

# Centres of Excellence for *Women's Health* RESEARCH BULLETIN

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## Does Sex Matter?

### When it comes to health, do sex and gender matter?

Exciting new research is emerging from Canada's five Centres of Excellence for Women's Health that addresses this provocative and important question. Funded by Health Canada to explore the social determinants of health, the Centres are beginning to amass significant findings that will be of value to researchers, policy makers, women's health service providers and women themselves. This inaugural edition of the Research Bulletin presents summaries of studies, some complete, some in progress, that run the gamut from small, exploratory examinations of women's experiences of informal caregiving to large-scale analyses of administrative data collected by provincial ministries of health. A rich variety of methods and focus are in evidence, from qualitative discussions of the barriers teens face when they try to access information about sexual health to assessments of health status based on national surveys. These various new insights and data construct an early bridge across the gaps in our knowledge about the social determinants of health, including the role of health policy in shaping health, and the ways in which these determinants interact with sex and gender.

This Bulletin presents the studies in four broad categories. Studies that use gender as a critical analytic lens are presented first. They demonstrate that gender is a useful and discerning lens with which to examine population health trends, and raise questions about the accuracy of our assumptions about the similarities and differences between women's and men's health. Do women suffer from more ill health than men over the life course?

How do paid and unpaid work affect the health of both women and men? Traditionally, studies have assumed that paid work was the more important factor in understanding men's health, whereas unpaid work was key to women's health. Researchers are beginning to argue that we need to consider how both forms of work affect health for both women and men.

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## Centres of Excellence for Women's Health Program

Launched in 1996, the Centres of Excellence for Women's Health Program (CEWHP) is funded by Health Canada and administered by the Women's Health Bureau. The work of the program is a major component of Health Canada's Women's Health Strategy. Five centres, each a dynamic partnership of academics, researchers, health care providers and community-based women's and women's health organizations, are located in Halifax, Montreal, Toronto, Winnipeg and Vancouver. The Canadian Women's Health Network (CWHN) is also funded under CEWHP to support national networking and communications components of the program. Please see page 24 for contact information for the Centres, the CWHN and CEWHP.

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*Health Care Utilization And Gender: A Pilot Study Using the BC Linked Health Data and the National Gender Economic Costing Group* both investigate health services using sex/gender to detect patterns in consumers' use of health services. In each case, the researchers designed innovative methods to document health services utilization, taking into account the social roles, personal histories, and economic circumstances of men and women that lead them to have different, and hence, gendered experiences within the health system and/or of health conditions. Both of these reports will interest decision makers concerned with the effective use of health care resources.

Home care from the perspective of the person receiving care, and home care from the perspective of informal caregivers are the subjects of two different studies on health care reform. Both introduce us to the reality that families and patients who need or receive care in the home face enormous challenges in terms of managing the physical, psychological and financial effects of caregiving. In contrast, *Invisible Women*, examines a different aspect of health care reform, namely health planning under regional health authorities in Saskatchewan and Manitoba. This work demonstrates that these regional structures have little experience and/or technical expertise to incorporate concerns about women's health into their health plans or needs assessments.

Women reflecting the diversity of communities of women are the subject of the final group of studies presented here. These four reports detail the experiences of women with mental health problems, immigrant and refugee women, adolescent girls, and rural and remote women. In each case it was found that being female exacerbates the difficulties of coping with ill health.

Consistently, these studies tell us that when it comes to health, sex matters. While in some cases, sex is the difference that makes no difference, in others, sex is the difference that makes *all* the difference. It is our job as decision makers, researchers and health care providers to find out which case is which in order to ensure that our health systems respond appropriately and that ultimately we are better equipped to improve the health of all Canadians.

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## HEALTH STATUS

# Gender, Work and Health: An Analysis of the 1994 National Population Health Survey<sup>1</sup>

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The research reported here is an analysis of the 1994 National Population Health Survey (NPHS) data. We used this data set to explore two broad questions:

Are there differences in the health of men and women?

To what extent do paid and unpaid work conditions and social, personal and material resources affect the health of women and men?

The NPHS is a longitudinal study of a nationally representative sample of household residents in Canada. In each of just over 20,000 households, limited information was collected from all household members and one individual, aged 12 years and older, was selected for a more in-depth interview. Our analysis uses data collected from a sample of 16,989 individuals whose ages range from 15 to over 80 years.

## 1. Are there differences in the health of men and women?

Our findings show that women and men experience similar types of problems, although the nature of the problems changes with age. Injuries and non-food allergies are most common among younger people, arthritis and rheumatism and back problems increase in frequency in middle age, and high blood pressure, heart problems and cataracts are more frequently experienced in the older groups. Using four general measures of health and several specific measures of mental and physical health, we then investigate the magnitude of gender differences. They do not show a clear excess of ill-health among women. The patterns vary by condition and age, confirming the argument of Macintyre, Hunt and Sweeting (1996)<sup>2</sup> that we need to further explore

the nature of gender differences rather than continuing to work with the taken-for-granted assumption that women experience greater ill-health than do men even though they enjoy longer life expectancy. At many ages, the health of women and men is more similar than we have often assumed, though we should not minimize the gender differences that do exist.

## 2. To what extent do paid and unpaid work conditions and social, personal and material resources affect the health of women and men?

Typically, research has examined two hypotheses. The differential exposure hypothesis suggests that women report more ill health than men because of higher levels of demands and obligations in their social roles and lower levels of resources to help them cope with these conditions. The differential vulnerability hypothesis makes reference to women's greater reactivity or responsiveness to life events and ongoing strains that are experienced in equal measure by men. It is argued that the different reactions of women are a result of women's general disadvantage in social roles and coping resources that affects the nature and meaning of stressors and, ultimately, the effects of the latter on health. In other words, social roles and resources are related to health in different ways for men and women. We considered each of these approaches to understanding the differences in men's and women's health that were observed.

Analysis of the distributions of paid work conditions, household circumstances and resources revealed mostly minor differences by gender. Women were more likely to have been

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<sup>1</sup> The authors wish to express their appreciation to the National Network on Environments and Women's Health (NNEWH) which provided funding for the research reported here and to Lisa Strohschein for her first-rate assistance with the statistical analysis.

<sup>2</sup> Macintyre, S., Hunt, K. and Sweeting, H. (1996). Gender differences in health: are things really as simple as they seem? *Social Science and Medicine* 42, 617-24.

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formerly married, they were less likely to be in the labour force, and more likely to be working part-time. They were also somewhat more disadvantaged than men when it came to job strain. Given the relatively small gender differences in *exposure* to these living circumstances, it was not surprising that – with the exception of pain – they contributed very little to accounting for gender differences in health.

With few exceptions, we found little support for the notion that comparable paid work experiences and household structure have a greater effect on the health of women than men. In other words, greater *vulnerability* is not a generalized health response of women to paid and household circumstances. We also found only limited evidence that material, social and psychological resources were involved in pathways linking work circumstances to health in ways that differed between the sexes.

In sum, gender differences are less pronounced than is often supposed and paid work, household structure, social support and personal and material resources play a limited role in explaining the differences in men's and women's health that do exist.

One reason for the variable gender differences in health that we observed may be that changes in women's and men's roles have led to a narrowing of differences in health. Yet it is impossible to tell whether this is so until longitudinal studies of health document in much greater detail the changing nature of gender roles.

The absence of support for our explanatory model may, in part, be a result of the types of measures which were available in the NPHS data set. It is unfortunate that, despite the detailed data on aspects of paid work, the survey contains so little information on the household itself. There are no data on the division of labour within the household and the time spent on domestic labour, child care, care of dependent adults and other household responsibilities. In this regard it appears to be blind to key features of women's lives.

Even with more comprehensive and sophisticated measures which would permit a fuller exploration of the determinants

of gender differences in health, it may still be difficult to grasp the effect of gender on health. Gender permeates all aspects of social relationships and social institutions and it may be an insurmountable task to separate it from the social and material conditions of men's and women's lives that we study in order to understand gender differences. Yet this should not deter efforts to understand the links between gender and health. In exploring these it is critical that we draw on both quantitative and qualitative data in order to develop a more textured understanding of men's and women's lives.

Not only gender, but also women's health should serve as a focus of research. While it is important to continue to seek to understand the nature and source of gender differences in health, it is also important to focus on women's health per se. "Women's health" is more than reproductive health or psychosocial health. A greater range of problems must be included in investigations of the health of women (arthritis, for example) and there must also be a greater recognition of how they vary through the lifespan. Moreover, since data collection institutions have been blind to the realities of women's lives, a focus on women may serve to identify such ongoing bias.

Limited evidence of gender differences in health does not mean that inequalities between men and women are unproblematic. While it is important to document and explain differences in health status, ill-health should not be the sole measure of social disadvantage.

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## HEALTH STATUS

# Women's Health in Atlantic Canada: A Statistical Portrait

Ronald Colman, Director, General Progress Indicators (GPI Atlantic)

This report to the Atlantic Region Policy Forum on Women's Health and Well-Being illustrates the utility of a gendered health determinants approach for developing strategies for improving population health and women's health and, ultimately, for reducing long-term health care costs. The report notes the highly interactive nature of the determinants of health and points both to data limitations and the need for more research in the area. While not a comprehensive overview of women's health in the region, the report presents statistical evidence to illustrate the need for strategic investments in several key determinants of health to improve women's health in Atlantic Canada.

Highlights of the report include:

1. Gender-based analysis reveals differences in teenage smoking, activity limitations among seniors, and different exercise and physical activity trends among Atlantic men and women not otherwise evident in population level data.
2. Increasing stress levels are negatively impacted mental health and psychological well-being among women, which in turn is related to adverse physical health outcomes.
3. Despite increased educational parity, the persistent gender wage gap and high poverty levels among single mothers and unattached elderly women negatively impact health.
4. High levels of social support and voluntary work are a key buffer against stress and ill-health in the Atlantic provinces. However, the shift from hospital to home care threatens the well-being of informal caregivers, mostly women, and illustrates the need for adequate supports for these caregivers.
5. The Atlantic region receives far less than its fair share of health research funds.

While this report was prepared to provide an overview of women's health issues in the Atlantic provinces, the gender analyses provide directions for interventions to improve the health of men. For example, while fifteen years ago Maritimers were more physically active than most Canadians, today men in all four Atlantic provinces rank below the Canadian average. A sex-disaggregated data analysis revealed that overall population averages conceal sharply divergent trends among men and women in the region. That is, while Atlantic women have generally increased their rates of leisure time physical activity, there has been a dramatic decline in physical activity by men in all four Atlantic provinces. In the long term, this means that while men in the region had a relatively low risk of heart disease in 1985 compared to other Canadians, they now have a significantly higher risk than Canadian men in general. In this case, a gender analysis suggests that health officials target men in promoting sports and exercise programs. In fact, the male and female trends are so dramatically different that an overall population analysis without a gender breakdown completely misses the point of who is at greatest risk from a lack of physical activity and sends misleading signals to policy makers.

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## HEALTH SERVICES

# Health Care Utilization And Gender: A Pilot Study Using the BC Linked Health Data

Arminée Kazanjian, Isabelle Savoie and Denise Morettin, BC Office of Health Technology Assessment

## Objectives

The goal of this pilot study was to evaluate the feasibility of linking large administrative databases, related to the different programs of the Provincial Ministry of Health, to conduct a population-based study of health care use and gender in British Columbia. We wanted to know if we could use the databases to discover if men and women use health services differently. Did they use selected medical procedures differently? Could analysis of the BC Linked Health Data be used to quantify the relevance of gender in the use of health services and help achieve a better understanding of women's health issues?

The specific objectives of the pilot study were to evaluate the feasibility of using the BC Linked Health Data to: a) Describe the volume and type of health services used by women. b) Examine the relationship between determinants of health (including gender, family structure and socioeconomic status) and the use of health services. c) Explore the measurement of health outcomes relevant to women.

Our hypotheses were that differences in women's and men's family-related roles are manifested in patterns of health care utilization and that socioeconomic status combined with family structure will result in different patterns in the use of health services.

## Methods

To select the data, we linked each of the Medical Services Plan and Hospital Admission and Separations databases separately to a Co-ordinating File, based on the provincial Registration and Premium Billing files. To safeguard the anonymity of individuals, we assigned study identifiers rather than using individuals' medical services contract numbers. Data analysis of health services utilization was conducted for the 1996/1997 fiscal year.

The dependent number on the Registration and Premium Billing contract was used to establish whether there were dependent children (under 18 years old) in the family (a proxy

measure for family structure). Family structure categories (single male; single female; one-adult with children, etc.) were determined by the sex of the contract holder, the sex of a second adult and whether children were listed as dependents. Premium subsidy level was used as a proxy measure for socioeconomic status.

Coronary heart disease and depression were chosen as two conditions, respectively representing an acute and a chronic condition. The medical procedures we looked at included hospitalization for depression and revascularization for coronary heart disease.

Our sample consisted of 97,840 individuals (49,354 unique families): 49,301 females (50.4%), 48,486 males. 25% of the sample was children.

## Findings

1. This study establishes that gender-based analyses using the BC Linked Health Data are feasible.
2. Analysis of the data from our sample shows that when family composition and socioeconomic status are combined, there appear to be gender-based differences in the use of health care services.

The BC Linked Health Data and the methodology we developed in this study offer exceptional opportunities for more complex and rigorous research on women's health and health care utilization, and on the interaction between disease and social roles and the life-course.

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## HEALTH SERVICES

## National Gender Economic Costing Group

Lorraine Greaves and Olena Hankivsky, British Columbia Centre of Excellence for Women's Health

This is an interdisciplinary research group led by Lorraine Greaves comprised of researchers with legal, economic, political science, sociology and policy perspectives. The group is developing a model and methodology for the gendered economic costing of various diseases, illnesses and experiences specifically related to women's health. There has been a substantial amount of research conducted on the economic costs of various health issues and social problems such as substance abuse, smoking, gunshot wounds, AIDS, schizophrenia, cardiovascular disease and violence against women. However, a gender-sensitive approach to costing is not yet well developed.

This means that many costs incurred by or on behalf of women may not be adequately measured. For example, home-care giving costs, which may result from early hospital release, deinstitutionalization or other aspects of health reform, may fall disproportionately on women. A full economic costing of home care would thus include not only the costs of unpaid work provided by women doing home care, but also the less direct costs that have both short- and long-term consequences. Examples of these may be labour force interruption, foreshortened careers, moving costs, or loss of pension and other benefits. Other categories of costs may include health care costs related to injuries, stress or depression. In general, such personal or individual/family

costs often go unrecorded in economic costing models and need to be assessed in a gender-sensitive manner.

This work builds on previous research costing violence against women and children to the health system, as well as assessing the costs to other segments of society, including individuals, providers of service and third parties such as employers and insurers. The current project is focussed on the methodological issues in economic costing, with a view to making economic costing both gender-sensitive and comprehensive. There are methodological debates in economic costing work, and varied approaches that can be taken. This project is identifying methods and approaches that take women's experiences into account, and reflect adequately all of the varied costs associated with certain women's health issues, services or conditions, both short and long term, direct and indirect. With the exception of economic costing of violence against women to the system, no gendered economic cost analyses have been undertaken in Canada.

Secondly, the project will assess the ethical implications of economic costing and its various uses in policy analysis and development. Policy analysis and development derived from economic cost studies that do not take gender into account may lead to faulty assumptions, costly mistakes, inappropriate or incomplete services and unintended consequences. For

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IN GENERAL, PERSONAL OR INDIVIDUAL/  
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example, Pharmacare policies that do not assess individual spending on alternative remedies and identify the gendered and cultural differences in such patterns are incomplete.

Health reform measures that focus on hospital-based cost cutting or health system utilization reduction that do not assess the economic displacement costs of reform and restructuring are potentially very costly to individuals and families. Policies on home care that do not assess the gendered social and economic influences on care giving patterns are incomplete. Identifying and estimating these costs will add another dimension to policy development that is often missing. The work of the National Gender Economic Costing Group aims to redress these elements and eventually contribute to sharpening policy through its program of activities.

Two background papers on methodological and ethical issues of such a model are under development during 2000. In 2001, the group will apply its model to several case studies in women's health or services impacting on women in conjunction with other Centres of Excellence and other partners. Case examples such as the economic costs of home care giving, alternative therapies or midwifery will be pursued. Meanwhile, members of the group continue to work on economic costing projects related to other substantive areas such as violence and abuse of children and seniors.

A related project under way at the British Columbia Centre of Excellence for Women's Health project is estimating the Economic Costs Of Child Sexual Abuse in Canada, led by Olena Hankivsky. The study will provide preliminary national estimates of the direct and indirect costs attributable to child sexual abuse. Direct costs are being estimated from expenditures in four policy and program domains: Health, Social and Public

Services, Justice, Education/Research and Employment. Indirect costs are being estimated using morbidity and mortality data from various national and provincial surveys.

This study has a direct impact on women's health in its estimates of the direct and indirect costs to individuals. The long-term effects of child sexual abuse on adult survivors (many of whom are women) include substance use, post-traumatic stress disorders, mental illness (especially depression) and sexual transmitted diseases. In addition, employment related costs affect both adult survivors and employers, often over the long term.

This work builds on earlier work conducted by Greaves and Hankivsky on the costs of violence against women and children. Developing an estimate of the economic toll of child sexual abuse will have many benefits, including an improved understanding of the mental and physical health effects of this issue and the financial costs to governments, agencies, services and individuals.

This project is supported by Health Canada's Family Violence Initiative. The National Economic Gender Costing Group is funded for three years by the Social Sciences and Humanities Research Council's Research Innovation Development Fund.

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EMPLOYMENT-RELATED COSTS (OF CHILDHOOD  
SEXUAL ABUSE) AFFECT BOTH ADULT SURVIVORS  
AND EMPLOYERS, OFTEN OVER THE LONG TERM.



## HEALTH CARE REFORM

# Moving in the Right Direction? Regionalizing Maternal Health Services in British Columbia

Cecilia Benoit, Department of Sociology, University of Victoria, Dena Carroll, BC Ministry of Education, and Pat Kaufert, Department of Community Health Science, University of Manitoba, with the assistance of Beverly MacLean-Alley

Canada has devoted substantial resources to the specialized medical fields of obstetrics and gynecology and on the maintenance of large hospital maternity wards, particularly within the past fifty years. Despite important reductions in maternal and infant mortality rates, significant service gaps remain for maternity clients. Concern has been expressed about a range of issues, such as the narrow provision of services covered under provincial health plans, lack of choice in service providers, limited accessibility for marginalized women, cultural-insensitivity of health professionals, and patriarchal employment practices. Provincial health care systems have been seen as spending health resources inefficiently and failing to address these problems. For true health care reform to take place, focused attention must be given to the appropriate provision of quality maternity care services for all women, as well as to ways to increase the efficient use of health care resources.

Health care reform has preoccupied policy makers in provinces across Canada. A favoured reform strategy for most areas of the country (Ontario being a notable exception to this trend) has been regionalization. The model under way in British Columbia (BC) involves many of the strategies adopted elsewhere across the country: decentralization of health care planning; devolution of decision-making powers; and the creation of newly-developed regional health authorities/community health councils. Apart from reducing waste and inefficiency, it is anticipated that regionalization will give residents in their geographic communities greater voice to discuss their health care needs and concerns and, ultimately, foster the delivery of health services closer to people's homes.

The study asks two central questions:

1. Has regionalization improved women's access to quality maternity care in their local communities?

2. Specifically, has regionalization resulted in non-urban women's greater voice in health care planning at the Regional Health Board level? In addressing these questions, two research methodologies were used. Workshops exploring women's health care issues were held with maternity clients in two non-urban areas of the province. In addition, fourteen individual interviews were held with policy advisors, health professionals who provide maternal health services in BC, and a small number of non-urban maternity clients.

Although non-urban maternity clients noted some potential benefits of regionalization, they also expressed concern about a reduction of maternity care services close to their homes. Two respondents, who had recently given birth when interviewed for this study, noted a decline in the level of care they received by nurses in both the local hospital and at the public health clinic. In determining this, they compared their most recent maternity experience with that of an earlier child born before the local Health Board was established. Both respondents agreed that the decline in service was partly a result of the hospital's Early Maternity Discharge Program, designed to help reduce hospital costs by sending new mothers and their babies home within 48 hours post-partum. Respondents were particularly concerned that the stress levels of new moms had increased, and that more babies were becoming dehydrated and subsequently re-admitted into the hospital due to inadequate nursing. According to respondents, hospital nurses have less and less time to give advice to new moms regarding the art of breast-feeding and newborn care. Participants in the two focus groups mentioned above largely echoed these themes suggesting a decline in the quality of maternity care at the local level.

Maternity respondents also expressed dismay that regionalization had not been able to address the lack of

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physicians in non-urban areas, despite the over-abundance of physicians per capita in the province. Respondents spoke of the trauma associated with having to leave their communities to give birth, putting them at a distance from valuable support networks. While respondents said that they were pleased to learn that midwives are now legal and funded by the Ministry of Health, they doubted that non-urban health regions would gain access to midwives in the near future. They noted that they knew of no midwives practising either in their own community or in the surrounding health region. Respondents went on to say that, much like physicians, most BC midwives within the provincial health care system are located in either the Vancouver or Victoria metropolitan areas. Advantaged regions of the province are securing midwives to compliment the oversupply of GPs and obstetricians who also deliver maternity care. In the face of this, respondents expressed concern that their local hospital was about to have one of their two resident obstetricians retire from active practice, while the other was leaving the community because of better job options elsewhere.

Government advisors and health professionals interviewed as part of the study had mixed reviews about whether regionalization was actually achieving its initial goals. Regionalization, according to most of them, brings with it the potential to revitalize health care services through innovative health policies and greater opportunities for local people to help shape change. Respondents noted as well that because the Regional Health Boards are made up of local people, public concerns will be more tangible and the people will have more of an opportunity to have their voices heard. In addition, Health Authorities will have an opportunity to become innovative in developing region-specific health policy and services. One respondent suggested the health care system might also become more transparent; another noted that the newly regionalized system might help to flatten out the Ministry of Health's top-down hierarchy.

However, decentralized health care delivery is accompanied by challenges at each system level. Government advisors and health professionals interviewed expressed a number of their concerns:

1. Potential loss of important preventive health programs;

2. Communication difficulties between regions and province;
3. Threat to access for marginalized women;
4. Financial cost involved in an expanded health care bureaucracy;
5. Possible influence of politics and patronage upon regional recruitment and decision-making;
6. Need to monitor Health Boards in order to find out whether the goals and expectations of the people they serve are actually met; and
7. Physicians' refusal to renegotiate their means of remuneration.

This study provides a snapshot of how maternity clients are affected by many of the policy changes that are taking place at provincial and local levels. Further, it points out how policy advisors and health professionals themselves are concerned about the long-term effects of many of the changes now under way. More research on the impact of regionalization on core health services, including maternity care, is urgently needed to ensure that policy and practices address the needs of the communities they serve, and that equity in access to quality maternity care is not compromised. Studies of the impact of regionalization in other provinces would add significantly to the findings of this preliminary project.

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## HEALTH CARE REFORM

# Invisible Women: Gender and Health Planning in Manitoba and Saskatchewan and Models for Progress

Tammy Horne, WellQuest Consulting, Lissa Donner, Consultant and Wilfreda E. Thurston, Community Health Sciences, University of Calgary

The purposes of this project were (1) to examine the degree to which gender sensitivity and women's health issues were reflected in the planning processes of regional health authorities in Manitoba and Saskatchewan, and (2) to provide information which the Prairie Women's Health Centre of Excellence could use in advising governments, regional health bodies and others on how to make regional needs assessments and health plans more sensitive to the needs of women.

The research team evaluated needs assessment and health plan documents and interviewed key stakeholders within the regional health bodies that had provided the written documents. The study considered such issues as efforts undertaken to reduce barriers to participation in health planning, whether data were disaggregated by sex, the use of evidence-based decision making in the planning process, and collaborative initiatives between health authorities and women-serving organizations. A total of 8 out of 11 Manitoba Regional Health Authorities and 17 of the 32 Health Districts in Saskatchewan participated in the study.

The analysis of the needs assessments revealed that:

1. Gender was rarely considered as a variable in assessing local health needs and that consequently, the health needs of women were rarely considered separately from the health needs of men;
2. Regional health bodies published little sex-disaggregated data and had little access to sex-disaggregated data from other sources such as Statistics Canada or the provinces;
3. Despite a commitment from Manitoba Health that women's health was a priority, Regional Health Authorities were not provided with information about women's health nor given guidance on how to assess the health of women in their communities.

The analysis of the health plans revealed that:

1. Regional health bodies in Saskatchewan and Manitoba have not given high priority to women's health;
2. Where women's health issues were considered, the most frequent references were to sex and gender-specific health

needs (i.e., reproductive health, breast and cervical cancer screening) and to women's role as mothers;

3. Despite official support of a determinants of health approach, there is little evidence of it in the health plans reviewed in this study;
4. There was little evidence in the plans of an appreciation for the differing health needs of diverse groups of women, including Aboriginal women, women from ethnic and visible minorities, lesbian women and women with disabilities;
5. None of the regional health bodies surveyed reported any training on gender issues for staff, management or Board members;
6. Rather than recognizing the additional burden on women of providing informal care to family members and friends, regional health bodies have promoted it by emphasizing women's presumed role as gatekeepers of family health.

The interviews with representatives of regional health bodies revealed that:

1. Women's health was discussed in the context of three categories: reproduction, family members and health service utilization;
2. Despite a widespread understanding of the determinants of health, gender was seldom mentioned and the other determinants lacked a gender analysis;
3. In some instances, a "backlash" was noted: some people were concerned that "all this attention to women's health" represents a loss for men and a threat to men's health.

No significant differences were found between Manitoba and Saskatchewan with respect to gender and health planning, despite different political environments at the time of the study and different official policy priorities with respect to women's health. There was, though, considerable variation among regional health bodies in their level of technical expertise in assessment planning, data collection and analysis. Rural regions are at a particular disadvantage with regard to both research literature and access to technical assistance.

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We recommend that regional health bodies be required to collect and report gender disaggregated data in their needs assessments and health plans and that provincial ministries of health provide health bodies with the necessary training, expertise and funding to accomplish these tasks. We also recommend that provincial ministries improve access to health information and establish an appropriately staffed offices of women's health with expertise in gender analysis to support the regional health bodies and other government departments which affect women's health such as finance, social/family services, housing and seniors' services.

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## HEALTH CARE REFORM

# Coping As A Rural Caregiver: The Impact Of Health Care Reforms On Rural Women Informal Caregivers

Bonnie Blakley and JoAnn Jaffe, Department of Sociology and Social Studies, University of Regina

Health care in rural Saskatchewan is rapidly changing. Many rural communities are losing their hospitals, long-term care facilities and, in some cases, primary care services. Care of the chronically ill or disabled is being deinstitutionalized. Respite or physical therapy services are scarce or becoming centralized and more difficult to access. The numbers of rural informal caregivers are increasing, while insecurity regarding medicare and the restructuring of health services is intensifying.

Policy-makers are introducing rapid changes to the health system, yet little is known about their impacts on rural informal caregivers. Policies appear to be based on myths and assumptions about rural women, families and communities. The Rural Women Informal Caregivers Study therefore asked four questions:

1. How are provincial and federal health reforms affecting the economic, social, psychological and physical well-being of women caregivers in rural communities?
2. How is the impact of health reforms on these rural women caregivers affected by the presence or absence of formal and/or informal social supports?
3. How do factors such as income, education, social status and employment affect the type of difficulties experienced by informal rural caregiving women?
4. What types of formal and/or informal supports do rural

women caregivers need and how can these needs be met through policy changes and community participation?

The North Valley Health District in east central Saskatchewan was chosen as the study site because of its proximity to Regina, it was a well-defined area and caregivers in the district had the potential to access the same number and type of health care services. The area includes smaller communities and can therefore be considered rural. The district has an estimated population of 14,992, having declined slightly in the late 1990s. Individual interviews using a structured questionnaire were conducted with 53 women between June and October 1998. Most interviews were conducted in the caregiver's home. Six interviews were carried out in public restaurants chosen by the caregiver. The interviews lasted between 45 minutes and four hours.

## Key findings

1. Women report that their health has deteriorated since taking on the caregiver role. Two-thirds of the caregivers in this study consider themselves to be healthy. Close to half of all the caregivers interviewed reported that their health had deteriorated since taking on the caregiver role. It is interesting to note that some of the caregivers who identified themselves as healthy still feel that their health has deteriorated since they started caregiving. These caregivers reported suffering from more stress headaches, chronic back pain, depression and emotional and physical exhaustion

since they began caregiving. As caregivers are compelled to care for more than one care-receiver over their lifetime and for longer periods of time, we can anticipate seeing greater numbers of stress related illnesses develop in caregivers.

2. Caregivers have variable experiences with using district health services and supports for caregiving. Caregivers identified a wide range of health district services as community supports but few were accessing more than one of these services. Caregivers felt that having more home care workers available, more knowledgeable home care workers, and not so many different home care workers would make home care more attractive to people. 25 caregivers believe that community support should focus on maintaining hospital and clinic services while 24 caregivers believe that community support should focus on expanding group and care homes. While some caregivers felt that home care services were 'great just the way they are,' others felt that home care was "useless" and would not use it.

3. How a caregiver reports her health is directly correlated to her level of family support and employment outside the home. Caregivers who do not consider themselves healthy are very likely to feel their health has deteriorated since they started caregiving. Remarkably, age and income seem to have very little effect on whether caregivers say they have become less healthy – although young healthy caregivers are slightly more likely to report that they have experienced deteriorating health. People with higher levels of education are more likely to consider themselves healthy, yet are also slightly more likely to say their health has deteriorated since they began caregiving. The most significant variables to explain both whether the caregiver considers herself to be healthy and whether her health is staying the same or deteriorating are family help and outside employment. Caregivers who are employed outside the home are much more likely to consider themselves as healthy and are unlikely to report their health as deteriorating since they started caregiving for a family member. In contrast, caregivers who do not work outside the home are both more likely to evaluate their health as poor and to feel it has deteriorated. A large number of caregivers who do not consider themselves healthy receive no assistance from family members with their caregiving duties. Meanwhile, caregivers who do receive help are more likely to consider

themselves as healthy, and are also less likely to feel that their health is deteriorating.

4. Caregivers need both formal and informal supports. Caregivers feel that having strong support from the community and family members would make their caregiving tasks easier. However, 30% of the caregivers believe there is nothing that can make their caregiving tasks less difficult. Although 26 caregivers reported receiving caregiving help from other family members, 27 did not. Older caregivers were more likely to report not receiving help from family. Caregivers not receiving help from family are often caring for very old people.

Rural women informal caregivers find themselves in a difficult situation. These women have to cope not only with the restructuring of their health care system but also of their communities. This study reveals that these changes are affecting caregivers' social lives, their work, and their health. Briefly, caregivers often found that the demands of caregiving in a rural community limited their social lives, interfered with their work lives, and was associated with a deterioration in their own health.

Various policy implications arise from this work:

1. Recognize that rural caregivers need social and emotional supports.
2. Recognize that family supports are often not available to the caregiver.
3. Improve access to community services.
4. Adequately fund support services and institutional care in rural communities.
5. Provide information on available services.
6. Recognize that rural caregivers tend to be older and have their own health problems.
7. Acknowledge that caregiving is work and provide financial remuneration for it.

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PRAIRIE WOMEN'S HEALTH  
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## HEALTH CARE REFORM

# Missing Voices in Long-term Care Policy Making: Elderly Women and Women With Disabilities Receiving Home Care

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This study explores the perspectives and aspirations of frail elderly women and younger women with disabilities who rely on care and assistance at home in Ontario. Their voices and their knowledge of the home care system are seldom included in current debates about long-term care policies that are, rather, dominated by the economically-driven imperatives of governments to manage efficiently and offload costs from the public ledger.

Home care has always been a poorly resourced and fragmented part of the health care system in Canada. It is subject to no national standards so that, over time, provincial governments have fashioned various mixes of public, voluntary and for-profit home care services. In Ontario, where the study is being carried out, the present government's commitment to cost-cutting and privatization in all health and social programmes has translated in home care into the form of a financially straitened system of "managed competition" that fosters the entry of for-profit providers into the home care marketplace.

To explore women's experiences of this turbulent and poorly supported service arena, the study takes a longitudinal (3 year) qualitative approach: longitudinal in order to capture and understand change in recipients' health and social situations and in the shifting home care environment, and qualitative in order to give primacy to women's definitions of their circumstances, concerns and aspirations. Since the study began 18 months ago, a sample of twenty-five (25) women who receive home care in an ongoing way has been located in a snowball fashion through community groups who are partnered with the project (e.g., Older Women's Network, Canadian Pensioners Concerned) and through other community and advocacy organizations. The participants are aged between 35 and 96; they live with a range of chronic conditions and disabilities and include a range of experience in terms of length of service receipt,

culture, and marital and family status. In terms of income, almost half are poor.

Participants are interviewed at regular intervals (4–6 months) and are invited to reflect on their health and social situations and on the services and assistance they receive at home. With their permission, interviews are taped and transcribed. Some of the central themes and tensions emerging from analysis of these transcripts concern women's experiences of the new home care 'marketplace' and they are summarized here.

## **Instability and Discontinuity**

Many participants note rapid and problematic change in both the provider organizations delivering their care and, more significantly, in the actual personnel coming into their homes. They describe the strains and demands of having to rely on unknown nurses and home care workers for help with tasks that are often intimate and complex and that require familiarity and personalized knowledge. Continuity and predictability have always been a critical challenge in the organization of home care as the quality of care is rooted in the everyday details and processes of service giving and in the relationships in which they are embedded. The system of 'managed competition' in Ontario has exacerbated this challenge as, by design, the array of provider organizations is expanding, their contracts are regularly reviewed and changed, the home care labour force is increasingly dislocated and insecure and thus – at the front line – relationships with service users are destabilized and discontinuous.

## **Tighter Rationing of Services**

In the new organization of home care in Ontario, case managers assigned to each home care client assess need and coordinate packages of services drawn from a mix of non-profit and for-profit providers with whom their employing

Community Care Access Centre has contracted. Study participants' accounts of their contacts with case managers reveal the application of increasingly narrow definitions of eligibility for care and assistance. Many report cuts in the hours of help allotted to them and new definitions of the tasks with which they can expect assistance; in particular, their accounts reflect a trend toward provision of only personal or medically necessary care and the withdrawal of assistance with household help or social support. Beneath these changes lies a critical redefinition of people's entitlements to public support and an implicit according of priority to narrowly medical and acute care rather to social and longer term supportive care. These changes are occurring in the private orbits of individual care recipients' homes with little or no public discussion or acknowledgement.

#### **Shifting the work and costs of care: Privatization**

As publicly provided home care is reduced or experienced as un dependable, study participants are pressed to seek alternative sources of help. The work and costs of care are, in effect, transferred to the private domain. Some participants sought the help of family members – a resort that was often layered by concerns about burdening people and indebtedness and is, of course, not an option for those who have no family members to whom they feel they can turn. Participants with the financial means to do so purchased extra help in the private market from commercial providers. This proved a satisfactory experience for some but, in some instances, participants complained that personnel were inconsistent and poorly prepared (experiences that critics would contend reflect the deteriorating employment conditions in the home care market and provider organizations' consequent difficulty in recruiting and retaining workers). The work and costs of care were also offloaded in other, even less explored or understood directions: to the informal economy (e.g. to privately paid cleaners/ support workers/ companions, to formal care providers who informally filled some of the vacuum left by retreating public services); to elderly and disabled women themselves who strove, often against great odds and at some risk, to look after themselves or their households alone; or to no one at all, leaving participants to go without, their needs unmet. Highlighting these barely

visible consequences of home care rationing and exploring their impacts on women in different social circumstances will be an important focus for future analysis.

#### **Heightened insecurity**

Unsurprisingly, these conditions in the home care marketplace generate insecurity and anxiety among home care users. Study participants face unstable or degenerative health conditions and disabilities as well as unstable home care services and a political climate communicating their disenfranchisement to public support. Damage to identity and selfhood and, often, fear of the future are embedded in participants' descriptions of their circumstances. Embedded in them, too, are strands of resistance and struggle manifest in, for example: the day to day resilience and ingenuity marshalled to manage at home, the formation of creative alliances with formal care providers committed to expanding and personalizing their responses to service users' needs and, for a few, the political channelling of indignation through advocacy organizations, letter-writing etc.

As the study proceeds, these and other themes and tensions will be explored and elaborated and results will be communicated as widely as possible to concerned community groups, the media, policy makers at different levels of government and academic audiences.

This ongoing research is supported by the National Network on Environments and Women's Health and the Social Sciences and Humanities Research Council.

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National Network on  
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## DIVERSE COMMUNITIES OF WOMEN

## Experiences of Immigrant and Refugee Women in Quebec with the Health Care System

Le Centre d'excellence pour la santé des femmes – Consortium Université de Montréal

The continuing influx of immigrants and refugees has transformed Canadian society, forcing revision of our public programs, including health care. Research indicates that the health of immigrants deteriorates with their length of stay in Canada and that they often comprise vulnerable groups (Chen et al., 1996). Since 1997, researchers associated with the Centre of Excellence for Women's Health – Consortium Université de Montréal (CESAF) have conducted ten studies with different populations of immigrant women in Quebec. All of the studies aim to understand the health experiences of immigrant women and whether they are receiving adequate and appropriate care from the Canadian health care system. This work adds an important gender focus to research on immigrant health in Canada as issues of family dynamics in the context of immigration have often been neglected. Highlights from several of these projects are discussed below; further information is available from CESAF on these or related projects.

Several CESAF-sponsored studies have been completed in partnership with women from the French-speaking countries in North Africa and the Middle East such as Algeria, Tunisia, Morocco and Lebanon, Spanish-speaking women from the Americas, women from China and Haiti, and South Asian women. For example, factors which influence health behaviours and the use of preventive health services of South Asian immigrant women living in Montreal were examined by Vissandjée et al. (1999). In order to assess the influence of the length of stay, two cohorts of South Asian women were selected: recent immigrants (1-3 years) and past immigrants (5 to 10 years). Preliminary findings reveal that 40% of the respondents perceive their health to have deteriorated since their arrival in Canada. Of the health behaviours examined, approximately three out of four women identify sleeping, nutrition and physical activity as essential for good health while 98% consider relaxation crucial for their health. Yet fewer than half of the women actually conduct these activities on a regular basis.

Migration also appears to affect women's perinatal experiences. Research suggests that it is not ethnic origin

which presents risk during the perinatal period but factors arising from migration such as the loss of family and other social and economic support networks which in turn may lead to poverty, isolation and/or psychological problems which renders immigrant women potentially vulnerable during the perinatal period. One outcome of CESAF work is improved tools to identify women in the general population requiring additional support during the perinatal period (Battaglini et al., 1999).

With regard to their preferences for physicians, Muslim women in Quebec indicated that the quality of care they receive in relation to reproductive and sexual health revealed that the majority of study participants preferred "Canadian" over Arab doctors, though they showed no preference concerning the preferred sex of their gynecologist (Gastaldo et al., 1998). These results concur with those of Weinfeld et al. (1998) which indicate that gender and ethnic matching in the delivery of health care services does not always translate into excellent care.

In looking for ways to improve access to health services for immigrant women, Weinfeld et al. (1998) explored the benefits of ethnic/gender matching between health professionals and women and men from different ethnic origins. This concept builds upon the notion of ethnic matching, a concept founded on the assumption that service provision is optimized when ethnicity, race, language, and geographic area of origin coincide between clients and health services providers. While intuitively appealing, it has not yet been established whether matching the ethnic origin of a professional with a client necessarily ensures better diagnosis or treatment, nor whether professionals of ethnic origin are necessarily free of prejudicial stereotypes regarding their own or other ethnic groups. This study augmented this notion of ethnic matching with gender matching in a study of the mental health issues facing immigrant women in Quebec and barriers to the use of culturally sensitive and social services. To date, the results of studies such as this offer a conflicting views of whether ethnic/gender matching leads to significant long-term health improvements.



Like most Canadians, Muslim immigrant women were primarily concerned about the quality of care available rather than with issues of immigration per se. Women with difficulties preferred to have their husbands translate during visits to physicians rather than friends or relatives, though they recognized that Canadian physicians perceived this as a form of dependency (Gastaldo et al., 1998). A majority of women respondents in most of the studies worried about cuts to health care expenditures, the lack of time for medical consultations, the length of time it sometimes took to establish a diagnosis and a lack of continuity in programs. These concerns echo those of other Canadian women.

An evaluation of a telephone service that provides health information, education and on-line consultations to women and men in Montreal from the perspective of its cultural sensitivity and adequacy at meeting the needs of immigrant women. Consultations on the service was undertaken with Spanish-speaking women from the Americas, Arab-speaking women from the Middle East and North Africa, and Chinese and Haitian women. The objective of this research was to examine the role/use, strengths and weaknesses of a health information service provided by CLSCs (community-based health centres) in the context of their use by these women and their families and to identify factors which promote continuity and quality of care (Vissandjée & Dallaire, 2000). The potential impact of this research is significant as the use of telephone call centres in health is currently being tried and

explored in several jurisdictions.

In initial work on the effects of age on migration, a literature review revealed that while migration is a challenging experience for anyone, it can be more so for older people because of the losses not only of family and friends but also of a familiar physical, social and cultural environment. Migration presents a challenge to one's identity, may impose communication barriers, and require significant changes to family structure and practices. Immigration may be especially challenging for older women as they are more likely than other migrants to be poor (Talbot et al., 1998).

Taken together, these studies, and others undertaken through CESAF, form a foundation for further research into gendered aspects of the migration experience. This work should benefit policy makers, program planners, health services providers and other researchers.<sup>3</sup>

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<sup>3</sup> Battaglini, A., Gravel, S., Poulin, C., Brodeur, J.- M., Durand, D., Deblois, S. (1999). *Identification des facteurs de vulnérabilité propres aux mères immigrantes en période périnatale*. Rapport d'étape présenté au Centre d'excellence pour la santé des femmes - Consortium Université de Montréal.

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## DIVERSE COMMUNITIES OF WOMEN

# “Hearing Voices”: Mental Health Care for Women

Marina Morrow and Monika Chappell, British Columbia Centre of Excellence for Women's Health

Women's mental health cannot be understood in isolation from the social conditions of women's lives. These conditions are characterized by social inequities such as sexism and racism which influence the type of mental health problems women develop and affect how those problems are understood and treated by health professionals and by society.

The differences between men's and women's experiences of mental health concerns, and in particular, the links between social conditions and women's mental health, have been well documented.<sup>4</sup> There is also an emerging body of clinical research on the ways in which chronic mental health problems develop differently in women and men as well as research on the connections between women's mental health status, biology and women's life cycle stages (e.g., Seeman, 1981 & 1983; Seeman & Lang, 1990). The recognition that mental health is in part socially determined has led to commitments in some national and provincial mental health policy frameworks to shift from a bio-medical understanding of mental health towards a “bio-psycho-social” understanding (BC Mental Health Plan, 1998; Canadian Mental Health Association, 1993). Additionally, some jurisdictions have singled women out as a group that needs particular attention (e.g., BC Mental Health Plan, 1998:27).

Nevertheless, the recognition of the socially determined nature of women's mental health has yet to be fully

realized in mental health policy development and in the delivery of mental health services. Despite stated commitments to women as a special population in mental health, there are as yet few mechanisms for examining the experiences of women with mental health problems on an ongoing and in a systematic way.

This project was carried out using a feminist collaborative process and involved interviews and focus groups with over 200 women with chronic and persistent mental health problems, service providers, women family members and caregivers in British Columbia.<sup>5</sup> The study revealed that a gendered analysis of policy and service delivery has not been systematically and consistently integrated into existing policy and service delivery structures. Services which recognize the specific needs of women are often dependent on the will of individual service providers, and women's mental health planning is ad hoc and unsystematic. The implications of this lack of a gendered analysis are profound in terms of consumer satisfaction, clinical outcomes and service utilization.

Drawing on interview and focus group data, this study details women's experiences of mental health services. While in some communities services were virtually non-existent, in others services were fragmented or inaccessible. Consumer survivors and family members described the challenges of obtaining affordable, appropriate, compassionate care while

<sup>4</sup> BC Ministry of Health and Ministry Responsible for Seniors. (1998). *Revitalizing and Rebalancing British Columbia's Mental Health System: The 1998 Mental Health Plan*. Victoria: Adult Mental Health Division.

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<sup>5</sup> The project was overseen by a 15 member Advisory Committee under the leadership of women mental health consumers and included mental health service providers, policy makers and researchers.

service providers recounted the challenges of providing such care under conditions of fiscal restraint and with limited human resources. Some attention is paid in this report to describing the experiences of women of colour, women with disabilities, Aboriginal women, younger women, senior women, and immigrant women. Women identified language and culture as barriers to accessing care as well as the stigma of being labelled a user of mental health services. The report also documents how mental health services are provided in a two-tier system which permits women with the economic means to maintain autonomy and privacy by seeking care from private counsellors and psychiatrists while low income women more often receive publicly funded – and hence publicly monitored – care.

We have begun to document trends in mental health reform in Canada, with a particular focus on developments in British Columbia. Mental health reform in Canada can be seen as part of a philosophical shift in the understanding and treatment of mental illness as well as changes in the fiscal and service-delivery structures for mental health problems. Across Canada, mental health reform has taken similar forms: the gradual down-sizing of large psychiatric institutions and a move to a de-centralized, regionalized mental health care delivery system. Mental health reform has also entailed changes to provincial mental health legislation and policy making mechanisms. These trends are having myriad effects upon the availability and focus of service delivery and thus affect service providers, families of persons with mental illness and consumers themselves. In general, gender has not been a

feature of the development, implementation or evaluation of the elements of mental health reform.

This broad exploratory study begins to point to the need for more systematic examinations of how the rearrangement of mental health fiscal and service delivery structures in Canada are affecting service delivery to women. Further, more concentrated research and program evaluation is needed to determine the kinds of policies and service delivery models that can best respond to women's unique mental health needs. Over the next three years, research on the effects of mental health reform on women in Ontario, Quebec and British Columbia will be undertaken by the British Columbia Centre of Excellence for Women's Health.

This work was funded by the BC Centre of Excellence for Women's Health, the BC Ministry of Health, the Minister's Advisory Council on Women's Health (BC) and the BC Ministry of Women's Equality.

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BC Centre of Excellence  
for Women's Health

THE REPORT DOCUMENTS HOW MENTAL HEALTH SERVICES ARE PROVIDED IN A TWO-TIER SYSTEM WHICH PERMITS WOMEN WITH THE ECONOMIC MEANS TO MAINTAIN AUTONOMY AND PRIVACY WHILE LOW INCOME WOMEN MORE OFTEN RECEIVE PUBLICLY FUNDED – AND HENCE PUBLICLY MONITORED – CARE.

## DIVERSE COMMUNITIES OF WOMEN

## Developing Understanding from Young Women's Experiences in Obtaining Sexual Health Services and Education in a Nova Scotia Community

Don Langille, Janice Graham and Emily Marshall, Interdisciplinary Studies, University of British Columbia, Dalhousie University, Melissa Blake, Christina Chitty and Heather Doncaster-Scott, Amherst Association for Healthy Adolescent Sexuality

This study aims to understand the barriers which prevent young women from receiving maximally effective sexual health education in their schools and related services from physicians and in pharmacies. Building upon survey work carried out in the context of the Amherst Initiative for Healthy Adolescent Sexuality, this report describes the lived experiences of young women in Amherst, Nova Scotia as they have attempted to acquire and act upon knowledge related to sexual health.

This work was carried out as a partnership between members of the Department of Community Health and Epidemiology at Dalhousie University and the Amherst Association for Healthy Adolescent Sexuality (AAHAS), a non-profit society with a mandate to work with existing community resources to enhance and protect the sexual health of young men and women in Amherst. Young women representing the diversity of the Amherst community participated in in-depth interviews which examined their experiences in school-based sexual health education programs, in particular "Personal Development and Relationships", offered in grades 7 to 9. Participants were also asked to describe how their physicians approached the issue of

sexual health, including providing information about sexual health and prescription of oral contraceptives. Finally, participants talked about what they had experienced in using pharmacies for access to condoms and oral contraceptives. Data from the interviews was analyzed using qualitative techniques to develop an understanding of how participants' experiences with sexual health education and services resulted in barriers to the most effective use of those community resources.

Barriers to sexual health education in schools related to three main areas:

1. School-based sexual health programs (a repetitive and boring curriculum, avoidance of specific topics, contradictions with teachings from home and church, lack of relevancy on a temporal basis, and lack of credibility within schools themselves for sexual health education programs)
2. Their teachers (perceptions of teachers as having different values from students and having judgmental attitudes, use of inappropriate personal examples in class, discomfort with certain sexual health topics, and in some situations, lack of knowledge of sexual health)

WAYS SHOULD BE EXPLORED TO IMPROVE YOUNG WOMEN'S ACCESS TO FAMILY PHYSICIANS SERVICES SO THAT THEY CAN TALK CONFIDENTIALLY WITH THEIR PHYSICIANS.

3. Students themselves (gender dynamics in sexual health education classes, and not seeing the teachers and guidance counsellors as resources for sexual health)

Some of the key messages articulated by participants for educational policy makers and educators were:

1. Schools should make sexual health education courses more difficult, with challenging projects and appropriate testing
2. Schools should pay particular attention to the creation of a comfortable learning environment for women, gay and lesbian youth, and students from all religious faiths
3. Schools should provide continuity of topics and teaching methods between sexual health education classes
4. Schools should develop methods for increasing the credibility of sexual health education
5. Teachers should carry out needs assessments for students at the beginning of the school year to add relevance to sexual health education
6. Teachers should include methods of teaching which allow students to explore how one might feel in different situations, and how one might handle those situations

Participants identified barriers to using and being helped by physicians' services as:

1. Comfort and communication with the physician – difficulty with trust in the physician- patient relationship, the age and (often) male gender of the physician, physicians' lack of time for discussion of sexual health, physicians' apparent reluctance to discuss sexuality
2. Young women's needs for support for a high personal level of comfort in looking after their sexual health – need for non-judgmental support for sexual health, the need for a confidential relationship with the physician and a lack of knowledge of their right to such confidentiality, apprehension about Pap testing
3. Physician access – obtaining physician services in Amherst, impact of presence of parents at the physician's office

Key messages for policy makers and medical practitioners related to physicians were:

1. Physicians should introduce the subject of sexuality with young women in ways such as, "You are at the age where some people are choosing to become sexually active. If you ever want to talk about your options for sexual activity or birth control, we can do that."
2. Physicians should explicitly tell young women that their conversations and examinations are confidential, and that they will tell no one, not even their parents, even if they ask the doctor about it.
3. Physicians should explain the Pap test in detail ahead of time, and not make it mandatory for obtaining oral contraceptives, at least initially.
4. Ways should be explored to improve young women's access to family physicians' services so that they can talk, and talk confidentially, with their physicians.

With respect to pharmacy services, participants located barriers in the elements of the pharmacy including the cost of condoms and oral contraceptives and embarrassment caused by the public aspects of condom purchasing.

Key messages provide by participants for overcoming these barriers at the pharmacy level were:

1. Display and sell condoms in an appropriately private location in the pharmacy to increase young women's ability to purchase them in a confidential manner
2. Educate cashiers at pharmacies not to be (or appear to be) judgmental of young people purchasing condoms
3. Make oral contraceptives available free when young women can't afford them; make condoms available free at teen health centres.

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## DIVERSE COMMUNITIES OF WOMEN

# “Voices and Faces”: A Qualitative Study of Rural Women and a Breast Cancer Self-Help Group via an Audio Teleconferencing Network

Jon Church and Vernon Curran, Faculty of Medicine, Memorial University of Newfoundland and Shirley Solberg, School of Nursing, Memorial University of Newfoundland

The aim of this research was to develop an explanatory model of the use of audio teleconferencing in the provision of social support to survivors of breast cancer among women living in rural Newfoundland. The specific objectives were:

1. To identify the process by which the use of audio teleconferencing provides social support and delineate the therapeutic factors in the process;
2. To identify what support needs these women have;
3. To determine which needs are being met and which are not being met; and,
4. To identify the role that the technology plays in providing the support.

Eleven women with a history of breast cancer volunteered for the study. They ranged in age from 30 to 78 and came from across the province of Newfoundland. The women were interviewed following their participation in teleconferences. All interviews were audio taped and subsequently transcribed and analyzed using a grounded theory approach.

This work demonstrates the potential and limits of contemporary communication technology to facilitate social support for breast cancer survivors. Women who took part in the audio-teleconferencing obtained support both through the local teleconference site and the interactions that occurred there and through the system-wide network and the exchanges over this medium. Participants described the two different forms of support as ‘faces’ and ‘voices’ respectively.

The process of faces and voices consisted of four distinct

but overlapping stages:

1. Getting connected on the network;
2. Finding a voice;
3. Connecting with others; and
4. Becoming empowered.

In each of these four stages, certain conditions facilitated a woman's ability to receive social support.

Many people assume that women in rural areas, while distanced from formal means of social support, have greater informal means of support through family and friends and community cohesiveness, and the latter compensates for the lack of formal support services. Our study clearly shows this assumption is not supported. The women talked about the effects of the diagnosis on their spouses or other family members. They did not feel that family and friends, no matter how supportive, could understand what they were experiencing because you really had to be there to understand. They believed it was very important to talk with other women who knew what living with breast cancer was like to help them deal with the tremendous emotional upheaval they were experiencing. Others spoke of not wanting their communities “to know all my business”, and spoke of how the teleconferencing network was invaluable in lessening both family and community burdens of dealing with the disease process.

Empathy is suggested as a strategy for health professionals to use in meeting patient's emotional needs yet the women in this study challenged how well health professionals can meet patients' needs for empathy. They felt that the support they

received from other women with breast cancer was qualitatively different from that received from individuals without the disease. They wanted to talk to women who have been through a similar experience to themselves but more importantly they wanted to know that other women survived breast cancer. This finding has important program implications not only for health professionals but for how we structure cancer support groups.

One of the obvious means of solving formal support in smaller communities is to combine all cancer survivors in one group. The women we interviewed caution against this approach. While they conceded there are some commonalities among all people living with cancer, they also believe that the needs and concerns of breast cancer survivors are unique. Optimal support, therefore, comes from a group of women composed of breast cancer survivors. Moreover, the women appreciated having access to long-term survivors as well as women in active treatment. They also appreciated the presence of a facilitator who was knowledgeable about breast cancer and could discuss with them the latest in

treatment options, on-going or up-coming clinical trials, or breast cancer "news" presented in the media.

This study contributes to a greater understanding of an innovative social support programme for rural women and how to foster connection among women in diverse areas in need of support. It also contributes to an understanding of how women use technology to improve their well-being. Additionally, it identifies conditions that foster or inhibit the kind of social support that women with breast cancer receive.

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FOR WOMEN WITH BREAST CANCER COMES FROM  
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