

**HOME CARE AND WOMEN: AN ANNOTATED BIBLIOGRAPHY
OF CEWHP HOME CARE DOCUMENTS**

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This annotated bibliography was prepared for the National Coordinating Group on Health Care Reform and Women. The literature referred to in this bibliography was selected from healthcare-related research material published through the Centres of Excellence in Women's Health Programme (CEWHP). CEWHP is funded through the Women's Health Bureau, Health Canada, and involves five (5) centres of excellence in women's health across the country. Each centre is dedicated to facilitating and conducting research on women's health involving both academic and community partners.

References are limited by what research has been conducted through the Centres that is specific to health care, and subsequently by what of this research makes reference to home care services. It is important to note that home care cannot always be discussed in discrete terms, but remains a relevant topic in broader discussions of health care in many contexts. As a result, I have included material that references the formal use of home care services as well as that which mentions home care services in a less formal way, either as a means to enrich the research or to provide context for the larger discussion.

Armstrong, Pat, "Women, Privatization And Health Reform: The Ontario Case", National Network on Environments and Women's Health, 1999. [NNEWH].

This paper provides a broad overview of the impacts of health care reforms in Ontario, with a focus on privatization. Home care is discussed in terms of the shift from institutional care to long-term community care. One section of this document focusses on long-term community care, specifically the legal and administrative structure of the programmes associated with it. Attention is paid to the gendered nature of caring work and of care recipients, along with a discussion about the role of Community Care Access Centres (CCACs) in shaping the provision of home care services. Lack of standardization and fluctuating control and authority of CCACs have frightening consequences for women as formal and informal providers of care, as recipients of care, and as citizens.

Aronson, Jane, "Frail and Disabled Users of Home Care: Confident Consumers or Disentitled Citizens?" in Canadian Journal of Aging (forthcoming). [NNEWH].

Based on interview data with female long-term users of home care services in southern Ontario, Aronson examines how elderly and disabled people in Ontario are being repositioned in relation to publicly funded home care, which is itself in transition. She discusses the "mixed economy" of home care and the role of Community Care Access Centres (CCAC's) and concludes that, contrary to popular discourse, home care users are not active 'consumers' negotiating the terms of their own care. Rather, the new home care market has resulted in unequal access to and provision of these services, leaving citizens with little power and few options for quality care.

Aronson, Jane and Sheila M. Neysmith, "Manufacturing Social Exclusion in the Home Care Market" in Canadian Public Policy (forthcoming). [NNEWH].

This piece uses results of interview data from research with elderly and disabled female long-term home care users in southern Ontario. Aronson links discourses on citizenship, the design of home care programmes and the local experiences of users of home care in order to explain the processes of social exclusion experienced by elderly and disabled users of these services. Social exclusion is tied to funding cuts and the medicalization of home care services.

Ash, Katherine and M.M. (Peggy) MacLeod, "Health Practices of Community Living Senior Women: Final Report", no date. [PWHCE].

This study examines the health practices of elderly women in Saskatoon, Saskatchewan. While this document accounts for home care in only a very limited way, it does discuss home care services in terms of the limited services available. A focus on disease and disability prohibits assistance with elements of care such as bathing and house cleaning. The authors point out that the women in their research who use home

care services were affected by these limitations, and often suffer from social isolation as a result.

Bernier, Jocelyne and Marlène Dallaire, "The Price of Health Care Reform for Women: The Case of Quebec", Centre D'Excellence pour la Santé des Femmes, 1999. [CESAF].

This document provides a broad analysis of health care reforms in Quebec, with a focus on trends towards privatization of health care and the consequences of these reforms on women in Quebec. The research is based on a review of government documents and other research about changes to the Quebec health care system. Home care services are discussed in terms of the increase in private service providers along with an examination of long-term services that are currently available to women caregivers and an assessment of the factors associated with the organization and delivery of these services. The authors discuss the need to address broader social and economic issues of home care as well as the disproportionate burden placed on women as both formal and informal (paid and unpaid) caregivers, including the effects of private for-profit home care companies hiring less-skilled workers for lower wages and the increasingly complex care assigned to informal women caregivers providing care in the home. The documents also outlines the gendered nature of caregiving work and the effects that this has on informal women caregivers.

Campbell, Joan, Gail Bruhm and Susan Lilley, "Caregivers' Support Needs: Insights From The Experiences Of Women Providing Care In Rural Nova Scotia", Maritimes Centre for Excellence in Women's Health, November, 1998. [MCEWH].

This document assesses research conducted with family caregivers in rural Nova Scotia, with a specific focus on the kinds of supports needed by caregivers. The purpose of the research was to identify gaps in existing caregiver supports based on caregiver perceptions. Results of the research indicate that there is little value placed on caregiving work; that caregiver needs remain virtually unmet in terms of information, training and support services; that there is a lack of adequate home care services; and that there is a lack of adequate respite care provided to caregivers. Caregivers interviewed indicated a desire for financial compensation for the care they provide and a desire to be included in the policy process. The authors discuss the gendered nature of caregiving work and the ways that rural areas in Nova Scotia are differentially impacted by the lack of supports provided to caregivers.

Ducharme, Francine, Louise Lévesque, Marie Gendron, Jean-Marc Gagnon, Émilie-Gamelin, Lise Hébert, Nicole L'Heureux and Olivette Soucy, "Élaboration et évaluation par des aidantes d'un proche âgé hébergé atteint de démence, d'un programme d'intervention favorisant leur santé. Étude pilote selon une approche participative et constructiviste" [Development and evaluation, by women serving as caregivers for an elderly family member with dementia, of an action plan to improve their own health. Pilot study using a participatory, constructionist approach¹], Centre D'Excellence pour la Santé des Femmes, 2000. [CESAF].

This project serves as a pilot study designed to develop an intervention program for residential and extended-care centres to empower women caregivers to take charge of their own health. The study examines the sources of stress and health needs of women (wives and daughters) caring for a family member with dementia. Results of the study demonstrate that the role of caregivers does not end with the formal placement of the care recipient, but remains very demanding. The project illustrates problems family members encounter in expressing their concerns in residential and extended-care centres.

Fuller, Colleen, "Reformed or Rerouted?: Women and Change in the Health Care System", British Columbia Centre of Excellence for Women's Health, 1999. [BCCEWH].

This document provides a broad overview of health reforms in British Columbia with a focus on the impacts of these reforms on women. Home care is briefly discussed here in the context of the shortage of nurses available to provide home care services, and the subsequent impact that this shortage has on early-discharge patients and the women caregivers who look after them. Home care is also discussed briefly in terms of the lack of public health insurance coverage available for these services and the disproportionate financial effects that this has for women who pay more out-of-pocket health care expenditures than men. These expenses are incurred due to the lack of insurance coverage for services that women use and when women do not meet eligibility requirements for private plans (e.g. "pre-existing conditions" like pregnancy).

Greaves, Lorraine, Olena Hankivsky, Georgia Livadiotakis and Lindsay Saunders, "Socioeconomic Costs of Palliative Caregiving: A Gender Analysis", (forthcoming), BCCEWH/MCEWH/CESAF. [BCCEWH].

This document represents a cross-centre initiative between BCCEWH, MCEWH and CESAF to collect data on palliative home care. The research focusses specifically on palliative caregivers of cancer and AIDS patients and represents quantitative and qualitative data around the gendered social, psychological and economic costs of acute palliative care for caregivers at home. Participants in the research include both women and men as both formal and informal caregivers. Results of this research are currently unavailable as the project is still in progress.

¹ Translation provided by Jocelyne Bernier, CESAF. Information about CESAF research projects on home care gathered from summaries provided in English by Jocelyne Bernier.

Guberman, Nancy, "Caregivers and Caregiving: New Trends and Their Implications for Policy", Centre D'Excellence pour la Santé des Femmes, 1999. [CESAF].

This document was produced for the Home Care Division of Health Canada, and examines caregivers and caregiving in the context of current changes to the health care system. The focus on caregiving means that issues of home care and home care services are touched on throughout the document, however the author devotes a significant section to a discussion of home care services specifically as they impact on caregivers. She states that home care acts as a necessary respite for the caregiver, but that services require more diversity for both the caregiver and the care recipient. She suggests that there is a need for increased home care services, especially chore and psychosocial services.

An analysis of existing research on caregivers reveals that while home care services are not designed for or aimed at the caregiver, they nonetheless are used more frequently by them than are those services that are designed specifically for caregivers (e.g. respite care), and as such, home care services should take caregivers needs into account. The drawbacks of home care services are discussed as they relate to caregivers, specifically difficulties accessing the services; insufficiency of services; homogeneity of services; lack of continuity in service delivery; and variations in service provision and eligibility across the country. Guberman also discusses the low rates of service use by caregivers and suggests that this is an area ripe for further research. This research should take into account gender, ethnicity, age, relationship of caregiver to care recipient among other factors. The document also discusses home care in relation to not-for-profit volunteer care, the development of the private-for-profit home care sector and provides suggestions for upgrading home care services.

Hawranik, Pamela G. and Laurel A. Strain, "Health of Informal Caregivers: Effects of Gender, Employment and Use of Home Care Services", Prairie Women's Health Centre of Excellence, June 2000. [PWHCE].

The authors discuss the health status of informal caregivers, with particular attention paid to gender, employment status and the use of homecare services. Their discussion is based on three (3) different sets of research data, one (1) of which is based on their own direct research. In terms of home care, their analyses suggest that the use of home care services is associated with higher levels of caregiver burden for only certain informal caregivers and may be related to the difficulties experienced negotiating the health care system and/or the gender of the caregiver. Depending on the parameters, both men and women expressed poor health at different times. Focus group interviews reveal that informal caregivers are reluctant to utilize home care services due to lack of knowledge about their availability and difficulties experienced obtaining a good fit of care. These struggles were seen to impact the health of informal caregivers in numerous ways. The authors provide strategies to address issues raised in the research.

Horne, Tammy, Lissa Donner and Wilfreda E. Thurston, "Invisible Women: Gender and Health Planning in Manitoba and Saskatchewan and Models for Progress", Prairie Women's Health Centre of Excellence, 1999. [PWHCE].

This document provides a gendered analysis of health planning in Manitoba and Saskatchewan. While home care is not discussed directly at length, it is mentioned throughout the document in terms of women as informal caregivers and in terms of the devolution of care from the institution to the community. Home care is mentioned in the context of a general failure to recognize women's health issues when health planning takes place in these provinces. The authors demonstrate that there is little recognition that women are more likely to provide informal care when relatives are transferred home from hospital or that there is increased burden on women in these instances.

Jaffe, JoAnn and Bonnie Blakley, "Coping as a Rural Caregiver: The Impact of Health Care Reforms on Rural Women Informal Caregivers", Prairie Women's Health Centre of Excellence, 1999. [PWHCE].

Home care is directly discussed only briefly in the context of a study of rural women informal caregivers in Saskatchewan. Findings point out that, although more than half of all informal caregivers interviewed used home care services, these services were not flexible or designed to meet caregiver's individual needs. Formal discussion of home care accounts for only a small part of this document, however the broader discussion of who receives informal care, who is doing the caregiving, the difficulties associated with informal caregiving and suggestions for improving the situation of women caregivers in Saskatchewan is relevant to discussions about home care services.

Lauzon, Sylvie, Jacinthe Pépin, Maria Elisa Montejo, Jean-Pierre Lavoie and Marlène Simard, "Bilan critique des études menées sur les expériences des aidantes naturelles à partir d'une perspective émique" [Critical review, from an emic perspective, of studies of the experiences of women caregivers], Centre D'Excellence pour la Santé des Femmes, 1998. [CESAF].

This project analyzes research on women caregivers since the 1990's in order to explain the determinants of women caregivers' health. It assesses the methods used to study women caregivers and highlights the results of the research and its limitations. The study provides a springboard for analyzing women caregivers' needs in the wake of health care reforms.

Lavoie, Jean-Pierre, Jacinthe Pépin, Sylvie Lauzon, Pierre Tousignant, Helène Belley and Nicole L'Heureux, "Les modèles de relations entre les services formels et les aidantes naturelles. Une analyse des politiques de soutien à domicile du Québec" [Types of relations between public services and unpaid caregivers: analysis of home care policies in Quebec], Centre D'Excellence pour la Santé Des Femmes, 1998. [CESAF].

This projects examines long term home care services currently available to women caregivers in Quebec, and assesses the factors associated with the organization and delivery of these services. It examines how people involved in providing long term home care services perceive the needs and experiences of women caregivers. The authors examine home care policy and planning documents by the Minister of Health and Social Services in Quebec, regional health boards, CLSCs and the Federation des CLSC, and conclude that there is little attention paid to the situation of women caregivers and their needs. In general, women caregivers are perceived as resources rather than clients and are not seen as requiring services for themselves. These findings help to explain the low rate of service use by women caregivers in Quebec.

Lessard, Diane, Lucy Barylak, René-Cassin, and Dominique Côté, "Aidantes naturelles et services de soutien, acquérir du pouvoir sur sa situation" [Unpaid caregivers and support services: empowerment strategies]. Centre D'Excellence pour la Santé Des Femmes, 2000. [CESAF].

This document provides an assessment of support services available to women caregivers in order to improve the delivery of these services. The purpose of the project is to identify the needs of women caregivers and examine whether the available services reflect these needs. The research occurred in a unique setting of a support centre for caregivers, and points to the need for respite care, moral and socio-emotional support and security. This research also illustrates that the existence of services is not always a guarantee of their success; that the flexibility of the services greatly influences their use; and that control over the resources allocated is a prime factor in the women caregivers' empowerment. The report notes that "[translation] a current challenge for women caregivers in the health system is that of getting their status recognized and clearly establishing their place in relation to services."

Maritimes Centre for Excellence in Women's Health, "Home Care and Policy: Bringing Gender Into Focus", Policy Discussion Papers, No 1, March 1998. [MCEWH].

This document is a policy discussion paper, which focusses on home care and the disproportionate and differential impacts on women as both formal and informal caregivers. It provides policy considerations, discussion around the social and economic costs of home care, the need for and relevance of gender-based analysis in shaping policy and argues for a recognition of social, demographic and economic differences in home care policies and providers .

Regroupement des aidantes et aidants naturel(le)s de Montréal, RAANM, "Au Coeur de l'aide, au coeur du changement" [forum bringing together women caregivers from the various self-help groups, workers, researchers and other persons interested in the issues connected with women caregivers' health], Centre D'Excellence pour la Santé des Femmes, 1998. [CESAF].

This forum brought together 252 people in November 1998, a majority of whom were women caregivers and workers, especially CLSC workers. It allowed for rich expression of the experiences, problems and needs of women caregivers, both in their relations with the care recipient and with institutional services. Workshops brought to light changes that are needed and some avenues for action: 1) to meet the needs of women caregivers and their families; 2) to improve the quality and accessibility of services; and 3) to promote recognition of women caregivers. This forum led to the creation of a provincial committee of support groups for women caregivers. The report on the forum illustrates, on the basis of actual experiences, the impact of the changes in the health system on women caregivers, as well as the negative impact on their health. The report inspired CESAF's recommendations concerning the impact of the changes in the health system on women caregivers. This forum allowed for identification of concepts and strategies for recognition of women caregivers.

Scott, C.M., T. Horne and W.E. Thurston, "The Differential Impact of Health Care Privatization on Women in Alberta", Prairie Women's Health Centre of Excellence, 2000. [PWHCE].

This document focusses on the scope of health care privatization in Alberta, and its impact on women. The authors discuss the lack of gender-based analysis in policy as well as the history of health and social policy in Alberta in order to provide context for the privatization of health care. The authors focus on policy initiatives implemented by the Alberta governments since the late-1980's in order to illustrate the path that health care privatization has taken there. Home care is discussed in terms of the added burden experienced by families, and the differential impacts on women in the community. With this in mind, it is noted that the Alberta government has failed to acknowledge gender in their discussion or implementation of home care and/or community-based care policies.

Talbot, Lise R., Olivette Soucy and Luciana Soave, "Vers l'utilisation des services de réadaptation adaptés aux familles multi-ethniques dont une personne présente une déficience motrice ou sensorielle" [towards the use of rehabilitation services adapted to multi-ethnic families in which there is a person who has a motor or sensory disability], Centre D'Excellence pour la Santé des Femmes, 1998. [CESAF].

This document identifies the needs and expectations of multi-ethnic (Italian, Haitian and Vietnamese) families who have a family member with a motor or sensory disability. It examines the environmental factors that facilitate or hinder the use of adaptation/rehabilitation services; these services include standard home care services, as well as home-based or institutional out-patient educational and/or rehabilitation services. This project elaborates the ways that immigrant women and families are

marginalized when caring for someone with a motor or sensory disability, including language barriers and a lack of awareness of the needs of these families on the part of service providers. This project resulted in a model for intervention between immigrant families and adaptation/rehabilitation professionals.

Tremblay, Marielle, Nicole Bouchard, Claude Gilbert, Martine Couture, Guylaine Boivin, H el ene Roberge, Marl ene Simard and Nicole L'Heureux, "Les aidantes naturelles et la prise en charge de personnes en perte d'autonomie : sant e des femmes et d efi des solidarit es familiales et sociales" [Women caregivers and responsibility for frail persons: women's health and the challenge connected with family and social solidarity?], Centre D'Excellence pour la Sant e des Femmes, 2000. [CESAF].

This project examines the impact of transferring care from a formal to informal context, in terms of the increased burden on women caregivers when they must assume the responsibility for caring for a frail family member. The study focusses on the regional context of current health care reforms, specifically examining the situation of rural women caregivers in Quebec. The authors examine women caregivers experiences with access to resources, distance from or limited availability of services from health care institutions and the family dynamics of small communities. Findings reveal that women must sometimes care for more than one frail family member at the same time, and that they are required to provide specialized care which results in a large burden of responsibility. The authors also identify the transfer of services to the private family sphere as a form of privatization.

Williams, A., P.S. Wagner, M. Buettner, A. Coghill, C. Charlebois, T. Ens, K. Foster, B. Gustafson, D. Hart, N. Johnson, E. Jamison, M. Parcher, "Women's Formal Home Care Work in Transition: The Impact of Reform on Labour Process Change", no date, Prairie Women's Health Centre of Excellence. [PWHCE]².

This study examines the perceived quality of work life of three (3) groups of home care service providers, registered nurses, licensed practical nurses and home health aides, after the restructuring of Saskatoon Home Care. All groups reported less work satisfaction and poorer overall health and well-being since the changes to home care in Saskatchewan. The authors report differences between the provider groups in terms of satisfaction with their work and their overall health and well-being, using the Index of Work Satisfaction. Their data suggest that home health aides were most affected by changes to home care in the province, although all groups reported frustration with the continued restructuring. The authors provide suggestions for policy directions for home care, including a need for recognition of the value of home care work and for more autonomy to be given to home care workers.

² This document is currently unavailable for public distribution. It is available for internal CEWHP use only.

Willson, Kay and Jennifer Howard, "Missing Links: The Effects of Health Care Privatization on Women in Manitoba and Saskatchewan", Prairie Women's Health Centre of Excellence, 2000. [PWHCE].

This document provides a broad analysis of the many facets of health care privatization in Manitoba and Saskatchewan, with a focus on the effects of this privatization on women. Significant attention is paid to home care, including its history and changes since the onset of health care reforms. The authors examine the implications of shifting the provision of care to for-profit organizations, the transfer of costs to individuals, and the impact of reforms on informal caregivers. Discussions of other aspects of privatization of health care touch on home care issues throughout the document.

Summary

There is a broad spectrum of research on home care and women that has been done through the Centres for Excellence in Women's Health Programme (CEWHP) and its affiliated Centres. While most of the research at the Centres focusses on the health of informal caregivers, other topics include elderly and disabled women, support needs of informal caregivers, home care in terms of policy and in terms of the larger context of health care reforms. Little research is available on palliative care; the health and/or needs of home care service providers; or the experiences and/or needs of immigrant or ethnic families.

In terms of the availability of documents on home care by Centre, CESAF has produced the most research on home care with nine (9) documents, focussing mainly on the health and/or support needs of informal caregivers. They are the only Centre to have produced research on the needs of immigrant and ethnic families, and have also produced research on home care policies in Quebec and a literature review of home care research. PWHCE has produced seven (7) home care documents, with projects covering elderly women, the health of informal caregivers, and an analysis of health planning policies. They are the only centre to have examined home care service providers. NNEWH has produced two (2) documents about elderly and disabled women and MCEWH has produced one (1) project about the support needs of informal caregivers and a policy document. BCCEWH has only one (1) document on home care to date, with a focus on palliative care. All Centres have produced documents examining the scope of health care reforms in their regions, however only PWHCE, NNEWH and CESAF documents touch on home care issues.