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## Who Cares?

Providing care to people in their own homes is frequently seen as a rational and cost-efficient alternative to institutional care, made doubly attractive by the fact that most care recipients express a preference for care that allows them to remain in their own homes. Much of this care is provided by unpaid caregivers, as well as nurses, home health aides, personal attendants and other home care service providers. As noted by the National Forum on Health (1997), "Home care services can assist in preventing, delaying or substituting for long-term care or acute care alternatives."<sup>1</sup> It is also important to consider that caregiving in the home is usually understood as women's work, performed as a labour of love for family or friends. This view masks the fact that unpaid caregiving is work that requires time, skills and resources and may not always be voluntary. Who provides care in the home, and under what conditions, is not just a personal matter. It is affected by decisions made to manage costs in the health care system.

New research from the Centres of Excellence for Women's Health asks us to take a closer look at the tasks, meanings and consequences of caregiving in the home and in relation to health care reform. Applied to this research, the question *Who Cares?* elicits a double meaning. Taken literally, the answer is women, as women represent the majority of paid health care workers in institutions and paid and unpaid health care workers in the home. There is a second meaning to the question. Participants in a number of the studies reported on in this issue of the *Research Bulletin* declare that we are *not* caring enough about paid and unpaid caregivers and care recipients.

It is hard to talk about the human experiences of illness, disability, rehabilitation and death and the ways in individuals and communities do or do not support these experiences. The studies presented here illuminate

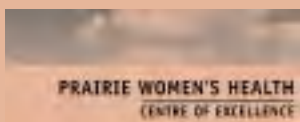
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and Health Centre  
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Vancouver, BC  
Canada V6H 3N1  
www.bccewh.bc.ca  
Tel: (604) 875-2633  
Fax: (604) 875-3716  
bcccewh@cw.bc.ca



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Tel: (204) 982-6630  
Fax: (204) 982-6637  
pwhce@uwinnipeg.ca



National Network  
on Environments and  
Women's Health

**National Network  
on Environments  
and Women's Health**  
Centre for Health Studies  
York University  
4700 Keele Street  
Suite 214 York Lanes  
Toronto, ON  
Canada M3J 1P3  
www.yorku.ca/nnewh  
Tel: (416) 736-5941  
Fax: (416) 736-5986  
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www.medicine.dal.ca/acewh  
Tel: (902) 470-6725  
Toll Free: 1-888-658-1112  
Fax: (902) 470-6752  
acewh@dal.ca

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**Centres of Excellence  
for Women's Health**  
Women's Health Bureau  
Health Canada  
Postal Locator 1903C  
3rd Floor  
Jeanne Mance Building  
Tunney's Pasture  
Ottawa, ON Canada K1A 0K9  
Tel: (613)952-0795 Fax: (613)941-8592  
cewhp@hc-sc.gc.ca



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<b>Copy Editor/Proofreaders</b>	Translation Group Limited Robyn Fadden, Lynnette D'anna, Carole Maillet

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## ■ In the end, someone, whether family member, paid health care provider, or a combination of both, must care.

cont'd

some of the day-to-day realities of diverse caregiving situations: family members and health professionals caring for stroke survivors, mothers caring for children with cancer and palliative care workers (friends and paid caregivers) caring for people with AIDS. These studies also investigate the circumstances of paid caregiving in the home and hospital in an environment of restructuring, and the emerging reality of paid caregivers passing on caring tasks to unpaid caregivers. Indeed, some of the research presented here shows how the boundaries between the two groups of caregivers blur as family members are required to provide highly technical medical care or to be on-call to the care recipient 24/7. These diverse situations demonstrate that, in the end, someone, whether family member, paid health care provider, or a combination of both, must care.

The National Forum on Health warned of the potential for health system reform to impose burdens on women, arguing that “community-based care” should not “become a euphemism for the conscription of women to provide unpaid health care services.”<sup>2</sup> While caregiving can be a deeply meaningful experience, it may also impose psychological, social and economic costs upon the caregiver. A consistent recommendation from the studies highlighted here is that caregivers and care recipients alike require more support in order to sustain home care as a viable option for

health care. A significant challenge raised in this issue of the *Research Bulletin* is how to support caregivers with sufficient resources. At the same time, how can we create choice so that women who do not have the time, resources, skills or desire to care are not conscripted into it?

Who cares? We all should because over our lifetime we are all likely to require care, and many of us will find that we are needed to provide it. As one step towards creating better conditions for care—in the home or elsewhere—delegates to the National Think Tank on Gender and Unpaid Caregiving (November 2001) drafted the Charlottetown Declaration on the Right to Care. Reproduced in its entirety here, the declaration stresses that home care needs to be the objective of a publicly funded health care system—so that everyone will care.

Ann Pederson  
 Manager, Policy and Research  
 British Columbia Centre of Excellence for Women's Health  
 apederson@cw.bc.ca

### NOTES

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## COSTS AND BENEFITS OF CAREGIVING

## Final Payments: Socioeconomic Costs of Palliative Home Caregiving

*This article presents the preliminary findings of a study conducted by three of the Centres of Excellence for Women's Health. It has been prepared by members of the research team, Lorraine Greaves, Olena Hankivsky, Georgia Livadiotakis, and Renée Cormier of the British Columbia Centre of Excellence for Women's Health.*

Palliative care, aimed at the relief of suffering and improving the quality of life of people who are dying, is a significant part of home and continuing care programs in Canada. Formal (paid) and informal (unpaid) care providers may be involved in caring for a dying person. Research has often overlooked the social, psychological and economic costs of such caregiving. In addition, there has been no gender analysis of the costs to paid or unpaid caregivers of providing this care. However, it is established that most home and community care is provided by women family members and friends on an unpaid basis. These women often incur substantial costs and experience a physical and emotional toll related to their caregiving role.<sup>1</sup>

*Final Payments: Socioeconomic Costs of Palliative Home Caregiving in the Last Month of Life* (2002) is a pilot study based on retrospective interviews with 81 male and female palliative caregivers from three provinces who cared for a person with cancer or AIDS. People with cancer and AIDS receive the most palliative care in Canada. The sample was designed to include a mix of male and female (paid and unpaid) caregivers, and male and female patients. Data were collected and analyzed to determine gender differences, differences between formal and informal caregivers, and regional (British Columbia, Quebec and Nova Scotia) and diagnosis-related differences.

A cost-identification process was used to estimate the social, economic, emotional, psychological and spiritual burden on the caregiver during the last month of the patient's life. To assess economic costs, caregivers were asked to estimate how many hours they spent per caregiving task, and the total number of caregiving hours per week. They were also asked to estimate lost income and any compensation that they received. These measures revealed that informal caregivers performed approximately \$6,000 worth of caregiving labour in the final four weeks of the patient's life. (Informal caregivers spent roughly 79 hours per week and formal caregivers roughly 26 hours providing care in this period.)

Unpaid caregivers, as expected, incurred more out-of-pocket expenses than paid caregivers. In addition, 75% of unpaid caregivers reported having to travel away from home at their own expense to give care. Significant gender differences were evident in costs incurred. For example, female caregivers of AIDS patients were more likely than male caregivers of AIDS patients to purchase medical items for their patient.

Female and male caregivers (both formal and informal) differed in the nature of the tasks they undertook and the support services they engaged. Females were more likely to dress their patient and obtain services such as massage, while males were more likely to assist with financial and legal

**■ Unpaid caregivers performed approximately \$6,000 worth of caregiving labour in the final month of the patient's life.**

affairs and to obtain individual counselling services for their patients. Female informal caregivers spent more time in caregiving tasks and were most likely to report a physical impact from their efforts. In addition, female informal caregivers of cancer patients reported the biggest impact on their family life as a result of caregiving.

In self-assessments of caregiving work, twice as many informal caregivers as formal caregivers reported feeling dissatisfied with the care they gave. Among informal caregivers, almost twice as many females expressed this when compared to males. Regrets about impatience, not spending enough time with the patient and wishing they had been more open about death were some of the comments. These retrospective wishes are possibly reflective of the responsibility for emotional caregiving that women may take up in relationships and family life.

The caregivers reported spiritual and psychological experiences that ranged from discovering greater meaning to becoming emotionally exhausted. More than half of the informal caregivers reported that the most difficult aspect of caregiving was watching the patient deteriorate and knowing they were going to die. "There is such a sense of helplessness," a caregiver from Nova Scotia said. "No matter what, you know the outcome." In general, male and female caregivers reported equal rates of emotional hardship.

Perhaps not surprisingly, a key element of the findings relates to the benefits rather than the costs of providing palliative home care. Ninety-four per cent of all caregivers reported that their experience gave meaning to their lives. "What I did for him was important," one caregiver said. "This gave me some consolation." Another reported, "[I knew] I had done something for someone, especially when they are deserted by their own family because of AIDS."

As would be expected, different diagnoses indicated different kinds of caregiving teams. Caring for AIDS patients usually

involved friends as informal caregivers. Cancer patients usually had family members or spouses as carers. Caregivers of AIDS patients were more likely to purchase specific items to assist in the caregiving, and more often reported economic hardship in their patient's family as a result of the caregiving effort. Cancer caregivers were more likely to request additional, skilled nursing services than AIDS caregivers.

This study reveals some gender differences in palliative caregiving, but gender was less predictive than the formal/informal status of the caregiver in defining the experience of the last four weeks of a patient's life. Perhaps the most revealing data, however, emerge from the recommendations made by the caregivers, who called for more training and education on palliative care and more efforts to remunerate unpaid caregivers through compensation or tax schemes that would recognize and facilitate their involvement in palliative caregiving.

For a full copy of *Final Payments: Socioeconomic Costs of Palliative Home Caregiving in the Last Month of Life* contact:



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## NOTES

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## COSTS AND BENEFITS OF CAREGIVING

## Mothers Caring for Children with Cancer

Juane Clarke, Paula C. Fletcher, Wilfrid Laurier University, Margaret A. Schneider, University of Waterloo, National Network on Environments and Women's Health

Each year an estimated 1,300 to 1,400 children in Canada are diagnosed with childhood cancers, joining the 8,000 to 10,000 children who are already coping with the diseases.<sup>1</sup> Considerable research has been done on the impact of psychosocial variables, such as social support and coping and adjustment, on the parents of children who have cancer.<sup>2</sup> Much less is known about the health care that mothers provide in the home to children who have cancer or the impact of this care work on the women's own health and well-being.

The research described in this article represents the first part of a three-year study of mothers of children with cancer. The objectives of the research carried out in 2001 were to explore the specific caring tasks that these women perform and to capture the women's perceptions of the health impact of those tasks. We conducted 10 focus groups in cities in Ontario and Quebec with a total of 49 mothers whose children had been diagnosed with cancer during the previous five-year period. The women ranged in age from 29 to 50 years old. A wide variety of ethnic and cultural backgrounds was represented.

The majority (53%) of the women's children had been diagnosed with Acute Lymphoblastic Leukemia (ALL), a rapidly progressive, acute form of leukemia characterized by the presence of too many under developed infection-fighting white blood cells, called lymphocytes, in the blood and bone marrow. Like all blood cells, leukemia cells travel through the body. Depending on the number of abnormal cells and where these cells collect, patients with leukemia may have numerous symptoms including fever and chills, anemia, frequent infections, weight loss and easy bleeding or bruising.<sup>3</sup> In our study, the children with ALL and those with other forms of cancer had been cared for, on average, 27 months in hospital and 45 months in the home.

We used two qualitative methods to analyse the data. The first was Patton's (2002) method of phenomenological analysis.<sup>4</sup> (Phenomenology emphasizes the meanings people

give to their experiences.) The second method, grounded theory and Strauss's (1967) constant comparative method,<sup>5</sup> allows for a comparison of experiences among participants, revealing commonalities and differences. Using audiotapes recorded during the focus groups, we analysed and coded data according to emerging themes.

A significant finding was related to the impact of health care work on paid work. Of the women who had been working outside of the home when their child was diagnosed (60%), over 42% had to leave their jobs to care for their child.

**■ "I had to learn how to give injections. I had to learn how to use the [drug delivery] pump."**

Others (19%) had reduced the number of hours they worked, or changed the nature of their work (7%). Only two women's paid work lives had not changed. In contrast, although the majority of the women in the study (90%) were married or living with a partner, only 2% of their partners had stopped work. Of these partners, 49% reported that their work lives had not changed.

The women's description of their health care tasks reveal three categories of work: illness management, emotion work (expression or management of emotion in the interests of another), and the work of establishing boundaries and limits with family members in order to care for their children and work within the strictures of the health care system.

Advocacy was a primary task of illness management within the health care system. The women acted as advocates to ensure that their child's medical needs were met and that

mistakes in treatment were not made. “Something that you realize very quick when your kids are sick is that you have to be there,” one woman said. “You may have to step on a few toes.” In order to access treatment, most of the women drove their children to primary treatment centres that were, on average, 165 kilometres away. In most cases (95%), the treatment the children received was chemotherapy; in addition, 58% had undergone surgery and 46% had had radiation. The women said it was necessary for them to monitor all aspects of treatment, often performing the tasks of a makeshift nurse once their child returned home.

One woman, who described herself as being “the least medically capable person” before her child got sick, details some of the skills she had to learn in order to care for her child. “I had to learn how to give injections. I had to learn how to use the CAD [computerized ambulatory drug delivery] pump. In the middle of the night one night, the VON [Victoria Order of Nurses] came and we programmed the pump incorrectly, so I was on the phone, almost 3 hours, talking to the nurse [who said], ‘Are you comfortable with changing the [IV] bag?’ And I said, ‘That doesn’t enter into it. Tell me how to do it.’”

“Emotion work” refers to tasks that involve managing one’s emotions and putting aside one’s own emotional response to care for someone else. In this context, it may mean doing so to ensure the smooth functioning of the medical care system or the family. Some women described feeling a profound degree of fear and the necessity of coping with it without sufficient support from medical staff. “When you are on treatment there is a safety zone,” one woman explained. “When you are off then you wonder if [the cancer] is going to come back. There is no way of knowing until they are off the treatment and start living without the medicine to see

what the body actually does. Those few months are scary. I tried to explain that to certain people—to the nurses, to the doctor. I felt that I was given a kind of false hope at the time. I thought, there needs to be some kind of emotional *something* that can help you live with the fear.”

The women also dealt with the responses of other family members to the child’s illness, as well as with family members’ other personal needs. “It’s not just the kid that has cancer, it’s your other children, your husband, your extended family, you know, dealing with all of that,” one mother said. “How do we deal with the other child that has other disabilities, or the healthy child, supposedly? All problems become magnified.” Another woman said, “The hard part too is the guilt ... We know, humanly, that it is impossible for us to be there for our other children.”

Some women had to establish new boundaries with family. One woman scheduled family members’ visits so as not to interfere with the child’s medical treatment. “[My mom] would say, ‘Why can’t I come to the hospital at this time?’ and I would say, ‘You can’t because of this schedule and these are the hours, and she would say, ‘Well that doesn’t suit me best.’” In contrast, some women noted that their families were extremely supportive.

Women said that performing home health care work was tiring and frustrating. As one woman said, “Sometimes we don’t have much left ... because you’re emotionally drained, you’re physically drained, financially drained... It’s very hard to give when you have nothing to give.”

Over the next two years we will continue to collect data about mothers of children with cancer through focus groups

**■ “When you are on treatment there is a safety zone. When you are off then you wonder if [the cancer] is going to come back. There needs to be some kind of emotional something that can help you live with the fear.”**

and interviews in Ontario and on the east and west coasts. We hope this research will lead to recommendations for systemic changes within health care policy, the hospital setting and home care to improve mothers' access to support and ameliorate the detrimental impacts of caregiving on their health and well-being.

The full report, *Women's Health Work with Children with Cancer*, can be obtained from:



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www.yorku.ca/nnewh  
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Fax: (416) 736-5986  
nnewh@yorku.ca

## NOTES

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## COSTS AND BENEFITS OF CAREGIVING

# Always On-Call: The Health of Informal Caregivers for Seniors

Pamela Hawranik, Associate Professor, Faculty of Nursing and Centre on Aging, Laurel A. Strain, Professor, Faculty of Arts and Director of Centre on Aging, University of Manitoba, prepared for the Prairie Women's Health Centre of Excellence

Providing care to a family member or friend can involve a progressive increase in care responsibilities over a period of years while the caregiver continues to fulfil the demands of employment, meet their own personal needs and those of other family members. The impact of caregiving can hold serious consequences for a caregiver's physical and psychological health. To examine the nature of this impact, we asked informal caregivers of seniors to share their experiences of caregiving and to discuss the factors that affected their health and their ability to manage caregiving along with their paid work and other responsibilities. We used several methods. The summary presented here addresses findings from focus groups and

interviews with 30 informal caregivers and a workshop with community service providers that were conducted in Winnipeg in 2000.

People were considered caregivers if they assisted a family member or friend over the age of 65 with everyday activities such as preparing meals, shopping, bathing or transportation. Twenty-four of the thirty caregivers were female. Of the 30 caregivers, 14 were spouses, 13 were adult children, two were other relatives and one was a friend. Twenty-five of the caregivers were providing care to one older adult and five were caring for two older individuals. Thirteen of the older adults had some form of cognitive



impairment. None of the caregivers received any direct financial reimbursement for providing care.

Five broad themes emerged from the discussions. The first had to do with the impact of caregiving on health. Fourteen of the thirty caregivers stated that their health worsened during the caregiving period. They identified both physical and emotional symptoms as responses to the older adult's behaviour or care needs. The symptoms included sleeplessness, crying episodes and fatigue. One woman, who cared for her husband who has cognitive impairment, said, "I get these crying jags and that's why I thought maybe things were getting a little hard for me." Another woman who was employed part-time and also cared for her mother who has Alzheimer's disease said, "I was so exhausted for a couple of years that I would come home and go to bed at 6:00 at night and get up in the morning at 6:00 —twelve hours." Caregivers who identified psychological problems indicated that caregiving was one contributing factor operating in conjunction with other life events. They stated that they felt an unending responsibility for their family member or friend. This sense of responsibility never left them, even when a hired worker remained with the older adult while they were absent. "I can never quite get them out of my mind," one caregiver said, "I'm always kind of on-call for them."

A second theme emerged when several caregivers described how caregiving took a toll on their friendships and their relationships with others. "It's a gradual isolation," one woman said. "Your life and part of your activities and part of who you are get dropped one by one." Others noted that, over time, friends displayed reluctance to contact them, and the caregivers themselves stopped phoning or going out with friends. A married caregiver caring for her parents said, "We must arrange our lives to ensure someone who can be trusted is with my parents. My husband and I...we never went on a holiday for three years." In most cases at least one family member lived near the caregiver or could be reached by telephone for advice or help. This assistance, however, was not necessarily considered to be helpful. In some cases a mutually agreed-upon plan for task sharing was present. Other caregivers did not expect other family members, such as children or grandchildren, to assist them. Those who had sole responsibility for caregiving often expressed frustration and fatigue.

The senior's desire for independence despite cognitive and functional limitations represented a third theme and a specific challenge for some caregivers. "So, under protest, she got a walker," one daughter said. "It's sitting folded up behind her TV, covered with a blanket. She also refuses to use a cane." One caregiver noted how her parents said they were fine even when she observed their failing health. "I came to the conclusion they were so terrified of being separated they would cover up for each other."

■ **"I can never quite get them out of my mind. I'm always kind of on-call for them."**

Eleven of the thirty caregivers were employed. This fourth theme carried a number of meanings: employment was seen as a resource by some, while for others it was a double bind. Nine of the eleven caregivers enjoyed their work and found it provided relief from their caregiving responsibilities. Three caregivers perceived their primary role as providing care to their family member and had modified their employment in order to do so. For these caregivers, the number of hours they spent giving care prevented them from working full-time, which resulted in financial difficulties.

Many of the participants in the focus groups said that programs and services for caregivers were limited in availability, difficult to discover and obtain, and that community service providers often excluded them from assessment and planning. Many stated they were not aware of the services that were available. When they did use services, they were frustrated by frequent changes of staff, lack of staff knowledge about the care recipient's health, inadequately trained staff and inconsistent performance by care providers. One woman summed up the fifth broad

theme of the study findings when she said, "My biggest problem with my folks has not been my folks, it has been home care. They used to send me six different people in a week." In contrast, several caregivers spoke of the relief they felt when the home care services were of good quality: "When [name of worker] was there and I came home I felt so relaxed because...there wasn't a thing I could see that I had to do and it was so good."

The issues raised by the informal caregivers were discussed at a workshop with 31 community service providers from 22 agencies. The representatives explored the barriers and challenges to providing support and devised strategies to address the gaps in services that had been raised by caregivers. Based on the workshop, the interviews and focus groups, it is clear that greater awareness of the availability of support services to informal caregivers and seniors is needed.

Both informal caregivers and seniors should be supported by these services. Inviting informal caregivers to collaborate in the assessment and planning process, along with seniors and community service providers, would enhance understanding of caregiving issues and help devise innovative strategies to deal with them.

For a full copy of the report, *Health of Informal Caregivers, Effects of Gender, Employment and Use of Home Care Services*, contact:



**Prairie Women's Health  
Centre of Excellence**  
56 The Promenade  
Winnipeg, MB  
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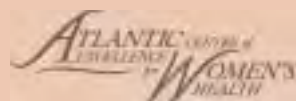
## Work/Life: A Healthy Balance?

How does women's unpaid caregiving affect their health and well-being, family life, sense of empowerment and livelihood? *The Healthy Balance Research Program* (HBRP) is a five-year project that aims to foster a "healthy balance" between women's health, family life and earning a living. Led by the Atlantic Centre of Excellence for Women's Health and the Nova Scotia Advisory Council on the Status of Women and funded by the Canadian Institutes of Health Research, the project will also investigate the relationships between caregiving and ethnicity, culture, location and age.

As a first step, a background paper was commissioned from Pat Armstrong and Hugh Armstrong of York University and Carleton University, respectively. In "Thinking It Through: Women, Work and Caring in the New Millennium" (2001), the authors develop guidelines to help researchers and policy makers grapple with the complex issues of women's paid and unpaid health care work. (An abridged version of this paper appears on page 15.)

"Research Gaps and Recommendations" (2002) represents the synthesis of the findings of a second HBRP study. The full study produced a bibliography of caregiving research and lists of survey instruments. (The searchable database will soon be available on the internet.) Based on gaps identified in the literature, the authors concluded that a gender-based and "multidisciplinary approach to caregiving that acknowledges the subjective components of health and balance, and the positive, reciprocal and interconnected aspects of the caring relationship can provide an important context" for future research on caregiving.

For the full reports contact:



**Atlantic Centre of Excellence for Women's Health**  
P.O. Box 3070  
Halifax, NS Canada B3J 3G9  
www.medicine.dal.ca/acewh  
Tel: (902) 470-6725 Toll Free: 1-888-658-1112  
Fax: (902) 470-6752  
acewh@dal.ca

## CAREGIVING AND HEALTH CARE REFORM

# Blurring the Boundaries: Women's Caring Work and Manitoba Health Care Reform

Barbara J. Payne, Karen R. Grant, Cheryl Christian, Department of Sociology, David M. Gregory, Faculty of Nursing, University of Manitoba, National Network on Environments and Women's Health

Sweeping changes to the Manitoba health care system since the early 1990s have shortened hospital stays, closed hospital beds, reduced and reorganized staff (particularly nurses and paraprofessionals), increased user fees for selected services and created regional health boards.<sup>1,2</sup> The impact of these structural changes on paid and unpaid carers has largely been ignored. Our study, *Women's Caring Work in the Context of Manitoba Health Reform*,<sup>3</sup> was designed to discover if and how caring work has been transformed as a result of health care reforms and how care providers have been affected.

Although relatively few attempts have been made to clarify the definition and meaning of "care," a primary objective of this study was to develop a concept of care based on the experiences of paid and unpaid carers. An additional objective was to examine how well-established social and professional hierarchies within the health care system have influenced caring work. Recognizing that the restructuring of health care services can have a direct impact on all community members, we also examined public perceptions of Manitoba health care reform and how it is affecting the provision of care.

As it would not be feasible to study caring work in relation to every medical condition, we focussed primarily on carers of individuals who had experienced a cerebrovascular accident (CVA), or what is commonly known as a stroke. The course of acute care and rehabilitation for CVA patients is often long in duration and involves a wide range of paid and unpaid carers.

To explore the challenges facing paid carers, we utilized three sources of data. Fourteen focus groups were held with ninety-six female carers working in institutional settings throughout Winnipeg. These groups were made up of female Registered Nurses, Licensed Practical Nurses, physiotherapists, occupational therapists, speech pathologists, pharmacists, home care aides, cardiac rehabilitation personnel and social workers. To explore whether or not responsibilities associated with paid

caring work had been transferred away from the public sector, 24 unstructured tape-recorded interviews were also conducted with unpaid carers who were female relatives of CVA survivors. A study of public perceptions of health care reform was conducted using the 1998<sup>4</sup> and 2001 Winnipeg Area Study (WAS). The WAS is an annual community survey involving a random sample of 750 Winnipeg residents. To learn more about individual attitudes regarding health care reform and caring work, a combination of open-ended and forced choice questions were incorporated into the two waves of the WAS.

## The Meaning of Care

Both paid and unpaid carers described caring work as a complex and emotional connection between two people. While the exact nature of care provided by paid and unpaid carers varied significantly depending on the severity of the CVA and the amount of support available to the carers, common elements of caring work were identified. These included (1) providing physical care (e.g., meal preparation and administration of medicine), (2) offering emotional support (e.g., comforting, reassuring, sharing, motivating), (3) assisting in social adaptation (maintaining, creating, adapting to new roles and relationships that emerge as carers are confronted by illness and care responsibilities), and (4) acting as an advocate or link between the care recipient, paid carers, other unpaid carers and the health care system.

Both groups of carers reported that health care reforms had made it difficult, if not impossible, to meet or balance care recipients' needs for physical, emotional and social support. In fact, the carers suggested that an increasing number of critical errors are routinely made in the health care system. Forced to care for greater numbers of patients with limited resources, paid carers described how the basic physical needs of care recipients, including the administration of medicines and help with bathing and lavatory use, were often not met. A licensed practical nurse said, "Many patients are misdiagnosed, over-medicated and sent

home too early.” A majority of respondents described a health care system driven by budget concerns and a “revolving door” or early discharge approach that jeopardized the quality of care.

### Transfer of Caring Work

Paid carers reported being forced to elicit or rely upon the help of the relatives of care recipients because of early discharge procedures and limited resources in the health care system. As one registered nurse explained, “We don’t have the nurses to go out and see [patients]. [We’re having to] ask the family members to put the eye drops in, or change the wound or set up the pills.”

## ■ Paid carers reported being forced to elicit or rely upon the help of the relatives of care recipients because of limited resources in the health care system.

Unpaid carers received little or no guidance, teaching or follow-up support from the health care system. They frequently reported that the responsibilities and pressures of caring work had largely been imposed upon them. They described their caring work as a highly stressful and often frustrating experience, and said they received little or no recognition for the daily care they provided. This situation exacted a steep price: an overwhelming majority of the women indicated that their physical, emotional and financial well-being and social integration in the community had deteriorated.

Caring for loved ones who have had an acute CVA involves significant long-term challenges. The effects of CVA may include paralysis, aphasia (loss or impairment of the power to use or comprehend words), and personality changes such as irritability, anger and confusion. Unpaid carers described the

social stigma and stereotypes associated with stroke survivors that created additional hardships. These difficulties, they said, were exacerbated by unmet needs for medical equipment and therapies, abandonment by the health care system, burnout and social isolation.

### Professional and Social Hierarchies

Paid and unpaid carers alike reported feelings of animosity and alienation within a physician-driven health care system. Nurses, for example, felt their experience and judgment were often ignored or devalued by physicians. Unpaid carers also expressed frustration about their subordination and undervalued role in the health care system. They found both doctors and nursing staff to be unapproachable in the midst of demanding and increasingly stressful and bureaucratic health care environments. Both paid and unpaid carers reported that intimacy and expression of feelings were out of place in a system that values cure over care.

### Public Concerns

Public perceptions identified in the WAS also alluded to frustration and confusion about health care reform. Winnipeggers reported concerns about access to family practitioners, waiting times for high-tech medicine and surgeries, “hallway medicine,” quality of care and the creation of a budget-driven health care system. Only small portions of the WAS samples were involved in caring work (9% of the 1998 sample and 7.3% of the 2001 sample). However, a number of respondents indicated that they were called upon to provide more care as a direct result of government cutbacks in funding and services. The stress, frustration and financial costs to care providers were noted in a number of interviews.

### Discussion

The results of this study indicate that health care reforms have compromised the quality of care and caused physical, social, emotional and financial distress for carers. How can we address these problems? One of our recommendations is to make “caring teams” the foundation of the Manitoba health care system. These teams would value the contributions of both paid and unpaid carers equally in an attempt to address the alienation and frustration that they experience. As unpaid carers are forced to assume greater responsibility for the care of their loved ones, more appropriate and flexible resources need to be devoted to

support them through home care services, respite, day-programs, physical and speech therapies and counselling services. As health care reform continues to blur the boundaries between the formal health care system and unpaid carers and generates heightened public concern about quality of care, the creation of citizens' panels must also become a top priority. Including the participation of both paid and unpaid carers as well as members of the general public, these panels would provide Manitobans with an opportunity to directly influence public policy decisions and more effectively meet the needs of women providing care.

For a copy of the full report, *Women's Caring Work in the Context of Manitoba Health Reform*, contact:



National Network  
on Environments and  
Women's Health

**National Network on Environments  
and Women's Health**  
Centre for Health Studies  
York University  
4700 Keele Street  
Suite 214 York Lanes  
Toronto, ON Canada M3J 1P3  
www.yorku.ca/nnewh  
Tel: (416) 736-5941 Fax: (416) 736-5986  
nnewh@yorku.ca

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## CAREGIVING AND HEALTH CARE REFORM

# Labour Process Change: Women's Paid Home Care Work in Saskatoon

Allison Williams, Research Faculty, Saskatchewan Population Health and Evaluation Research Unit, Assistant Professor, Department of Geography, Susan Wagner, Professor, College of Nursing, and Monic Buettner, University of Saskatchewan, prepared for the Prairie Women's Health Centre of Excellence

Nona Glazer (1993) first concluded that health reform is changing labour processes and contributing to the deteriorating working conditions of home care practitioners in the United States.<sup>1</sup> Many Canadian scholars have discovered a similar phenomenon taking place north of the border.<sup>2</sup> As health care reform relocates care away from institutional services, there has been and continues to be an unprecedented growth in home care. Deinstitutionalization, as well as an aging Canadian population, are creating a demand for more complex home care. The home care sector itself is being restructured in the hope of making the delivery of care more cost-efficient. As a result, the female-dominated home care labour force is undergoing significant changes. Practitioners'

work lives, overall quality of life and health are being affected.

Research indicates that practitioners are experiencing an intensification of work, evident in an increase in job responsibilities and a decrease in the time to carry them out. These changes contribute to a third job transformation—an increase in work stress. Poor working conditions are the major cause of practitioner "burnout" (generally understood as exhaustion of physical or emotional strength or motivation usually as a result of prolonged stress or frustration) and high turnover rates, greatly impacting the quality and availability of this workforce.<sup>3</sup> In addition to the obvious impact on the home health care labour force, burnout and turnover threaten

continuity and quality of care for patients and families.

Saskatoon District Health (SDH) Home Care provides home support services (including personal care, meals, respite care and home management), nursing care, volunteer workers, and a "meals on wheels" service. After a number of restructuring strategies were implemented by SDH Home Care, our research team collected quantitative and qualitative data to explore how the work lives and health of paid home care practitioners were affected. These data included practitioners' assessments of the quality of work life, overall quality of life, and personal health and well-being. We used a collaborative research partnership model and worked with SDH Home Care management and a research advisory committee of staff members.

The home care practitioner groups that participated in our study were female Registered Nurses (RNs), Licensed Practical Nurses (LPNs) and Home Health Aides (HHAs). RNs assess client needs, plan and coordinate health care, deliver nursing services, evaluate care, and teach and counsel clients and caregivers (formal and informal). A trained HHA's duties include helping with personal care, applying bandages to assist circulation, administering oxygen, dispensing medication and aiding with catheter and bowel care. At the time of the study, most LPNs' duties were identical to HHAs' duties, although they were trained to perform some nursing tasks such as changing dressings and dispensing medication if the client is stable. Until restructuring, HHAs and LPNs practiced under the supervision of an RN.

A period of restructuring took place in SDH Home Care from April to September 1999, which were the six months that we selected for the study period. The main elements of change were: (1) the integration of all practitioner categories into geographic teams, (2) role changes for practitioners, (3) transfer of medication management from RNs to both HHAs and LPNs, and (4) changes in office personnel.

1. Geographic teams: In order to bring services closer to the client, decrease travel time for practitioners and facilitate greater collaboration in case management, SDH Home Care divided the health district into four quadrants. Practitioners could choose which quadrant they wanted to work in, but even those who stayed in the same area experienced changes of co-workers and supervisors. Work schedules also changed

with the reorganization of service areas.

2. Role changes: RNs now operate as "resource people" to facilitate problem solving with HHAs. RNs provide more clinical support, with the goal of assisting HHAs and LPNs to be more independent. To enhance peer support and communication, client binders are used in the home and practitioners carry personal pagers. Management-staff meetings are more frequent, with the RN/LPN group, the HHAs, and quarterly quadrant meetings including all practitioner groups. The goal of these meetings is to help build collaborative case management teams.
3. Transfer of medication management: The scope of practice has increased for both HHAs and LPNs, with some practitioners giving medication under a specific protocol. The medication is pre-packaged by pharmacists in consultation with RNs and "pre-loaded" in bubble packs so each dosage is set, allowing clients and/or family members greater autonomy. If the client is unable to take the medicine by themselves, trained home care staff may now visit to help them. RNs provide training and are available on-call to provide assistance.
4. Changes in office personnel: Instead of each practitioner group being supervised independently, supervisors are now responsible for quadrant groups made up of all three groups of practitioners together. This new arrangement is intended to leave more client care decision-making to the practitioners in the field.

The quantitative data reveal that all practitioners, regardless of their position, rated work satisfaction and overall health and well-being as being poorer over the study period when compared to the previous six months. HHAs rated their overall health and well-being lower than the other practitioners and were found to be using comparatively more sick/stress days. The qualitative data suggest that, in terms of both emotional and physical health, HHAs are clearly most affected by restructuring changes. These findings support the hypothesis that restructuring affects the health and well-being of practitioners and particularly the health of those lower on the human health care hierarchy.

Eighteen policy directions were suggested to the management of Saskatoon Home Care by the research team. These include the implementation of policies to enhance the control HHAs

feel over work, more time allowed for patient care visits and more opportunities for practitioners to have input into planning policies and procedures, particularly when these are slated for change. SDH Home Care management has implemented a number of recommendations from the study; the role of LPNs, for example, has been expanded and now excludes any HHA duties.

This research has practical significance for human health care policy. Exploring the effects of restructuring strategies sheds light on women's caring work, women's health and the place of women in society.

For a full copy of the report, *The Impact of Women's Formal (Paid) Home Care Work in Transition*, please contact: Susan Wagner, College of Nursing, University of Saskatchewan at (306) 966-6244 or [ps.wagner@usask.ca](mailto:ps.wagner@usask.ca).



**Prairie Women's Health  
Centre of Excellence**  
56 The Promenade  
Winnipeg, MB  
Canada R3B 3H9  
[www.pwhce.ca](http://www.pwhce.ca)  
Tel: (204) 982-6630  
Fax: (204) 982-6637  
[pwhce@uwinnipeg.ca](mailto:pwhce@uwinnipeg.ca)

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## CREATING BETTER CONDITIONS FOR CARE

# Guidelines for Examining Women, Work and Caring in the New Millennium

Pat Armstrong, Department of Sociology, York University and Hugh Armstrong, School of Social Work, Carleton University, the Atlantic Centre of Excellence for Women's Health and the Nova Scotia Advisory Council on the Status of Women

Care work is women's work. Paid and unpaid, located at home, in voluntary organizations or in the labour force, the overwhelming majority of care is provided by women. It is often invisible, usually accorded little value and only sometimes recognized as skilled.

A new study called *Thinking It Through: Women, Work and Caring in the New Millennium* draws on Canadian and international literatures to analyse the forces, structures and relationships that construct women as carers and

undervalue care work. It is designed as a companion piece to *One Hundred Years of Caring in Canada*, which is based on Canadian research on caregiving among adults. This work outlines kinds of care (e.g. personal care for people with disabilities, skilled home health care for family members discharged from hospital) and kinds of caregivers (e.g., paid and unpaid).<sup>1</sup> The purpose of *Thinking It Through* is to develop guidelines that will help researchers, policy makers and the general public think about the meaning and consequence of women's paid and unpaid care

work and ultimately help create good conditions for care.

To accurately assess women's care work, *guidelines should, first of all, be concerned with both similarities and differences*. Because there are so many common patterns in women's work it is useful to group women together. "Lumping" refers to a way of looking at data, theory and concepts in order to see what women, as women, share. It also helps us to expose the forces that keep these patterns in place and those that change them. But what of the fundamental differences among women related to class, race, culture, age, marital status, sexual orientation and location, as well as variations in patterns for the same women over time? For example, in the last twenty years considerable variations have developed

## ■ Care is often invisible, usually accorded little value and only sometimes recognized as skilled.

in what has been defined as women's caring work. Our grandmothers did not clean catheters, insert needles or adjust oxygen masks as part of the care work they did at home. "Slicing" refers to a method for considering different views or "slices" of the same circumstance, research question and evidence in order to create multiple and complex pictures of particular peoples in particular places. In Miriam Glucksmann's revealing analyses of British women's work she speaks of "slicing" to look at the various ways work is divided up within what she calls the "total social organization of labour."<sup>2</sup>

Slicing a question about women's work helps expose the complex and contradictory nature of that work and our concepts about it. Slicing allows us to see that there is very little that is natural about women's work in general or their caring work in particular. Women's caring can be understood

only within unequal relationships, structures and processes that help create women as carers and undervalue this caring work. Slicing assumes that contexts and locations matter. It encompasses the considerable pressures from forces outside of women's immediate control, as well as women's active participation in shaping their own lives. It allows that some women resist care work, some embrace it.

Our guidelines recommend both lumping and slicing in order to explore what is both common and different among women and among women over time and across space or location.

A second guideline is that *analyses of women's work should locate women within both their general and their specific environments*. Globalization, changes in the nation state, and the increasing reliance on markets, communities and families to provide care all establish contexts for women's work. Contexts also include notions about these. For example, notions about the inevitability of globalization and changes in the Canadian state distract us from the fact that these processes and changes result from decisions and practices rather than from forces beyond human control. Canadians still establish many of the conditions for work and for deciding how, when and where care is provided. In providing supports, benefits, services and regulations or in not providing these, state practices establish the conditions for care inside and outside the formal economy. The benefits and negative consequences of these decisions are unevenly distributed between women and men, and among women.

In Canada the state still provides most of the financial funding for paid care. But market mechanisms that have become popular with governments increasingly form part of the context of women's lives and need to be carefully scrutinized for their impact on care and care work. Once defined as public goods largely produced and distributed outside the market, care services are increasingly defined as market goods. What happens when for-profit techniques are applied to care services? For example, consumer purchasing means unequal purchasing because market power is based on resources; as a result, inequality between women and men, as well as among women, will be perpetuated. How is continuity in care across services to be provided if services are competing with each other and are owned by for-profit firms that treat information as trade secrets essential to



competition? What is not profitable will be left to individuals or charitable organizations to provide. We have to ask where, when and under what conditions markets are appropriate and what their impact is on care.

“Sending care to communities” most often means sending care to families and, within families, to women. But sending care to the community may mean undermining those communities and does not necessarily mean more local participation or control. As Stacey Olikier says, on the basis of her research on welfare, “We might find damage to personal networks and personal relationships, which could threaten families’ capacities to care. The damage might take the form of constriction and greater fragility in networks, the replacement of caregiving support with support for subsistence, and a decline in communal commitments to care.”<sup>3</sup> Without time, space, economic resources and other supports, all communities may be at risk.

Thus, as a third guideline, *it is necessary to examine the ways globalization, states, markets, communities and households penetrate and structure each other, each influencing how the others operate.* The blurring of the lines between paid and unpaid work, and public and private sectors of the economy, makes it more difficult to see the links between these sectors and more difficult for women to draw boundaries about and around their work responsibilities.

Fourth, *critical questions need to be asked about who pays for care and at what cost to whom.* Some of the costs of care are financial. Some are in time, some in emotional and social resources and some in lost opportunities. These costs may be borne mainly by individuals, by families, by community organizations or by governments. Sometimes all share in the costs, although they seldom do so in equal portions or in similar ways. Whatever the distribution, the ways costs are borne and shared have significant consequences for women. Each method of funding has an impact on access to care, the nature of care and the costs to the caregiver.

Fifth, *it is important to explore questions about the time and locations of care.* Where, when and for how long is care provided? If we think about where care is given, we can see, for example, that a care recipient may regard the home as a place of quiet comfort. For the caregiver and family,

however, home may be a place for entertaining friends. For the paid caregiver, a workplace should be ordered in a manner that meets their standards of care. Each participant may have different, and conflicting, space needs. Time interacts with space and, like space, it is also about social relations. When time is money, care as a relationship may be sacrificed: there may be or may not be time for a hug—an often unmeasured but critical component of care for provider and recipient.

A sixth guideline is that *the nature of power and the means of enhancing the control women have in providing and receiving care should be explored.* Power is primarily about access to

## ■ Our grandmothers did not clean catheters, insert needles or adjust oxygen masks as part of the care work they did at home.

resources. Some of these resources are material, like income and services, drugs and diapers. Some are political, like the right to participate fully in decision making in ways that have an impact, or the right to equal pay and other employment protections, or the right to education and information. Some are social, like having time and space for friends and relaxation. Some are symbolic, like having care recognized as work that requires time, space, money, physical capacity, emotional involvement and social support. The more resources are distributed by market mechanisms, the greater the disparities in resources, and thus, in power.

Finally, *care needs to be understood as the objective, not the problem.* Care is a relationship rather than simply a task. We need to recognize the conflicting, often contradictory demands on care providers and determine how to handle

these so that women can exercise the right to care in ways that take their needs and capacities into account.

This paper is part of a five-year partnership program of survey and case study research called "A Healthy Balance: A Community Alliance for Health Research on Women's Unpaid Caregiving" led by the Atlantic Centre of Excellence for Women's Health and the Nova Scotia Advisory Council on the Status of Women. For a copy of the full report,

*Thinking It Through: Women, Work and Caring in the New Millennium*, contact:



**Atlantic Centre of Excellence  
for Women's Health**

P.O. Box 3070  
Halifax, NS Canada B3J 3G9  
www.medicine.dal.ca/acewh  
Tel: (902) 470-6725  
Toll Free: 1-888-658-1112  
Fax: (902) 470-6752  
acewh@dal.ca

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## CREATING BETTER CONDITIONS FOR CARE

# The Charlottetown Declaration on the Right to Care (2001)

*This Declaration was initiated during the National Think Tank on Gender and Unpaid Caregiving, held in Charlottetown in November 2001, led by the National Co-ordinating Group on Health Care Reform and Women, a group that crosses the Centres of Excellence for Women's Health, and hosted by the Maritime Centre of Excellence for Women's Health (now the Atlantic Centre of Excellence for Women's Health) and the PEI Health Research Institute, of the University of Prince Edward Island. This article was prepared by Ann Pederson, British Columbia Centre of Excellence for Women's Health and Patsy Beattie-Huggan, The Quaich Inc.*

It was apparent throughout the *National Think Tank on Gender and Unpaid Caregiving* that taking action to improve the conditions of care was a common objective of the 55 participants. Experts from the academic, policy and caregiver communities drafted *The Charlottetown Declaration on the Right to Care* to suggest principles for a national home care strategy that would ensure equity for both women and men, and make home care an integral part of a publicly administered health care system.

## The Charlottetown Declaration on the Right to Care

*Canadian society has a collective responsibility to ensure universal entitlement to public care throughout life without discrimination as to gender, ability, age, physical location, sexual orientation, socioeconomic and family status or ethno-cultural*

*origin. The right to care is a fundamental human right.*

*The right to care requires: access to a continuum of appropriate, culturally sensitive services and supports; appropriate conditions; the choice to receive or not receive, or to provide or not provide unpaid care; that there is no assumption of unpaid care; access to reasonable alternatives and sufficient information.*

*Care is: essential; an inter dependent relationship; skilled work; multidimensional; diverse.*

*Care should be: equitable; available; accessible; continuous; responsive; and transparent. Care should incorporate diversity and be participatory; enforceable; standards-based; be publicly administered; and respectful.*

*These rights to care must be viewed through lenses that recognize the importance of gender analysis, diversity, interdependence between paid and unpaid care, and linkages among social, medical and economic programs.*

## Understanding the Declaration

*The right to care is a fundamental human right.* Canadian society has a collective responsibility to ensure universal entitlement to public care throughout life. Such care must be provided without discrimination as to gender, ability, age, physical location, sexual orientation, socioeconomic and family status, ethno-cultural origin, or ability to pay.

*The right to care requires access to a continuum of services and supports.* Our public health care system began by financing hospitals and then moved on to pay for physicians. But the Hall Royal Commission (1964) that led to Medicare clearly understood an effective and efficient public system had to provide a full range of coordinated services and supports, including public home care.<sup>1</sup> The Commission asserted that only with a continuum of services would people receive care at the most appropriate level, move easily from one service to another and avoid costly duplication. Such a continuum does not currently exist. Caregivers and recipients also need supports such as training, care leave, job security and income programs. Such services and supports must be culturally sensitive.

*The right to care requires appropriate conditions.* We know that health is determined by cultural, physical and social environments, social support, security, gender, economic and educational resources, and coping skills, as well as by biology, genetic makeup and health services. These all count in the provision of care, and some are even more important given the fragility of people who are ill or have a disability. Homes are not necessarily havens and hospitals can be dangerous to the health of patients and providers if conditions do not meet their particular needs or ignore the determinants of health.

*The right to care requires the choice to receive or not receive, or to provide or not to provide unpaid care.* As the Prime Minister's National Forum on Health (1997) reports, women "conscripted" into care end up in poor health and may be unable to provide adequate care.<sup>2</sup> Women who need care

may not want to receive such care from relatives conscripted into service. At the same time, many who want to provide care may need help to do so (e.g., flexible hours at work, support from other family members), and both care providers and those receiving care may need help from government for financial assistance and health and social services.

*The right to care requires that there is no assumption of unpaid care.* Care is not a choice if it is assumed families in general and women in particular are willing and able to provide care. The majority of women rely on income from paid work.

## ■ Home care must be an integral part of a publicly administered health care system.

*The right to care requires access to reasonable alternatives and sufficient information.* For many, but not all, the home may be the best place for care. For some, but not many, facilities may best serve their needs; such alternatives must be available to ensure appropriate and culturally sensitive care. Reliable, accessible information on the benefits of and problems with alternatives and on how to access them, as well as on how to give and receive care, is a necessary component of a public care system.

To ensure the right to care, it must be understood that *care is essential*. We cannot leave people without necessary care. And care must also be understood as *an interdependent relationship*. It is not simply about what one person does to or for another: care involves reciprocity.

*Care is skilled work*, requiring education, training and experience; it is not something women do naturally by virtue of being women. Care includes everything from feeding, injecting and hugging to bandaging, chatting and intubating.

*Care is diverse*. People are different. Their cultures and experiences shape their needs and how those needs ought to be addressed.

*Care should be ... equitable*. Equitable does not mean the same care for everyone. It means a fair distribution of care based on appropriately assessed needs, and a fair distribution of care work. The *Canada Health Act* (1984) defines equitable care as care provided under “uniform terms and conditions.” This principle should apply to home care.

... *Available*. Public services must be provided within a reasonable distance without unreasonable delays.

... *Accessible*. The *Canada Health Act* says that necessary services must be provided in a manner that “does not impede or preclude, either directly or indirectly” access to care. This includes user fees or other charges that can undermine the right to care.

... *Continuous*. A smooth transition among services and a range of services, and continuity in care providers and services, is essential.

... *Responsive and Transparent*. Care should respond to the particular needs of those giving and receiving care. People need to know how to access such services and how decisions about services are made. This includes decisions about what care is publicly provided and what is not.

... *Incorporate diversity*. Responsive care recognizes cultural, regional, age and gender diversity, as well as differences related

to sexual orientation, and socioeconomic and family status. Particular attention must be paid to traditional practices and activities of First Nations, Inuit and Métis peoples.

... *Participatory*. Both those providing and those receiving care should be involved in decisions about how, when, where and by whom care is provided. The public should be part of determining how the system is organized and how care is delivered.

... *Enforceable*. It is necessary to put mechanisms in place to ensure that the rights to care are protected.

... *Standards-based*. Standards for care must be based on evidence about the effectiveness and the appropriateness of care.

... *Publicly administered*. In terms of cost savings and coordination, there are clear benefits to a publicly administered health care system. It is also easier to hold such a system accountable.

... *Respectful*. Respectful care recognizes that paid and unpaid caregivers and care recipients have individual preferences, abilities, feelings, experiences and histories.

*These rights to care must be viewed through lenses...*: Lenses are analyses and methodologies that are able to recognize the importance of gender, diversity, interdependence between paid and unpaid care, and linkages among social, medical and economic programmes.

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## NOTES

1. Canada. Royal Commission on Health Services. Ottawa: Queen's Printer, 1964-1965.
2. National Forum on Health. An overview of women's health. Implications for policies and programs. In: *Canada Health Action: Building on the Legacy*. Volume II. Ottawa: Health Canada, 1997. Web reference: <http://www.nfh.hc-sc.gc.ca/publicat/finvol2/vol2.htm>. Retrieved June 11, 2002.