

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

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## What do Women Want?

THE FOCUS OF THE SECOND ISSUE OF THE *Research Bulletin* is health services delivery. Studies described in this issue give us glimpses into what women want from the health care system in their roles as providers of health care, users of the health care system and decision makers. Although not an exhaustive review of the issues, this set of articles makes it clear that what women want is a high quality, responsive health care system in which they see attention given to women's priorities, needs and preferences.

This issue describes efforts to make the Canadian health care system more effective and appropriate for women. Some of the articles describe specific innovations in care delivery—the introduction of midwifery services, the creation of specialized facilities tailored to particular ethnocultural groups to address a service gap—while others document some of what women are saying needs to change in order for the system as a whole to meet their needs better. Canvassing women's experience is an important input into designing a more effective system.

The issue begins with a report on a series of studies commissioned by the National Coordinating Group on Health Care Reform and Women that investigated what is known about the effects of privatization on women. While little research has investigated the differential effects of health care reform on men and women, these studies suggest that privatization affects women more and differently from men because of their unique relationship to the health care system. For example, because women perform the majority of unpaid caregiving in the family, they are more likely to be affected by the de-insuring of services, the transfer of services from one service provider to another, or limitations on access to respite care.

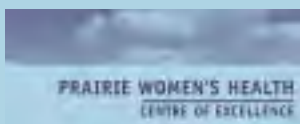
Similarly, because women are greater consumers of health care services, both for themselves and on behalf of their family members, they are more affected by the introduction of user fees, the transfer of care to the community, bed

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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.



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closures, labour conflicts and technological change. While the specific pattern of effects varies across the country, women in all jurisdictions are witnessing the effects of these changes. Whether these effects are positive or negative for women, research that examines privatization must be sensitive to the question of gender.

Two reports, "Marginalized Voices from Vancouver's Downtown Eastside" and "Women-Centred Care in the Context of Cervical Cancer Screening in Ethnocultural Groups" look at the delivery of specialized ethnocultural health services from the perspective of minority women who use these services for disease prevention and general health care. Efforts to create and provide such specialized services have not always been successful; these studies provide insight into the reasons why and suggest ways success might be enhanced. Services for cervical cancer screening, for example, were considered successful when screening was carried out by female practitioners who used appropriate language, were culturally sensitive and were available to provide information about other health concerns. Aboriginal women also wanted to see greater representation of Aboriginal women on staff and in clinics' decision-making structures. These studies raise the question of whether the health care system needs to develop a number of community-specific services, or whether the ingredients that make these services work can be made more generally available in all health services and to all users.

Another pair of studies on health services examines the supports that are needed by unpaid family caregivers, the majority of whom are women. While the study from rural Nova Scotia describes caregivers' self-reported needs for help, the one from Quebec documents an experiment in supporting caregivers through one of Montreal's local community health centres. One of the innovative recommendations of the Quebec study is that caregivers be tracked and studied as clients themselves. Such record keeping draws explicit attention to the caregiver as someone in need of support and recognition, in addition to, but separate from, the person who is receiving health care services.

The final two reports in this issue of the *Research Bulletin* look at studies of midwifery services. The first describes a series of

## WOMEN WANT HIGH QUALITY CARE AND A VOICE IN DECISION-MAKING.

studies on the implementation of midwifery as a new health profession within British Columbia. The second outlines experiences of women in Saskatchewan and Manitoba who have received midwifery care. The BC case study demonstrates some of the internal and external challenges facing midwifery as it becomes a regulated practice. Ideally, the lessons learned in BC will help jurisdictions such as Saskatchewan and Manitoba as they implement their own midwifery programs.

So, what *do* women want? These recent studies begin to reveal at least part of the answer. Women want access to high quality care. We want disease prevention services that feel safe and that we understand. We want flexible, individualized services. We want alternatives for perinatal care and birthing. We want recognition of the impact of providing care for others and support for providing that care. And we want a voice in decision-making for ourselves, our families and our communities.

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## HEALTH CARE REFORM

# Privatization and Women's Health in Canada: Tracking the Effects of Health Care Reform

National Coordinating Group on Health Care Reform and Women: Pat Armstrong, York University, Karen Grant, NNEWH & University of Manitoba, Jocelyne Bernier, CESAF, Ann Pederson, BCCEWH, Kay Willson, PWHCE, Carol Amarantunga, MCEWH, and Madeline Boscoe, CWHN

In the last decade, the Canadian health care system has undergone significant restructuring. The system has been evolving ever since its inception in the late 1950s, but the extent and intensity of the “reforms” has been greatest in the 1990s when most provincial governments launched health care reform measures. In each and every jurisdiction where health care reform has been initiated, it has been couched in terms of a crisis of rising costs. Northcott (1993:362) maintains that “The crisis rhetoric appeals to the emotions and calls for exceptional sacrifice—sacrifices that the ageing population, the health care system, and the taxpayer are being called upon to make.”

When we look at the various strategies implemented by governments to reform health, it is clear that they are mainly intended to reduce how often individuals use the system, or reduce the length of time they spend in the system, to reduce the cost per unit of care, and/or to reduce the overall costs of health care. These aims are achieved using measures such as: day surgery, delayed admission, and early release; de-listing of services and restrictions on entitlement to insured services; the imposition of ceilings on the number of physician services that will be reimbursed (through restricted billing practices); bed closures; reductions in health care personnel (notably nurses and other allied workers); adoption of labour-replacing and productivity-enhancing technologies; and various managerial/organizational reforms (e.g., Total Quality Management and Continuous Quality Improvement). Even while these types of changes are being implemented, governments still strive to maintain high quality health care and to achieve efficiencies in terms of costs.

Much has been written about health care reforms, yet research assessing the effects of these reforms on the health of Canadians and on their access to services has been remarkably limited in scope. To date the work of the

National Coordinating Group on Health Care Reform and Women has focussed on examining the impacts of health care reform on women as patients, providers, and decision-makers, and on coordinating research on health care reform and gender between the five Centres of Excellence.

The Coordinating Group began its work by using privatization as the thematic lens through which to capture the range of initiatives occurring in both reform strategies and research on women. For our purposes, we defined privatization in broad social and cultural, and not merely economic, terms. That is, privatization includes the transfer and relocation of service delivery, care work and costs, as well as the adoption of for-profit methods for care delivery and management.

We commissioned nine papers on privatization. One paper focuses on the context of health care reform and sets out the global and local pressures influencing change (Armstrong, 1999). Seven papers prepared regional scans on privatization in order to capture the range of initiatives in reform strategies, as well as in research on women's health. Based on these papers, and in light of the many research gaps identified in the scans, a paper on methodology and research was commissioned (Grant, 2000). An analytic glossary that examines the language and discourses related to health care system restructuring and reform is in progress. A plain language document (in English and French) that raises awareness of the impact of health care privatization on women in Canada was published (Wilson et al., 2000) and has been widely distributed to the women's health community across Canada (an online version is at <http://www.cwhn.ca>). The Coordinating Group organized a dialogue with key health care researchers and policy makers in Ottawa in February, 2000, and has subsequently been invited by Senator Michael Kirby to provide expert testimony at the Senate hearings on the health care system.

This sizeable body of work, to be published as a book later this year by Gramond, reveals much about the state of Canadian research on health care reform, including the following points:

1. There are significant gaps in the research on health care reform.
2. The extant research tends to privilege quantitative data, even when the measures used are inappropriate or incomplete (e.g., traditional biomedically-oriented indicators such as mortality, morbidity, and health care utilization are commonly used, but do not tap into the full range of experiences and effects of health care reform).
3. Relatively little of the research is gender-sensitive. In general, gender is ignored altogether, and the experiences of women and men are treated as if they are similar even in the absence of evidence to support such a claim.
4. Where researchers focus on the privatization of care, they treat it primarily as an economic concept, thereby ignoring the potentially significant social impacts and consequences of privatization on those receiving care, and also on those providing care, many of whom are women.

5. While our focus was on privatization, inevitably our investigations revealed that “quality of care” was a central, albeit poorly understood, concern that merits more detailed scrutiny.

Our work is now extending into an examination of the definition and measurement of quality of care, synthesizing the Centres' research on home care, and investigating models of primary care for women across the country.

One of the most exciting features of this research is that it involves collaboration between individuals in the academic, community and policy sectors. It represents an opportunity for university-community alliances in research, along with direct access to knowledge transfer and uptake processes between researchers and those in government.

Copies of the individual scans are available from the Centres of Excellence. The report on Alberta is available through the Prairie Women's Health Centre of Excellence and a report on privatization in Newfoundland is available from NNEWH. The other documents are available as noted below. Most documents are available in either official language.

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Scott, C. M., T. Horne and W. E. Thurston. (2000). *The Differential Impact of Health Care Privatization on Women in Alberta*. Winnipeg: PWHCE.

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# Marginalized Voices from Vancouver's Downtown Eastside: Aboriginal Women Speak about Their Health Care Experiences

Cecilia Benoit, Department of Sociology, University of Victoria and Dena Carroll, Aboriginal Health Consultant

Canada is not unique among high-income countries in its current efforts to restructure health and social welfare systems to control costs, while at the same time trying to provide its citizens with opportunities for greater control over their health care. Despite efforts from various quarters to “give voice” to the country's marginalized populations, research on general health service delivery in urban areas of British Columbia and other Canadian cities shows that Aboriginal women face formidable barriers in accessing provincial health services. This study seeks to document the voices of Aboriginal women living in Vancouver's impoverished Downtown Eastside as they assess the effectiveness of Native health services in their community.

The few research reports that are available indicate that Aboriginal women make relatively low use of preventative screening services for women such as Pap smears, mammogram screening, and breast exams by a health practitioner (BC Provincial Health Officer, 1996; BC Women's Health Bureau, 1999). Further, Aboriginal women tend to have great difficulty finding adequate care during pregnancy; this has been especially true for those using substances of one kind or other (Poole, 2000). While these few studies are revealing, a lack of general knowledge of urban, Aboriginal women's access to health services limits our ability to improve health service delivery, policy development, and program planning.

Over the past decade, urban Aboriginal health centres controlled by Aboriginal people have emerged to address the unmet health concerns of Aboriginal people living in metropolitan areas. The purpose of our research was to address the gap in social science literature on how Aboriginal health centres are accomplishing this. Specifically, the aim of

our research was to give voice to Aboriginal women by asking them to identify whether the service delivery model employed at the Vancouver Native Health Society (VNHS), an Aboriginal health centre located in Vancouver's Downtown Eastside, currently provides them with the appropriate professional services and educational programs that they need to take control of their health. We conducted focus groups with Aboriginal women who were either clients of VNHS, or of Sheway, a program for pregnant, substance-using women, or were residents of the Downtown Eastside. Additional individual interviews were held with VNHS staff, health professionals, and community leaders in health care.

From the focus groups with Aboriginal women the two most significant issues that emerged were access to and availability of support services. In terms of access, the women emphasized the importance of a non-judgmental, encouraging, informal environment, greater gender sensitivity, and a more women-centred focus. In addition, they expressed a need for a more central service focus on Aboriginal women's health concerns, for more culture-based programming including traditional healing methods and therapies, and for more personal security and assurance of anonymity.

Although some women also identified the need for Aboriginal-only services and programs, there was no consensus on whether this was a critical issue in the Downtown Eastside. Some of the support service needs that women identified were enhanced services for children, access to parenting support and education programs, access to food, supplies and other assistance during emergencies, access to better dental care, and access to integrated community health support networks.

Health service providers and administrators were interviewed supported many of the concerns articulated by Aboriginal women. They also raised concerns about the impact of the regionalization of health services on the delivery and control of Aboriginal health services and programs. Although there was overwhelming support from administrators and service providers to develop a new, comprehensive Aboriginal Healing Centre in Vancouver, a number of outstanding questions about location and access, types and control of services and programs, and ways to build on the current success of VNHS were raised. Another equally important question was how Aboriginal people themselves, as well as administrators, caregivers and families, would be consulted and involved in exploring and addressing these questions.

The women using VNHS and Sheway recommended greater formal and informal participation by Aboriginal women in the decision-making processes of the services. Other recommendations included the need to enhance internal organizational structures to increase communication among staff, to change staff hiring strategies in order to recruit more Aboriginal personnel, to expand services to include exclusive access times for Aboriginal women, to create educational programs for mothers parenting older children, and to increase attention to preventative health and advocacy needs.

Aboriginal women are experts on their own health care. This report integrates what we have learned from their expertise and provides recognition and support for future health service delivery strategies that would help improve Aboriginal women's health status.

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ABORIGINAL WOMEN EMPHASIZED THE IMPORTANCE OF AN ENCOURAGING, INFORMAL ENVIRONMENT, A MORE WOMEN-CENTRED FOCUS, MORE CULTURE-BASED PROGRAMMING, AND GREATER REPRESENTATION OF ABORIGINAL WOMEN IN THE DECISION-MAKING STRUCTURES OF HEALTH SERVICES.

# An Exploration of Women-Centred Care in the Context of Cervical Cancer Screening in Ethnocultural Groups

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Under-utilization of mainstream health services by women from ethnocultural minority groups has led to the development of specialized health services. These services provide an important focus for the study of women-centred care. The purpose of this study was to identify and describe critical elements of women-centred care within the context of three cervical cancer screening clinics in Vancouver that serve Asian, South Asian, and First Nations women. A further aim of the study was to identify the factors that influenced full implementation of women-centred care within these clinics. A collective case study design was used, with each of the three clinics treated as a separate case. The clinics serving Asian and South Asian women began as community-based initiatives and offered a limited number of evening appointments with services provided by women from the two ethnic communities. Because of challenges encountered in drawing women to the clinic, The First Nations Pap Test Clinic, a time-limited demonstration project developed by researchers and a community advisory committee, was not in operation at the time of the study but was included for comparative purposes. Data were drawn from open-ended interviews with key

informants from each clinic and with women from the Asian and South Asian communities. Women who had received services from the First Nations Pap Test Clinic while it was in operation were not included because of the time that had lapsed since the clinic's closure, but some of the people involved in the organization of the clinic were interviewed. A total of 35 women and 14 key informants participated in the study. Following thematic analysis, cross-case analysis was completed by comparing and contrasting issues and contextual factors influencing women's and providers' experiences.

The clinics' cervical screening services were characterized by attention to ethnocultural values, women's desire for thorough explanations, and the importance of a comfortable setting. While participation rates varied across clinics, women were positive about their experiences in obtaining cervical screening at the specialized clinics. Some women's expectations that they could address a range of health concerns with female health providers at the clinics were stymied by structural barriers that prevented staff from addressing issues beyond those directly related to cervical screening.

SOME WOMEN WOULD HAVE PREFERRED TO ADDRESS A RANGE OF HEALTH CONCERNS WITH FEMALE HEALTH PROVIDERS AND WERE STYMIED BY THE RESTRICTED MANDATE OF THE SPECIALIZED CLINICS.



Cross-case analysis revealed three key elements of women-centred care: respectful and culturally appropriate interactions between women and health providers; the importance of providing acceptable alternatives for women; and the need for comprehensive health services. Full embodiment of these components within the context of cervical screening was hampered by structures in the health care system. For example, we found that a woman's choice about which health care professional—a doctor, nurse practitioner or nurse—provides Pap testing services is limited by the fee-for-service model of reimbursement. This model does little to address women's preferences for female providers or to acknowledge the social context of women's health care concerns.

Evidence from this study shows that women were attracted to the Pap test clinics because they expected to be able to discuss health care concerns with a female health care provider. We recommend, therefore, that the mandates of

the clinics be revisited. Policies that support comprehensive women's health services that encompass, rather than segregate, cancer screening are required. Other models for providing health care to women in ethnocultural minority groups, including the use of clinics staffed by nurse practitioners, should be evaluated. Funding criteria should accommodate specialized services, as well as provide for complementary language services.

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## UNPAID CAREGIVING

# Caregivers' Support Needs: Insights from the Experiences of Women Providing Unpaid Care in Rural Nova Scotia

Joan Campbell, Gail Bruhm, Provincial Coordinator, Family Caregivers Association of Nova Scotia, and Susan Lilley

Rather than positioning unpaid family caregivers at the periphery of homecare policy, this study acknowledges their central role. Insights gathered from a group of 46 family caregivers in rural Nova Scotia point to a pressing need to recognize and support the contribution of this unpaid, almost exclusively female, sector of the health care system. The caregivers we spoke with report that the system does not value their role as primary caregivers, nor does it provide them with appropriate information, training, services and urgently needed respite care. Family caregivers need to be involved in shaping the policies, programs and treatment

choices that affect them and those they care for.

A major thrust of Canadian policy on both long-term care and health care reform is to shift care from institutions to communities. As seniors, the disabled, and the chronically ill receive less institutional care, more responsibility is transferred to their caregivers, who in most cases are family members. Yet governments are redirecting only a fraction of the savings from closing hospitals and substituting care by unpaid family members to provide support for those caregivers and care recipients in the community.

It is important to note that this national shift to community-based care is not gender neutral. The label “family caregivers” obscures the fact that women constitute the majority of caregivers. Two-thirds (66%) of unpaid family caregivers are women. This represents approximately 14% of all Canadian women over the age of 15. Of those caring for people with dementia, 72% are women.

The needs of caregivers are likely to be greatest, and the resources fewest, in small communities and rural areas. This research project used structured dialogue to gather the views and experiences of rural caregivers. We invited both male and female unpaid family caregivers to share and analyze their stories of caregiving. We wanted to obtain practical knowledge about formal and informal services, programs and supports for caregivers. Another aim was to give voice to and validate caregivers' experiences.

Data were collected and analyzed through four, day-long workshops, each held in a different health region of Nova Scotia. Nine to 16 caregivers participated in each workshop. Caregivers analyzed their individual and collective experiences through a process entailing structured dialogue, identification of insights, grouping of insights into themes, and the creation of narrative statements about each theme. Content analysis was carried out by the researchers, working

with the collected insights and narrative statements from all four workshops.

Study participants were selected from the non-urban population of Nova Scotia. The 46 caregivers who participated included Blacks, Aboriginals, and Acadians. Although the workshops were open to male caregivers, all of the participants were women, half of whom were between the ages of 31 and 50, and roughly one-third of whom were between 51 and 65. A few participants were over 65, and one was under 31 years old.

The majority of the participants described themselves as being on duty 24 hours a day, seven days a week. Fifteen percent told us they provided 24-hour care “with no relief” and 63% said they did so with “occasional relief”. The ages of the people they cared for range from four years old to nearly one hundred. While some have been providing care for only a few months, others have been doing so for as long as 40 years. The average length of time that had been spent providing care was 7.4 years.

Many of these caregivers have given up employment in order to provide care. Fewer than one-quarter have paid employment. Close to half of those who were not currently employed reported that they had left a paying job or changed jobs because of caregiving responsibilities.

**THE LABEL “FAMILY CAREGIVERS” OBSCURES THE FACT THAT 66% OF UNPAID FAMILY CAREGIVERS ARE WOMEN. OF THE WOMEN WHO PARTICIPATED IN OUR STUDY, MANY HAD GIVEN UP EMPLOYMENT IN ORDER TO PROVIDE CARE. THE HEALTH CARE SYSTEM NEITHER ACKNOWLEDGES NOR APPRECIATES THIS CONTRIBUTION.**

Four common themes emerged from caregivers' collective insights into their stories:

1. a need to see the work of caregivers valued and to value this work themselves,
2. personal needs, which were expressed in the phrase "surviving the caregiving trap",
3. practical needs for services and supports, financial assistance, and information,
4. and, health care system issues.

Additional themes were also significant, although not as important for these caregivers: the impact of caregiving on other family members; the positive aspects of caregiving; community responses to recipients of care; transportation in rural Nova Scotia; and making caregivers' voices heard.

Participants expressed frustration and dissatisfaction with the current support available from the Nova Scotia government, service providers, families, and communities. They felt that the government did not keep the promise it made to provide comprehensive community care when closing local hospitals. According to these caregivers, the shift from institutional to community care in rural Nova Scotia must be accompanied by a commensurate transfer of resources so that services become comparable to the best available in urban centres. More support services, better matched with caregivers' actual needs and the needs of those they care for, as well as information on how they can provide care more effectively are needed. These caregivers spoke candidly about the considerable burden of responsibility associated with caregiving. Above all, they expressed a need for more respite or relief time to care for themselves, so that they can maintain their own health to carry out their caregiving role and contribute to their communities.

The caregivers who participated in this study have four critical messages for policy makers:

1. Recognize caregivers' contributions. The health care system neither acknowledges nor appreciates their contribution as

primary care providers. This lack of recognition results in frustration and in inappropriate services and programs. Health policy must recognize caregivers as essential to the success of homecare programming.

2. Engage caregivers in the policy process. Although Nova Scotia's *Blueprint for Health System Reform* (1995) recommended that informal caregivers be included in policy development and planning, these caregivers do not feel they have been included. They believe their knowledge, experience, and personal stake in the outcomes are essential ingredients for homecare policy development. They have many practical suggestions for supports and services, and they are prepared to make their voices heard. Improvements in policy and programs are more likely if caregivers are partners in the decision-making process.
3. Provide support services and information. These caregivers feel trapped in a downward spiral of stress and ill-health that impairs their effectiveness as caregivers. The service they most need is timely and appropriate respite care.
4. Value caregivers' work. By reducing costly institutional care through free labour, unpaid caregivers subsidize health reform and contribute substantially to the economy. Caregivers want compensation through payment for their work, tax relief, pension benefits, or other means. Sustainability of a community-based health system that relies on family care depends upon providing compensation to family caregivers.



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# Caregivers and Support Services: Becoming Empowered

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## Introduction

This study was undertaken to improve our understanding of how to provide support to women who give unpaid care to family members. Specifically, we were interested in learning about the support needs of caregivers, their expectations regarding support services, the adequacy of existing services, and which services, interventions or practitioners facilitate caregiver empowerment, if any. These goals required us to examine how existing services are organized, as well as how they are used by caregivers.

## Theory

This study uses an empowerment framework. Empowerment is not something that one provides to another person, but rather something that one enables. The literature suggests that key steps in empowerment include personal development, political action, and participation with peers. Critical reflection of, for example, the sex-based division of labour that leads to caregiving as women's work, constitutes a step towards feeling empowered. For the purposes of this study, then, we defined empowerment as "a social process through which people increase their power, mastery or control over their own lives and eventually contribute to social changes that improve their quality of life and that of their peers." Group participation is at the heart of empowerment interventions. Antithetical experiences are those that lead to feelings of helplessness, dependency, being trapped, and having no control or choice.

## Methods

This study investigated the Caregiver Support Centre (CSC) at CLSC René-Cassin in Montreal. The CSC focuses on the caregiver, offering diverse services in a flexible manner that are integrated with other CLSC services and based on user consultation. Twenty-eight study participants were recruited from among women who were using the CSC services. For

comparison, four additional caregivers who used other support services were also interviewed. The study was conducted using phenomenological and qualitative methods.

The caregivers were selected on the basis of their relationship to the care receiver (spouse or daughter), the diversity of services they used, and their family circumstances. Study participants were recruited with the assistance of CSC or CLSC staff. Caregivers were initially contacted by practitioners who explained the objectives of the study and obtained the women's consent to participate. Research team members then contacted the women for interviews.

## Study Participants

The study sample included 32 caregivers, 16 of whom were wives and 16 daughters. The mean age of the wives was 73.5 years and the mean age of the daughters was 55.6 years. Wives were providing care to their husbands while the daughters were providing care to their mothers. The mean number of years that the women had been caregivers was 8 years for the wives and 6.25 years for the daughters.

With respect to use of CLSC services, the Drop-in was visited as often by the wives as the daughters. Wives were more likely, however, to use the Foyer to socialize and to attend conferences than were the daughters.

Caregivers also used other home care services from both the private and public sectors. One wife and six daughters received respite through in-home help from the CLSC. Six wives and seven daughters used private in-home help for their family member. Five wives and 14 daughters had assistance with bathing provided by the CLSC. Seven wives and nine daughters received private home help with housework.

### Caregivers' Needs and Expectations

The first objective of this research was to understand the needs of caregivers and their expectations of service delivery. Caregivers reported that they needed: more respite time; moral support (often undervalued in favour of practical or material support); information about the care receiver's illness, especially at the beginning of the caregiving process; help with house work, transportation, accompanying the care receiver, care receiver's personal hygiene and activities of daily living; financial assistance in order to hire home care help to spend time with the care receiver, do domestic work, pay for medications, provide transportation and accompany the care receiver; and recognition and support for their legal rights (some caregivers have to fight to obtain services or oppose legal decisions that concern them or their family).

Caregivers' expectations were found to vary according to the care receiver's needs and the urgency to meet those needs. Caregivers' expectations also evolved over time as they used services and came to depend on the services' minimum threshold of response to their needs or questions. Caregivers were also concerned about their own social integration, their perceived social value, and their ability to maximize their own potential. They wanted to be able to anticipate the future and tried to prepare for it by gathering information through research on what to expect and what measures should be taken.

### Empowering Caregivers

In order to improve support to caregivers, another objective of this study was to understand the way available services are

organized and used. Having a range of different services to choose from and having the option of combining them allowed caretakers to meet a variety of their needs. But combining services is only an option when services are available from different sources, as is more likely the case in respite care, and proposed or available services are not always suitable for a particular caregiver. Coordination of services can become another activity in itself. Nevertheless, flexibility in organizing services leads to greater caregiver control over the planning of daily activities and makes it easier for caregivers to meet their individual needs.

A third objective of this study was to identify which services, interventions or practitioners contribute to caregiver empowerment. We found many things enhanced caregivers' feelings of empowerment, including respite care, having someone to count on, feeling able to freely express ideas and concerns, and understanding the family member's illness. Respite or free time, for example, contributed to empowerment for some caregivers because it provided a few hours a week for the caregiver to relax or do essential errands. Knowing that they could count on someone for support was also key to a sense of empowerment. Being able to express themselves freely, knowing that there was someone to confide in who would legitimize their feelings, also freed caregivers from the burden of the perceived judgement of social norms. It was also important for caregivers to understand the care receiver's illness: this entailed access to information, whether for dissemination or for their own understanding. Improved understanding of the illness enabled the caregiver to respond more

CAREGIVERS ARE VULNERABLE TO FEELING THAT THERE ARE NO ACCEPTABLE LIMITS TO THEIR CAREGIVING. DECONSTRUCTING THE SOCIAL NORMS OF CAREGIVING AND THEIR RELATIONSHIP TO GENDER ROLES LEGITIMATES WOMEN'S EFFORTS TO MEET SOME OF THEIR OWN NEEDS AS WELL AS THOSE OF THE CARE RECEIVER.

appropriately to the course of the illness and to experience an improved quality of life.

Caregivers are vulnerable to feeling that there are no acceptable limits to their caregiving. Actively deconstructing the social norms of caregiving and their relationship to gender roles contributes to the development of an alternative perspective, which can legitimate women's efforts to meet some of their own needs as well as those of the care receiver. To feel appreciated by others and to appreciate themselves is an empowering experience for caregivers.

We found that caregivers appreciate being guided and directed. Assistance with finding their way through the health care system is an important act of support and reduces worry and workload. Obtaining suitable, flexible services enhances empowerment because such services enable caregivers to individualize care according to their needs.

Ties of solidarity, reciprocity and friendship through support groups, especially long-term groups, encouraged empowerment because caregivers could provide each other with information and practical knowledge. Mutual aid and feelings of solidarity were mentioned as factors that improve self-image and feelings of competency. Taking social action to change conditions for all caregivers and to gain greater control over resources also resulted in feelings of empowerment.

Factors that hinder empowerment included a lack of recognition of caregivers' needs, whether this arose from a lack of understanding about caregiving or a conflict of opinions and values. The health care system, for example, does not recognize caregiving as an alternative to placement. Another factor that discouraged empowerment was the devaluing of caregivers' skills in situations where caregivers needed to provide information about the care receiver and couldn't make themselves understood. Confrontations with technocratic services also tended to lessen caregivers' participation and power in choosing which services would be most useful. Difficulty in obtaining adequate services may also lead to feelings of helplessness. In particular, caregivers were discouraged by services that were only intermittent, often withdrawn, or had waiting lists.

## Recommendations

On the basis of our study we recommend that:

1. There should be on-going training programs for practitioners and decision-makers on issues related to caregiving.
2. At the university level, students who will work with caregivers and care receivers as helping professionals in the future should receive appropriate training and education.
3. Practitioners should act as contact persons as well as organizers of services for caregivers.
4. Files should be kept on caregivers as distinct from care receivers. Caregivers should participate in the identification of their needs.
5. Service delivery should take gender into account, as well as age, socio-economic status, cultural expectations, and the relationship between the care receiver and caregiver.
6. A variety of support groups (combining information, therapy, leisure, self-help and mutual aid) should be available to meet variations among caregiver needs.
7. A minimum level of services should be available in all community and social service centres and integrated in such a way that caregivers would have access in their relative's area, even if the caregiver lives elsewhere.
8. A comparative study of public and private home care service provision is needed.
9. If possible, the same public support personnel should remain involved with a case to maximize continuity.

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## MIDWIFERY

## Challenges of Integration: Perspectives on the Regulation of Midwifery in British Columbia

Jude Kornelsen, Visiting Scholar, University of British Columbia, School of Nursing and Elaine Carty, University of British Columbia, School of Nursing

After a long and arduous struggle stretching back more than two decades, midwifery in British Columbia began its tenure as a legalized and publicly-funded profession on January 1, 1998. This was a cause for celebration for the midwives and consumer groups who had worked for legalization, and for the birthing women in British Columbia who could now enjoy a pluralistic birthing environment. However, as with any social change, there have also been unanticipated consequences. To evaluate these, researchers at the British Columbia Centre of Excellence for Women's Health are examining some of the effects of the legalization of midwifery. The program of research, which considers the integration of midwifery from various perspectives—consumers, midwives, other maternity health care providers—endeavours to lay the foundation for continued research within the province as well as for inter-provincial and international comparative research.

Three papers have been completed in the *Perspectives on Midwifery* series. The first, "Reality, Opinion and Uncertainty: Views on Midwifery in BC's Health Care System," considers the way information was provided to practitioners and administrators—and their response to it—prior to the registration of midwives through the provincial Home Birth Demonstration Project Tour. The tour, undertaken by the Ministry of Health and the Ministry Responsible for Seniors, presented information about midwifery and home birth to hospitals around the province. A researcher accompanied the

tour to most of its destinations in order to observe how information was disseminated and how the practitioners and administrators who attended responded to the committee. A clear sense of the underlying concerns with midwifery was evident in the questions that were posed and in the response to the committee. This study, which includes recommendations regarding the presentation of midwifery to other professions, provides part of the context for understanding inter-professional relationships when a new profession is introduced into the health care system.

The second paper in the series, "In Transition: Nurses Respond to Midwifery Integration," explores perinatal and community health nurses' knowledge, attitudes and beliefs about midwifery practice in British Columbia as midwifery was being introduced into the health care system. Specifically, it investigates the level of knowledge obstetrical nurses had about midwifery licensure qualifications and scope of practice as mandated by the College of Midwives. We also explored the beliefs of obstetrical nurses regarding the impact of midwifery practice on the quality of care, health care costs, nursing practice and inter-disciplinary relationships. Quantitative and qualitative data showed nurses' attitudes towards midwives ranged from supportive to hostile. Strongly negative reactions were correlated with misinformation about midwives' skills, training requirements and scope of practice. Recommendations for in-services and other educational forms are made based on the findings of this study.

THE LEGALIZATION OF MIDWIFERY IN BC WAS A CAUSE FOR CELEBRATION AMONG MIDWIVES AND CONSUMER GROUPS AND A SOURCE OF TENSION IN THE INTER-PROFESSIONAL RELATIONSHIPS BETWEEN MIDWIVES, NURSES AND PHYSICIANS.

Phase Two of the project involved re-administering the survey to measure changes in knowledge, attitudes and beliefs that occurred during the eighteen-month period after regulation. This second paper will be available early in 2001.

A policy paper, "Pushing for Change: Challenges of Integrating Midwifery into the Health Care System," rounds off this first series by summarizing the immediate inter-professional challenges faced by midwives as newcomers to British Columbia's health care system. Working from a historical context to understand current inter-professional relationships, the findings of the Home Birth Demonstration Project Tour and of the study of registered nurses' attitudes and beliefs are used to suggest reasons why some nurses and physicians object to midwifery. The implications of these relationships for patient care and the profession of midwifery are explored, and recommendations are made to a variety of health authorities and professional organizations for ways to improve relations.

Our second series of studies, "Structural Influences and the Regulation of Midwifery," considers how policy and legal parameters have affected the practice of midwifery in a regulated environment. The first paper, "Experiences of Registering to be a Midwife in BC," is an applied ethnographic study that investigates the experiences of the first group of women who applied to register. In the paper we report on the participants' experiences of each step of the process and their comments about the more global aspects of their experiences of assessment.

We found that the nature of the experience for each applicant depended primarily on five factors:

1. the applicants' primary site of practice before the assessment process (home or hospital);
2. the nature of the applicants' training (nursing training or apprentice/direct entry training);
3. the applicants' geographical location in the province (rural or urban);
4. whether the applicant was in a position of political influence;
5. whether the applicant spoke English as her first language.

These recommendations work towards establishing a more equitable process for registration that would increase both the number and diversity of midwives in the province.

The second paper in this series is titled "Life as a Registered Midwife," and documents how registration has had an effect on midwives' professional and personal lives. In-depth interviews were done with 35 midwives from across the province to see whether there have been changes in their scope of practice as defined both by the regulations of the College of Midwives and the state of inter-professional relationships with general practitioners, obstetricians and perinatal nurses. We also examined the process of applying for and receiving, or not receiving, admitting privileges to hospitals and changes in the nature of clientele compared to pre-regulated practice. This paper will be available January 2001. Several other studies are still under way, including a study of family physicians' attitudes towards midwives in BC (forthcoming) and a study of women's satisfaction with their birth experiences that compares the care given by midwives and physicians in hospital.

Taken together, all current and forthcoming studies within the program of research provide a glimpse into the changes that have been brought to the maternity health care environment in BC by the profession of midwifery. They also provide a foundation for further investigations that will be taken up by the Midwifery Research Group. The MRG is a joint undertaking between the BCCEWH, St. Paul's and BC Women's Hospital's Department of Midwifery, and the University of British Columbia, made up of individuals with a commitment to on-going midwifery-related research. Its mandate is to gain funding and support for the development of a strategic program of research for clinical and non-clinical midwifery-related topics. The groups' interest in midwifery is not limited to the British Columbia experience: we are also looking at comparing the experience in British Columbia to that of other provinces and to international data.

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## MIDWIFERY

## Midwifery Care: Women's Experiences, Hopes and Reflections

Lorna Breitzkreuz, Cathy Ellis, Midwives Association of Saskatchewan, Meaghan Moon, Manitoba Traditional Midwives Collective, and Cindy Hanson, The International Midwifery Day Committee

The midwifery philosophy of care considers birth within the social, biological and psychological context of women's lives. This holistic view translates into a model of practice that places women at the centre of control of the birth experience. Until recently, midwives practising in Manitoba and Saskatchewan have, for the most part, been accountable to the women they serve. However, with the move to regulation and the recognition of midwifery as an autonomous profession, changes in the delivery of midwifery services are inevitable. The purposes of this project were to document women's experiences of midwifery care, to determine if the kind of care women received from their midwives was satisfactory, and to see if this care corresponded with what midwives think women want.

### Methods

We used a participatory approach to gather data from both midwives and women who received care from midwives. Using this approach, investigators were participants as well as project researchers. The research team consisted of three midwives, three consumer interviewers and one midwifery

consumer, most of whom belong to midwifery associations and consumer groups. Researchers consulted members of their respective groups in the development of the project. A total of 16 women who had used midwifery services participated in open-ended interviews about their experiences with midwifery. Four midwives in Saskatchewan and seven in Manitoba participated in focus groups in which they discussed their beliefs regarding the care women were looking for from midwives. Both the interviews and focus groups were tape recorded and the tapes transcribed and analysed for themes.

### Findings From the Mothers

Dominant themes that emerged from the interviews with the mothers fell broadly into three categories: the issues associated with accessing a midwife, the quality of care and quantity of the time that midwives spend with women, which encompasses the personal care and support women felt midwives gave them and their families and the style of care or practice that midwives provided, and, thirdly, recommendations for policy development on midwifery.

**WOMEN FELT THAT THE PERSONALIZED ASPECTS OF MIDWIFERY SERVICES FAR EXCEEDED THEIR EXPECTATIONS AND SHOULD BE PRESERVED THROUGH REGULATION BY ENSURING WORKLOADS THAT WILL PERMIT CONTINUED QUALITY CARE.**

## Access

Knowing where and how to find a midwife was a great challenge for many women. Women spoke about a lack of information to help them find a midwife; chance often played a role in locating one. Rural women were particularly disadvantaged in obtaining access to midwifery care. Cost was also a factor in limiting women's access to midwifery services, although every woman in this study found ways to overcome financial obstacles.

## Quality of Care and Quantity of Time

The length and frequency of midwifery visits surpassed the expectations of study participants. The mothers reported that the quantity of time midwives spent with them allowed them to ask questions, explore a variety of aspects of birth, and to develop a positive relationship with the midwife. Personalized care and support included home visits, being given sufficient resources to make informed choices, and care that was consultative but not directive. These factors contributed to women feeling empowered and personally strengthened by their midwife-assisted birth. Women also felt that their family as a whole was supported by the midwife. Midwifery care was described as holistic, unobtrusive, low-tech and competent. The women were surprised at the level of post-partum care and described midwives making meals, giving sponge baths, taking laundry home, cleaning the house and being available to talk during the post-partum period. All of these elements of care fostered strong feelings of trust and safety between the women and their midwives.

## Findings from the Midwives

Each of the midwives' focus groups identified five elements they believe that women want from midwifery. In Saskatchewan these were: cost of care, the midwife's experience and training, the midwife's philosophy, continuity of care by familiar caregivers (the same midwife/partner attending the woman throughout pregnancy, labour, delivery and postpartum, with emphasis on labour and delivery), and competence (the belief that the midwife could detect and deal with most problems). Midwives in the Saskatchewan focus groups also thought that women considering home births would be concerned with the political aspects of midwifery.

Midwives in Manitoba thought that women wanted to know about the midwife's scope of practice, her philosophy, and her background and training. They stated that women wanted individualized care and a commitment to the woman during the childbearing year. They believed that cost of care was also of concern to most women.

## Recommendations

The goal of this research project was to find out if midwifery clients felt that their needs were being met by midwives. Reflecting upon their experiences in answer to this question, women recommended that there be:

1. public funding of midwifery services,
2. midwifery services in rural and northern communities, as well as in urban centres,
3. regulation of midwifery as an autonomous profession;
4. workloads that permit time for quality care,
5. midwifery practice available in a variety of settings, including home, hospital and birth centres,
6. continued personalized services in the home, and
7. education campaigns demonstrating the value of midwifery services targeted to medical personnel, health administrators, and the public.

As midwifery is currently in the process of being regulated in Saskatchewan and Manitoba, this project provided a timely opportunity for midwifery clients to suggest policy recommendations.

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