug dependence, and alcohol dependence (Tolman & Rosen). In addition, chronic strains most frequently reported by IPV survivors include financial strain, homelessness, eviction, discontinuation of utility services, food insufficiencies, physical and mental illness, and harassment (Campbell, 2002; Ford-Gilboe et al.; Tolman & Rosen).

Stress Moderators

Early research relevant to stressful life events was based on the assumption that all life events (positive or negative) are potentially stressful, with the degree of stressfulness varying with the magnitude of readjustment required by the specific event (Holmes & Rahe, 1967). Research has since revealed that stressor impact (beneficial or detrimental) is determined by five factors: the time-frame in which the stressor occurs, the past and present mental and physical health status of the individual, the nature and intensity of the stressor, the amount of energy required by the individual to adjust, and, most important, the moderating resources available to the individual (Davies et al., 1997; Pearlin, 2002; Wheaton, 1999).

Moderators, including the individual's coping repertoire, level of social support, and mastery (sense of control over one's life), represent the social and personal resources that individuals and families mobilize to contain, regulate, or otherwise ameliorate the effects of stressors (Pearlin, 2002). Moderating resources help us to understand why individuals exposed to the same stressors experience an array of different outcomes. Moderators serve a protective function that can be exercised in three ways: by acting proactively to preclude or prevent the occurrence of a stressor, by modifying or minimizing the harmful impact of stressful conditions, and by perceptually controlling the meaning of the stressor in ways that reduce their threat and potential painful consequences. From the few studies that have examined the coping repertoire of single mothers, it evident that this population uses an array of strategies to manage chronic and traumatic stress, including active and passive strategies such as obtaining social support, seeking spiritual guidance, engaging in active problem-solving, and using passive appraisal or avoidant coping

(Felsten, 1998; Hall, Gurley, Sachs, & Kryscio, 1991; Wagner & Menke, 1991). For further exploration of coping as a moderator of stress, see Pearlin (1989, 1999, 2002) and Pearlin and Johnson (1977).

Stressor Outcomes

The final major component of the Stress Process Model is the outcome (Pearlin, 2002). Outcome refers to physiological and psychological manifestations of "organismic" stress (Pearlin, 1989). Studies looking at stress and health outcomes among single mothers often compare single-parent families with two-parent families and have consistently documented greater psychological distress among separated and divorced parents than among two-parent families (Avison, 2002; Cairney et al., 1999; Davies et al., 1997; Lipman, Offord, & Boyle, 1997). The authors of these studies suggest that dissolution of a marital or common-law relationship is often accompanied by increased levels of stress or chronic strain (for example, economic hardship, parenting difficulties, and child-care demands) that continue long after the divorce or separation and, consequently, increase single mothers' risk of experiencing psychological distress or depression (Avison). Consistent with the Stress Process Model, much of this work has purposely attempted to uncover the ways in which single mothers' response to stress differs not only by family structure but also by social and economic status (Pearlin, 1999, 2002). Pearlin (1999, 2002) proposes that the stress process occurs within a social context whereby life events and/or chronic strains largely arise from, and are influenced by, social structures and people's location within them. Finding its roots in critical social theory, the model suggests that systemic embodiment of unequal distribution of resources and opportunities inevitably results in stressful conditions for those with the lowest status (Pearlin, 1999, 2002).

Researchers examining the association between childhood adversity and mental health suggest that childhood maltreatment (physical, emotional, and sexual abuse) creates early vulnerability to psychiatric difficulties that is activated by periods of interpersonal stress in later life (Davies et al., 1997; Lipman et al., 1997). Davies et al. used data from a case-comparison longitudinal survey of single and married mothers in London, Ontario, to examine the relationship between early-life adversities, depressive episodes, and family structure. Higher rates of depression among single mothers were related to greater exposure to stressors (i.e., low maternal attachment, parental depression, parental substance abuse, and child abuse/neglect) in the woman's family of origin that, in turn, increased the likelihood of early-onset depression and subsequent depressive episodes.

The association between poverty and psychological distress among single mothers is well documented (Avison, 2002; Bryne & Brown, 1998;

Gyamfi et al., 2001; Lennon, Blome, & English, 2001). Among single mothers with the lowest incomes, the 12-month prevalence rate of major depressive disorder ranges from 12% to 36% (Lennon et al.). Bryne and Brown's assessment of depression levels among single mothers receiving SA revealed that 32.5%, 10.4%, and 2.5% reported symptoms consistent with major depression, dysthymia (moderate chronic depression), and double depression (major depression and dysthymia), respectively.

Employment, regardless of income, offers some protection against depressive episodes (Belle, 1990). Hall, Williams, and Greenberg (1985) examined the relationship between social support, everyday stressors, and mental health in a sample of low-income single mothers. They report that mothers who had extremely low incomes or were unemployed were more likely to report severe depressive symptoms (48%). More recently, Gyamfi et al. (2001) investigated the association between financial strain and maternal depressive affect among single mothers who were formerly ($n = 95$) and currently ($n = 95$) receiving SA. Employed mothers reported fewer symptoms of depression and stress than non-employed mothers. However, for those women transitioning from welfare to work, being employed did not reduce financial strain. The authors suggest that the lack of change in financial strain reflects the fact that a majority of single mothers transitioned from welfare to low-paying jobs without benefits. They also note that while employed mothers continued to experience financial strain, the strain no longer affected the level of depression. Among the unemployed, however, financial strain was positively correlated with depression. The authors surmise that employment and a resultant increase in levels of perceived self-efficacy may mediate depressive symptoms.

Low-income women are the target of many social programs, ranging from welfare and workfare programs to interventions designed to prevent problems in pregnancy and to enhance maternal competence. While research has identified factors that may cause psychological distress in single mothers, few studies have specifically examined variations in stressful events and psychological distress among single mothers caused by differences in employment status or access to income. A greater understanding of the factors that contribute to health disparities among subgroups of single mothers is essential for the development of effective public health nursing interventions.

Purpose and Hypotheses

The purpose of this study was to assess the association between employment status or access to income, stressful life events, and depression among single mothers. Three hypotheses were formulated: Hypothesis 1:

SA recipients will report greater stressful events than employed single mothers. Hypothesis 2: *SA recipients will report greater depressive symptoms than employed single mothers.* Hypothesis 3: *Employment status and stressful events will predict depression among single mothers.*

Method

Design

This cross-sectional, descriptive correlational study used survey data to assess predictors of depression in two groups of single mothers, those employed and those receiving SA, as part of a larger study examining the association between employment status, stressful events, coping repertoire, and psychological distress (Samuels-Dennis, 2004).

Participants

A convenience sample of 96 single mothers (48 employed and 48 receiving SA) was recruited from community agencies in a large city in the Canadian province of Ontario. Power analysis determined that a sample of 91 single mothers was needed based on $\alpha = .05$, multiple regression with five independent variables, and a medium effect size (Cohen, 1992). Women were asked to participate in the study if they met the following criteria: (a) 18 years or older; (b) self-identified as a separated, divorced, widowed, or never-married woman who was the primary caregiver of at least one child 4 to 18 years old; (c) employed or receiving SA; and (d) fluent in English.

Women were recruited using: (a) contacts in health and social agencies that provide services to single mothers and their children; (b) a list of active SA recipients generated by Ontario Works, the provincial welfare provider; and (c) referral of other single mothers by the study participants. Twenty-one potential Ontario Works participants could not be reached because of cancelled telephone service. Of the 74 SA recipients contacted, 70 agreed to participate and 48 returned completed questionnaires, for a response rate of 68%. Of the 75 employed single mothers contacted, 73 agreed to participate and 48 returned completed questionnaires, for a response rate of 65.8%. The combined response rate across the two groups was 67%.

Instruments

Exposure to stressful life events was captured using the Social Readjustment Rating Scale (SRRS) (Holmes & Rahe, 1967). The SRRS was developed to identify the incidence of recent life changes and to measure the intensity of anticipated readjustment to 43 specific life events. It is a short survey in checklist form that assesses participant exposure to stressors such as divorce, physical illness, and financial difficulties. Life Change Units (LCUs), assigned to the various life events, allow researchers to determine the cumulative amount of stress an individual has experienced over a 24-month period. The SRRS was adapted to assess single mothers' exposure to chronic strains, daily hassles, and traumatic stressors. The LCU component of the scale was excluded and eight stressors relevant to woman abuse, mental illness, and homelessness that were not previously captured using the SRRS were added to the checklist. Single mothers were asked to indicate if they had encountered specific events in the past 24 months by checking the appropriate box. The total number of life events experienced was computed by summing the number of checked boxes. Possible scores ranged from 0 to 51, with higher scores indicating more stressful events. Face validity of the revised SRRS was determined by a panel of three experts. Test-retest scores for the unaltered SRRS range from .72 to .91 and internal consistency ranges from .59 to .83 (Holmes & Rahe). In this study, Cronbach's alpha reliability coefficient was .69.

The BDI-II is a self-report instrument designed to measure the severity of depression in adults and adolescents aged 13 years and older (Beck, Brown, & Steer, 1996). It contains 21 items and was developed to assess symptoms corresponding to the criteria for diagnosing depressive disorders listed in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition* (DSM-IV) (Beck et al.). Participants were asked to indicate the extent to which they had experienced each symptom on a four-point Likert scale (0 = I do not feel sad; 3 = I am so sad or unhappy that I can't stand it). A total score is computed by summing the ratings of all 21 items and reflects the following clinical interpretation: 0 to 13, minimal depression (representing normal ups and downs of everyday living); 14 to 19, mild depression; 20 to 28, moderate depression; 29 to 63, severe depression (Beck et al.). Internal consistency and 1-week test-retest values range from .92 to .93. In the present study, Cronbach's alpha reliability coefficient was .93.

Data Collection

After ethical approval had been obtained, a questionnaire was delivered or mailed to the homes of women who had consented to participate. No incentives were offered for participation in the study. A return envelope with prepaid postage was included with each questionnaire. Participants completed and returned the questionnaire by mail. Follow-up phone calls were made to those single mothers who had not returned the questionnaire after 3 months.

Data Analysis

Data were analyzed using SPSS Version 12. Descriptive statistics appropriate to the level of measurement were generated for all study variables. *T* tests were used to test hypotheses 1 and 2, while multiple regression analysis was used to examine the extent to which employment status and stressful life events contributed to variations in depressive symptoms among the single mothers. The significance level for all analyses was $\alpha = .05$.

Results and Discussion

Demographic comparisons between employed mothers and mothers receiving SA are presented in Table 1. Comparative analysis revealed that the two groups were similar in age ($\bar{x}_E = 38.60$, $SD = 7.203$, $\bar{x}_{SA} = 40.0$, $SD = 6.425$, $t = -.990$, $p = .325$). However, SA recipients had a significantly larger number of children currently in their care ($\bar{x}_E = 1.92$, $SD = .942$, $\bar{x}_{SA} = 2.42$, $SD = 1.048$, $t = -2.458$, $p = .016$). Chi-square analysis indicated marked differences in racial makeup of the groups ($\chi^2 = 19.337$, $p = .001$) and the highest level of education reached ($\chi^2 = 26.736$, $p = .001$).

Hypothesis 1

The first hypothesis was that SA recipients would report more stressful events than their employed counterparts. As predicted, SA recipients encountered a larger number of stressful life events than employed mothers ($\bar{x}_E = 6.94$, $\bar{x}_{SA} = 8.81$, $t = -2.233$, $p = .028$: see Table 2). Financial strain was more pronounced among SA recipients (50% vs. 18.8%), as this group reported that their financial status was much worse than usual, experienced greater difficulty paying their rent or mortgage (56.3% vs. 16.7%), and were more frequently evicted from their homes (8.3% vs. 0%). Employed mothers reported significantly greater improvements in their financial status (20.8% vs. 0%) and a greater amount of the financial stability required to obtain a loan for a major purchase such as a car or mortgage (33.3% vs. 0%).

The results prove the hypothesis that employment does offer protection against poor health. SA recipients reported significantly greater health problems (physical, mental, and social). In the 2 years prior to completion of the questionnaire, 79.2% of SA recipients, compared to 22.9% of employed mothers, experienced a serious physical or mental illness; in addition, they reported a considerably larger number of personal injuries or accidents (25.0% vs. 8.3%) and more frequent minor illnesses (54.2% vs. 31.3%).

Table 1 *Sociodemographic Characteristics of Single Mothers, by Employment Status*

	Employment ($n = 48$)		Social Assistance ($n = 48$)	
	n	%	*n*	%
Race				
Caucasian	14	29.2	21	43.8
Afro-Canadian	27	56.3	11	22.9
Native	1	2.1	1	2.1
South Asian	1	2.1	9	18.8
Asian	4	8.3	1	2.1
Latino	1	2.1	3	6.3
Arabic	0	0.0	1	2.1
Other	0	0.0	1	2.1
Number of Children				
1	18	37.5	9	18.8
2	20	41.7	19	39.6
3	7	14.6	13	27.1
4	2	4.2	5	10.4
5 or more	1	2.1	2	4.2
Annual Income				
$0–19,999	4	8.5	47	97.9
$20,000–39,999	23	48.9	1	2.1
$40,000–59,999	10	21.3	0	0.0
$60,000–79,999	9	19.1	0	0.0
$80,000 and above	1	2.1	0	0.0
Marital Status				
Single	22	45.8	20	41.7
Separated	14	29.2	7	14.6
Divorced	12	25.0	19	39.6
Widowed	0	0.0	2	4.2
Level of Education				
Grade school	0	0.0	5	10.4
High school	9	18.8	27	56.3
College/university	27	56.3	15	31.3
Graduate/professional	12	25.0	1	2.1

Table 2 *Comparison of Stressful Events According to Employment Status*

	Employed (***n***=48)			**Social Assistance** (***n***=48)			
Stressful Event	%	$\bar{x}$	*SD*	%	$\bar{x}$	*SD*	*t*
Started/changed school	14.6	.15	.357	20.8	.21	.410	-0.796
Graduated from school	22.9	.23	.425	12.5	.13	.334	1.335
Problems in school	4.2	.04	.202	8.3	.08	.279	-0.838
Failed school	2.1	.02	.144	0	.00	.000	1.000
Got married	2.1	.02	.144	0	.00	.000	1.000
Marital separation	12.5	.13	.334	8.3	.08	.279	0.663
Divorce	10.4	.10	.309	14.6	.15	.357	-0.612
Reconciled relationship	10.4	.10	.309	6.3	.06	.245	0.733
Increased arguments with partner	20.8	.21	.410	8.3	.08	.279	1.744
Improved relations with partner	10.4	.10	.309	8.3	.08	.279	0.347
Emotionally abused by partner	20.8	.21	.410	22.9	.23	.425	-0.244
Physically abused by partner	2.1	.02	.144	4.2	.04	.202	-0.581
Sexually abused by partner	0	.00	.000	2.1	.02	.144	-1.000
Change in residence	41.7	.42	.498	39.6	.40	.494	0.206

Table 2 (cont'd)

Stressful Event	Employed ($n=48$)			Social Assistance ($n=48$)			t
	%	$\bar{x}$	*SD*	%	$\bar{x}$	*SD*	
Repeated difficulty paying rent or mortgage	16.7	.17	.377	56.3	.58	.539	-4.374*
Eviction from home	0	.00	.000	8.3	.08	.279	-2.067*
Mortgage or loan for a major purchase	31.3	.31	.468	0	.00	.000	4.622*
Foreclosure of mortgage or loan	0	.00	.000	0	.00	.000	–
Pregnancy	8.3	.08	.279	8.3	.08	.279	0.000
Abortion	2.1	.02	.144	8.3	.46	.504	-1.377
Gained new family member	6.3	.31	.468	2.1	.02	.144	1.016
Son or daughter left home	6.3	.06	.245	22.9	.23	.425	-2.356*
Change in amount of contact with family members	31.3	.06	.245	45.8	.08	.279	-1.469
Trouble with in-laws	14.6	.46	.504	4.2	.65	.483	1.761
Change in amount and type of recreation	45.8	.15	.357	64.6	.04	.202	-1.861
Change in church activities	33.3	.33	.476	54.2	.54	.504	-2.082*
Change in social activities	47.9	.48	.505	68.8	.69	.468	-2.096*
Physical or mental illness	22.9	.23	.425	79.2	.79	.410	-6.598*
Personal injury or accident	8.3	.08	.279	25.0	.25	.438	-2.224*

Death of a close friend	8.3	.08	.279	14.6	.15	.357	-0.956
Death of a close family member	20.8	.27	.676	31.3	.38	.703	-1.159
Death of a pet	2.1	.02	.144	10.4	.10	.309	-1.694
Change in health of family member	20.8	.21	.410	20.8	.21	.410	0.000
Frequent minor illness	31.3	.31	.468	54.2	.54	.504	-2.309*
Minor violation of the law	6.3	.06	.245	6.3	.06	.245	0.000
Jail time served	0	.00	.000	0	.00	.000	–
Loss, robbery, or damage of personal property	10.4	.10	.309	20.8	.21	.410	-1.405
Vacation	39.6	.40	.494	6.3	.06	.245	4.188
Spouse started/stopped work	4.2	.04	.202	0	.00	.000	1.430
Started work for the first time	14.6	.15	.357	22.9	.23	.425	-1.041
Promotion	8.3	.08	.279	4.2	.04	.202	0.838
Demotion	0	.00	.000	0	.00	.000	–
Laid off from work	10.4	.10	.309	14.6	.15	.357	-0.612
Fired from work	2.1	.02	.144	6.3	.06	.245	-1.016
Trouble with boss or co-workers	18.8	.19	.394	6.3	8.81	3.595	1.866
Major improvement in financial status	20.8	.21	.410	0	.00	.000	3.517*
Financial status a lot worse than usual	18.8	.19	.394	50.0	.50	.505	-3.378*
Total Stressors	–	6.94	4.573	–	8.81	3.595	-2.233*

*$p < .05$; t value not calculated due non-occurrence.

Social interaction evident in changes to church and social activities was significantly greater among SA recipients (54.2% vs. 33.3% and 68.8% vs. 47.9%, respectively). In addition, change in family composition (a son or daughter leaving home) was reported more frequently by SA recipients (22.9% vs. 6.3%). These results speak not only to the limited amount of social interaction available to single mothers receiving SA, but also to the poor quality of social interaction and the social exclusion that is endemic to this population (Nezlek, Hampton, & Shean, 2000; Raphael, 2004).

Hypothesis 2

The second hypothesis was that single mothers receiving SA experience higher levels of depressive symptoms than employed single mothers. SA recipients were found to experience significantly higher levels of depressive symptoms than their employed counterparts ($t = -7.634$, $p < .000$). Mean BDI-II scores for the employed and SA groups were 13.85 ($SD =$ 9.694) and 30.79 ($SD = 11.907$), respectively. This finding is alarming when compared to Bryne and Brown's (1998) finding of 32.5% of SA recipients experiencing major depression and 10.4% moderate depression. As expected, a disproportionate burden of illness is carried by SA recipients. Among SA recipients, 66.7% and 22.9% reported symptoms consistent with severe and moderate depression, respectively, while for the employed group the figures were 14.6% and 25.0%. In a broader context, employed mothers experienced depression at twice the rate for the general population, while SA recipients experienced depression at 11 times the rate for the general population (Health Canada, 2002).

Hypothesis 3

Hierarchical multiple regression analysis was used to examine the extent to which employment status and stressful events predict depression among single mothers (Table 3). Prior to analysis, employment status was dummy coded in the following way: 1 = employed full time or part time; 2 = SA. Demographic variables, including employment status, age, and number of children, were entered at step 1 of the analysis, while the number of stressful events was entered at step 2. At step 1, mother's age, number of children, and employment status predicted 37.7% of the variance in mother's depression [F (3.89) = 17.951, $p = .000$)]. At step 2, the addition of stressful events contributed an additional 2.9% to the explained variance of depressive symptoms, and this change was significant [F (4.88) = 4.290, $p = .041$)]. The final model (age, number of children, employment status, and stressful events) explained 40.6% of the variance in depressive symptoms, with employment status being the primary contributor ($\beta = .591$, $p = .000$).

Table 3 *Predictors of Depression among Single Mothers*

Step	*R*	*R* Square	Adjusted *R* Square	Standard Error of the Estimate
1	.614[a]	.377	.356	10.831
2	.637[b]	.406	.379	10.636

Final variables in the equation

		Standardized Coefficients			Correlations	
Steps		**Beta**	***t***	**Sig.**	**Partial**	**Part**
1	Age	-.043	-.514	.608	-.054	-.043
	Number of children	-.112	-1.292	.200	-.136	-.108
	Employment status	.637	7.309	.000	.612	.611
2	Age	-.014	-.166	.868	-.018	-.014
	Number of children	-.100	-1.166	.247	-.123	-.096
	Employment status	.591	6.687	.000	.580	.549
	Total stressful life events	.178	2.071	.041	.216	.170

Tolerance = .919.

[a] Predictors: employment status, age, number of children.

[b] Predictors: employment status, age, number of children, total stressful life events.

There are two explanations for the patterned association between socio-economic status (SES) and mental illness (Yu & Williams, 1999). The social-selection hypothesis suggests that mental illness keeps individuals from obtaining or retaining jobs that would preserve their SES status or enhance their social mobility. Within this perspective, it may be argued that the presence of mental illness, perhaps in childhood or early adolescence, leads to lower socio-economic status by interfering with the single mother's ability to advance her education or acquire appropriate job skills (see Gyamfi et al., 2001). In contrast, the social-causation hypothesis argues that socio-economic adversities linked to low-SES positions cause or exacerbate mental health problems among single mothers (Yu & Williams). The Stress Process Model represents a social-causation hypothesis, and the findings of this study illustrate that single mothers in the lowest socio-economic positions do indeed experience higher rates of psychological distress and functional impairment. While employment or access to income does not explain single mothers' depression entirely, the socio-economic context of women's lives accounts for a considerable portion of single mothers' psychological well-being; 98% of SA recipients, compared to 8.5% of employed mothers, had incomes below $20,000, a finding that has fundamental implications for access to the social and material resources (e.g., food, shelter, transportation, and social activities) needed to promote one's health (Raphael, 2004).

Discussion and Implications

The purpose of this study was to examine the factors that contribute to health disparities among subgroups of single mothers. Specifically, the study explored the association between employment status, stressful experiences, and depressive symptoms. The findings present us with some significant health promotion challenges and opportunities. Health promotion represents a comprehensive social and political process that embraces not only actions directed at strengthening the skills and capabilities of individuals, but also actions directed at changing social, environmental, and economic conditions so as to reduce their negative impact on individual health (World Health Organization, 1986). The findings of this study present a number of health promotion challenges and opportunities for both SA programs such as Ontario Works and public health nursing. They suggest that, first, workfare programs intended to address the mental health concerns of single mothers could achieve greater success in ensuring the mothers' ability to obtain and sustain employment; second, the prevalence and severity of depression among single mothers indicate the need for a reorientation of health services towards a multidisciplinary approach to mental health promotion; and third, the need to ensure that the basic necessity of single-parent families for food and secure housing is met through the development of healthy public policies.

In recent years, federal and provincial governments in Canada have invested extensive resources in the reform of SA and welfare programs. Ontario Works currently provides temporary financial assistance to those individuals who are determined to be most in need while they satisfy obligations to find and retain employment (Ministry of Community and Social Services, 2001). Implicit to welfare reform is the assumption that SA recipients are similar, in status and function, to the general population. However, the findings of this study suggest that mental health concerns pose a strong barrier to employment. Ecologically sound workfare strategies are needed to address the many factors that affect women's employment status, including physical and mental illness and lack of employment training, child care, and social support (Youngblut, Brady, Brooten, & Thomas, 2000). When the Bough Breaks (Browne et al., 2001) is one ecologically sound intervention program that has proved effective in reducing levels of dysthymia, enhancing social adjustment, and increasing single mothers' success in obtaining and sustaining employment. It speaks to the social and economic feasibility of providing single mothers receiving SA with services such as health promotion and case management, recreation and skill development for children, employment retraining, and child care.

The pervasive functional impairments that accompany depression require a multidisciplinary approach whereby mental health professionals (i.e., nurses, general practitioners, psychologists, psychiatrists, and lay practitioners) use a number of strategies to enhance the social functioning, coping capacity, and health promoting behaviours of single mothers. The findings of this study suggest that single mothers who experience psychological distress would be most effectively served by health and service providers who use an array of mental health promotion strategies appropriate to the multiple problems that single mothers may experience over their lifetime — for example, IPV, homelessness, and economic hardship. Nurses with advanced knowledge and understanding of mental illness, including its assessment, diagnosis, and management, have an essential role to play in helping single mothers to manage and overcome psychological distress. An intervention study conducted by Beeber, Holditch-Davis, Belyea, and Funk (2004) demonstrated the feasibility of master's-prepared nurses positively impacting on not only single mothers' mental health status but also their success in managing depressive symptoms, improving problematic life issues, accessing social support, and parenting effectively while symptomatic. It is important to note, however, that enhanced expertise must be accompanied by a conscious and systematic effort to understand the context and culture of single mothers' lives. Likewise, nursing interventions for single mothers must be innovative and tailored to their personal needs and life goals (Beeber et al.; Cauce et al., 2000).

Public health nurses are ideally positioned to influence the development of public policies designed to reduce chronic and daily stressors that may exacerbate psychological distress among single mothers. The findings of this study suggest that housing insecurity is an important stressor for single mothers, particularly those receiving SA. Adequate living allowance and rent geared to income programs would significantly reduce this problem. While the average rent for a two-bedroom apartment in Ontario is $1,165, a single mother with two children currently receives SA of $1,215 monthly (Canadian Council on Social Development, 2003). The socio-economic conditions under which single mothers live increase their risk for homelessness. Risk for homelessness and its negative impact on the psychological well-being of single mothers cannot be underestimated (Bogard, Trillo, Schwartz, & Gerstel, 2001). Bassuk, Browne, and Bucker (1996) identify three factors that greatly affect the ability of a poor single mother to retain housing: lack of education ensures that single mothers have the lowest-paying jobs and will likely live below the poverty line even when employed full time; frequently, one quarter of a single mother's monthly income goes to child care; and pervasive physical, emotional, and sexual violence, in both childhood and adulthood, decreases single mothers' physical, emotional, and social well-being and, in turn, their ability to work outside the home. As posited by the Stress Process Model, the present findings suggest that the health of single mothers is determined by the structural social inequality that predominates in Canadian society (Avison, 2002; Davies et al., 1997; Pearlin, 1989; Tolman & Rosen, 2001). The involvement of public health nurses in developing public policies designed to address the structural inequalities that impede single mothers' access to food and secure housing is essential to promoting the mental health of those mothers.

This study has several limitations. The cultural diversity of the sample (Caucasian 36.8%, Afro-Canadian 40%, Aboriginal 1.1%, South Asian 10.5%, Asian 5.3%, Latino 4.2%, Arabic 1.1%) may limit the generalization of its findings to less culturally diverse populations. Second, a substantial number of women ($N = 21$) who were eligible for participation in the study were not included because their telephones had been disconnected. This group might have presented data different from those presented by women who were able to maintain their telephone subscriptions and consequently participated in the study. Third, the modified SRRS was not pretested and was by no means exhaustive of the types of stressor frequently encountered by single mothers. Fourth, the small sample size precluded an examination of whether depressive symptoms were similar for those single mothers who were employed but whose incomes resembled those of SA recipients. A larger sample, including single mothers from three socio-economic groups — those employed with middle and high incomes, those employed with low incomes, and those receiving SA — would allow researchers to examine this issue more thoroughly. Additionally, comparable studies may employ a qualitative or mixed-method (quantitative and qualitative) approach to exploring the incidence of stressful events not captured by the SRRS, as well as the perceived positive or negative impact of those stressors. Another essential area for further investigation is the prevalence of comorbid conditions — more than one mental illness such as post-traumatic stress disorder, anxiety disorders, and bipolar disorders — and its impact on employment status.

Conclusion

This study used the Stress Process Model to examine trajectories of depression among single mothers in the context of socio-economic status. Analyses of variations in patterns of stressful events and depression by employment status (employment or SA) revealed that single mothers receiving SA reported a larger number of stressful events specific to housing instability, social isolation, family composition, physical and mental illness, and financial instability than employed single mothers. The prevalence of depressive symptoms in this sample of single mothers was extremely high, with more than 65% of participants reporting symptoms consistent with moderate or severe depression. However, much of the burden of illness fell on participants with the lowest socio-economic status. Fifteen percent of employed parents reported symptoms consistent with severe depression, compared to 67% of SA recipients. Results of multiple regression analysis revealed that 41.5% of the variation in depressive symptoms among single mothers was explained by employment status and stressful events, with employment status contributing most of the variance.

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Comments or queries may be directed to Joan Samuels-Dennis, School of Nursing, Health Sciences Addition H3A, University of Western Ontario, 1151 Richmond Street, London, Ontario N6A 5C1 Canada. E-mail: jsamuel4@uwo.ca

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Joan Samuels-Dennis, BScN, RN, MSN, is a doctoral student in the School of Nursing, University of Western Ontario, London, Ontario, Canada.

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Résumé

Les pratiques en matière de santé chez les Canado-Vietnamiennes : les influences culturelles en matière de dépistage de cancers du sein et du col utérin

Tam Truong Donnelly

Les cancers du sein et du col utérin figurent parmi les facteurs de morbidité et de mortalité majeurs chez les femmes canado-vietnamiennes. Les Vietnamiennes sont à risque en raison de leur faible taux de participation aux programmes de dépistage de ces cancers. S'appuyant sur le modèle exploratoire de santé et de maladie de Kleinman, cette étude a pour but d'explorer les points suivants : la participation des Canado-Vietnamiennes au processus de dépistage de cancers du sein et du col utérin; la pertinence des services de prévention du cancer actuels desservant cette population; et l'influence des facteurs sociaux, culturels, politiques, historiques et économiques façonnés par les rapports sociaux entre les races, les sexes et les classes sur les pratiques de ces femmes en matière de dépistage. Quinze femmes canado-vietnamiennes et six prestateurs de soins ont été interviewés. L'analyse des entrevues révèle la présence de plusieurs facteurs qui influent sur la participation des femmes aux programmes de dépistage du cancer. Cet article fait état du processus par le biais duquel les connaissances et les croyances culturelles influencent les pratiques des femmes en matière de santé. L'étude révèle que les facteurs culturels suivants influent sur le taux de participation des femmes aux programmes de dépistage des cancers du sein et du col utérin : les connaissances et les valeurs culturelles relativement au corps féminin; la conceptualisation de la santé et de la maladie; et les croyances et valeurs en ce qui a trait à la relation patiente-prestateur de soins. L'auteure émet certaines recommandations concernant la promotion du dépistage des cancers du sein et du col utérin chez les femmes canado-vietnamiennes.

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The Health-Care Practices of Vietnamese-Canadian Women: Cultural Influences on Breast and Cervical Cancer Screening

Tam Truong Donnelly

Breast and cervical cancer are major contributors to morbidity and mortality among Vietnamese-Canadian women. Vietnamese women are at risk due to their low participation rate in screening programs for these cancers. The purpose of this exploratory qualitative study, informed by Kleinman's Exploratory Model of Health and Illness, was to explore the participation of Vietnamese-Canadian women in screening for breast and cervical cancer; the appropriateness of current cancer-prevention services for Vietnamese women; and the influence of social, cultural, political, historical, and economic factors, shaped by race, gender, and class, on the screening practices of Vietnamese-Canadian women. Fifteen Vietnamese-Canadian women and 6 health-care providers were interviewed. Analysis revealed that several factors influenced the women's participation in cancer screening. This paper reports on the process by which cultural knowledge and beliefs contributed to the women's health-care practices. The study revealed that the following cultural factors influenced the women's level of participation in screening programs for breast and cervical cancer: cultural knowledge and values with regard to women's bodies, conceptualization of health and illness, and beliefs and values concerning the patient/health-care provider relationship. The author offers recommendations on the promotion of screening for breast and cervical cancer among Vietnamese-Canadian women.

Keywords: Vietnamese women's breast cancer and cervical cancer screening, Vietnamese Canadian women's cancer preventive care, immigrant women's cancer preventive care, cultural influences on cancer screening practices

Introduction

Breast cancer is the second leading cause of cancer-related death for Canadian women over 50 years of age (National Cancer Institute of Canada, 2004). Although breast cancer is less common among Asian immigrant women, Asian women who migrate to Western countries have a significant increase in breast cancer risk compared to women in their native countries, and their breast cancer rates approach those of the general population (National Asian Women's Health Organization, 2004). Evidence shows that Asian women are the group least likely to have had a mammogram (King County Public Health, 2004; McPhee, Stewart, et al., 1997; Pham & McPhee, 1992; Sadler, Dong, Ko, Luu, & Nguyen, 2001) and are more likely to be diagnosed at advanced stages of breast cancer (Hedeen, White, & Taylor, 1999; Pham & McPhee; Yi, 1994a, 1995).

Cervical cancer is the most common cancer among women in the countries where Papanicolaou (Pap) smears are not routinely performed (BC Cancer Agency, 2000). Evidence shows that Vietnamese women have a significantly higher incidence and mortality rate for cervical cancer than other populations (Black & Zsoldos, 2003; Cheek, Fuller, Gilchrist, Maddock, & Ballantyne, 1999; Lesjak, Hua, & Ward, 1999; McPhee, Stewart, et al., 1997). People of low socio-economic status and ethnic minorities have the greatest need for improvements in cancer prevention (Alberta Cancer Board, 2004; Gentleman, Lee, & Parsons, 1998). The 2001 Canada Census revealed that almost one quarter of all Vietnamese-Canadian women have an income of less than $9,999 per year (Statistics Canada, 2001).

Early detection and treatment of breast and cervical cancer through screening programs significantly reduce the morbidity and mortality of these diseases (BC Cancer Agency, 2004a, 2004b). In the province where this study was conducted, it is recommended that women over the age of 20 have a clinical breast examination annually and perform breast self-examination regularly (BC Cancer Agency, 2004a), even though it has been argued that self-examination might not reduce breast cancer mortality and may increase women's chances of having a benign breast biopsy (Thomas et al., 2002). Regular mammography is recommended for women according to their age/risk group or at least every 2 years after age 50 (BC Cancer Agency, 2004a). Pap testing is recommended at least every 2 years for all sexually active women until age 69; women over 69 may stop having regular Pap smears if all their previous smears have been normal (BC Cancer Agency, 2004b).

Data from the Statistics Canada 1994/95 National Population Health Survey illustrate that Asian women are less likely than women in the general population to have Pap testing; more than nine times more Asian-born than Canadian-born women had never had a Pap test (Gentleman et al., 1998). A community-based survey of 776 Chinese women in British Columbia (Hislop, Teh, Lai, Labo, & Taylor, 2000) found that the proportion of Chinese women receiving Pap tests was lower than the provincial average (74% of the women had at least one previous Pap test and 56% had a test within the preceding 2 years). In 1996, the rate of Pap testing among Canadian immigrant women was 67%, compared to 90% for non-immigrant women (Black & Zsoldos, 2003).

Statistical data on the current rate of participation in screening for breast and cervical cancer among Vietnamese-Canadian women are not available. The sparse data available from the United States and Australia suggest that Vietnamese women have a lower rate of participation in cancer screening than the general population (Cheek, Fuller, & Ballantyne, 1999; Jenkins, Le, McPhee, Stewart, & Ha, 1996; Lesjak et al., 1999; McPhee, Stewart, et al., 1997; Yi, 1994a, 1994b). A recent study by Sadler et al. (2001) with 275 Vietnamese-American women found that their rate of mammography was below the recommended level and that only 36% reported having adequate knowledge about breast cancer screening. This low rate of screening suggests that Vietnamese women may be at risk for lack of detection and treatment of cancer in its early stages (Cheek, Fuller, Gilchrist, et al., 1999; Lesjak et al.; Sadler et al.).

A survey conducted in California found that Vietnamese social beliefs and values contribute to Vietnamese women's level of participation in screening for breast and cervical cancer (Jenkins et al., 1996; McPhee, Bird, et al., 1997). The way in which Vietnamese people conceptualize health and the causes of illness shapes their view and utilization of Western medicine (LaBun, 1988; Maltby, 1998; Stephenson, 1995; Uba, 1992). It has been argued that the benefits of Western biomedicine cannot be realized unless health services are provided in an accessible and culturally appropriate manner (Anderson, 1990; Waxler-Morrison & Anderson, 2005).

The present study was conducted in a western Canadian city whose immigrant population makes up 38% of its 2 million inhabitants. The Vietnamese population of the province in which the city is located has been estimated at 25,675 (Statistics Canada, 2001). The overall purpose of this qualitative study was to explore the participation of Vietnamese-Canadian women in screening for breast and cervical cancer, the appropriateness of current cancer-prevention services for Vietnamese-Canadian women, and the influence of social, cultural, political, historical, and economic factors that are shaped by race, gender, and class on the screening practices of Vietnamese women. Three research questions were addressed: (1) *How do Vietnamese-Canadian women participate in breast and cervical cancer screening programs?* (2) *What is the process by which the decision to engage in regular breast and cervical cancer screening is reached, and what are the key factors influencing this process?* (3) *How do contextual factors such as social, cultural, political, historical, and economic factors at the intersection of race, gender, and class affect screening for breast and cervical cancer among Vietnamese women?*

This paper reports on the process by which cultural knowledge and values influence the decision of Vietnamese-Canadian women to undergo screening for breast and cervical cancer. Other findings regarding the women and their health-care providers will be reported elsewhere. In this paper, I will describe, first, the theoretical framework guiding the exploration of cultural influences on cancer prevention among Vietnamese-Canadian women, then the research design, and, finally, the findings of the study. I will then present a discussion and recommendations.

Ethical approval for the study was obtained from the University of British Columbia Ethics Board. Pseudonyms are used in referring to comments by the participants.

Kleinman's Explanatory Model

Arthur Kleinman (1980) theorizes that a given society's attitude towards and use of health services is shaped by the way in which it conceptualizes health and illness and its cultural beliefs, values, behaviours, and expectations regarding treatments. He further asserts that a person's explanatory model, which is specific to one's social group and culture, explains sickness etiology, symptoms, pathology, course of illness, and treatment (Kleinman, 1978). Conflicting explanatory models, coupled with cultural insensitivity, will lead to a relationship and communications breakdown between the client and his or her health-care provider. These factors, in Kleinman's view, are deterrents to client compliance, satisfaction, and appropriate use of health services. Kleinman (1978) defines culture as "a system of symbolic meanings that shapes [an individual's] social reality and personal experience" (p. 86). He considers social reality and clinical reality to be two important dimensions of health care (Kleinman, 1980).

Social reality symbolizes human interactions, which consist of meanings, norms, social structures, and expected behaviour within a society. The manner in which individuals view and react to illness and in which they choose among health-care options and evaluate their effectiveness are influenced by their social reality (Kleinman, 1980). Clinical reality, on the other hand, is a health-related aspect of social reality. It is "the beliefs, expectations, norms, behaviours, and communicative transactions associated with sickness, health care seeking, practitioner-patient relationships, therapeutic activities, and evaluation of outcomes" (Kleinman, 1980, p. 42). Social reality and clinical reality are culturally constructed and shaped in different social-structural settings within a society (Kleinman, 1980). To provide effective health care and to ensure client cooperation, Kleinman suggests, health professionals need to treat disease and illness in a way that clients can relate to culturally, socially, and individually.

Kleinman's explanatory model was used as a framework to examine the influence of cultural knowledge and values on the behaviour of Vietnamese-Canadian women with regard to screening for breast and cervical cancer. It was theorized that the view of Vietnamese women towards screening for breast and cervical cancer is influenced by their social reality and clinical reality, which consists of their beliefs about health and illness, their treatment expectations, and social norms regarding communication, health-care seeking, and relationships.

Research Design

Participants

Maximum variation purposive sampling, "the process of deliberately selecting a heterogeneous sample and observing commonalties in their experiences" (Morse, 1994, p. 229), was used in this study. Participants were recruited though letters sent to community agencies. Prior to interviewing, informed consent was obtained and the participants were assured that they had the right to withdraw from the study at any time. The identities of the participants were protected through the use of codes and pseudonyms. The researcher was a Vietnamese woman who had the experience of being a refugee in Canada. Being fluent in Vietnamese, she was able to conduct interviews in Vietnamese and to understand and closely attend to the participants' narratives.

The participants consisted of 15 Vietnamese immigrant women and 6 health-care providers. The immigrant women ranged in age from 49 to 78 years. Justifications for this selection were (a) the need for the age group to overlap for both breast and cervical cancer screening, (b) the aging population, (c) the increased risk for breast and cervical cancer with advanced age, and (d) the decreasing rate of screening utilization with advanced age. Of the immigrant women, all spoke Vietnamese; 5 came from Northern Vietnam and 10 from Southern Vietnam; they had been in Canada an average of 22.7 years (range = 9–26 years); their educational level ranged from Grade 2 to university completion in Vietnam.

The health-care providers consisted of 4 male Vietnamese physicians and 2 female community health nurses. (Although an effort was made to recruit female physicians, the only two female Vietnamese-speaking physicians available were too busy to participate.) The physicians had been working in Canada from 4 to 21 years. One of the community health nurses had been working with Vietnamese women for more than 15 years, the other for 4 years. All the health-care providers except for one of the community health nurses spoke Vietnamese fluently.

Data Collection

An exploratory qualitative approach was used to obtain detailed contextual information and to illuminate the diversity and complexity of the participants' thoughts and health-related behaviours. In-depth interviewing in the participants' language was the main method of data collection. A semi-structured questionnaire using open-ended questions in both Vietnamese and English was designed for the study. The questions concerned health-care knowledge and attitudes and past and current practices regarding clinical breast examination, breast self-examination, mammography, and Pap testing. They also investigated the respondent's motivation to engage in cancer-screening activities, their perceived barriers to such activities, and their perceptions about the best possible strategies for promoting breast and cervical cancer screening among Vietnamese women. The interviews with the immigrant women lasted from 3 to 4 hours. The interviews with the health-care providers lasted from 30 to 60 minutes. Four of the interviews with health-care providers were conducted in Vietnamese and two in English. The data were transcribed and analyzed by the researcher in the primary language of the participant. The interviews were stopped when no more new information could be identified in the data.

Data Coding and Analysis

Data collection and analysis were carried out concurrently. Data analysis was an ongoing, four-step process. (1) As data were obtained, they were transcribed in the language used by the participant. To ensure accuracy, the transcripts were rechecked against the audiotapes and corrected. A hard copy was printed for preliminary data analysis. (2) In the early stages of analysis, the transcripts were coded to identify preliminary themes. A list of code categories was formulated. These categories were refined as subsequent data were gathered. (3) Data coded in one category were examined for their relevance to data in other categories. The final outcome of this analysis was a set of interrelated concepts and themes. This process of analysis involved the systematic, rigorous development of code categories and subcategories, which were flexible, evolving, and used for the coding of subsequent transcripts. (4) Themes and concepts were used to compare within and across transcripts. From this, a higher level of data conceptualization and broader theoretical formulations were generated. To ensure rigour, the researcher sought input on the preliminary results from six participants who she believed could give insightful and reflective responses. This group comprised two immigrant women, three physicians, and one community health nurse. This process enabled the researcher to clarify, expand, and discuss with participants the emergent themes, ideas, and concepts. It also allowed the researcher to validate the findings, develop a deeper understanding of the data, and gain further insight into the cultural process and social structures that influence the breast and cervical cancer screening practices of Vietnamese women.

Findings

Vietnamese social values differ from those of the general Western population. This divergence contributes to Vietnamese women's level of participation in screening programs for breast and cervical cancer (McPhee, Stewart, et al., 1997). However, Jenkins et al. (1996) found that their data did not support the notion that traditional beliefs and cultural practices pose barriers to the use of preventive health services. In the present study, analysis of the data revealed three themes illuminating the influence of culture on the participation of Vietnamese women in screening programs for breast and cervical cancer. The themes were: cultural knowledge and values concerning women's bodies, women's conceptualization of health and illness, and beliefs and values with regard to the relationship between the health-care provider and the patient.

Cultural Knowledge and Values Concerning Women's Bodies

The private body: Embarrassment and hesitation. The data suggest that conceptualization of the body as private greatly influences the ways in which Vietnamese women seek and receive examination for breast and cervical cancer. The women's narratives reflect the Confucian teaching "Nam nu tho tho bat than" (a woman and a man should never touch or be close, but should avoid each other). One of the immigrant participants commented, "A woman's breasts and cervix are private places; nobody but her husband should ever touch them." Because of this cultural designation of a woman's body as private, the women were uncomfortable with breast and cervical examination. The majority of the women participants said they were very embarrassed about having a breast examination or a Pap smear:

> *It's very uncomfortable when you let the doctor examine it, very uncomfortable, very difficult. It doesn't matter if it's a female or a male doctor. I don't like anybody to touch those things… It makes me uneasy.* (Mrs. Hai)

In contrast to the findings of other studies (Cheek, Fuller, Gilchrist, et al., 1999; Lesjak et al., 1999; Yi, 1995), the present study found that the degree of acculturation (good command of English, greater familiarity with Western ways of living, and number of years the women had lived in the host country) might not increase women's participation in screening for breast and cervical cancer. Mrs. Phi had been living in Canada for 26 years, spoke English and French fluently, and had adapted well to the Canadian way of life:

> *Language is very important. But it's not just the language. Our culture doesn't permit us to talk about or share such taboo subjects with others. Talking about a woman's body cannot be publicly… I'm embarrassed even to touch my own breasts, let alone other people. They [health-care providers] need to understand that. …the cervix is even more taboo* [tham kin], *more embarrassing. So they just don't go… That's what I mean by understanding Vietnamese culture. Even though we're here…we were always like that, so we remain the same. If there are no female doctors we hesitate to go for these kinds of check-up.*

The body as an experiencing agent/the embodiment experience. The women's accounts revealed the role of beliefs and values concerning women's bodies in determining their health-care practices. Analysis revealed a picture of the Vietnamese woman's embodied experience of physical examination. The breast and cervix are considered the most private parts of a woman's body and should not be seen or touched by others. Discourse about examination was described as embarrassing, and verbal hesitation and the use of euphemisms and gestures during the interviews conveyed the depth of these embodied values. The women often cited this sense of embodiment as a force in directing their health-care practices. Furthermore, their health-seeking behaviour was guided by their physical sensations. The women did not think they had a health problem unless they were experiencing unusual physical discomfort. Because breast and cervical cancer are non-symptomatic in the early stages, the women did not conceive a risk for these diseases. This affected their willingness to overcome their sense of embodied selves and other social barriers to participate in screening programs. For several participants, the embodiment of health was defined in part as the absence of disease and illness. One is in good health if one feels well enough to work and has no physical symptoms of disease:

> *We're healthy if we can go to work as usual. We go to the doctor only when we have a disease or some evidence that we're sick… Normally we know we're healthy if we can work. If we feel that we're sick, have something wrong, or we're tired or in pain, then we go to the doctor.* (Mrs. Phan)

The manner in which the women experienced illness served to determine when and from whom they sought help. They were uncomfortable with the notion of allowing a doctor to examine their breasts or cervix when there was "nothing wrong." Ms. Lyn said, "I'm very embarrassed showing my breasts when nothing is wrong, very embarrassed." Similarly, Mrs. Mai said, "Pardon me, but if you have nothing wrong and yet you lie on the table like that…that's very embarrassing… It's not the same as having your teeth checked."

It is clear that women's bodily experience is an important indication of how they will seek health care. However, as Kleinman (1980) suggests, these Vietnamese women also reacted to illness and made their health-care choices based on their social reality, which included their beliefs about health and illness.

Cultural Conceptualization of Health and Illness

***"Health is gold"* (suc khoe la vang).** The women often pointed to the importance of health by referring to the Vietnamese proverb "health is gold" *(suc khoe la vang):*

> *Health is gold… Health is number one… I'll always ask you, "How are you?" I'd never phone you and ask, "How much money do you have?"… When we see each other, the first thing we ask is "How are you?"* [Chi co khoe khong?] *And I'd be very happy if you said you're fine.* (Mrs. Mai)

More significantly, in the context of participation in cancer-prevention activities, they placed great emphasis on the meaning of health and illness for both themselves and their families. For some Vietnamese, a person acts as an agent within family relationships. Many Vietnamese people internalize Confucianism, Taoism, and Buddhism — traditions in which the self is closely tied to family kinship networks, social position, and social obligations. For several of the women, therefore, health was important because without it one cannot accomplish much or take care of one's family — financial stability and the family's welfare depend on it:

> *We have to be healthy so we can go to work to make money, because if we don't, then how are we going to pay the rent and all the bills…? We have to be healthy so we can handle all those things, take care of our family… If we aren't healthy, we can't…take care of our children.* (Mrs. Mai)

Disease and illness are caused by an imbalance within the body. An ideology of mind-body harmony informed the women's conceptualization of what makes a healthy body and what causes disease and illness. They believed that because health is achieved through a balancing of several forces, such as Am (yin) and Duong (yang) or the equilibrium of "hot" and "cold," disease and illness will result if the body is thrown out of balance. Western biomedical conceptualizations of a healthy lifestyle were woven like a thread throughout the women's narratives. Although the women cited poor diet, low activity level, emotional distress, and bad weather as factors that can throw the body out of balance and cause illness, they believed that a healthy lifestyle serves to prevent disease:

> *We get sick and get diseases [breast and cervical cancer] because of how we eat, because of our diet. First, not eating properly... Second,...not exercising. Third, not eating enough fruit. Fruit is very important. Eat a lot of fresh fruit. And swim a lot... [then] you'll have no diseases.* (Mrs. Chi)

Many of the women's narratives reflected the emphasis of Western medicine on reducing fat intake and maintaining a healthy body weight. These Vietnamese women, like many Canadians, were concerned with controlling their weight and their cholesterol levels. Mrs. Mai, aged 72, believed she needed to change her diet in order to stay healthy:

> *To keep ourselves healthy, we need to eat properly...not too much or too little. Here we worry about fat in the blood. So don't eat too much fat... Here it's different; back in Vietnam the more food we ate the better, but here it's not good to eat too much. Food is plentiful here but I wouldn't eat a lot. Control your eating.* (Mrs. Mai)

Although the women's discourse about what one should do to remain healthy paralleled contemporary biomedical discourse and their dietary practices were influenced by Western ways, their understanding of food and eating habits may also have been culturally specific. Some of the women believed that foods that are considered *doc* (poisonous), such as bambo shoots, could cause health problems and that certain foods could affect the body's healing process:

> *Diet is directly connected to medication. If you take cough medication, you shouldn't eat chicken. If you have an operation, you shouldn't eat beef. If you don't follow that, your disease will take longer to cure. If you have an operation and don't abstain from these foods, then your wound will take longer to heal...you'll have a big scar* [theo lon]. (Mrs. Phi)

Disease and illness are caused by a bacterial invasion. The women's explanations for the cause of diseases, especially cervical cancer, were directly connected to the bacterial-invasion theory of contemporary biomedicine. From the women's perspective, bacterial invasion occurs as a result of either poor personal hygiene or negative environmental conditions. A common belief among the women was that a woman could get cervical cancer if she was not clean "down there" or if she had sexual relations with an "unclean man":

> *Women get cervical cancer because they're not clean down there. You get the disease when the bacteria get inside you... Women can get the bacteria from their unclean husbands. There are men who don't pay attention to*

> *their hygiene and then sleep with their wives. Those wives then get the bacteria in their cervix.* (Mrs. An)

Prevention of cervical cancer was, then, focused on cleanliness and sexual practices. In their discourse on the causes of cervical cancer and sexually transmitted diseases, the women often alluded to sexual relationships. The new Vietnamese policy encouraging people who have left the country to return for visits has resulted in many Vietnamese Canadians travelling to Vietnam. Several of the immigrant women expressed a concern that many men who had been back to Vietnam got "the disease":

> *Hygiene is important… That thing should be kept cleaner than the mouth even. You clean your mouth, how many times a day? You clean that thing just as often… Also, you have to keep an eye on your husband. Don't let him do anything wrong. If he does something wrong, it doesn't matter how clean you are, you'll get the disease.* (Mrs. Chi)

Disease and illness are predetermined by a higher power. A culturally specific aspect of the women's views about the causes of ill health was the belief that disease and illness are predetermined by a higher power. Several of the women believed strongly that everything is determined by "nhan duyen" and "dinh menh" (destiny). According to this universal law, one has little control over one's life: what is destined to happen will happen; it is up to God *(mac troi)*. A person who adheres firmly to this belief does not seek treatment, believing that a cure is up to God. Mrs. An, a 70-year-old woman, described a conversation she had had with her 40-year-old daughter, who had breast cancer:

> *She told me, "Mom, I'm not going to the doctor." I don't know exactly what she thinks, but she decided not to go to the doctor. The doctor tried to talk to her many times. He said, "You're still very young. I don't want to see you die." She said, "Doctor, I have God. My destiny is in God's hands. I don't want to have the operation."* (Mrs. An)

Mrs. An's daughter had discovered a small lump under her arm. Despite the doctor's recommendation, she refused to have a mastectomy and lived for 7 years without treatment of any kind before passing away. Mrs. An said that one of the reasons why her daughter refused surgery was her faith in God. She thought that her daughter's surviving with breast cancer for 7 years pain-free was a miracle, a gift from God. However, not all the women viewed good health as God's doing nor illness and death as predetermined. One 73-year-old woman had this to say:

> *I don't believe in destiny. If we keep ourselves healthy, then we'll be healthy. God won't be able to help. We'll be healthy if we take care of ourselves. If you…don't look out for oncoming cars and you die, would*

> *you say that is your destiny? You have your eyes — you have to watch out for those cars. You can't say that God plans all that. No, it's not your destiny.* (Mrs. Mai)

Although many of the women expressed a firm belief in modern medicine, some remained sceptical about its ability to diagnose and treat contemporary diseases. For Mrs. An, cancer was a name given to diseases that cannot be cured by biomedicine. Such a belief might have been one of the reasons why some of the women did not seek treatment for cancer: if cancer cannot be cured, then seeking treatment for it is a waste of time and family resources:

> *I think that whatever diseases they can't cure they call cancer. If they try many different treatments but can't cure the disease, then they call it cancer… A disease that they can't cure they call cancer and a disease that takes too long to treat they call an allergy.* (Mrs. An)

Beliefs and Values Concerning the Patient/ Health-Care Provider Relationship

The relationship between the health-care provider and the client, which Kleinman (1980) identifies as an aspect of clinical reality, is considered an important component of health care. Thus Vietnamese women's use of screening for breast and cervical cancer is influenced by how they view this relationship. Physicians hold high social status in Vietnam, just as they do in Canada. Because physicians are in the business of saving lives and relieving suffering, they are regarded as people of character. The Vietnamese saying "bac si nhu tu mau" (doctors are gentle mothers) equates the care of a physician with that of a mother:

> *A doctor should act like a gentle mother. Even if the doctor is young, he should be friendly and calm and show respect for others. He should speak to his patients in such away that they feel they can come and talk to him.* (Mrs. Chi)

The patient/physician relationship is a hierarchical one, with the doctor holding considerable power. The participants identified lack of information as one of the many barriers to women participating in screening for breast and cervical cancer. Yet many of them had difficulty asking their doctors for information. According to a female Caucasian health-care provider, some of the Vietnamese-Canadian women were intimidated by their physicians, and asking them for information was not the norm:

> *What [the women] grow up with and what they know traditionally is this huge hierarchy. Whatever information the doctor gives you, then that's the*

> *information you get. You're questioning his authority if you ask questions… Although they [the Vietnamese women] have family physicians who are Vietnamese-speaking, one of the things they talk about is…they want to get information but [find it] difficult to ask the doctor. They feel awkward asking their doctor. …unless the doctors [suggest] screening…they wouldn't…say, "I need to have my breast screened" or "I need to have a Pap [test]." They wait for the doctor to take the initiative.* (Mrs. McDonald)

The heavy workloads of physicians and the limited availability of Vietnamese physicians (especially female physicians) have hindered the provision of health services for this population. The fact that Vietnamese physicians lack the time to spend explaining, talking, and listening to their patients has resulted in dissatisfaction with the care they are able to provide. Effective health care requires the building of trust between the physician and the patient. Dissatisfaction with the care provided has led to problems in the patient/doctor relationship, which in turn affects the willingness of Vietnamese women to seek medical help, especially with something that is viewed as very personal such as breast or cervical examination. For the participants, this situation created barriers to health care:

> *I think we should go to the doctors who aren't so busy, who have more time for us. I think the doctor should have more time to talk to you. If he's too busy, I don't feel there's time for me to talk to him. I go to see him but I don't think he has time to talk to me. There's no time to talk about what I need to know or to ask questions… They have no time. They're very busy. They have many patients. When I see him, I wait and wait. It doesn't matter what day or what time I go…I have to wait.* (Mrs. Hai)

Discussion and Recommendations

Congruent with Kleinman's theory, this study found that the explanatory models of disease and illness used by Vietnamese-Canadian women influenced their level of participation in cancer-prevention programs. Although some of the beliefs and values expressed by the participants differed from those of the general population, many of their conceptualizations about health, disease, and illness were congruent with the contemporary biomedical perspective. It is not clear, however, the extent to which these traditional beliefs and values deter Vietnamese women from seeking regular breast examination and Pap testing. The data show that the beliefs and values of Vietnamese women about women's bodies as private, which leads to a pervasive feeling of embarrassment, is a barrier to women seeking breast and cervical cancer screening.

For some Vietnamese women, especially older women, merely talking about the subject causes embarrassment. For example, in discussing breast cancer, a group of women on a Vietnamese radio program that airs weekly tried to avoid using the word *vu,* which means "breast," speaking instead of "ung thu nguc," or "cancer of the chest." When they realized that this was inappropriate, they began to call it "ung thu nhu hoa," or "cancer of the two flowers." Finally, after much consideration, they began to call the disease "ung thu vu," which means "breast cancer." Health promotion and disease prevention programs for immigrant women need to take into account the fact that the dearth of health-care providers, especially female health-care providers, is a major deterrent to Vietnamese women seeking breast and cervical examinations.

Consistent with the findings of Kleinman (1980), this study found that the physician-patient relationship influences women's health-care practices. For the immigrant women in the study, the hierarchical relationship between a woman and her physician served as a barrier, preventing them from seeking help. In refraining from asking for more information, they did not acquire sufficient knowledge about the disease processes to even consider undergoing breast or cervical examination. Although some of the physician participants recalled speaking with women about testing for breast and cervical cancer, interviews with the immigrant women revealed that they did not remember any such discussions with their doctors. This calls into question the effectiveness of patient-physician communication. Nguyen and McPhee (2003) assert that effective communication allows physicians to understand their patients' life priorities, decision-making behaviours, and comprehension of the risk of developing cancer and the benefits and risks of testing. They observe that physicians' care is guided by scientific evidence, whereas patients want care that addresses their largely culturally determined personal values. Thus, to have cancer screening methods that have maximum impact at minimum cost, we need decision-making that is shared by the patient and the physician, especially when the patient and the physician come from different cultures. Health-care providers must attend to where, when, and how they provide their patients with information about screening for breast and cervical cancer.

The women's emphasis on their embodiment experience as the basis for their health-care practices served as a potential barrier to their active participation in cancer screening. Because breast and cervical cancer are non-symptomatic in the early stages, it was difficult for the women to conceive of being at risk, and this, in turn, affected their willingness to overcome other barriers to seeking health care. Thus promotional information should address the misconception that the absence of symptoms does not negate the need for screening. Educational materials should clearly explain *why* and *how* early detection of breast and cervical cancer can increase women's treatment options and increase survival rates. Furthermore, information about breast and cervical cancer and screening should be provided in the language that is most understandable and accessible to the women.

Black and Zsoldos (2003) and Lam et al. (2003) suggest that education campaigns and outreach programs that use community lay health workers can be particularly effective in raising awareness, among Vietnamese women, of the importance of Pap testing, because such workers use their cultural knowledge and social networks to effect change. Thus cancer-prevention programs require collaboration between researchers, community members, and community-based organizations, thereby ensuring the sharing of expertise, knowledge, skills, and capacities.

The findings of this study show that the family of an immigrant woman can play a crucial role in her decision whether to seek screening for breast and cervical cancer. Some of the women who participated in the research saw health and illness not only as connected to an individual's body but within the broader social context of their lives — interconnected with factors such as a woman's ability to care for her children, participate in family activities, and contribute to the family's economic survival. This conceptualization of health and illness differs from that in Western ideology, which emphasizes the individuation of self. The reluctance of the women to access health services may have been the result of competing priorities, such as the family's financial situation, employment concerns, or the children's education. Thus outreach material that explains why participation in cancer screening can benefit both the individual and the family might be a more culturally sensitive and effective way of promoting cancer prevention among Vietnamese immigrant women. This idea was well expressed by one of the participants:

> *You have to say why it's important to prevent the disease. You have to explain to them that even though looking after husbands and children is important, keeping themselves healthy is also important. It is this: if you're sick, then you stand to lose everything. Whatever you've invested in, you lose. You have to say that if they're sick, then all their hard work, their savings, will be gone. They work so hard for their children, but if they fall ill, all will be gone. So if they could just take one day a year to go for these examinations, they'd be able to enjoy the fruit of their hard work for the rest of their lives. You need to explain why going for these tests is good in that way. Saying that these tests will help them live longer is not going to work.* (Mrs. Le)

Conclusion

Several authors have pointed out that the mismatch between the concepts of health inherent in Western biomedicine and those valued by different ethnocultural clients can result in barriers to access to care and ultimately in poor health status (Kearns, 1997; Kearns & Dyck, 1996; Kleinman, 1978, 1980). Because clients tend to reject services that are incongruous with their health-care values and beliefs, providers should learn to recognize and negotiate between different ways of viewing health and delivering health care.

In the present study, the Vietnamese women's conceptualization of disease and illness was, to some extent, culturally specific (for example, the notion that disease and illness are predetermined by a higher power). However, their ways of preserving their health reflect the discourse and practices of Western biomedicine. Furthermore, it is evident that not all of the women's beliefs and values acted as barriers to their seeking Western health care. The comment that "health is gold" actually served as a motivator for the women to engage in cancer screening.

Although the results of this study cannot be generalized to all Vietnamese-Canadian women due to both the small size of the sample and the nature of qualitative research, the findings reveal that barriers to the use of preventive Western medicine might be due to other factors besides the women's traditional beliefs, values, and health-care practices. Therefore, the methods of addressing the screening practices of Vietnamese-Canadian women with regard to breast and cervical cancer should also be assessed, using theoretical and research methodology that examines the influence of not only culture but also social, political, historical, and economic background.

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Comments or queries may be directed to Tam Truong Donnelly, Faculty of Nursing, University of Calgary, 2500 University Drive NW, Calgary, Alberta T2N 1N4 Canada. Telephone: 403-220-8377. Fax: 403-284-4803. E-mail: tdonnell@ucalgary.ca

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Tam Truong Donnelly, RN, PhD, is Assistant Professor, Faculty of Nursing, and Adjunct Assistant Professor, Department of Community Health Sciences, Faculty of Medicine, University of Calgary, Alberta, Canada.

Résumé

Les croyances et les pratiques des femmes des Premières nations au sujet de la prise de poids pendant la grossesse et la période d'allaitement : implications en matière de santé des femmes

**Helen Vallianatos, Erin A. Brennand, Kim Raine,
Queenie Stephen, Beatrice Petawabano,
David Dannenbaum et Noreen D. Willows**

De nombreuses femmes cries vivant dans le nord du Québec prennent du poids de façon excessive pendant la grossesse et conservent ce poids entre les grossesses. Un tel état engendre des problèmes de santé materno-fœtaux et une augmentation des taux de maladies liées à l'obésité. Cette étude qualitative descriptive a pour objectif d'explorer (a) les perceptions que détiennent les femmes cries concernant la prise de poids pendant la grossesse et la perte de poids après l'accouchement; (b) les obstacles auxquels les femmes font face quant au maintien d'un poids santé; et (c) la santé et le contexte socioculturel. Des entrevues semi-structurées ont été menées auprès de 30 femmes qui avaient accouché au cours des 12 derniers mois. Nombre de femmes ont témoigné des effets néfastes que produit une prise excessive de poids sur leur santé. Néanmoins, elles avaient de la difficulté à maigrir en raison de contraintes individuelles, tels le manque de temps et les croyances culturelles concernant l'alimentation pendant l'allaitement, et aussi à cause de contraintes collectives, dont l'absence de services à l'enfance et de programmes communautaires à l'intention des mères.

Mots clés : prise de poids, grossesse, allaitement

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Beliefs and Practices of First Nation Women about Weight Gain during Pregnancy and Lactation: Implications for Women's Health

**Helen Vallianatos, Erin A. Brennand, Kim Raine,
Queenie Stephen, Beatrice Petawabano,
David Dannenbaum, and Noreen D. Willows**

Many Cree women in northern Quebec experience excessive weight gain during pregnancy and retain the weight between pregnancies. This contributes to poor maternal-fetal outcomes and increased rates of obesity-related health problems. The purpose of this qualitative descriptive study was to explore (a) Cree women's perceptions of weight gain in pregnancy and weight loss following pregnancy, (b) the barriers that women face in maintaining a healthy body weight, and (c) the sociocultural context of health. Semi-structured interviews were conducted with 30 women who had given birth within the preceding 12 months. Many women spoke of the negative health consequences of excessive weight gain, yet they found it difficult to lose weight due to individual constraints such as lack of time, cultural beliefs about diet while breastfeeding, and community constraints including lack of child care and lack of community programs for mothers.

Keywords: First Nation women's health, weight gain, social determinants of health, pregnancy, breastfeeding

Introduction

First Nation women are considered at risk for pregnancy complications (e.g., gestational diabetes), negative infant outcomes (e.g., low birth weight [< 2500 g] and high birth weight [> 4000 g]) (Health Canada, 2003). Among the James Bay Cree of northern Quebec, approximately 75% of women begin pregnancy overweight or obese and almost 50% gain excessive weight during pregnancy (Brennand, Dannenbaum, & Willows, 2005). Repeated cycles of pregnancy may magnify some adverse outcomes if women retain weight gain from each pregnancy. Recent research indicates that between 12.8% and 18.6% of Cree women develop gestational diabetes mellitus (GDM) and that overweight or obese women are at greatest risk (Brennand et al.; Rodrigues, Robinson, & Gray-Donald, 1999); these rates of GDM are significantly higher than the 2% to 4% prevalence in the general population of pregnant women (Meltzer et al., 1998). Gestational diabetes and obesity are two risk factors for high birth weight. Among the James Bay Cree, more than one third of newborn infants are macrosomic, weighing more than 4,000 grams (Armstrong, Robinson, & Gray-Donald, 1998; Brennand et al.).

Interventions for First Nation women to prevent pregravid obesity and excessive weight gain in pregnancy must be developed if maternal/fetal outcomes are to be improved. Unless the range of factors affecting the health of Cree women is considered, however, interventions will meet with little success (Special Working Group of the Cree Regional Child and Family Services Committee, 2000), as sociocultural context has both positive and negative effects on women's ability to pursue and maintain health.

The objective of this study was to explore Cree women's perceptions of weight gain in pregnancy and the barriers to maintaining healthy body weight. In this paper, following a description of methods and analysis, we offer some background on the James Bay Cree in order to provide a historical context for assessing current health experiences. We then present our analysis of Cree women's voices, highlighting the ways in which social determinants affect their ability to adopt health-promoting behaviours.

Field Site and Methods

Context

Due to concerns about excessive weight gain in pregnancy, the Cree Board of Health and Social Services of James Bay supported a qualitative descriptive study to examine women's perceptions of weight gain in pregnancy as well as barriers to healthy living. The project was conceived by community members. Three of the authors (DD, QS, and NDW) were members of a working group comprising health-care professionals in the region. The purpose of the working group was to develop strategies for better understanding Cree women's perceptions of weight gain in pregnancy and weight loss following pregnancy, with the goal of improving prenatal and postnatal care. This community-based study was conducted with Cree women living in James Bay (Eeyou Istchee) over a 2-month period in 2004. Semi-structured interviews were developed and conducted with the aid of a community clinician (DD) and two Community Health Representatives (CHRs) (QS and BP), who were Cree community members trained in health-care education and promotion.

Description of Communities

The CHRs recruited participants from two of the nine communities in the region. The first community was home to approximately 3,500 people, with the nearest town being 90 minutes away by automobile. Fresh produce was available in only one grocery and was expensive (Willows, Iserhoff, Napash, Leclerc, & Verrall, 2005). Prepared food (e.g., deep-fried chicken and French fries) was also available in this grocery, and was usually sold out by dinnertime. Of the two restaurants, community members patronized one more than the other because it was more affordable; this restaurant served mainly fast food and was usually busy.

The second community was smaller, with approximately 3,000 people, and more remote. Little fresh produce was available in the main grocery, and it was expensive and often of poor quality. Healthy foods were difficult to find. Most food items available were either frozen (e.g., pizzas, French fries, egg rolls) or of little nutritional value (i.e., junk food); the latter items were predominantly displayed at the checkout counters. A second, smaller, grocery was stocked with frozen products and foods of little nutritional value, and this was where young people congregated in the evenings.

Both communities had a fitness centre but the hours were erratic and paid membership was required. Neither community had a swimming pool.

Methods

This qualitative descriptive study (Sandelowski, 2000) was designed to gain an understanding of Cree women's concepts and experiences of weight gain in pregnancy and weight loss postpartum, in order to better comprehend both the barriers that women face in maintaining a healthy body weight and the sociocultural context of health in Cree communities. The trustworthiness of qualitative research reflects efforts to meet the criteria of credibility, transferability, dependability, and confirmability (Guba, 1981). Credibility was ensured through the use of interviews, a means of data collection commonly used in qualitative descriptive studies (Sandelowski), the longstanding professional relationship between the principal investigator (NDW) and members of the community and the Cree Board of Health, and efforts to elicit candour on the part of participants (e.g., obtaining informed consent). Although the transferability (generalizability) of the study is limited by the heterogeneity of First Nation cultural beliefs and practices, we have described the historical and current context of the participating communities to enable comparison with other communities (Shenton, 2004). By describing the methods employed, we have met the criteria of dependability and confirmability (Shenton).

The interviews consisted of open-ended questions on women's concepts of a healthy weight, diets, and appropriate weight gain and on barriers to achieving health. A convenience sample of 30 Cree women were interviewed (14 from one community and 16 from the other). All the women had delivered an infant within the preceding 12 months. Women in these communities typically have their children when young and all participants were aged 30 or under. Fluency in English was not a requirement for participation as CHRs were able to translate questions and responses from Cree into English and vice versa. This factor was considered important, because by selecting only women with a good command of English we could have excluded women with less formal education or those who did not travel far from their communities. All the women gave informed consent to be interviewed and had the option of ceasing the interview at any point or requesting that their interview data not be used. The interviews were conducted in the participants' homes or in community centres and lasted approximately 30 minutes. The study was approved by the Human Research Ethics Board of the Faculty of Agriculture, Forestry and Home Economics, University of Alberta.

Data Analysis

The interviews were audiotaped, translated into English where required, and transcribed. Data analysis was content-based (DeVault, 1990). In other words, we examined the data for patterns of what women said, instead of conducting a narrative analysis of the content. This method is useful for exploring themes. Qualitative data were coded by reviewing all cases. Codes were formulated through line-by-line analysis of concepts that were identified in the data. Comparative analysis led to the development of categories. This level of analysis examined how women used the codes defined in the first stage. Themes were developed from the categories that emerged from the data and through a comparison of these concepts with those reported in the literature. Data analysis was conducted by one researcher (HV). An important aspect of trustworthiness in qualitative research is that the interpretation represent not only the perspective of academics but also that of the participant communities — in other words, reciprocity (Harrison, MacGibbon, & Morton, 2001). In keeping with reciprocal research, the CHRs read the manuscript to ensure that it represented the women's viewpoints, and members of the Research Committee of the Cree Board of Health were given the opportunity to review the resultant manuscript.

Background

We now offer a brief historical overview of James Bay in order to provide a historical context for the difficulties faced today in pursuing a healthy lifestyle. Traditionally, the Cree lived in small mobile family groups and subsisted by foraging (Preston, 1981). With the arrival of Europeans in the area in the 1600s, and especially upon the arrival of Christian missionaries in the mid-19th century, pressure steadily increased to change traditional lifeways. Settlement in permanent villages was "encouraged," with a concurrent rise in infectious-disease epidemics and a gradual decline in traditional means of subsistence. Cree religious and health systems, among other aspects of their culture, were undermined (Niezen, 1997). Families were separated so that children could be educated according to Canadian government standards. Children were sent to residential schools as recently as the 1960s (Kirmayer, Boothroyd, Tanner, Adelson, & Robinson, 2000).

The *James Bay and Northern Quebec Agreement* of 1975 allowed for hydroelectric development in the area. In return, the Cree received a formal land-claim settlement, monetary compensation from the provincial and federal governments, and local autonomy (confirmed with the *Cree/Naskapi [of Quebec] Act* of 1984). Although these agreements have resulted in improved access to schools and to infrastructure development (electricity, water, sewage), a number of problems have developed or have worsened, including unemployment, loss of traditional means of subsistence, contamination of the traditional food supply due to flooding, loss of traditional customs, widespread alcoholism, substance abuse, and psychosocial problems (Adelson, 2000; Berkes & Farkas, 1978; Frideres & Gadacz, 2001; Kirmayer et al., 2000; Niezen, 1997). One must understand the legacy of this dramatic cultural change in order to understand the macro-level factors affecting the health of Cree peoples today.

Results

Characteristics of Participants

The average age of the 30 participants was 21.7 years (range = 18–30 years). All of the participants were overweight or obese, defined as BMI > 25.0 (Health Canada, 2003). The majority of participants (73%) had more than one child. None had postsecondary education, with slightly more than half having completed high school. Although proficiency in English was not an inclusion criterion, all of the women were able to read and speak English either fluently or with some hesitancy. The majority of the women cohabited with the father of their youngest child in either a marital or a common-law relationship. Younger mothers were more likely than older mothers to be residing with their parents or with their child's paternal grandparents. The male partner often worked outside the community, which required the woman to live alone with her children for extended periods. Most of the participants were not employed outside the home.

Weight Gain During Pregnancy: "Only a little"

About two thirds of the participants stated that gaining weight during pregnancy was "normal." (Most of the women defined normal weight gain as between 20 and 30 pounds.) Only 30% of the participants thought they had gained too much weight. The main criterion used to assess adequacy of weight gain was birth outcome. If the health of the baby and mother was fine, then the women assumed that the amount they had gained was "good." For example, when one participant was asked why she thought she had gained the right amount, she replied, "Because she [her baby] was eight pounds when she was born."

The importance of not gaining too much weight was also discussed. The participants said it was important to gain "only a little" or one could face a number of health risks and complications during the birth:

> *What do I think about gaining weight? It's…not healthy. It's not normal. Well, maybe it's normal…to a certain extent. The weight of the baby is supposed to be the only weight gain. That's what I thought. Not me, because then I risk…getting diabetes or other stuff… [I should gain] just the baby, the baby's weight.* (19-year-old mother of one)

The women were exposed to "Western" conceptions of health and beauty through satellite television, magazines, and, for some, the Internet. They frequently expressed dissatisfaction with their bodies. Some voiced concern about what excessive weight gain would do to their figures. Although the participants considered it normal to gain weight during pregnancy, they did not want to gain weight:

> *It's okay at first, like, while you're pregnant, because you know that you're carrying your child, but…afterwards when you have your baby, it's sort of like "Okay, like, I've never been this big before." …it kind of puts you down at first, but then you realize that you were carrying your child and, you know, it's just something that I guess the changes in your body do, so it was okay afterwards…once I really realized why I gained the weight.* (20-year-old mother of two)

The women's fears about weight gain centred around its effect on their figures postpartum:

> *What do I think of it [weight gain during pregnancy]? [pause] Well, I don't like to gain weight. Like, I hate being fat.* (18-year-old mother of two)

Yet changes in body size and shape were seen as a normal part of motherhood. One mother described her weight challenges after pregnancy, when her weight plateaued:

> *I find it kind of hard, especially, like, emotionally. I don't really like the way I look because I can't go back to my normal pant size. I have to…buy other clothes, so…at this point I have to wear baggy clothes just to hide my figure…and it's kind of sad but it's how I am… I guess I have to get used to it because I'm a mother now.* (19-year-old mother of one)

Weight Loss Postpartum: "Important…but hard"

Losing weight postpartum was considered important by the majority of women, primarily because of the implications for maternal health and energy levels. The women understood the relationship between overweight/obesity and health problems:

> *When you gain weight…your…blood pressure goes up or you end up being diabetic, or you have a heart problem…. You get high blood pressure, you get nosebleeds a lot because you're overweight, and you get sweaty.* (26-year-old mother of five)

The mothers were concerned for their own well-being because child care requires vigour and physical effort. Being heavy limits one's ability to run after toddlers or to take part in the play activities of older children:

> *It takes a lot of hard work to raise a child…and in order for you to do that, to be able to…do the things that they do — you know, take them out for a walk — you have to be a healthy weight.* (20-year-old mother of two)

Despite the importance of losing weight postpartum, the majority of women said they had difficulty doing so. A number of explanations were given for the challenges they faced, which can be categorized as individual constraints, cultural beliefs, and lack of community support and services.

Individual constraints. A number of factors affected the women's ability to pursue a healthy lifestyle and lose their pregnancy weight. The participants said they lacked the energy to exercise and to watch what they ate. Staying at home could be isolating, and for some women food became a way to fill a void. Eating was something to do to pass the time.

A 21-year-old mother of two said, "Once she's sleeping [the baby]… How do I say this? I have nothing else to do except eat."

Lack of time to cook or to exercise was another factor. This was an issue for both working and stay-at-home mothers. Working mothers wanted to spend their non-working hours with their children. Stay-at-home mothers had difficulty taking care of the domestic chores in addition to watching older children. They found it hard to make the time to exercise.

Lack of knowledge about a healthy lifestyle — or at least how to use such knowledge — was another factor. The participants did not know how to make better choices with regard to diet or level of physical activity. Furthermore, they found it difficult to break old habits. An 18-year-old mother of two said, "I didn't watch how I ate, and I didn't know how to." Some women used pregnancy as an excuse to eat whatever they wished or craved and found it a challenge to break the pattern:

> *You kind of keep those habits that you had…during the 9 months of your pregnancy. You don't want to let go. For one example, I didn't really drink that much pop before I was pregnant, but when I was pregnant I loved to drink, you know, diet Coke…it's kind of hard to let go of those things…you kind of still get used to it…you're so comfortable with it. It's hard to change…the eating habits you gained through your pregnancy. That's what I noticed. And especially when you want your baby to gain weight, you might as well eat with her.* (19-year-old mother of one)

Cultural beliefs: "You have to eat to breastfeed; you have to get the milk flowing." The majority of the women breastfed their infants. From their elders, the participants had acquired cultural beliefs about the need for maternal food consumption sufficient to ensure the health and well-being of both mother and infant. However, women of previous generations lived in the bush; they had a low-fat diet and engaged in vigorous physical activity. Traditionally, weight loss was believed to affect milk production: a woman who lost too much weight would be unable to produce enough milk to feed her infant and the child would be malnourished. Women were encouraged to eat in order to initiate and continue lactation. The participants believed, in essence, that the breastfeeding mother is eating for two:

> *…you were told in order for you to have more milk, for you to produce more milk, that you have to eat because you're eating for two people, and even after you're pregnant…you're still going to be feeding two, so you have to eat more.… And you always felt good when you gained weight too, because you know that you're going to have, you think you're going to have more…milk for your baby.*

The participants had difficulty losing their pregnancy weight because of beliefs about eating during lactation, as illustrated by the comment of a 25-year-old mother of three:

> *It's not that important [to lose weight postpartum], but maybe later on in years.... Because you have to eat often when you breastfeed, drink often, and it's very hard to lose weight when you're breastfeeding. That's what I think.*

However, the participants did not perceive the quantity of food consumed by a breastfeeding mother as necessarily affecting her body size or shape, because the added consumption went into the breast milk: the baby would "suck up all your calories."

> *You can't gain or lose weight when you're breastfeeding, because...everything normally goes to your breast and a small amount goes to your stomach. So you're not really losing or gaining any weight. It doesn't matter how much you eat.* (26-year-old mother of five)

They considered it important for the mother to eat well, because the quality and quantity of her intake affected the quality and quantity of her milk supply. They also believed that the mother's milk composition affected the health of the baby. One mother said she watched her diet carefully, avoiding junk food and pasta and eating yogourt and traditional foods, so that her infant would not suffer from colic. Another mother avoided spicy foods because these would hurt her infant's stomach.

The participants also believed that breastfeeding was good for the health of the child. They perceived breastfed infants as less likely than bottlefed infants to become ill, even after they have been weaned:

> *Well, my grandmother always told me...that it was hard a long time ago when they were living in the bush because she had to breastfeed because they had no milk, they had no fridge... They were in the bush all year round...she had to breastfeed her kids all the time...by the time they turned 1 then she started feeding them solid foods, so she told me it was best to breastfeed a child because they'd get sick less when they got older... I guess she was right, because I breastfed my eldest daughter for 6 to 6 ½ months and she hardly gets sick, so I'm glad I did.* (26-year-old mother of five)

Thus, traditional cultural beliefs emphasized the importance of eating and drinking while breastfeeding in order to ensure the health of both mother and child. However, the difficulty of many breastfeeding mothers in losing weight was related to their food choices, as pointed out by a 25-year-old mother of four:

> *[Weight loss after pregnancy] depends on…if they're eating the right foods or not, like, if they just eat…fast foods… I think that's how they don't lose it.*

Lack of community support and services. Use of daycare and babysitters was not common among the participants, and they often cited lack of finances and transportation as a barrier to accessing community services such as fitness programs. The lack of community services for new mothers prevented many women from pursuing a healthy lifestyle. One of the main complaints centred on the lack of child-care facilities. The women, especially single mothers, could not exercise if they could not leave their children in quality, affordable child care. The participants also pointed to the lack of exercise facilities, especially programs for new mothers. In addition, new mothers were often kept indoors because of inclement weather, so housekeeping was their only form of physical activity.

The participants expressed great interest in the idea of exercise programs for new mothers, such as walking clubs and aerobics classes. Fitness programs that included children, such as "mothers and tots" activities, were also suggested:

> *[If] there was some support…after pregnancy it would be really something, like an exercise group or swimming or something like that for a woman, especially with their children too. …a swimming activity with your baby — that would be really cool!… Around here…it's kind of hard to get a…sitter after hours…most of the time alone… The father is there but [he] has to go to work.* (19-year-old mother of one)

Although there were nutritionists based in the communities, the participants did not see them as an effective means of reaching the people. They believed that more creative ways of providing nutrition education to new mothers had to be found, such as community cooking classes or home-based nutrition evaluation:

> *What I find in the community…is people listen to the radio a lot, and I think we can inform them through the radio about what they can eat… and there's different things that can be done, like cooking classes…or get-togethers at somebody's house, and just learn, teach, learn from each other…how to cook healthy meals.* (30-year-old mother of two)

A few of the women said that elders could be involved in such activities. They believed that as a source of traditional knowledge about healthy lifeways, elders could make a contribution by contrasting current lifestyles with life in the bush.

Defining Healthy Lifestyles

If healthy interventions are to be developed, women's perceptions of a healthy diet and appropriate physical activity will have to be better understood. The factors that women identify as barriers to pursuing a healthy lifestyle can also be used in the development of programs. For many of the participants, keeping a healthy diet meant eating plenty of vegetables and fruits, in essence following the *Canada Food Guide* (in fact, a few of the women mentioned this publication). They also considered traditional foods (wild or country foods) an important aspect of a healthy diet:

> *I think what helped me the most was eating traditional food. Even though I never really liked one food [one kind of traditional food], I ended up liking that traditional food… And it kind of helped me. I didn't really have to eat a lot… It, like, stuck there with me and the baby, you know, for a while it lasted. And when I was eating…just that regular food there, that they sell in supermarkets, I noticed that I felt hungry more.* (19-year-old mother of one)

These foods connote more than just health. They also symbolize Cree culture or way of life.

All of the women defined physical activity as walking. They viewed walking as an effective way of exercising without having to go to a gym or leave the house at a particular time. They considered walking the best form of exercise during pregnancy because it does not overstrain women. Many of the participants expressed the view that exercise during pregnancy was important not only for health reasons, such as preventing gestational diabetes and other complications, but also because it resulted in an easier labour and birth. A 26-year-old mother of five explained:

> *To walk at least two to three times a day during pregnancy [is needed] just to keep healthy and just to keep strong, to keep your legs strong and your bones strong, because you'll need them when you…go into labour.*

Other ways of staying physically active included housework, swimming, and not "sitting around" or napping during the day. Most of the participants believed they had maintained a healthy lifestyle while pregnant, eating properly and being physically active.

As with traditional foods, traditional lifeways (i.e., living in the bush) had cultural meaning for the women, and they saw physical activity as a part of life in the bush:

> *It's more active when you're living in a bush, like when you're on a trap line and you go with your grandparents or whoever you're living with. You do more stuff, you do more active stuff when you're in the bush…. You're*

> *not really sitting around all the time, you're always doing something, there's always something to do. Especially when you're pregnant.... I would recommend...a lot of pregnant [women] to go out in the bush with their families when they know they're pregnant. Be more active when they're in the bush, it's a lot more work.* (26-year-old mother of five)

Discussion

The purpose of this study was to explore the social determinants of the health of First Nation women through interviews with James Bay Cree mothers. The findings indicate that many factors interact to form barriers to a healthy lifestyle. The participants were aware that gaining excessive weight had negative implications for their health, but they generally found it difficult to control their weight gain during pregnancy and to lose weight postpartum. Eating to ensure a healthy baby was integral to their cultural beliefs about maternal dietary practices. Factors at the individual, family, and community levels all played a role in the participants' ability to control their weight during and after pregnancy.

Although the health of First Nation women should be considered in historical context, because the effects of colonialism and domination may affect the health and well-being of individuals and communities (c.f. Waldram, Herring, & Young, 1995; Young, 1994), it must be acknowledged that women have agency to effect positive change. In addition, every community possesses the capacity, resilience, and strengths to be health promoting; for this reason, interventions and programs should focus on the inherent resources and cultural dynamics of a given community (Kretzman & McKnight, 1993).

The participants showed a mixed understanding of the appropriate amount of weight gain during pregnancy. For women who are overweight or obese, the recommended weight gain is 15 to 25 pounds (Health Canada, 1999). The weight gain considered normal by the participants, all of whom were overweight or obese, was often higher than that recommended by health professionals for optimal pregnancy outcome. The participants interpreted messages on weight gain in a cultural context. If the mother and infant were healthy and the birth was uncomplicated, the mother assumed that she had gained an appropriate amount of weight. The majority of participants did not own scales, so it is unlikely that home weight monitoring took place; thus weight regulation was contingent upon regular prenatal care. What may be more important is how the women felt about their health and their body size and shape. In fact, the participants who did express concern about their change in weight as mothers focused on how their clothes fit and the corresponding changes in body shape, or on avoiding illness such as gestational diabetes and high blood pressure.

Being "healthy" meant eating the "right" foods, being physically active, and being in touch with traditional lifeways (i.e., spending time in the bush). Healthy eating meant consuming vegetables, fruits, and traditional (country) foods and avoiding junk or fast foods. Being physically active meant including movement in one's daily routine, through household chores, minding children, and walking. To live in the bush was perceived as a healthy way of life, for the bush was viewed as a traditional place where being healthy was part of life. This perspective on health corresponds to the Cree concept of *miyupimaatisiiun*, or "being alive well," in which the emphasis is placed on quality of life rather than on aspects of the physical body (Adelson, 2000; Niezen, 1997). Previous studies with First Nation communities in northern Canada also found a relationship between traditional lifeways, country foods, and health (Borré, 1991; Freeman, 1988; Wein, Freeman, & Makus, 1996).

The Cree definition of health as a way of living also illustrates the web of factors that affect health and well-being within social, political, and historical contexts. Health researchers and practitioners should examine health in an ecological context — in the sociopolitical as well as the physical environment. The present findings clearly demonstrate the confluence of factors that impact on women's lifestyle choices. The participants' dietary intake and level of physical activity were influenced by time, energy, and knowledge constraints. Using their knowledge about healthy eating was a particular challenge. Although the women were aware of the importance of making healthy food choices, they often succumbed to the temptations of the prepared, refined foods available in grocery stores and restaurants. For them, the planning and preparation of healthy meals was labour-intensive, time-consuming, and expensive, and it was simply easier to resort to store-bought foods. The increasing trend towards the consumption of store-bought products in northern communities, despite the high value placed on country foods, is well documented (Berkes & Farkas, 1978; Duhaime, Chabot, & Gaudreault, 2002; Wein, Sabry, & Evers, 1989).

Part of the difficulty in maintaining a healthy lifestyle was the lack of domestic help. Many of the participants were single or were partnered with a man who was employed outside the community. These types of family structure meant that there were few people on whom the women could rely for child-care assistance. Both stay-at-home and employed mothers spoke about the lack of affordable quality child care.

The participants also spoke of the need for community facilities where new mothers could exercise while having their children nearby and the need for a place for new mothers to gather, share, and learn from each other. Community changes cannot happen in a vacuum. The sociopolitical context of these Cree communities must be considered. Nutrition seminars, cooking classes, and home-visiting programs require trained personnel. Such personnel are usually non-Cree from the south who have little training in the Cree language and culture (see Adelson, 2000). The biomedical model of health, which does not incorporate Cree models of health and food, continues the process of colonization (Niezen, 1997). For many Aboriginal peoples, perceptions of healthy eating are embedded within cultural meanings of food and health (Willows, 2005). In the holistic Cree concept of *miyupimaatisiiun,* the interaction of the social and physical environments is embodied in the individual. This concept could be a starting point for responding to the multifactorial aspects of weight gain among young mothers. Interventions that target individuals, emphasizing behavioural changes, may have limited success, for they do not consider the environment in which these women live. We advocate programs that have cultural meaning for the Cree and that value Cree concepts of well-being (such as eating well when breastfeeding). Such programs can be developed only through the inclusion of Cree voices — elders, healers, and the mothers themselves. The problem of obesity among Cree women must be addressed using a multi-pronged approach.

This study is limited in two respects. First, the participants were encouraged to respond in the language of their choice; translation of Cree into English may have resulted in a failure to capture subtleties of the ideas they expressed. Second, we used a convenience sample of young mothers from two communities; the women in those communities may not necessarily share the participants' views on appropriate weight gain and loss during and after pregnancy.

In conclusion, the health of First Nation peoples is, on average, poorer than that of the general Canadian population. A social determinants perspective allows us to highlight the multifaceted nature of health and well-being and to see how the health of an individual is affected by the current social and physical environments, which, in turn, are shaped by historical events (Waldram et al., 1995). The present findings show clearly that before we can begin to moderate weight gain among Cree women, we need to understand the factors and processes, at the individual, family, and community levels, that influence their ability to adopt healthy lifestyles.

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Comments or queries may be directed to Noreen D. Willows, Department of Agricultural, Food and Nutritional Science, 4-10 Agriculture/Forestry Building, University of Alberta, Edmonton, Alberta T6G 2P5 Canada.

Helen Vallianatos, PhD, is Postdoctoral Fellow, Centre for Health Promotion Studies, University of Alberta, Edmonton, Canada. Erin A. Brennand is a medical student at the University of Alberta. Kim Raine, PhD, RD, is Director, Centre for Health Promotion Studies, and Professor, Department of Agricultural, Food and Nutritional Science, University of Alberta. Queenie Stephen and Beatrice Petawabano are Community Health Representatives, Cree Board of Health and Social Services of James Bay (Quebec), Canada. David Dannenbaum, MD, CCFP, is with the Public Health Department, Cree Board of Health and Social Services of James Bay (Quebec). Noreen D. Willows, PhD, is Assistant Professor and Community Nutritionist, Department of Agricultural, Food and Nutritional Science, University of Alberta.

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Résumé

La perspective des femmes atteintes de démence et recevant des soins de leur fille adulte

Catherine Ward-Griffin, Nancy Bol, Abram Oudshoorn

Le vécu inhérent à la prestation des soins aux personnes atteintes d'Alzheimer est relativement bien documenté. Toutefois, peu de recherches ont été réalisées du point de vue de la personne souffrant de démence. L'objectif de cette étude, qui s'inscrit dans une recherche qualitative sur les relations mères-filles en contexte de démence, notamment sur le processus de soins, est de recueillir les perceptions et les expériences des mères soignées par leur fille adulte. Guidés par des perspectives féministes et axées sur les étapes de vie, les chercheurs ont mené des entrevues en profondeur et semi-structurées auprès d'un échantillonnage diversifié de 10 femmes non-institutionnalisées et atteintes de troubles cognitifs légers à modérés. En général, les perceptions et les expériences des femmes sur le plan de la santé étaient façonnées par les rapports sociaux entre les sexes et par la manière dont ils sont construits. Bien que les mères rapportaient des interactions surtout positives avec leur fille, les idéologies culturelles de l'individualisme et des rapports axés sur la famille se traduisaient par des sentiments de « culpabilité-reconnaissance ». Les participantes géraient leurs expériences contradictoires dans la situation où elles recevaient des soins de leur fille en *donnant elles-mêmes des soins,* en *s'abstenant de demander des soins,* en *déterminant les soins* et en *acceptant les soins.* Les auteurs recommandent l'apport de changements à l'échelle des pratiques, des politiques et de la recherche, qui doivent tenir compte de déterminants sociaux de la santé pertinents, comme les rapports sociaux entre les sexes et le soutien social. Ces changements contribueraient à la santé et au bien-être des femmes atteintes de démence.

Mots clés : femmes

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Perspectives of Women with Dementia Receiving Care from Their Adult Daughters

Catherine Ward-Griffin, Nancy Bol,
and Abram Oudshoorn

The caregiving experience within Alzheimer disease is fairly well documented. However, little research has been conducted from the perspective of the person living with dementia. The purpose of this study, part of a larger qualitative investigation of mother-daughter relationships within the care process of dementia, was to elicit the perceptions and experiences of mothers receiving care from their adult daughters. Guided by feminist and life-course perspectives, the researchers conducted in-depth, semi-structured interviews with a diverse sample of 10 community-dwelling women with mild to moderate cognitive impairment. In general, the health perceptions and experiences of the women were shaped by gender and how its meaning is constructed. While mothers reported mostly positive relationships with their daughters, cultural ideologies of individualism and familism manifested in feelings of "grateful guilt." Participants managed their contradictory experiences of receiving care from their daughters by *doing care, undemanding care, determining care,* and *accepting care.* The authors recommend changes in practice, policy, and research, with the aim of addressing relevant social determinants of health such as gender and social support, thereby promoting the health and well-being of women with dementia.

Keywords: aging, dementia care, women, health promotion

Background

Alzheimer's disease (AD) is an insidious, pervasive, debilitating disorder that destroys the affected person's capacity for self-care (Wuest, Ericson, & Stern, 1994). It not only has a profound impact on individuals diagnosed with the disease, but also affects the lives of family members caring for them (Wuest, Ericson, Stern, & Irwin, 2001). As Canada's elderly population grows, an increasing number of individuals will require care for AD. The prevalence of dementia nearly doubles with every 5-year increase in age from the age of 60, rising to 32% in those aged 90 to 94 (Hofman, Rocca, & Brayne, 1991). Studies have found that the prevalence of AD is higher in women (Evans, Ganguli, Harris, Kawas, & Larson, 1999). Moreover, the prevalence of AD in Canada is expected to increase from approximately 364,000 persons in 2000 to over 750,000 persons by 2030, with roughly half of those individuals living in the community (Canadian Study of Health and Aging [CSHA] Working Group, 1994).

There has been significant emphasis on the development of services that enable people with AD to remain in their own homes whenever possible. Although there is a growing commitment to assist the individual with dementia and his or her family, there are many challenges to achieving optimal dementia care in the home. Restructuring of hospital and social services, closure of long-term-care facilities, and underfunding of home care (Aronson, 2004; Chappell, 1999) have led to an increasing reliance on family care. The current trend towards the favouring of home care over care in a hospital or other institution is motivated in part by concerns about spiralling health-care costs (Armstrong & Armstrong, 2004; Neysmith, 1991; Strang & Koop, 2003). Only one in four people caring for a relative with dementia receives formal care services (CSHA Working Group, 1994). Consequently, families rather than paid caregivers assume and/or coordinate the majority of home-based care (Armstrong et al., 2003). Since most care recipients and family caregivers are women, these shifts in the delivery of health care tend to affect women to a greater degree than men (Armstrong & Armstrong; Gregor, 1997; Morris, 2004).

Given these challenges to the achievement of optimal home-based dementia care, the needs of women involved in dementia care, particularly those afflicted with AD, demand careful attention. The inclusion of the perspectives and voices of women who receive care is essential to the analysis of how social determinants, such as gender and social support, affect women's health. Health Canada identifies gender as one of the 12 determinants of health, because gender is a factor in both participation in and the consequences of health care (Armstrong, 2004). The purpose of this qualitative study, guided by feminist and life-course perspectives, was to explore the perceptions and experiences of women with mild to moderate dementia and their adult daughters in the giving and receiving of care. The aim of this paper is to report on the mothers' accounts of receiving care from their daughters, thereby bringing elderly women from the margin to the centre of the debate on dementia care. The daughters' perspectives on providing care to their mothers with dementia are reported elsewhere (Ward-Griffin & Bol, in press). The paper will conclude with recommendations for change in practice, policy, and research, with the aim of promoting the health and well-being of women with dementia.

Literature Review

Relationships between Persons with AD and Family Caregivers

The literature is replete with studies of the problems of caregiving, many of which view the individual with AD as a significant source of caregiver burden (Beeson, Horton-Deutsch, Farran, & Neundorfer, 2000; McCarty, 1996, Stevenson, 1990). Recently, however, researchers have focused on the relational aspects of dementia care (Globerman, 1994; Ward-Griffin & Bol, in press; Wuest, Ericson, & Stern, 1994). In a grounded theory study with 15 family caregivers, Wuest, Ericson, and Stern found that the interactions of persons with AD and family caregivers fell on a continuum from intimacy to alienation through dimensions of dawning, holding on, and letting go. Similarly, Ward-Griffin and Bol found that daughters caring for women with dementia reported difficulties in maintaining a reciprocal relationship with their mothers, using negotiating strategies such as "finding a balance," "leading the way," and "carrying the load." In another qualitative study with relatives of persons with dementia, Globerman suggests that families in crisis may find their usual roles and relationships inflexible and need help negotiating their relationships, particularly around their expectations of one another. Other investigations have found that the quality of interactions between persons with dementia and their family members prior to the onset of dementia is an important factor for predicting emotional strain, quality of life, and caregiving satisfaction (Mui, 1995; Spaid & Barusch, 1994). While the effects of the quality of this dyadic relationship on the well-being of the caregiver have been documented, a gap remains in the literature regarding the effect of such relationships on the health and well-being of the person with dementia.

Another limitation of the published research on individuals with dementia and their caregiving relatives is a tendency to distort the reciprocity in their relationships. Neufeld and Harrison (1995) report that 20 women caring for older family members with cognitive impairment described reciprocity as "give and take"; however, caregivers were unable to establish the same kind of reciprocal relationship with the person with dementia as they did with others. Keefe and Fancey (2002) also explored the importance, for caregiving daughters and their older mothers without dementia, of giving and receiving. They found that mothers and daughters had different perspectives on reciprocity, with mothers minimizing their past contributions. In contrast, Talbot (1990), in a study with 55 elderly widowed mothers without dementia, found that mothers gave much and received little, which may contribute to the negative effects of these relationships on the mothers. Finally, Carruth (1996) explored reciprocity among adult children of persons with and without dementia and found that the diagnosis of dementia did not contribute to the explained variance of caregiver reciprocity. These findings suggest that incongruent perspectives of reciprocity between mothers and their adult children may shape the experiences of giving and receiving dementia care. Clearly, further research in this area is warranted.

Research on the Perspectives of People with Dementia

Although the aforementioned studies increase our knowledge about the process and outcomes of caregiving within dementia, we have limited knowledge about the relationships between individuals with dementia and their family caregivers, particularly from the perspective of the individual with AD. Most research in dementia has relied solely on the perspectives of the caregiver, whose stresses and coping strategies have been of much interest. Although there is a tendency to "bind together" the interests of individuals with dementia and their caregivers, especially within community care (Reid, Ryan, & Enderby, 2001), the interests of people with dementia and their caregivers do not always coincide (Askham, 1991). Rarely have the perceptions of the persons with AD been examined, because of their dementia (Cotrell & Schultz, 1993) and the difficulty in recruiting individuals with AD (Long, Sudha, & Mutran, 1998). However, the belief that it is impossible for people with dementia to express their views or describe their experiences has been increasingly rejected in recent years (Clarke & Keady, 2002; Gilmour & Huntington, 2005; Whitlatch & Feinberg, 2001). Research has demonstrated that individuals with mild to moderate cognitive impairment are able to answer questions about their own care with a high degree of accuracy and reliability (Whitlatch & Feinberg) and are willing and able to share their personal narratives (Moore & Hollett, 2003; Svanstrom & Dahlberg, 2004; Usita, Hyman, & Herman, 1998). The exclusion of persons with dementia indicates a failure to acknowledge their ability to report accurately on their current situation (Cotrell & Shultz), rendering them as passive participants in the care process — as if they were the objects rather than the subjects of their circumstances (Aronson, 1991).

Although persons with dementia and their families are uniquely qualified to define priorities for improving dementia care, they have rarely been asked to do so. In recent years, however, there has been increasing interest in the experiences of people who have been diagnosed with dementia (Aggarwal et al., 2003; Gilmour & Huntington, 2005; Moore & Hollett, 2003; Morhardt, Sherrell, & Gross, 2003; Reid et al., 2001; Sabat, 1998; Svanstrom & Dahlberg, 2004; Werezak & Stewart, 2002). Gilmour and Huntington, in their qualitative study with five men and four women with dementia, found a need to maintain control and independence with the increasing need for support in everyday tasks. Similarly, Cox, Anderson, Dick, and Elgar (1998) found that individuals with dementia expressed a desire for reliable health-care workers who support their independence and treat them as individuals. Reid et al. interviewed 19 people with dementia as part of a larger study on unmet respite-care needs among caregivers and day-care attendees in England; they found that those who attended groups valued them for the support offered and provided, the potential for developing friendships, and the company offered. Similarly, Aggarwal et al., using a flexible, individualized approach, interviewed 27 people at all stages of dementia in residential and day-care settings, as well as their relatives, on the subject of care services and their experiences; the persons with dementia reported lack of choice and the need for independence and more social aspects of care, while their relatives were more positive about the services. This discrepancy in response between persons with dementia and their relatives suggests a need to approach people with dementia to elicit their views.

Based on two semi-structured interviews with each of three women and three men with dementia who lived at home with their spouses, Werezak and Stewart (2002) developed a theoretical framework outlining the continuous process of adjusting to early-stage dementia, which comprised five stages (antecedents, anticipation, appearance, assimilation, and acceptance). Similarly, Pearce, Clare, and Pistrang (2002) conducted separate interviews with 10 community-dwelling older men with dementia and their wives to elicit the men's appraisals of their illness and coping strategies. The participants' accounts suggested that the men were engaged in a process of attempting to manage their sense of self. The ways in which the men attempted to manage sense of self were thus affected by their appraisals of and reactions to their difficulties, which in turn had an influence on and were influenced by their relationships and social identities. As previous studies suggest (Evans et al., 1999), women and men may cope with dementia differently, which warrants a more detailed gender analysis of dementia care.

Proctor (2001), in a qualitative study with elderly women with dementia, focused on relationships, gender, and issues of power. Using Brown and Gilligan's (1993) Voice Relational Method, Proctor interviewed four women twice about their experiences with health services. The findings illuminated the situation of power in the women's relationships, particularly their relationships with health professionals. The women felt that they could not challenge doctors and nurses about decisions regarding their welfare, thereby illustrating how gender and (dis)ability shape interactions between caregivers and care recipients.

Although dementia is usually seen as an older person's disease, a grounded theory study (Harris & Keady, 2004) with younger people with dementia in the United States ($n = 23$) and families of younger people with dementia in the United Kingdom ($n = 15$) resulted in the emergence of eight inductively generated themes: (1) difficulty obtaining a diagnosis, (2) issues of self-hood and self-esteem, (3) changing relationships within the family structure, (4) awareness of changes in self, (5) workforce and retirement/financial issues, (6) feelings of extreme social isolation and exclusion, (7) "off-time" dependency, and (8) lack of meaningful occupation. While the findings suggest that people with dementia and their families are confronted with unique social issues, there is a need to explore common experiences among people of any age diagnosed with dementia, such as the feelings of isolation associated with the loss of social roles. It is also important that the life course not be segmented, as this can lead to divisive conceptualizations of care and service provision between and among those receiving care and those giving it. Moreover, the tendency in the literature to focus on static life stages indicates a failure to capture the continuity of gender identity and experience over the life course, particularly for women (Aronson, 1991).

In summary, despite increasing interest in the experiences of people who have been diagnosed with dementia, there is still a dearth of research into the ways in which persons with dementia negotiate relationships in their social world. In particular, little is known about the specific relationship between women with AD and their adult daughters, and how the care process influences their health and well-being, particularly from the mother's perspective. If we are to broaden our understanding of the complexities of the care process in AD, research will have to consider the perspectives of both the caregiver and the care recipient (Cox & Dooley, 1996). Finally, we need to increase our knowledge about gender and how it shapes intergenerational care within the mother-daughter relationship. This information will help us to identify those societal conditions that require change, with the aim of promoting the health of women with dementia.

Method

As part of a larger qualitative investigation of mother-daughter dyads within the care process of dementia, we were interested in developing a better understanding of the experiences of community-dwelling women with AD receiving care from their daughters. Evidence suggests that the care experience differs by gender, family relation, and health status of the care recipient (Dupuis & Norris, 2001). Therefore, this study focused exclusively on women with mild to moderate cognitive impairment receiving care from their adult daughters. Specifically, we were interested in addressing the following research questions: (1) *How do women with AD and their adult daughters describe their experiences of receiving/providing care?* (2) *How do women with AD and their adult daughters describe their relationship?* (3) *What contextual factors influence the care provided/received?*

Theoretical Framework

This qualitative study was guided by socialist-feminist theory and a life-course perspective. This type of inquiry gives primacy to individual subjective perceptions of care experiences, while at the same time seeking to understand the fluctuating nature of the mother-daughter relationship over time. Feminist scholars have identified the importance of the tie between mother and daughter. Given their skills and expectations in maintaining social ties, it is not surprising that, in adulthood, mothers and daughters share stronger relationships than fathers and sons (Fingerman, 2001). Feminist theorists have also questioned the premise that autonomy is the final virtue to be equated with maturity. Thus the emphasis in feminist writing has been on the bond between mothers and daughters (Fingerman).

Social-feminist scholars, most notably Stoller (1993) and Ungerson (1990), have provided explanations for the ways in which caring is defined and how it is organized. Since a feminist perspective views women's everyday caring experiences as inextricably connected to the larger political, social, and economic environment (Hall & Stevens, 1991), elicitation of women's narratives about the intergenerational care process identifies larger cultural values and ideologies. As discussed earlier, the caregiving literature tends to portray elderly mothers as burdensome to their overworked daughters. Feminist inquiry offers an alternative view — that caring is an intergenerational process between two women. Finally, the goal of feminist research is to develop knowledge, thereby creating positive changes with the aim of improving the lives of women in this intergenerational relationship.

This study also took a life-course perspective in order to understand the interactions and exchanges between mothers and adult daughters throughout their lives. This perspective is appropriate since it assumes that the meaning of care (giving and receiving) is based on a lifetime of experiences rather than on the current event or situation (i.e., dementia) (Fingerman, 2001). A life-course perspective also captures the care relationship between two generations of women and its shaping of women's health and well-being.

Recruiting and Sampling Methods

After approval had been secured from the Ethics Review Board of the affiliated university, multiple recruitment strategies (e.g., key community agencies, doctors' offices, community centres) were used to obtain a diverse sample of community-dwelling women with mild to moderate cognitive impairment and their adult daughters. In an attempt to reach participants who may not have had access to these services, colourful flyers and notices about the study were sent out and posted in the offices of family physicians and at community sites such as libraries and seniors' centres. Also, health professionals providing services to women with dementia and/or their families, such as clinical nurse specialists, community nurses, and social workers, were contacted by telephone or in person to enlist their help in identifying potential participants. Follow-up letters and telephone calls to community agencies were made 2 to 3 weeks later. Finally, through use of the snowball technique, some daughter participants indicated that their sister(s) would be interested in taking part in the study. Consequently, three mothers had two or more adult daughters participating in the study.

Inclusion criteria for mothers and daughters were consent to participate, ability to speak English, and receiving/providing at least 2 hours of care per week. In addition, mothers had to score 17 or higher on the Standardized Mini-Mental Status Examination (SMMSE) and to demonstrate good verbal and comprehension skills (e.g., ability to state date of birth). According to Molloy and Clarnette (1999), a SMMSE score of 21 to 24 is indicative of early dementia and a score of between 10 and 20 is indicative of moderate dementia. Based on the clinical experience of one of the investigators, the cut-off score was set at 17, to ensure accurate, reliable interview data. In the end, of the 20 mothers with dementia in the larger study, 10 were unable to participate in the interview due to low SMMSE scores.

All potential participants were given written information about the purpose and nature of the study and were asked to take part in two interviews 6 to 9 months apart. Multiple interviews are often necessary with persons with dementia, to ensure sufficiently rich data and to compensate for the day-to-day fluctuations in their abilities (Moore & Hollett, 2003). Moreover, since we were interested in understanding how the progress of dementia may shape the mother-daughter relationship, we selected an intermediate time frame, one that would potentially capture this aspect of the relationship without risking participant attrition. However, two mothers who were interviewed at time 1 could not be interviewed at time 2 due to a low SSME score. Written consent was obtained immediately prior to the first interview and all participants were assured of confidentiality (e.g., use of pseudonyms). The assent of each participant was reaffirmed at the beginning of the second interview.

Sample

The participants ranged in age from 75 to 98 years (mean age = 88) and obtained SMMSE scores of 18 to 28 out of a possible 30 (mean = 22). Six of the women identified as Canadian, seven were widowed, and most had two or more adult children involved in their care. Four of the women had not completed secondary school. Incomes ranged from less than \$20,000/year (n = 4) to \$60,000/year (n = 1). All but one of the mothers lived in the same city as at least one of her daughters. At the time of the first set of interviews, four of the mothers lived in their own home, four lived in their daughter's home, and two lived in a retirement home in the community.

On average, the mothers and daughters saw one another 3 days per week. The daughters reported that they had been providing daily to weekly assistance to their mothers for an average of 49 months, with a range of less than 1 year to more than 6 years. All mothers received some degree of help, such as personal care, transportation, housekeeping, or meal preparation, from their daughters.

Data Collection

If both mother and daughter in a dyad consented to participate in the study, separate in-depth interviews were arranged at a mutually convenient time and place. The decision to not conduct conjoint mother/daughter interviews was largely based upon the belief that the participants would be more forthcoming in their reports if interviewed alone. Furthermore, there is considerably less research documentation on the perspectives of persons who receive care (Allen & Walker, 1992), and the research team believed it was important to capture voices previously unheard. On three occasions, however, mothers required or requested the presence of a relative, usually the daughter or a granddaughter. During these interviews, one of the two parties occasionally drew the other into the conversation to confirm or verify some information. Therefore, it is possible that the mother's responses in these situations were influenced by the presence of her relative. One advantage of the conjoint interviews was the opportunity to collect observational data with respect to mother-daughter interactions. Thus, interviewing the mother and daughter together did not necessarily yield a less complete picture of the relationship, although it did yield a different one.

Audiotaped interviews, lasting approximately 45 minutes, were conducted initially, followed by a second set of interviews with a total of eight mothers (the SMMSE scores of two of the original 10 participants were below 17). One mother was interviewed twice because she needed extra time to fully discuss her relationships with her four daughters. All of these interviews were held at the mother's residence. At the end of the first interview, all participants completed a brief demographic questionnaire. Finally, full field notes were written after each interview.

Using an in-depth, focused interviewing approach (Merton, Fiske, & Kendall, 1990), the interviewer asked the participant non-directive questions designed to trigger dialogue about her experiences in providing/receiving care, the mother-daughter relationship, and the factors influencing the process of care. Through this approach, the participants were encouraged to discuss what they considered to be the most important aspects of the care process and of their relationships. The research team's use of this approach to interviewing was informed by the work of feminist scholars (Oakley, 1982; Reinharz, 1992) and other researchers who interview persons with dementia (McKillop & Wilkinson, 2004; Moore & Hollett, 2003; Reid et al., 2001). All three investigators strove to build rapport with the participant and to provide support and information during the interview. Guided by clinical evidence in dementia care, the research team employed additional interview strategies for use with individuals with AD (e.g., using visual aids, providing questions on yellow paper, ensuring a quiet environment). Thus, the study sought to include people with dementia in research about their experiences, creating the potential for personal empowerment consistent with feminist goals.

Data Analysis

The major procedures for qualitative data analysis followed the guidelines of Lofland and Lofland (1995). After each interview, full field notes were written to record perceptions, insights, and observations (Morse & Field, 1995). The field notes, a method commonly used in qualitative research, added richness and depth to the data and also guided the planning of interviews. As data analysis proceeded, memos or notes were used to keep track of the researchers' insights and included justifications for making analytic decisions.

Gathering and analyzing data were simultaneous processes (Lofland & Lofland, 1995). Transcription and analysis of the interviews began immediately after the first interview and proceeded as data were collected. Shortly after each interview, individual researchers read the transcription and independently made a preliminary data analysis. Team analysis was used to clarify concepts (e.g., guilt, gratitude) and themes (e.g., undemanding care). Ultimately, the principal investigator explored the connections among the themes and prepared an overarching conceptual interpretation of participants' experiences, which was finalized through team analysis.

Throughout data analysis, Guba and Lincoln's (1989) criteria for establishing credibility, transferability, dependability, and confirmability were used. Credibility was established through prolonged engagement with the data, persistent observation, and audiotaping and verbatim transcription of all interviews. Transferability of the findings to other settings was promoted by providing a rich description of the context and methods entailed in generating the data. Dependability and confirmability of the data were promoted by maintaining an extensive audit trail.

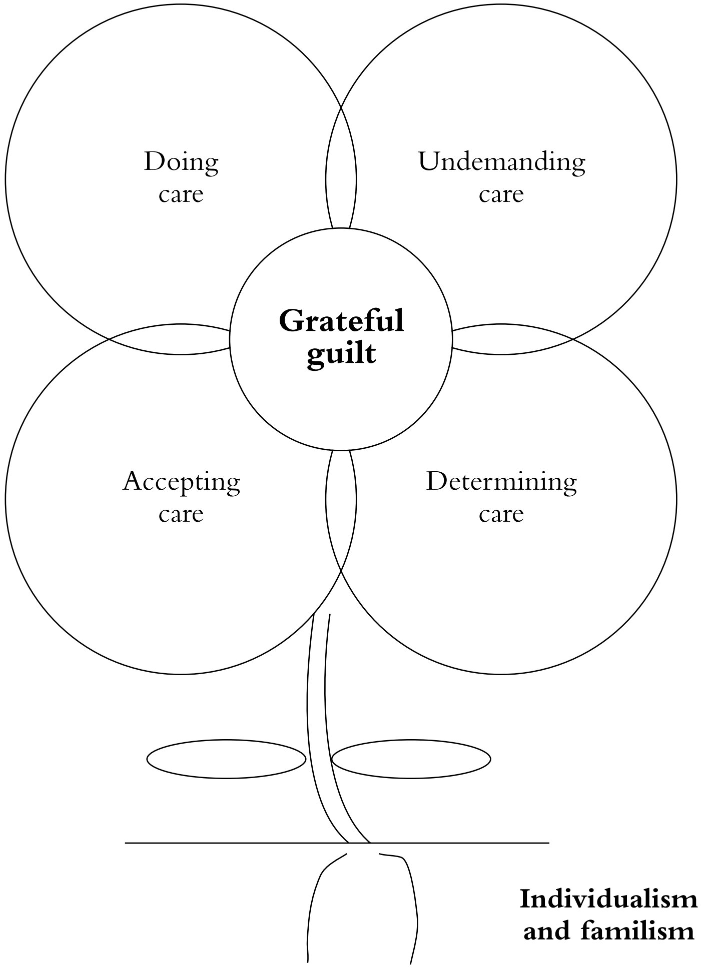
Findings

Building on the theoretical perspectives outlined above, the accounts of mothers and daughters were treated as both individual perceptions of caregiving and care receiving and "points of entry" into social processes far beyond the realities of the participants (Smith, 1987). In adopting a method that addresses both sides of the care relationship, the research team sought to uncover a number of features that are not addressed in policy, such as the relationship itself, emotional labour, and the complex exchanges of care (Henderson & Forbat, 2002). The goal of the study was to explore the perceptions and experiences of community-dwelling women with dementia and their daughters. In this paper we report only on the perspectives of the mothers. A full account of the different types of mother-daughter relationship, using the dyad as the unit of analysis, will be published elsewhere.

Based on our interview and field-note data, the mothers' perceptions and experiences of receiving care from their daughters are conceptualized in the form of a flower (see Figure 1). The familiar AD logo, the forget-me-not, was purposely selected to depict how mothers managed their contradictory experience of needing care. Each petal of the flower represents one of four responses: *doing care, undemanding care, determining care*, and *accepting care*. The appraisal of the situation, the conceptualization of need, and the acceptability of the care received were all subject to negotiation between the mother and daughter. Implicit in the process of negotiation is the recognition that people are active participants, capable of constructing their actions to deal with social situations (Gerson & Peiss, 1985). All mothers spoke of feeling grateful for the care received, but at the same time they felt guilty for being a burden to their daughters.

While the mothers reported mostly positive relationships with their daughters, the findings revealed that cultural ideologies and constraints manifested in feelings of "grateful guilt." The two major underlying ideologies, individualism and familism, appeared to be at the root of these responses. The mothers' experiences of receiving care from their daughters and the contextual factors shaping those experiences will now be described and illustrated through the use of comments by the participants.

Figure 1 ***Receiving Care within Dementia: Mothers' Perspectives***



Mothers' Experiences of Receiving Care

Analysis of the mothers' experiences of receiving care from their daughters illuminated four interrelated responses.

Doing care. The first response was *doing care*. Simply stated, this was the mothers' perceived ability to perform self-care. Although the focus of the study was care *received* by the mothers, this finding highlighted how mothers' *provided* care, primarily to themselves. Most of the mothers asserted that they continued to live independently, apart from their daughters. They claimed that they would not "do that" to their daughters, implying that they did not wish to be "a burden" to their children. When the mothers were asked if they felt it was better to live with or apart from their daughters, many were explicit in their views about being independent:

> *I think it [living apart] is better. We each have our own sense of independence… I think people need their independence as much as possible… I think it's better to be apart if it's at all possible.* (Margaret)

> *I wouldn't want to live with my kids, not one of them. I'd go into a home first. I've been independent. I wouldn't want to interfere with their lives… I was brought up to be independent.* (Georgina)

Adherence to cultural values of independence was driven mostly by the need to be productive and self-reliant:

> *I clean my own windows, do my own housework… When I have to stop doing that, then it's time to go.* (Anne)

> *I try not to give up the things that I'm interested in, and things that I do, to keep myself busy.* (Helen)

> *I don't ask her [daughter] to do anything for me. I'm an independent person and I do things for myself.* (Bess)

> *Never ask anybody for anything and you have nobody to thank.* (Georgina)

Undemanding care. Closely aligned with doing care, *undemanding care* emerged from the women's accounts as a second thematic response. Withholding requests for assistance was the predominant response reported by the participants. Consistent with Aronson's (1990a) finding of mothers appreciating their daughters' "busy family and work lives" and not wanting to add to their burden, many of the mothers in this study attempted to prevent their daughters from doing too much by suppressing their own wishes and needs. This was particularly noticeable with respect to their need for social interaction:

> *It's very, very difficult for me to stay here all the time by myself…there's always this empty feeling of sitting by yourself… But I don't complain. I never tell her I'm lonely.* (Helen)

> *I don't want to take her life away from her. I've had mine. But I hate when she goes, when she says, "I'll just lock up the door, you know, for security." Oh yeah, now I'm all by myself again.* (Anne)

For fear of asking too much of their children, the mothers sometimes found it easier to ask for nothing. The following comments also shed light on the Western cultural belief that the family of procreation takes primacy over the family of origin:

> *I don't bother them. I never call them. [If] they come, they come, if they don't, they don't. They're busy and they have families… I can't expect them to…they all have responsibilities and families… I don't demand nothing from them.* (Georgina)

> *I don't see her as often as I'd like, but she's busy, like all young people are. Her time is taken up with important things now and you have to respect that… She's grown up and has a lot of responsibility... She needs to take care of her own home. I don't ask her to do anything for me.* (Bess)

Determining care. Torn between wanting to be independent and needing assistance, the participants actively responded to the dilemma by *determining* the extent and type of care they would receive from their daughter. They tended to ask for or were prepared to accept care only under certain conditions, thereby maintaining some degree of control over the care received, as well as addressing the tensions they experienced in needing help. Moreover, all of the participants accepted assistance from their daughter only if it did not restrict or jeopardize the daughter's independence. As illustrated in the following comments, the mothers were mindful of the demands on their daughters' lives and made an effort to restrict care to the absolute minimum:

> *I know that if I called and said, "Hey, I'd like to see you — I'm lonely," she would be here. But I don't do that. She has her own life to lead.* (Helen)

> *You want your daughter to have a full life. You want her to have time to do what she wants to do…so I feel better when I know she has her things to do too.* (Margaret)

> *I mustn't bother her too much. She's a busy lady.* (Bess)

Determining care also entailed decisions about what types of assistance were acceptable. Shopping, laundry, and banking were considered "normal" daily chores for adult daughters to perform for their mothers:

> *It's part of her day to come and take me shopping, like it would be if my mother was around.* (Margaret)

> *She's been kind enough to do some of my laundry, because I hate to send my good clothes to the laundry here. So if I have two or three pieces of laundry, she does it for me and brings it back.* (Helen)

> *She helps me with the banking. It's not because I can't do it myself. She has a car and it's handier for her to get my stuff than for me to do it.* (Bea)

However, some participants realized that, due to deteriorating memory, they needed their daughter's assistance with other activities, such as dispensing medication and keeping doctors' appointments:

> *She sometimes gets my pills out…but I quite often do them myself… I think last week I goofed. I don't know. I think I missed a couple of pills. I think it mixed me up. I was trying to think, how can I do this to get the right ones in? So sometimes she helps me with that.* (Elizabeth)

> *When I was in the hospital she was able to talk to the doctors and the nurses in a way that I couldn't… Sometimes when I wasn't getting the drift she would get that across… She also goes to the doctor's [office] with me. She listens. She keeps it all straightened in my mind.* (Margaret)

> *She took me to the eye doctor's today, but I don't like to put too much on her shoulders because she's got enough to do already… I try not to bother her because God only knows…how she does what she does. I hate to be a pest or a nuisance…so I make that [requests] a minimum.* (Helen)

Finally, the participants not only exercised their right to restrict the care being provided currently, but also spoke about the future. Moreover, such responses seemed to serve the purpose of lessening their sense of dependency and preserving their sense of pride:

> *I'll ask for help when I need it… If I was at that stage [of needing more help], I'd put myself in a nursing home.* (Ethel)

Accepting care. The final response, *accepting care,* occurred when mothers passively accepted assistance from their daughter regardless of whether, in their opinion, they needed it or not. This response was particularly common among mothers who were receiving regular, almost daily, care from their daughter. In fact, some daughters occasionally reminded their mothers of the care that they received:

> *My kids tell me, "You never had it so good, Ma."* (Helen)

> *I know that I'm not really with it…so I know that she helps me out, which is fine. Sometimes we joke about it. I think that was what she was saying when she came home last night. She said, "You know what, Mom? You got it made, really."* (Elizabeth)

Clearly, many participants were well aware of the time and energy their daughters spent providing care and did not want to appear ungrateful. In response, they gradually relinquished control of their care to their daughters:

> *I really do rely more on her. When she makes a plan or something like that, I try to make sure I go along with it because that's something she's spent some thought on… Now she just goes ahead and does things for me.* (Margaret)

> *I'm lucky. I'm lucky to have the help when I need it. [Daughter] was right here when I needed her. She took care of me like a little sister, which was wonderful.* (Helen)

> *I see her quite frequently and she is very, very good… She brings me my meals… She does all she possibly can and I look forward to her coming over. I can depend on her.* (Georgina)

Other participants were aware of their reliance on others and did not want to risk losing their assistance. This placed the mothers in a precarious position, which often led to their relinquishing the right to control their lives:

> *My daughter is my mainstay and I accept what she tells me.* (Sarah)

> *If she thinks it's better for me [living with daughter], then it's alright… I take her word for it. She should know more than I do…and I'm exceedingly grateful to her for doing what she does, because a lot of young people that I know of nowadays wouldn't be so willing… She takes care of everything here and everything I need is covered. She takes the money out of the bank if she thinks I need it. And I don't have any responsibilities like that. Sometimes I wish I had, but if that's what she wants to do, then I don't care. All my life I took care of myself and all of a sudden I don't have to, but now I realize how wonderful it is, that I don't have to do anything.* (Helen)

Context of Receiving/Providing Care

Two factors tended to account for and shape the mothers' responses to the care they received from their daughters: individualism and familism. The personal values and belief systems that we develop and follow throughout our lives are rooted in the societal ideologies of individualism and familism (Hooyman & Gonyea, 1995). An ideology is a set of beliefs and attitudes about our social reality, as well as the practices and motives they manifest. Ideologies are powerful in that they are often invisible and therefore difficult to contest (Anderson, 1990). In other words, since care provided and received between mothers and daughters is viewed as "natural," ideologies often hinder our ability to imagine otherwise.

The values of individualism include self-reliance, self-determinism, privacy, living one's life independently, freedom from intrusion, and freedom from dependence on the will of others (Dalley, 1996). Many of the accounts described above reflect these values. Self-reliance and resisting dependency on others were the attributes of individualism most commonly described by the participants:

> *I think I'm independent, very independent. We were brought up to be like that. One thing that Daddy used to say, "Don't ask for favours, then you don't have to return them."* (Georgina)

> *I do the dishes…she didn't like how I did them but I still went ahead and did them anyway. I don't care if she gets mad or not, I'm gonna do it!… She doesn't need to have all this to do.* (Elizabeth)

The following comment illustrates the women's attempts to resolve the tension between being independent and being dependent, while also being grateful for any assistance offered:

> *She would do anything I ask her, and I don't ask her because I'm an independent person and I can do it myself. But if they want to do some little thing for me, I'm always very happy and genuinely grateful… I wouldn't ask them to… They're ready to help me in any way, shape, or form if I said the word, but I try to be independent.* (Bess)

The ideology of individualism depends on familism (Dalley, 1996), the second contextual factor that shaped the women's responses. When the emphasis is on family commitment and obligation, family members are expected to "care for" one another because they "care about" one another. With the notion of privacy of the family unit and minimal state interference, women's caring role within the family is perceived as "natural" and freely given. The participants respected these prevailing assumptions and values with regard to women's role as primary caregiver within the family. Iris, who had both daughters and sons, quoted a common saying to explain her son's limited ability to assist her, thus illustrating the intertwining of gender-role expectations and "family" caregiving:

> *A daughter is a daughter for life. A son is a son 'til he takes a wife.*

Indeed, another participant noted her good fortune in having a daughter who cared about her and sympathized with those who did not:

> *It's a wonderful feeling to know that your daughter cares enough about you to do these things, because I've met some people who don't have anybody to do anything for them and it's pitiful, but whatever she does for me seems to be of her own free will, and if I need anything…she's there for me, and you really can't ask for much more.* (Helen)

This comment also illustrates the participants' internalizing of ideologies — judging others and oneself against normative rules of conduct. Nourished by the strong roots of individualism and familism, "grateful guilt" was at the centre of the mothers' experiences in receiving care from their daughters. Conflicting emotions, such as guilt and gratitude, illustrate the invisible process of social control described by Hochschild (1979). Covert forms of power, particularly at the ideological level, reflect and reinforce dominant cultural assumptions about women and care. The following comments illustrate the mothers' questioning of whether they deserved or were entitled to the care they received from their daughters:

> *I don't want my daughter to feel that I'm going to be an anchor underneath… It makes me feel so guilty… I'm happy when she helps me, but at the same time I feel guilty.* (Anne)

> *She's very thoughtful. She brings me little dinners and stuff like that. I have no complaints…but I hope I deserve it.* (Georgina)

Most of the participants refrained from asking for their daughters' help for fear of "being a burden." The provision of assistance frequently led to feelings of guilt, mixed with gratitude. Some mothers reported that others reinforced these feelings of gratitude:

> *I'm very lucky, and many people have told me that too.* (Margaret)

Discussion

Despite the limitations of a small, homogeneous sample of women with mild to moderate dementia, the findings from this study extend our knowledge of the perceptions and experiences of older women living with dementia, with a particular focus on mothers' relationships with their caregiving daughters. The findings highlight a number of areas that need to be addressed by practitioners, policy-makers, and researchers as they work together to promote the health of older women with dementia. Specifically, we need to better understand how social determinants of health, such as gender, income, and social support, influence the health of women living with dementia.

First and foremost, we need to listen closely to what women with dementia have to say. Similar to the findings of other investigators (Aronson, 1991; Proctor, 2001), the accounts of women in this study revealed that their needs for care and social support were stifled by the internalization of dominant societal ideologies of individualism and familism. The findings affirm the wish of most people with disabilities not to be a burden to their families. Since there are few publicly funded supports to assist with the care of older women with dementia and other chronic conditions (Dalley, 1996; Guberman, 2004; Krogh, 2004), the mothers in this study had little choice but to depend on their daughters to meet their needs, which led to feelings of "grateful guilt." Nurses and other health professionals need to be aware of the extent to which they may perpetuate these feelings. For instance, praising the efforts of caregiving daughters may inadvertently reinforce the mothers' feelings of guilt and unworthiness. Changes in health-care practice have the potential to address older women's sense of disentitlement and marginal social status.

Second, the findings affirm the need to radically alter the home-care system to better meet the needs of community-dwelling women and their families. We must challenge the pervasive gendered ideologies of familism that undergird the implicit and explicit policies of family care (Hooyman & Gonyea, 1995) and develop alternative types of care. Policies that view families as the cornerstone of home care and women's proper role as caregiver within the family are harmful to women's health, both as caregivers and as care recipients (Guberman, 2004). References to "the family" in home-care policies that hide the gendered nature of family caregiving must be openly criticized, while alternative models of care based on the belief that the care of disabled members of society is a social responsibility, such as those models proposed by Neysmith (1991) and Guberman, must be developed. Empowerment, genuine choice, and partnerships between all concerned stakeholders are central to this approach to community care. Since public services are available to people who need them within this innovative approach to community care, mothers with dementia would have their needs met without having to rely solely on their daughters.

Third, genuine partnerships among care recipients, family caregivers, professionals, and policy-makers will be possible only when all voices are heard. Although the perspectives of women — as either providers or receivers of care — are seldom considered central to the policy debates on health and social care in an aging society (Aronson, 1990b), women with dementia are beginning to speak up about their personal experiences in living with AD (Sterin, 2002; Truscott, 2003). Morris (1992) urges the disability movement to adopt the feminist perspective of "the personal is political" by giving voice to the subjective experiences of individuals with a disability. A feminist perspective runs counter to the individualist ethic inherent in the focus on personal health behaviour by situating women's health within current social, economic, and political conditions. It fosters a collective rather than an individual response and challenges governments and other social institutions to assume responsibility for the health of women and the population as a whole (MacDonald, 2002).

Pringle (2003) makes a strong case for not only deepening our understanding of the lives of severely cognitively impaired people but also finding ways of "making moments matter" in the activities of daily living of those with dementia. Pringle asks, "How do we get nurses to sew a tapestry using multiple colours and strands?" with the aim of improving the quality of life of persons with dementia. One response would be for nurses to sit down with persons with dementia and their families and sew this tapestry together. In other words, women with AD not only need to be heard, but need to actively contribute to the construction of equitable policies that promote their health and well-being. Policy rarely reflects the voices of both sides of the care relationship, and indeed often fails to acknowledge the role of the relationship itself in how people construct meanings of their situation (Henderson & Forbat, 2002). Only when we acknowledge the overriding importance of this relationship in the provision of care, allowing for relationship-based social policy, will we be able to create a representative, colourful tapestry that promotes the health and well-being of women.

The fourth and final area that needs to be addressed in light of the present findings relates to future research directions. We need to explore how other social determinants of health, such as income and social inclusion, shape women's health experiences. Previous research shows that elderly people of financial means generally buy services and hire people to meet their needs, instead of choosing to be cared for by family and friends (Guberman, 2004). Most of the women in the present study lacked the financial resources to purchase caregiving assistance. This may have contributed to their sense of lack of control and their ambiguous relations with their daughters. It is essential that nurses and other health professionals understand the complex dynamics inherent in the relationship between the social determinants of health and inequities and address those inequities by speaking out against poverty, social exclusion, and gender-based discrimination.

It is also important that a variety of research methods be used to increase our understanding of the health experiences of women with dementia. According to Perry (2005), the biomedical model that guides the assessment and diagnosis of dementia is based on assumptions and approaches that, while critical to medicine, may be less consequential for nursing. Although screening tools are often employed in dementia research, Perry recommends that we consider extending our views of assessment and evaluation to include the individual's narrative. The present study collected narratives from individuals with dementia and their daughters, making it possible for us to hear the voices of both care recipients and caregivers. Regrettably, however, it included only those women with an SMME score of 17 or higher. Since those individuals in the later stage of dementia still possess an intact sense of personal identity (Sabat, 1998), future research in dementia care should include stories by individuals at all stages of dementia, thereby recognizing and supporting their personhood.

In conclusion, this study explored the perceptions and experiences of older women with mild to moderate dementia receiving care from their daughters. A feminist perspective helped us to uncover the ideological roots of dementia care and further our understanding of how these gendered ideologies shape the lives and health of older women with dementia. As well, we have suggested changes in practice, policy, and research, with the aim of transforming older women's feelings of "grateful guilt" into feelings of self-worth and dignity. These health-promoting practices and policies represent optimal growing conditions, which will ultimately support and nourish older women with dementia and their families.

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Authors' Note

Comments or queries may be directed to Catherine Ward-Griffin, School of Nursing, University of Western Ontario, London, Ontario N6A 5C1 Canada. Telephone: 519-661-2111, ext. 86584. Fax: 519-661-3928. E-mail: cwg@uwo.ca

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Catherine Ward-Griffin, RN, PhD, is Associate Professor, School of Nursing, University of Western Ontario, London, Ontario, Canada. Nancy Bol, RN, MScN, is Clinical Nurse Specialist, St. Joseph's Health Care, London, Ontario. Abram Oudshoorn, RN, BScN, is a doctoral student in the School of Nursing, University of Western Ontario.

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Translating Research

Developing an Evidence-Based Health Advocacy Intervention for Women Who Have Left an Abusive Partner

Marilyn Ford-Gilboe, Judith Wuest,
Colleen Varcoe, and Marilyn Merritt-Gray

Improving the health and health care of women who experience intimate partner violence (IPV) is one of the goals of our program of research. Up to this point we have focused on building knowledge about women's experiences of leaving abusive partners (Merritt-Gray & Wuest, 1995; Varcoe & Irwin, 2004; Wuest & Merritt-Gray, 1999, 2001), family health promotion post-leaving the abusive partner (Ford-Gilboe, Wuest, & Merritt-Gray, 2005; Wuest, Ford-Gilboe, Merritt-Gray, & Berman, 2003; Wuest, Merritt-Gray, & Ford-Gilboe, 2004), and how to improve health care (Varcoe, 2001). Currently, our Canadian Institutes of Health Research (CIHR) New Emerging Team is conducting research into the health, social, and economic effects of IPV on women in the early period after they have left an abusive partner. In this paper, we describe how we are transferring knowledge from our previous and current research to develop an intervention to promote the health and quality of life of women who have left an abusive partner.

Background

IPV is a pattern of physical, sexual, and/or emotional violence in the context of coercive control by an intimate partner (Tjaden & Thoennes, 2000). The health effects of IPV are well documented (Campbell, 2002; Walker, Logan, Jordan, & Campbell, 2004). There is some evidence to suggest that the health problems women experience because of violence persist long after the violence has ended (Wuest et al., 2003). Not surprisingly, women who have experienced IPV come into frequent contact with health-care providers, most often in relation to management of chronic health problems (Humphreys, Parker, & Campbell, 2001). However, qualitative accounts of women's experiences suggest that women frequently view these interactions as negative and unsupportive, leaving them feeling judged and disrespected (Gerbert et al., 1996; McMurray & Moore, 1994). Further, although shelters, crisis lines, women's centres, and elements of the justice system offer essential support to women leaving abusive partners, few health-specific supports are available to women during this transition. Despite growing interest within the health sector in improving the care provided to women who have experienced IPV, the phenomenon of violence has only recently been included in the education of health professionals, leaving the vast majority of health practitioners unprepared to recognize and respond to IPV in ways that are sensitive to the complexity of women's experiences and respectful of women's safety and choices. Access to quality services from a range of systems, including health care, is critical to the success of women's efforts to promote their health and develop new lives in the aftermath of violence (Ford-Gilboe, Wuest, et al., 2005).

There is a growing body of research that describes women's experiences and responses to violence, including their help-seeking efforts (Goodman, Dutton, Weinfurt, & Cook, 2003; Lempert, 1997), the process of leaving an abusive partner (Landenburger, 1989; Wuest & Merritt-Gray, 2001), and the relationships among various types of abuse and mental and physical health problems (Campbell, 2002; Humphreys et al., 2001; Walker et al., 2004). The subject of how this knowledge might be used to inform the development of interventions that address women's health in the aftermath of violence has been largely unexplored (Samuels-Dennis & Ford-Gilboe, 2005; Wathen & MacMillan, 2003). There is a critical need for evidence-based health-care interventions that effectively address the needs of women who have experienced violence.

Philosophical Assumptions

At the broadest level, our program of research is guided by a number of philosophical assumptions that reflect feminist, nursing, health promotion, and primary health-care principles and concepts. These assumptions include the following:

- IPV is not confined to interpersonal relationships but is sanctioned by broader social, cultural, and political structures that systematically oppress women, the poor, and those from non-dominant cultural backgrounds (Varcoe, 1996, 2002).
- Women's health is socially determined (Evans, Barer, & Marmor, 1994; Health Canada, 1999; Moss, 2002; Wuest, Berman, Ford-Gilboe, & Merritt-Gray, 2002) — by income and social status, education, social support, employment and working conditions, social environment, physical environment, personal health practices and coping skills,

health services, childhood development, gender, and culture (Lilley, 2000).

- The experiences of particular women must be at the centre of health care related to IPV. Although women have many commonalities, they are diverse — each woman and her experience of IPV and health are unique.
- Women and their children have the right to live safe, healthy, productive, autonomous lives and to participate fully in community life. A just and equitable society ensures that its citizens have reasonable access to the determinants of health that are modifiable, such as safe, affordable housing, quality education, and opportunities to earn a decent living.
- A primary health-care approach, which seeks to develop an integrated system of accessible, relevant, affordable services that address a range of issues important to health and that are delivered in local communities (World Health Organization, 1978), may be the most appropriate way to address the health of women post-leaving and to reduce fragmentation of services.
- Nursing approaches that are framed within a health determinants perspective, emphasize capacity building through collaborative relationships with clients and across sectors, and view individuals in the context of family and community (e.g., Allen & Warner, 2002; Doane & Varcoe, 2005; Ford-Gilboe, 2002) are particularly well suited to a primary health-care approach.

Considering the Evidence

To provide both a substantive focus and a structure for the intervention, we drew on three sources. First, we built upon our grounded theory, Strengthening Capacity to Limit Intrusion, which addresses the processes through which mothers and their children promote their health after leaving an abusive partner/father (Ford-Gilboe, Wuest, et al., 2005; Wuest et al., 2003). Second, we drew upon emerging findings from the first wave of our current work, the Women's Health Effects Study (WHES), a longitudinal investigation of women's health and resources in the early years after leaving an abusive partner (Ford-Gilboe, Varcoe, et al., 2005). These findings contribute to the substantive focus of the intervention. Finally, to most effectively apply these findings in an intervention, we sought relevant intervention studies. Here, we turned to studies examining the efficacy or effectiveness of community-based interventions for women who have experienced IPV, particularly the work of Sullivan and colleagues (Bybee & Sullivan, 2002; Sullivan, 2002; Sullivan & Bybee, 1999), as well as selected studies (e.g., Browne et al., 2001) testing health promotion interventions, delivered by nurses, to women from marginalized groups. We considered each body of work, moving back and forth among them, identifying and combining the lessons from each.

Lessons from the Theory of Strengthening Capacity to Limit Intrusion

Our feminist grounded theory study of family health promotion after leaving an abusive male partner (Ford-Gilboe, Wuest, et al., 2005; Wuest et al., 2003) provided the initial evidence for our approach to intervention. A grounded theory is a framework or substantive theory that captures a social process in social context (Glaser, 1978; Glaser & Strauss, 1967). Such a framework can provide useful direction for practice because it reflects the central problem for those being studied and how they process the problem. We interviewed 40 mother-headed single-parent families post-leaving an abusive partner (1–20 years) and found the central problem to be *intrusion* — external interference in their everyday lives that diverts attention away from family priorities and limits their choices for moving on (Wuest et al., 2003). The pervasive, enduring, unpredictable nature of *intrusion* is what makes it so problematic. *Intrusion* may stem from harassment and abuse from the ex-partner. However, equally intrusive are health outcomes associated with past and ongoing abuse, the costs or "strings attached" to seeking and obtaining help, and undesirable changes to patterns of living consequent to leaving, such as loss of the family home, income, or social relationships. In order to promote the family's health, families engage in *strengthening capacity to limit intrusion*. The key implication of these findings is that interventions designed to assist women post-leaving need to both reduce bureaucratic intrusion and complement women's efforts to build their capacity to limit intrusion and manage its consequences.

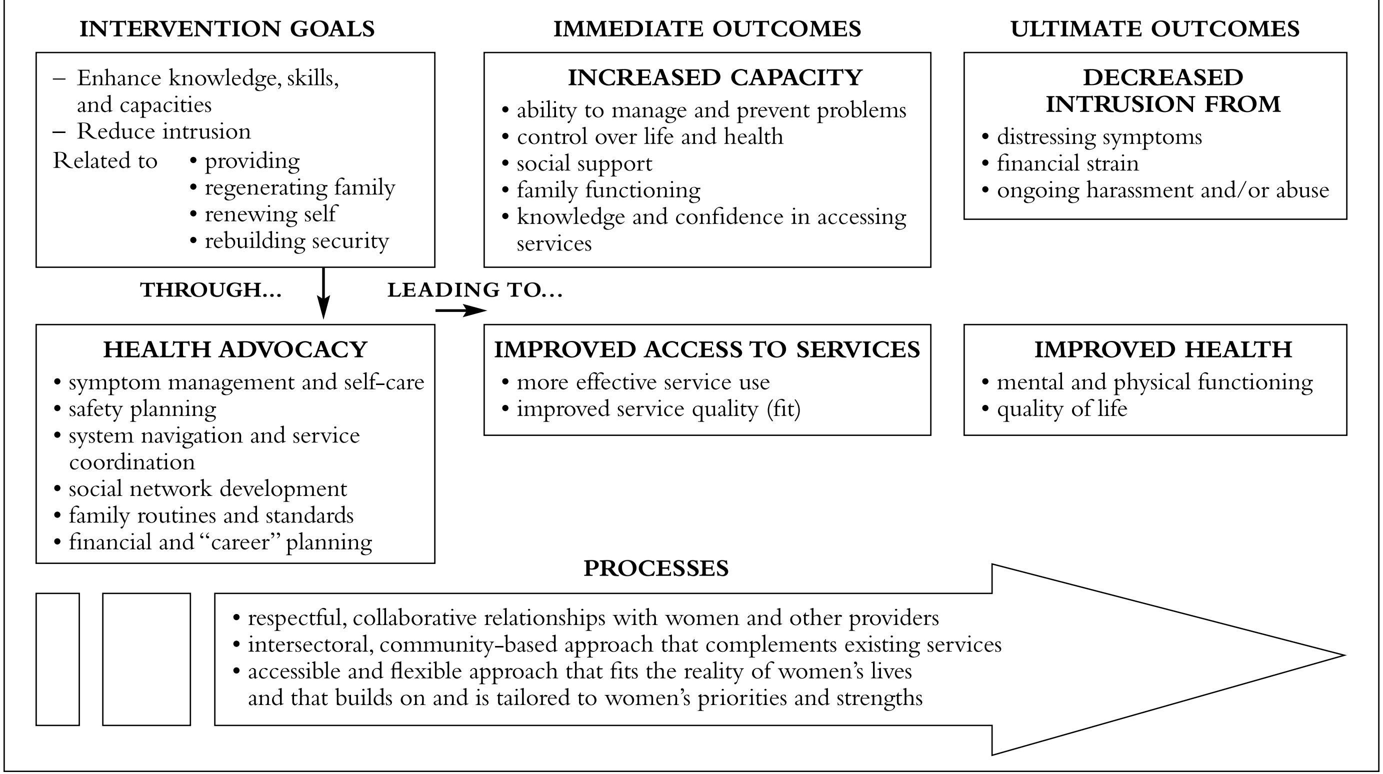
Our grounded theory offers specific direction for intervention by conceptualizing the processes used by families to strengthen their capacity to limit intrusion: *providing, renewing self, rebuilding security,* and *regenerating family* (Ford-Gilboe, Wuest, et al., 2005). *Providing* is a process of acquiring the material resources, energy, and skills necessary for survival over time. *Renewing self* refers to women's struggle to restore themselves and their children as individuals and realize their potential. *Rebuilding security* entails the creation of a life characterized by safety and belonging, as opposed to the risks, fear, and isolation associated with past abuse. *Regenerating family* is a process of replacing the previously destructive family environment with open and safe patterns of interaction. How families engage in each process depends on the level of intrusion (Table 1). When intrusion is high, women focus on meeting current practical needs as part of *surviving* through each of these processes. When intrusion abates and women increase their capacity to limit

Table 1 ***Processes of Strengthening Capacity to Limit Intrusion***

Process	**Surviving**	**Positioning**
Providing	*Managing without* entails identifying, finding, and making compromises to maintain what is basic for survival.	*Managing as if* they have adequate resources to get what they deserve includes taking risks to secure their future.
Renewing	*Living free* entails counteracting past control of the abuser over thoughts and actions by engaging in activities that bring immediate comfort and relief.	*Living better* entails proactively and purposefully developing personal capacity.
Rebuilding security	*Safeguarding* is limiting exposure to people or situations that threaten physical or emotional safety.	*Cautious connecting* is purposefully developing a sense of personal belonging and connection with the community.
Regenerating family	*Working as a team* entails constructing an explanation of why it was necessary to leave the abuser and changing the ways in which family members contribute to everyday family functioning.	*Living differently* is articulating and learning to live by new standards for interpersonal relationships.

Source: Ford-Gilboe, Wuest, et al. (2005).

Figure 1 *Health Advocacy Intervention*



intrusion, they are able to be more proactive and to position themselves for the future. Furthermore, the risk-taking involved in positioning for the future often results in increased intrusion, forcing women to refocus on survival, at least temporarily. Importantly, *strengthening capacity to limit intrusion* does not follow a predetermined trajectory but is an incremental process of change over time that is characterized by ongoing shifts between surviving and positioning and between each of the four sub-processes, in response to intrusion and the most significant family priorities at a particular point in time.

The four processes — *providing*, *renewing self*, *rebuilding security*, and *regenerating family* — define the core components of a holistic health intervention. While the theory was developed using family-level data, we consider the majority of the findings to be useful for guiding an intervention geared to women with and without children after leaving. To illustrate how each process might guide the intervention, we detail the direction for intervention implied by the process of *providing* (see Figure 1).

Based on grounded theory, the intervention should be designed with the aim of working with women to build capacity to limit intrusion, rather than only helping women to access services. Capacity building is the process of increasing the woman's knowledge and skill in making choices that are consistent with her long-term goals, including the knowledge and skills needed to (a) identify the risks and benefits of seeking help, decide when to withdraw from services, and advocate for greater control in decision-making; (b) prevent and manage symptoms associated with chronic health problems, thereby improving everyday functioning and quality of life; (c) use strategies to promote safety and limit exposure to re-abuse; (d) develop a network of mutually satisfying peer relationships; (e) learn new ways of relating to one another and working together as a family; and (f) develop plans for improving her standard of living that fit with her values and aspirations for career and home life. Finally, examination of the grounded theory suggested that, to be successful, the intervention requires a complex, intersectoral approach that includes, but is not limited to, health-related interventions. Processes for creating a more satisfying life post-leaving that are built from women's experiences (i.e., regenerating family, providing, renewing self, rebuilding security) can provide a meaningful structure for identifying women's priorities and developing strategies to address goals in each area.

Lessons from the Women's Health Effects Study

Whereas the grounded theory Strengthening Capacity to Limit Intrusion provides both general structure and substance for the intervention, findings from the WHES underscore the importance of a social determinants perspective on health and provide direction to ensure that the intervention is relevant to women's lives in the *early period* post-leaving. The findings of our grounded theory research related to intrusion from health problems highlight a gap in knowledge regarding the long-term health effects of IPV, particularly post-leaving. Typically, studies of the health effects of violence have relied on samples of women currently experiencing IPV or living in shelters. In no studies has women's health been examined in the early post-leaving period using a community-based sample.

The Women's Health Effects Study is an ongoing longitudinal investigation of a community sample of 309 women from three Canadian provinces (New Brunswick, Ontario, and British Columbia) in which data are being collected annually over 4 years. The study is being undertaken to (a) describe changes in women's health and personal, social, and economic resources in the early years after leaving an abusive partner; (b) examine, by testing a causal model, how changes in women's health may be explained by the interrelationships between the severity of past and ongoing violence and access to resources; and (c) estimate the economic costs associated with women's efforts to manage their lives and their health post-leaving. English-speaking women who had left an abusive partner at least 6 months but no more than 3 years previously and who screened positive on the Abuse Assessment Screen (Parker & McFarlane, 1991) were included in the sample. In wave 1, baseline data were collected through completion of (a) a life history calendar; (b) a structured interview designed to elicit information about women's resources, service use, and demographic characteristics; and (c) an in-depth abuse history and health assessment conducted by a registered nurse. A combination of standardized self-report measures, survey questions, and biophysical measures were used to measure the variables of interest.

Findings from the analysis of wave 1 data provide detailed evidence regarding the intrusion in women's lives post-leaving. The women had experienced multiple forms of abuse over their lifetimes. The majority of women (66%) reported experiences of abuse when they were children and most (59%) reported having more than one abusive intimate partner as an adult and 40% reported being sexually assaulted by someone other than their most recent partner. Although, on average, the women had been separated from the partner for just over one and a half years, 38% reported ongoing abuse and half reported continued harassment from the ex-partner. These findings stress the importance of an intervention that builds on women's efforts to *rebuild security,* takes past and ongoing experiences into account, and highlights the need for continued safety planning. Finally, of the 176 women in the sample who had dependent children living with them, 87% reported that their children had witnessed the violence directed at them by their ex-partner, highlighting the importance of considering women's issues within the context of family.

Wave 1 findings from the WHES offer specific direction for symptom management, identified in our grounded theory as an essential component of limiting intrusion through *providing*. In the WHES we collected self-report data on diagnoses and medication and used standardized measures to collect data on symptom patterns and severity. These data provide critical information about the primary health problems experienced by women who are in the process of leaving an abusive partner and provide specific direction for nurse interveners. For example, more than half of the women in the sample reported feeling worried or uptight, sad or depressed, difficulty sleeping, headaches, back pain, and difficulty concentrating in the preceding month. Almost one third of the women reported taking anti-depressant medications, a rate three times that reported by women in a similar age group in the 2003 *Canadian Community Health Survey*. These data suggest that nurses must be alert to the possibility of similar patterns and be prepared to support women in building symptom-management skills.

Findings from the WHES also deepen our understanding of interventions related to *providing, renewing,* and *rebuilding security*, particularly when linked to intrusion from changes in their pattern of living post-leaving. Across the sample, the mean annual family income for the current year was 50% lower than that for the year prior to leaving. Although almost half (45%, n = 139) of the women in the study were employed, the vast majority (90%) reported some difficulty living on their current incomes, with 50% of the sample indicating that it was "very difficult" or "impossible" to meet their current obligations. Not surprisingly, 22% of the women reported using a food bank in the preceding month. Of those who were not employed, 26% (n = 42) were actively seeking work, while 20% (n = 34) were disabled and unable to work. Sixteen percent of the women were currently enrolled in an education or training program. These findings suggest the importance of including women's efforts to improve their financial well-being as part of a comprehensive intervention.

Findings from the WHES on the use of health and advocacy services reflect the sources of help most accessible to women and offer insights regarding possible gaps in service. Health-service use was quite high. For example, 56% of women made at least one visit to their family physician and 14% used emergency room services at least once in the preceding month. Although the reasons for these patterns are not clear, options for service use should be explored with women in order to identify system gaps and link women with the best services for their needs. Findings related to women's use of other community services raise similar intervention points. Women's shelters provide information and support to help women access a variety of services, such as legal aid, housing, and health care, that they may need after leaving. Yet few women in our sample (16%) stayed in a shelter at any time in the first 6 months after leaving and only one third reported using advocacy services in the preceding month. Although most (82%) of the women were confident that they knew where to access services, 65% reported that it was somewhat or very difficult to access the services they required. Community services, including those in the health sector, are complex and frequently operate in "silos," resulting in poor integration and communication within and across sectors and barriers to accessing and using needed services. An effective intervention takes this fragmentation into account, providing support for women to navigate these systems.

In summary, the WHES offers specific direction for the intervention focused on the process of *strengthening capacity to limit intrusion* due to ongoing harassment, multiple experiences of abuse, health problems, economic problems, and service-access problems experienced by women in the first 3 years after leaving an abusive partner. The convenience sample of women who took part in the WHES may be systematically different from the population of Canadian women who are leaving abusive relationships. However, the early findings emphasize the importance of explicit attention to the health of women and provide insights into the range of issues that should be considered in designing an intervention to build women's capacity to limit intrusion, including intrusion due to continued harassment. Findings related to intrusion from economic problems underscore the importance of a social determinants perspective on health, while findings on patterns of service access and use point to the importance of designing an intervention that will foster continuity of relationships across service sectors and help women navigate complex systems.

Lessons from Intervention Research

While our program of research clearly informs the focus and structure of the intervention, extant intervention research offers additional direction, particularly for the intervention process. Working from our philosophical assumptions, we identified two bodies of work.

Community-based interventions for women who have experienced IPV. Relatively few studies have examined the impact of interventions designed to support women who have experienced IPV, and the quality of those studies varies considerably (Samuels-Dennis & Ford-Gilboe, 2005; Wathen & MacMillan, 2003). As part of a well-designed program of research in post-shelter advocacy, Sullivan and Bybee (1999) randomly assigned 143 women who were leaving a shelter to intervention and control groups. In the intervention group, trained advocates (undergraduate psychology students) worked with women in their homes and communities 4 to 6 hours per week over a 10-week period, providing individualized service to help women identify their needs, strengths, and goals, sharing information about services, and providing practical assistance to help women access needed services, while the control group were left to navigate the system on their own if they so desired. Outcome measurements for both groups were taken pre-intervention, post-intervention, and 6, 12, 18, and 24 months later.

Immediately post-intervention, the women who had received advocacy services were found to be more effective in obtaining needed resources, experienced less physical violence and psychological abuse, had fewer depressive symptoms, and reported higher levels of social support and quality of life than women in the control group. Importantly, the gains in reduced physical violence, increased social support, and improved quality of life observed in the intervention group were sustained over a 24-month period. Although levels of depressive symptoms and psychological abuse were generally lower in the intervention group compared to the control at each interval, these differences were not statistically significant and were not sustained after the 24-month follow-up (Sullivan & Bybee, 1999). Three years post-intervention, the advocacy intervention continued to exert positive effects on women's social support and quality of life but the impact on risk of re-abuse was no longer evident (Bybee & Sullivan, 2005).

The results of Sullivan and Bybee's research (Bybee & Sullivan, 2005; Sullivan & Bybee, 1999) are salient to the development of an intervention that targets the health of women who have left abusive partners. Their research supports the long-term benefits of advocacy support and validates the knowledge and expertise that lay advocates provide within a larger system of services. The advocacy model helped women navigate the "system" of services that were available, but, as "health" was not the particular focus, the intervention did not, unsurprisingly, affect depressive symptoms. Specifically including health services designed to support women in managing distressing symptoms may be beneficial in extending the benefits of advocacy for women in the post-leaving period.

The success of Sullivan and Bybee's (1999) intervention points to the need to include key features in our proposed intervention, such as an emphasis on process and capacity building, individualized planning, and practical aid in accessing services. Advocacy services are essential but not sufficient. A focus on symptom management and referrals for health care requires expertise that nurses can provide, both to support women in developing strategies for managing distressing symptoms and to tap into formal and informal networks in the health-care sector in order to expedite referrals and service delivery.

Health promotion interventions with marginalized populations. Other intervention studies have evaluated the contribution of nurses to health promotion interventions. We examined the work of David Olds and of Gina Browne to deepen our understanding of what is known about nursing interventions with populations of at-risk parents. Olds (2002) evaluated a 25-year program of research focused on improving the health, development, and future life trajectories of low-income mothers and children using home visiting during the prenatal and early-infancy periods. Testing of the program in two clinical trials provided evidence of positive effects on parental care; child abuse, injury, and neglect; number of subsequent pregnancies; workforce participation; and social assistance use. In a follow-up study of the children when they reached the age of 15, the children of nurse-visited mothers had fewer arrests and convictions, less emergent substance abuse, and less promiscuous sexual activity than controls.

Components of this intervention that are salient for our planning relate to the theoretical base, the nurse as interventionist, and the rigorous training, support, and guidelines for the interventionists. The program, which was based on theories of human ecology (Bronfenbrenner, 1979), self-efficacy (Bandura, 1977), and human attachment (Bowlby, 1969), focused on enhancing the material and social environment of the family; helping the family to meet small, achievable objectives in order to build the confidence needed to take on larger challenges; and promoting sensitive, responsive, engaged child care (Olds, 2002). Nurses were selected as the home visitors because of their specific training in managing complex clinical situations, competence to address the concerns of the family related to pregnancy and the health of the child, and ability to teach parents to identify emerging health problems and navigate the health-care system (Olds). In a comparative study conducted using both paraprofessionals and nurses, paraprofessional visiting produced small effects that rarely reached statistical significance, while nurse visiting had significant effects on many child and maternal outcomes (Olds et al., 2002). In the expanded Nurse-Family Partnership program that Olds is continuing to develop, the minimum educational requirement for nurse visits is a baccalaureate degree, with master's preparation required for nurses in supervisory positions (Olds).

Browne, Byrne, Roberts, Gafni, and Whittaker (2001) developed a public health nursing case-management intervention, When the Bough Breaks, designed to help sole-support parents on social assistance to return to work. This intervention was based on three characteristics for effective home-visiting programs identified by Olds and Kitzam (1990): an ecological model; nurse visitors who establish a therapeutic relationship and whose frequency and duration of visits is sufficient to address the range of factors that influence maternal/child outcomes; and targeting families at risk due to lack of economic, social, and personal resources (Markle-Reid, Browne, Roberts, Gafni, & Byrne, 2002). The 1-year intervention was comprehensive and included health promotion by public health nurses using a problem-solving approach during home visits, employment retraining, and subsidized after-school recreation or child care. In a randomized controlled trial with 756 sole-support parents receiving social assistance, the comprehensive health promotion intervention was found to be more effective than self-directed care in terms of the number of exits from social assistance and subsequent dollars saved. Furthermore, it was no more expensive in terms of use of health and social services than self-directed care. Intervention and control groups showed similar reductions in parent-mood and child-behaviour disorders as well as equivalent increases in parent social adjustment and child competence. There were substantial problems with dropout in this study, which may have affected the findings. Yet the findings illustrate the benefit of a comprehensive approach that addresses multiple determinants of health (i.e., recreation, coping skills, and access to services) in helping individuals receiving social assistance to develop the ability to enter the workforce. For our intervention, these findings validate the importance of working across systems to support women in building the capacity for economic stability through *providing*.

Women who have left abusive partners are at risk due to their abuse history, shifting resources and life circumstances, and health problems. Lessons from the work of both Olds and Browne confirm the effectiveness — for a range of health and social outcomes — of theory-based health interventions that address the determinants of health and are delivered by nurses. Additionally, Olds's (2002) research reinforces the need to develop solid guidelines for the intervention and to incorporate initial training and ongoing support for the nurses who carry out such interventions.

The Health Advocacy Intervention

Using the evidence from our qualitative and quantitative work and from the intervention studies reviewed, we began to develop a health advocacy intervention, structured by our intrusion theory, targeted to a range of health and social issues as experienced by particular women in the early period post-leaving and delivered by nurses in collaboration with others. We identified two broad goals for the intervention and drafted a model in which the key components and outcomes of the intervention are specified (Table 2). At the same time, we articulated a set of process prin-

Table 2 ***Exemplar of Direction for Intervention Derived from the Process of*** **Providing** ***in the Theory of Strengthening Capacity to Limit Intrusion***

Providing is challenging because the women's confidence in their ability to provide has been systematically eroded by abuse. They initiate this work with little energy or material goods and resources due to the abuse and the crisis nature of their leaving. Providing takes place by ☐ ***managing without*** *(surviving)* • negotiating and clarifying what they *need* (food, safe housing, household goods, clothing, medicine, sleep, relief of symptoms and health problems, income, meaningful work, transportation, child care) • scrounging for the basics for survival, which is exhausting due to intrusion related to the "costs" of help (the need to live up to standards, the limitations of help, and shifting eligibility criteria) • crisis management and juggling competing immediate demands	The goal of the intervention is not to exclusively assess and monitor, but to reduce intrusion and augment women's capacity to limit intrusion. • Help the women to name and identify what they need. They feel unworthy; help them to consider their range of needs (sleep, medicine, relief of symptoms, employment, training, credit, safe housing, child care, transportation, food, etc.). • Help the women to formulate strategies for managing intrusive symptoms, preventing health crises, obtaining and managing needed medication, accessing health services, and boosting their energy. • Help the women to access flexible employment and training opportunities. • Advocate by providing information on rights, eligibility, and ways to efficiently access resources and instrumental help.

☐ ***managing as if*** *(positioning for the future)* • negotiating for what they *deserve* (stable housing, tuition in order to return to school, money for counselling, recreational activities, treats) • risking — extending themselves beyond what is reasonable in order to secure their future; social norms and system structure force them to manipulate or do what may appear unreasonable, unsafe, or illegal in order to break through the economic ceiling, social class, and so on.	• Reduce the "costs" of the service being offered. • Initially help the women through crises, but then focus on helping them acquire the competence to self-manage crises. • Discuss (without censoring) what the women wish and hope for themselves and their children. • Avoid limiting or discouraging the women; they had to take extraordinary safety and financial risks to leave the abusive partner and may need to take similar risks to position themselves for the future. • Ongoing support is crucial to help the woman through the transition entailed in risk-taking (quitting her job in order to return to school, doing without in order to purchase a home). When risk-taking is successful, support should be continued until the woman has consolidated her gains. When it is unsuccessful, support should be continued while she regroups and considers her options without having to feel like a failure.

ciples to guide the practice approach taken by the nurses in working with women and other service providers over time. These process principles provide a foundation for the way in which the intervention is carried out and are critical to achieving specified outcomes. At a process level, the Health Advocacy Intervention is characterized by:

- flexible program delivery based on respectful, collaborative relationships with women and other service providers
- attention to safety, accessibility, and the practical reality of women's lives, tailored to and building on women's priorities and strengths
- an intersectoral, community-based approach that complements rather than duplicates existing services and has the potential to be sustainable.

The Health Advocacy Intervention seeks to improve women's access to the broader determinants of health in the early period post-leaving an abusive partner, in order to (a) enhance the knowledge, skills, and capacities that women need in order to support their health and well-being in the context of their family, community, and culture; and (b) reduce intrusion or the effects of intrusion, understood broadly as ongoing harassment, the cumulative health effects of multiple forms of abuse, undesirable changes to patterns of living, and bureaucratic barriers to adequate support. Importantly, women's priorities and efforts relative to providing, regenerating family, renewing self, and rebuilding security constitute a starting point for the intervention goals of building capacity and reducing intrusion. These four processes demarcate the *boundaries* of the intervention and encourage the nurse to consider: (a) the woman's priorities in each of these areas; (b) the types of intrusion that are most problematic and how these might be reduced or addressed to limit the impact on the woman and her family; (c) the knowledge, skills, and capacities that women need in order to work towards each priority; and (d) the ways in which the woman's efforts may change over time in response to the changing nature of intrusion, her developing ability to limit its effects, and shifts in her goals and aspirations.

The six components of the intervention specify classes of activity that flow from the intervention goals and are undertaken jointly by the nurse and the woman. *Symptom management and self-care* entails the identification and testing of various approaches to reducing the distress associated with symptoms, both those that the woman can direct herself and those that require support from other professionals. *Safety planning* focuses on assessing risks to safety and developing strategies to limit the effects of harassment or ongoing abuse that may draw on formal and informal networks as well as the justice system. *System navigation and service coordination* includes learning about available services, considering the benefits and costs of using such services, and developing effective ways of advocating for access to services that fit with preferences and priorities. *Social network development* entails the seeking out and developing of relationships with peers or extended family members that meet human needs for emotional support, social interaction, belonging, and/or practical aid. *Developing family routines and standards* focuses on taking stock of family patterns of interaction and developing strategies to reinforce standards for relating to one another that are important to the family. *Financial and career planning* entails reflection on the multiple ways in which women engage in meaningful work, at home and outside the home, and developing strategies to strive towards the woman's personal goals for financial security and meaningful work that fit with her preferences, resources, and other demands.

Finally, the immediate and ultimate outcomes specified in the model reflect reasonable changes that may occur for the women and/or their families as a result of engaging in collaborative health advocacy activities. Specifying these outcomes permits assessment of whether the intervention is producing results that are tied to theoretical concepts and are practical and desirable for women and their families. The model constitutes a starting point for engaging in consultation with stakeholders about the relevance and completeness of the intervention as well as the feasibility of testing it and eventually, if effectiveness is demonstrated, promoting its integration into the "system." The model also suggests that key stakeholders will include providers of existing services in the social service and anti-violence sectors, policy-makers, and women themselves. Such consultation will be critical to the success of the intervention, by (a) building on the considerable expertise of direct-service practitioners who know the reality of working within complex systems, (b) establishing collaborative alliances to reduce service fragmentation when testing the intervention, and (c) engaging in dialogue with policy-makers about the results of testing the intervention in order to enhance knowledge uptake.

Conclusion

The earlier phases of our program of research and intervention studies with women who have experienced IPV and women who are marginalized in other ways point in similar directions with respect to the development of a comprehensive intervention to improve the health and quality of life of women who have left abusive partners. Drawing on these different sources of evidence, we have proposed a health advocacy intervention for women post-leaving that is intended to reduce intrusion from multiple sources and to build women's knowledge, skills, and capacities; is tailored to women's priorities and the realities of their lives; and is carried out collaboratively with a range of stakeholders. The specific goals, activities, outcomes, and process principles described in the model provide a starting point for engaging in meaningful dialogue with stakeholders as we move towards testing the intervention.

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Comments or queries may be directed to Marilyn Ford-Gilboe, School of Nursing, H37 Health Sciences Annex, University of Western Ontario, London, Ontario N6A 3C1 Canada. Telephone: 519-661-2111, ext. 86603. E-mail: mfordg@uwo.ca.

Marilyn Ford-Gilboe, RN, PhD, is Associate Professor and T. R. Meighen Family Foundation Community Nursing Professor, School of Nursing, University of Western Ontario, London, Ontario, Canada. Judith Wuest, RN, PhD, is Professor and CIHR Investigator, Faculty of Nursing, University of New Brunswick, Fredericton, Canada. Colleen Varcoe, RN, PhD, is Associate Professor, School of Nursing, University of British Columbia, Vancouver, Canada. Marilyn Merritt-Gray, RN, MN, is Professor, School of Nursing, University of New Brunswick.

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Happenings

Researching the Social Determinants of Women's Health

Shirley M. Solberg

One of the objectives of Heath Canada's (1999) *Women's Health Strategy* was to increase our knowledge and understanding of women's health and women's health needs. The introduction to that document acknowledges the fact that we need to pay special attention to women's social and economic circumstances and how these are linked to women's health. Researchers have taken that need seriously and we are beginning to build a solid base of knowledge on social and economic determinants as well as other determinants of women's health that have been identified (Raphael, 2004). Teams of researchers have come together to strive towards this important objective. A number of key initiatives in Atlantic Canada have contributed to the knowledge base thus far.

Below, I will describe a large-scale project funded by the Social Sciences and Humanities Research Council and the Natural Sciences and Engineering Research Council, with additional funding from the participating universities and other partners. The project was carried out under the Major Collaborative Research Initiative Program (MCRI) and one of its objectives was to increase our understanding of the social determinants of women's health in coastal communities in the province of Newfoundland and Labrador. The present research developed out of an interdisciplinary project on sustainability in coastal communities; one of the findings of that work was the gendered nature of the effects of change on people in these communities.

The Coasts under Stress Project

The MCRI fosters the collaboration and integration of different researchers and research methodologies such that the research findings will make a major contribution to the country's society as well as its scholarship. The research supported by the MCRI is considered "leading edge."

Our project, Coasts under Stress (http://www.coastsunder stress,ca/), was a partnership between researchers on Canada's east and west coasts, with Memorial University of Newfoundland serving as the leading institution on the east coast and the University of Victoria on the west coast. We represented a wide variety of disciplines from the natural, social, and health sciences and the humanities. These included anthropology, biology, community health, earth sciences, economics, education, ethnobotany, fishery sciences, geography, history, ocean sciences, nursing, and women's studies. We formed partnerships with governments, businesses, non-governmental organizations, and First Nation groups, and we worked with people in the communities where the research was carried out. Training was an important component of the research, with many master's and doctoral students completing their research within the program.

The overarching question we chose to examine was: *What environmental changes (e.g., over-fishing) have interacted with social changes (e.g., industrial restructuring, health reform, the new global economy) to affect human and environmental health and well-being in coastal communities?* In addressing this question we were committed to a gender-based analysis that would allow us to look at differential effects on women and men living in selected coastal communities. Some of the work focused solely on women and their lives, as the group included a number of feminist researchers. This approach allowed us to examine in some depth the effects of various social determinants on women's health.

We used the metaphor of a sea star as our organizational framework. We formed five groups or clusters of researchers, representing the five arms of the sea star. Each cluster dealt with a different thematic aspect of restructuring and addressed specific questions. Most of the work described below was carried out within the cluster on human health, of which women's health was an important subset. Regular team meetings on both coasts and strategically placed bicoastal meetings throughout the life of the project served to facilitate the integration and coherence of the project, as well as allowing us to meet our overall goal and to provide some answers to our complex research question.

The Social Determinants of Women's Health

The research has contributed greatly to our understanding of both environmental and human health in coastal communities, and in particular some of the determinants of women's health. I will highlight some of what we learned, categorized by selected determinants found in the literature (e.g., Federal, Provincial, and Territorial Advisory Committee on Population Health, 1994; Raphael, 2004; Wilkinson & Marmot, 2003).

As part of the human health component, in the autumn of 2004 I surveyed 1,090 women in households in six different communities in northern Newfoundland. We also interviewed women in other areas of the province. As a follow-up to the survey, in the spring of 2005 I held public presentations and discussions in the communities. Following are some of the findings from the survey and discussions.

Income and its distribution. Restructuring has served to reduce the number of jobs in some of the coastal communities. As a result, household income and women's income are more limited. This has led to a more unequal distribution of wealth within the communities as fewer women are employed in key industries.

Employment and working conditions. In many coastal communities employment is precarious, seasonal, and uncertain. Women work in occupations with significant occupational health problems, such as shellfish asthma and work-related musculoskeletal disorders, and have few alternative choices should they develop a job-related health problem.

Social safety net. One of the main social safety nets we examined, given our research interest, was employment insurance. In communities where resource industries are threatened and service industries have short seasons, women experience difficulty securing employment insurance.

Education. There are few programs for women to retrain or pursue continuing education in smaller coastal communities. The women said they would like to develop new skill sets in order to seek alternative employment, but opportunities are limited.

Food security. A detailed look at women's food-consumption patterns in households over the past decades reveals some positive changes: lower consumption of saturated fats and salt beef and fish; higher consumption of milk. Consumption of fresh fruit has not changed appreciably. In some of the communities, food security is negatively affected by issues of availability and the high cost of fruit and meat.

Social environment. Out-migration from coastal communities is having an impact on the women left behind. Younger women are expected to take on more caretaking responsibilities, while many older women have lost the family support they need to maintain their households and to access services.

Physical environment. Women are concerned about changes to the physical environment and the decrease in job opportunities as a result of environmental degradation. They are concerned for themselves, their children, and the environmental health of their communities. Three quarters of the women surveyed voiced uncertainty about the future of their particular community.

Healthy child development. Women worry about their children having to bus long distances to attend school when the local school is closed due to restructuring of the education system. They are also concerned about bus schedules preventing their children from taking part in extracurricular activities, which contribute to child development.

Personal health and coping skills. Almost one quarter of the women rated their personal health as poor or fair. Many of the women found life stressful and believed the level of stress had increased from the previous year. Employment and financial conditions were a major source of stress. A number of the women were trying to make positive changes in their health practices, such as decreasing or stopping cigarette smoking or exercising as a means of coping with stress.

Health services. The restructuring of health services has not necessarily led to improved services for the women and has resulted in a number of gaps, such as in mental health services.

Social support networks. The support networks of some of the women were shrinking as spouses, children, other relatives, and friends were forced to relocate in order to find work. To illustrate the magnitude of the problem: only three of the women did not have a relative who had to leave the area to seek work during the preceding year.

Gender. The women believed that the health of women and men had been differentially affected by the recent changes. They regarded gender as an important determinant of health and expressed the view that health issues have to be addressed appropriately for both women and men.

Culture. The rural communities revealed a strong attachment to "place," and most of the women, despite the challenges they faced, were satisfied with their community as a place to live. The women expressed appreciation for the "quietness" and "safety" of life in their community.

The Benefits of a Health Determinants Approach

A social determinants approach to health has been critical in assessing the impact of restructuring on women's lives. Health problems are not separate from the conditions from which they arise. If we are to address health problems, therefore, it is crucial that we fully understand these conditions. One of the strengths of a social determinants approach is that it fosters interdisciplinary cooperation, which, in turn, can lead to a more profound understanding of the issues. In the Coasts under Stress project, researchers with a particular area of expertise contributed to everyone's understanding of a particular determinant — for example, political scientists were able to demonstrate to other team members that the approach to health-care reform favoured by policy development created some of the challenges the women in coastal communities faced as they sought to access health care.

An interdisciplinary approach allowed us to construct a social determinants model in order to examine the process by which various determinants interact to influence health (Colman, 2001). While no one determinant can explain the state of women's health, it can be very useful to examine various factors. One of our purposes in assembling a large team of researchers was to explore the interactions among the various factors. Discussions around these interactions served to enlarge our worldview on a number of issues. The process of working with a historian on nutritional policy, for instance, made it easier for the various team members to understand some of the responses, or lack thereof, to the changing patterns of household food consumption.

While understanding conditions is a necessary step in creating change, it is not sufficient in and of itself. It must be accompanied by knowledge translation, or the application of knowledge "to yield beneficial outcomes for society" (Canadian Institutes of Health Research, 2004). A social determinants approach entails broad policy change, because it leads the researcher to examine social and economic factors affecting health (Wilkinson & Marmot, 2003). At present we are preparing a policy document based on our overall findings, in order to address some of the policy and program implications of our research. In the coming months we will be holding a policy workshop to present our findings and recommendations. We will also share our findings with local health authorities.

When we embarked on the Coasts under Stress project, our ultimate goal was to report to policy-makers at different levels of the policy process on the implications of restructuring for the lives of people and for the health of communities and the environment. We hope the policy-makers will use this information to shape policy in a way that takes into account the changes and accompanying challenges facing coastal communities. In fulfilling our role in shaping this policy, we are committed to a gender-inclusive analysis.

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Comments or queries may be directed to Shirley M. Solberg, School of Nursing, Health Sciences Centre, Memorial University of Newfoundland, St. John's, Newfoundland and Labrador A1B 3V6 Canada. Telephone: 709-777-8311. Fax: 709-777-7037. E-mail: ssolberg@mun.ca

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Shirley M. Solberg, RN, PhD, is Professor, School of Nursing, Memorial University of Newfoundland, St. John's, Newfoundland and Labrador, Canada.