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Canadian Cancer Action Network Réseau d'action de lutte au cancer

Home Care, Palliative Care, and Compassionate Leave Benefits: A Review

Report prepared for the Canadian Cancer Action Network (CCAN)

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Executive Summary

Home care has been given more prominence recently through federal and provincial initiatives such as the Romanow Commission, the Kirby Committee, and the 2003 First Ministers' Accord. These Canadian initiatives have called for national standards and the definition of a core basket of publicly funded services for short-term acute home care, including acute community mental health, and end-of-life care. The federal government further agreed in the Accord to the provision of a compassionate care benefit program through the Employment Insurance Program and job protection through the Canada Labour Code for those who need to leave their employment to care for "a gravely ill or dying child, parent or spouse."

Home Care programs exist in all Canadian provinces and territories; some are more established than others. The lack of standardized data definitions, measures, collection tools and reporting, has made it difficult to make jurisdictional comparisons. Nevertheless, existing data provide indications of direction and change. In the 1990s there had been considerable need and growth in home care spending stimulated by a number of factors including an aging population, hospital downsizing along with shorter lengths of stay, as well as technological and medical advancements that allowed for more outpatient care. However, hospital downsizing and shortened lengths of stay has outpaced the development and expansion of home care programs. As a result, this growing need for home and community care has placed a significant burden of care on family and volunteer caregivers. The need for home care services and family caregiving is not likely to abate in the foreseeable future.

A review of programs across the provinces and territories indicate that access to all provincial/territorial home care programs is through a single point of entry. All jurisdictions make available and fund assessment and coordination, nursing, and personal support services. Most jurisdictions provide rehabilitation services, such as physiotherapy, occupational therapy, and, to a lesser extent, speech language therapy, as well as social work. However, availability and accessibility to these services is limited. Homemaking, social work, dietetics, respiratory care and respite care are less available. Moreover, service and funding limits result in service caps, waiting lists, inappropriate institutionalization, or unmet needs.

Expenditure data for the years 1997-98 to 2002-03 indicate that home care expenditures have generally increased in each province and territory. Quebec, PEI, and the three territories devote

less than 4% of their total health care budget to home care. Only Manitoba has consistently spent more than 6% of its health budget on this program. Increases in home care spending as a per cent of total health care spending has been marginal over the three year period. In fact in Saskatchewan, Manitoba, Ontario, PEI, and the NWT, home care as a proportion of total health spending has gone down.

Per capita spending[1] across the jurisdictions varied considerably, from 200% and 300% between the lowest and highest spending provinces, with Manitoba spending the most per capita on home care, and PEI the least. In 2001, Nunavut became the top per capita spender at $192 and PEI remained the lowest spender at $48. Despite its fiscal resources, Ontario increased its home care spending per person by only 3.8% compared with Newfoundland, which, with much fewer resources, increased its per capita spending by 38.2%. Ontario's small increase is not because it already spends a more generous amount than Newfoundland. Ontario's annual per capita spending for the three years is lower in each year than Newfoundland's. Manitoba and the three territories have the highest proportion of home care services paid for by public funds (over 90%). Quebec and PEI are the provinces with the lowest proportion of services funded by government, 62% and 67% respectively.

There is substantial variation in palliative or end-of-life care across jurisdictions. However, there appears to be impetus both at the national and provincial/ territorial levels to improving end-of-life care. A number of provincial pilot projects provide models for the delivery of integrated, quality palliative care. Model elements that appear to contribute to cost-effective, accessible, quality care with greater client satisfaction include 24-hour access to multidisciplinary provider teams, and full coverage for drugs, supplies and equipment. The use of technology in the home needs further exploration.

Although the vast majority of Canadians indicate that they would prefer to die at home, and family members want to provide care to their ill relation, the lack of job and income protection for family caregivers and lack of home care services have made this difficult to achieve. To address part of these issues, the federal government introduced a compassionate care benefits program on January 4, 2004. The benefit will provide a maximum of 6 weeks of employment

[1] These data are constructed from the home care expenditures in the CHCA report divided by provincial territorial population figures for the three years obtained from Statistics Canada. These figures are not adjusted for inflation.

insurance for employees who need to be absent from work to provide care or support for a family member who is gravely ill with a significant risk of death (within 26 weeks). Amendments have also been made to the Canada Labour Code to establish an entitlement to a period of leave of up to 8 weeks with job protection within a 26-week period for the purposes of providing compassionate care. However, this latter move only protects federally regulated employees. As a result, a number of provinces have amended their employment standards legislation to provide similar job and income protection measures for their residents who take advantage of the federal program.

While heralded as a positive step, reactions to the federal legislation have raised some concern. A significant number of workers (particularly women) are ineligible for the benefit because they do not qualify for EI. The program, moreover, offers no support to individuals who must interrupt their employment to care for an ill family member who is not at risk of dying but who has a serious illness or has had a debilitating procedure. Many consider the leave period too short.

Although the compassionate leave benefit is a key advancement in policy, it should be viewed as a first step toward the development of a comprehensive package of supports for caregivers. In most jurisdictions caregiver supports and respite continue to be viewed as a residual policy issue. The sustainability of the health care system depends in part on the participation of unpaid caregivers. Provinces should nurture this resource by developing policies that support caregivers.

In conclusion, the health care system needs to be modernized to reflect current models of delivery and be brought into line with Canadian values by implementing a national standard for home care. The federal and provincial/territorial governments must get on with the work of defining a core basket of publicly funded home care services. Home palliative care must be considered one of these core services and should include the cost of drugs, supplies and equipment. The federal compassionate benefit must be expanded to cover all workers and not just those eligible for employment insurance. With experience with the program, consideration should be given to extending the length of the benefit to accommodate those situations where it is warranted. All provinces should immediately revise their employment standards legislation to ensure that all workers can take advantage of the federal program. Governments should respect family caregivers as an essential component of care provision. As such, they should develop policies that nurture and support this resource.

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Introduction

Recently home care has been given more prominence notably through federal and provincial initiatives such as the Romanow Commission[2], the Kirby Committee[3], and the 2003 First Ministers' Accord[4]. Although home care funding and delivery fall under provincial jurisdiction, these Canadian initiatives have called for national standards and the definition of a core basket of publicly funded services for short-term acute home care, including acute community mental health, and end-of-life care. First Ministers in the Accord agreed that access to these services will be based on assessed need and that, by 2006, these services could include nursing/professional services, pharmaceuticals and medical equipment/supplies, essential personal support care, and assessment and case management. The federal government further agreed in the Accord to the provision of a compassionate care benefit through the Employment Insurance Program and job protection through the Canada Labour Code for those who need to leave their employment to care for "a gravely ill or dying child, parent or spouse."[5]

Home care has been defined as an array of services which enables clients incapacitated in whole or in part, to live at home, often with the effect of preventing, delaying, or substituting for long-term care or acute care alternatives.[6]

Home Care programs exist in all Canadian provinces and territories; some are more established than others. In the 1990s in particular there had been considerable growth in home care stimulated by a number of factors including an aging population, hospital downsizing along with shorter lengths of stay, as well as technological and medical advancements that allowed for more outpatient care. However, hospital downsizing and shortened lengths of stay has outpaced the development and expansion of home care programs. As a result, this growing need for home and community care has placed a significant burden of care on family and volunteer caregivers. The need for home care services and family caregiving is not likely to abate in the foreseeable future.

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[2] Commission on the Future of Health Care in Canada, 2004. *Building on Values: The Future of Health Care in Canada.* http://www.hc-sc.gc.ca/english/pdf/care/romanow_e.pdf
[3] Standing Senate Committee on Social Affairs, Science and Technology, 2002. *The Health of Canadians-The Federal Role: Final Report on the State of the Health Care System in Canada.*
[4] Federal/Provincial/Territorial First Ministers, 2003. *2003 First Ministers Accord on Health Care Renewal*. http://www.hc-sc.gc.ca/english/hca2003/accord.html
[5] FPT First Ministers, 2003. *ibid.* p.4.
[6] Federal/Provincial/Territorial Working Group on Home Care, Health Services and Promotion Branch, Health Canada. 1990. *Report on Home Care*.

Home care programs have been developed in response to local needs and available resources. As a result, provincial and territorial programs vary considerably. The source of variability stems from the differing governing legislations or lack thereof; the number of government ministries administering separate aspects of the program; different definitions of services and terminology or the absence thereof; scopes and nature of services included under the program; inconsistency in services that are publicly funded in whole or in part; the types of data routinely collected; and government reporting requirements. Availability of services is further affected by the fiscal resources of the jurisdiction, the availability of other types of care (physician, hospital), the availability of appropriate health and support personnel, and geographic distances and population density.

Data Problems

Because of the variation in home care programs and the lack of standardized data definitions, measures, collection tools and reporting, it has been difficult to make jurisdictional comparisons. The paucity of high quality information has impeded effective planning, management and evaluation of services. The type of home care data collected by the federal government dates back to a period when home care was a marginal program. Home care data are reported in the National Health Expenditures report under the category, "*Other Health Spending*" which also include medical transportation (ambulances), hearing aids, other appliances and prostheses, prepayment administration, health research and miscellaneous health care, training of health workers, voluntary health associations, and occupational health to promote and enhance health and safety at the workplace.

The definition of home care that is currently in use in the National Health Expenditure Database (NHEX) is based on the definition used by the Organization for Economic Cooperation and Development (OECD), under which only the health professional component of home care is intended to be included. The portion that is commonly referred to as home support is considered to be a social service expenditure outside the ambit of health care and is excluded when it can be identified. As a result, a critical portion of what is considered home care in Canada, namely services that prevent or delay institutionalization, as defined by the FPT Working Group and recognized by policy makers, is not systematically captured. Moreover, some provinces do not separate out social support expenditures from home care health expenditures, while others do.

The current approach of including only care by health professionals probably underestimates amounts and growth rates of public home care expenditures in Canada.

A Home Care Feasibility Study[7] funded by CIHI investigated the possibility of developing a set of estimates that separately identified the health professional and the home support components of home care. This study captured data from 1974-75 to 1999-2000. In their conclusions, the authors recommend a new approach toward home care estimates in the NHEX; namely, the development of two separate series - home health care and home support - the aggregate of which is total home care. The process of updating the data collected in this study is currently underway.

In recognition of the difficulties in home care data, CIHI launched the National Home Care Indicators Project in April 1999. The project was to develop, pilot and evaluate indicators that could be compiled using existing data sources and identified as priorities by stakeholders.[8] The study identified a number of informational domains that included demographic, functional, and health characteristics of home care clients, regional and provincial home care expenditures, distribution of direct cost for home care services, utilization of home care services, and assistance services provided by informal caregivers. With respect to home care expenditures, identified indicators included amongst others:

- provincial government home care expenditures as a percent of total provincial health expenditures,
- provincial government home care expenditures as a percent of total provincial health expenditures for facility-based acute and long term care services, and
- per capita provincial expenditures on home care by province

With respect to utilization of home care services identified indicators included amongst others:

- number of admissions per 1,000 (regional catchment area),
- number of service hours per 1,000 (regional catchment area), and
- average number of service hours, by type of home care services.

The data reported in this paper draws on currently available information with all its shortcomings. Conclusions drawn from these data, by necessity, should be viewed as tentative and suggestive.

[7] Ballinger, G, Zhang J, Hicks V, 2001. Home Care Estimates in National Health Expenditures: Feasibility Study. CIHI.
[8] CIHI, 2001. Development of National Indicators and Report for Home Care. Final Project Report. April.

Home Care Across Canada

With the caveat that data on home care are sparse and problematic, the Canadian Home Care Association (CHCA) in its annual report provides a snapshot of the types of services provided in each provincial and territorial home care program as well as some expenditure and utilization data.[9] Table 1 summarizes the types of home care services funded (although not necessarily wholly publicly funded) by provincial/territorial governments.

Access to all provincial/territorial home care programs is through a single point of entry. All jurisdictions make available and fund assessment and coordination, nursing, and personal support. Most jurisdictions provide rehabilitation services, such as physiotherapy, occupational therapy, and, to a lesser extent, speech language therapy, as well as social work. However, availability and accessibility to these services is limited in most areas. Homemaking, social work, dietetics, respiratory care and respite care are less available. Despite these descriptions of provincial/territorial service availability, the reality is not as optimistic. Service and funding limits result in service caps, waiting lists, inappropriate institutionalization, or unmet needs.

Table 2 provides a summary of other features of home care programs, including whether they are income tested, charge fees, have service limits, provide supplies, equipment, palliative and wound care. Eligibility and method of assessment vary considerably. Most provinces have some form of residency requirement for eligibility. Approximately half of the provinces/territories have no income testing. The other provinces generally apply income testing to home support services (personal support and homemaking). With the exception of the territories, which do not charge fees, direct fees usually apply to supplies, equipment, drugs, meals, respite, and home support services. British Columbia, Nunavut and the Northwest Territories purport to have no limits on services. The remaining jurisdictions place either limits on dollars or hours of service. Provinces indicate that limits are usually calibrated to be less than the cost of institutional care. However, a number of jurisdictions provide a fixed global budget to home care programs or regional health authorities within which they must manage costs regardless of needs.

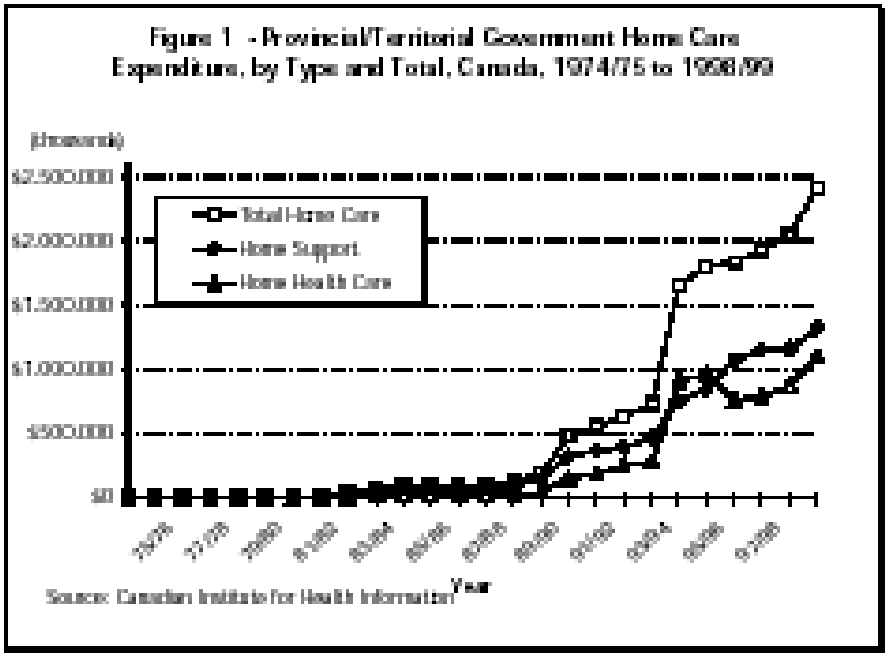
In the 2003 Accord on Health Care Renewal, First Ministers agreed to provide first dollar coverage for short-term acute home care, including acute community mental health and end-of-life care. Provinces and territories were to have defined by October 2003 a core basket of home

[9] Canadian Home Care Association, 2003 *Portraits of Home Care: A Picture of Progress and Innovation.*

care services that would be publicly funded in every jurisdiction. These discussions continue. Not meeting their own deadline leads one to believe that the issue may be contentious.

Home Care Expenditures

Total provincial home care spending has increased by over 350% between 1988-89 and 1998-99. See Figure 1. Similarly, in comparison to total provincial health expenditures, annual growth rates for home care spending are much higher for the same time period, 16.6% (home care) versus 4.2% (provincial health). As a result of these different growth rates, home care increased from 1.6% of provincial health expenditures in 1988-89 to 4.7% in 1998-99.[10]



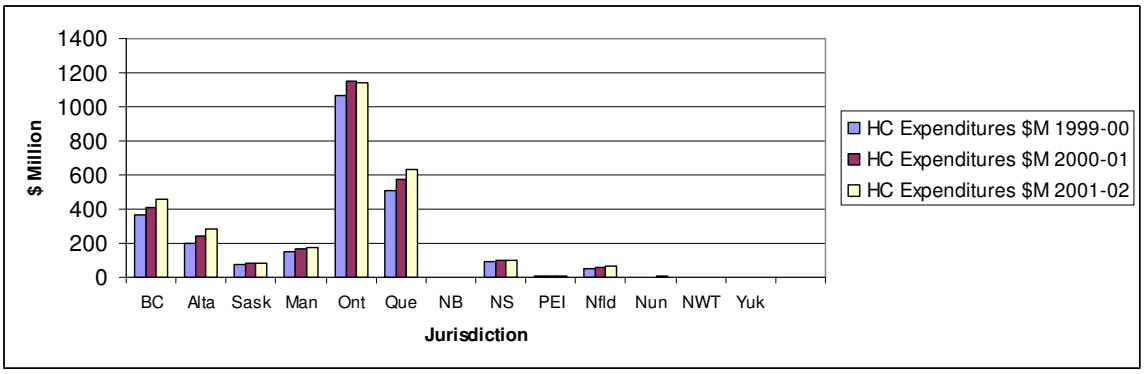
To assist in provincial/territorial comparisons, Table 3 summarizes available data on:

- provincial/territorial populations as reported by Statistics Canada for 2001;
- total provincial/territorial home care expenditures between 1997-98 to 2002-03;
- home care expenditures as a percent of provincial/territorial health care spending between 1997-98 and 2002-03;
- the percent of provincial/territorial home care that is publicly funded in 2000-01;
- per capita home care funding in 2001-02.

[10] Ballinger, G, Zhang J, Hicks V, 2001. Home Care Estimates in National Health Expenditures: Feasibility Study. CIHI.

Expenditure data are not systematically available for all provinces and territories or necessarily for all years. However, for the years 1997-98 to 2002-03, the data in Table 3 indicate that home care expenditures have generally increased in each province and territory. Figure 2 shows the increase over the three years (1999-00 to 2001-02) across jurisdictions for which data are available. These data, however, do not tell us much on how each province or territory compares in meeting home care needs because each jurisdiction varies in population size and fiscal capacity.

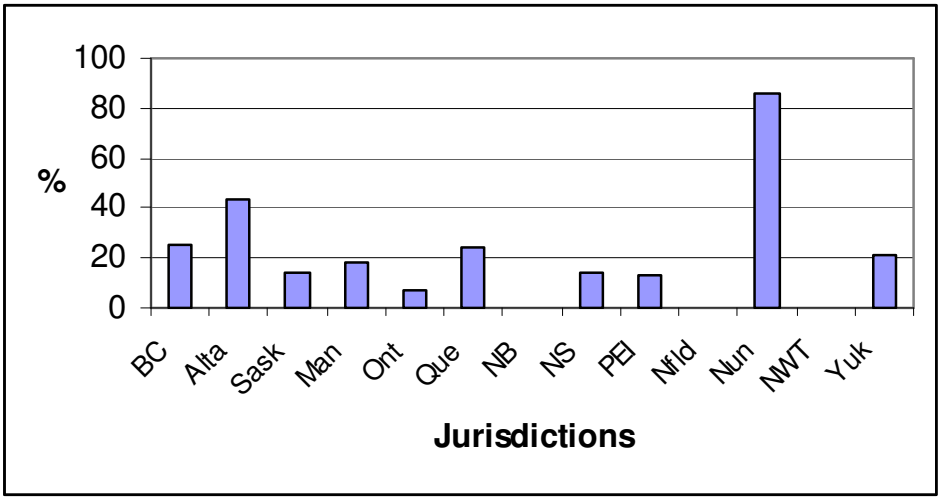
Figure 2: Home Care Expenditures 1999-00 to 2001-02



Source: Data from Canadian Home Care Association, 2003 *Portraits of Home Care: A Picture of Progress and Innovation*

A better indication of a province's commitment to investing in home care would be the percent increase in expenditures over time. Figure 3 shows the percentage increase for each province for the three years between 1999-00 to 2001-02. Once again fiscal capacity limits the ability of poorer provinces to make financial investments overall. The large increase in Nunavut's home care spending is misleading because the funding in the base year (2000-01) was small, and accordingly, any increase will translate into a large percentage increase.

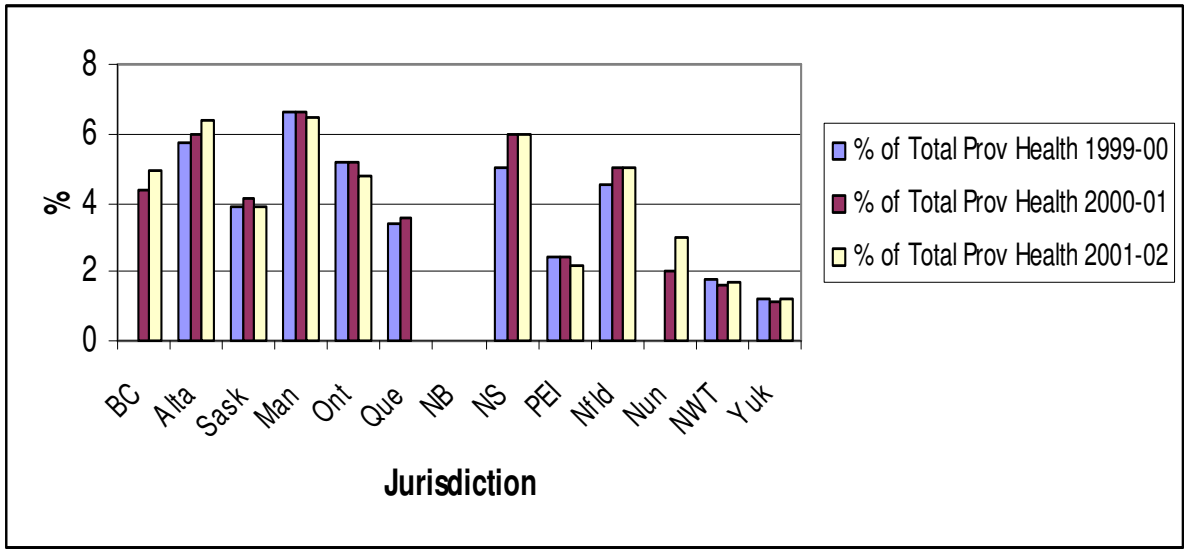
Figure 3: % Change in Home Care Expenditures across Canada, 1999-00 to 2001-02



Source: Based on data from Canadian Home Care Association, 2003 *Portraits of Home Care: A Picture of Progress and Innovation*

Home care spending as a proportion of total provincial health spending was identified by CIHI as a key home care measure. It is an indication of the relative emphasis placed by the provincial/territorial governments on this program compared with other health spending. Trends over time show the changing import of home care relative to other health sectors. Figure 4 shows home care spending as a proportion of total health spending in each province and territory over three years (1999-00, 2000-01, 2001-02).

Figure 4: Home Care as a % of Total Provincial Health Care Expenditures, 1999-00 to 2001-02



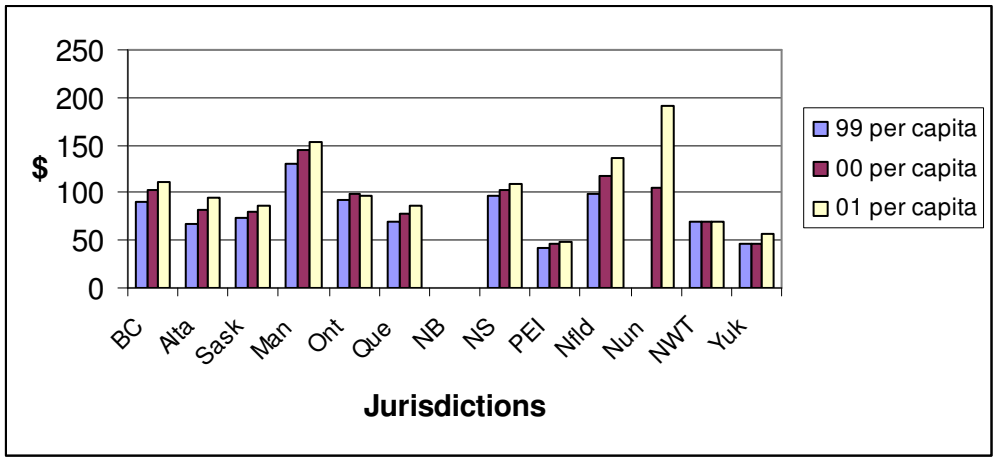
Source: Data from Canadian Home Care Association, 2003 *Portraits of Home Care: A Picture of Progress and Innovation.*

As can be seen from Figure 4, Quebec, PEI, and the three territories devote less than 4% of their total health care budget to home care. Only Manitoba has consistently spent more than 6% of its health budget on this program. Increases in home care spending as a per cent of total health care spending has been marginal over the three year period. In fact in Saskatchewan, Manitoba, Ontario, PEI, and the NWT, home care as a proportion of total health spending has gone down. To determine whether, these data indicate a decreasing commitment to home care, it would be necessary to compare provincial government home care expenditures as a percent of total provincial health expenditures with similar percentages for other programs. However, these data were not available. At face value, the data indicate a need for further exploration. Nevertheless, given the increasing pressure on home and community care, this trend must be reversed. Time will tell if the situation improves with the implementation of the federal commitment in the 2003 Accord to increase funding and the federal/provincial/territorial promise to improve access to home care.

Per capita spending is a measure that equalizes the differences in size of the provincial populations and budgets. Figure 5 provides per capita home care spending in each province and territory over three years, 1999, 2000, 2001. These data should be viewed as approximations as they are constructed from two different sources. Although the CHCA provided data on home care expenditures for the three years, it only included provincial/territorial population figures for 2001. The data in Figure 4 are constructed from the home care expenditures in the CHCA report divided by provincial territorial population figures for the three years obtained from Statistics Canada. These figures are not adjusted for inflation.

The per capita spending across the jurisdictions varied considerably, from 200% and 300% between the lowest and highest spending provinces over each of the three years. No comparable data was available for New Brunswick. In 1999 and 2000, Manitoba spent the most per capita on home care, and PEI the least. In 2001, Nunavut became the top per capita spender at $192 and PEI remained the lowest spender at $48. There may be a number of reasons for the disparity in per capita home care funding, which include the lack of comparable capacity in the acute and long term care sectors; differing rates of inflation; differing costs per unit of service; and a difference in the historical development of the program. Equalization payments from the federal government that transfers funds from the “have” to the “have not” provinces are intended to ensure that Canadians, regardless of residence, receive comparable levels of publicly funded services. These data indicate a need to explore further the reasons for the disparity in home care.

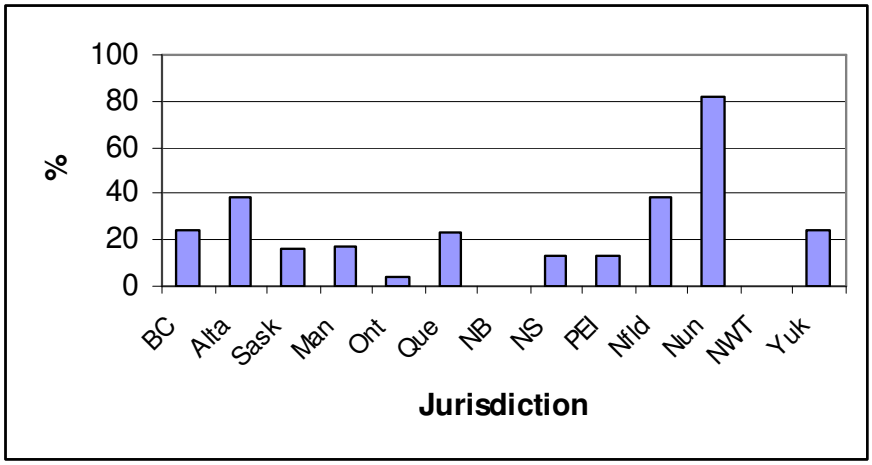
Figure 5: Provincial/Territorial Per Capita Home Care Spending, 1999-2001.



Source: PT population figures for 1999, 2000, 2001 from Statistics Canada, www.statcan.ca, accessed Dec. 23/03, 2:03 p.m.
Expenditure data from Canadian Home Care Association, 2003 *Portraits of Home Care: A Picture of Progress and Innovation.*

Figure 6 shows the change in per capita spending as a per cent over the three years 1999 to 2001. No data was available for New Brunswick and only data for 2000 and 2001 was available for Nunavut. The NWT showed no change in per capita spending over the three years. Despite its fiscal resources, Ontario increased its home care spending per person by only 3.8% compared with Newfoundland, which, with much fewer resources, increased its per capita spending by 38.2%. Ontario's small increase is not because it already spends a more generous amount than Newfoundland. Ontario's annual per capita spending for the three years is lower in each year than Newfoundland's.

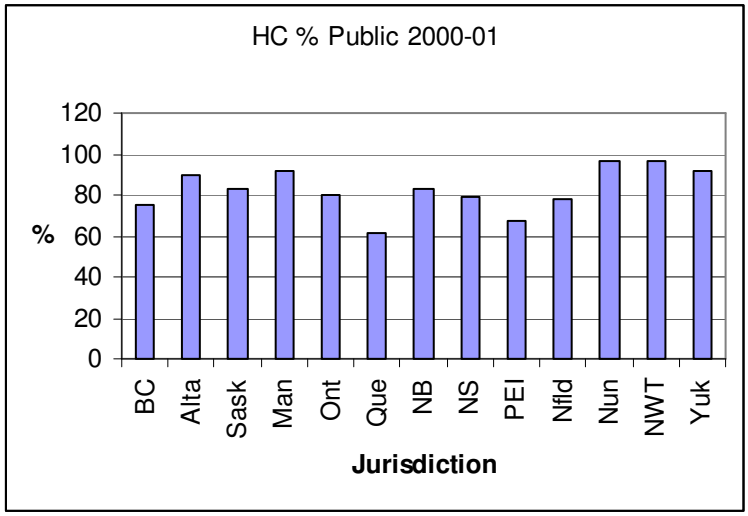
Figure 6: Change in Per Capita Home Care Spending by Province/Territory, 1999-2001



Source: PT population figures for 1999, 2000, 2001 from Statistics Canada, www.statcan.ca, accessed Dec. 23/03, 2:03 p.m.
Expenditure data from Canadian Home Care Association, 2003 *Portraits of Home Care: A Picture of Progress and Innovation.*

Another measure of access to services is the amount of service that is paid for by public funds as opposed to private funds, such as out of pocket charges or private insurance. Figure 7 shows the proportion (%) of home care services in each province and territory that was publicly funded in 2001. Manitoba and the three territories have the highest proportion of home care services paid for by public funds (over 90%). Quebec and PEI are the provinces with the lowest proportion of services funded by government, 62% and 67% respectively.

Figure 7: Percent of Provincial/Territorial Home Care Publicly Funded, 2001



Source: Canadian Home Care Association, 2003 *Portraits of Home Care: A Picture of Progress and Innovation.*

While allowing for local innovation and response to needs, federal, provincial and territorial governments need to ensure that Canadians have comparable access to a core basket of home care services and support. Development and collection of standardized data in each jurisdiction will provide the necessary evidence on areas of service need and enhancements.

Palliative Care

The Canadian Hospice Palliative Care Association estimates that only 5% of Canadians receive integrated and multidisciplinary palliative care. Meanwhile about 75% of Canadians receive these services in hospitals and long-term care facilities. Approximately 25% of Canadian deaths are related to cancer. Cancer patients receive 90% of the palliative care services. Most provinces do

not have palliative care as a core service and palliative care relies disproportionately on charitable donations.[11]

Considerable variability exists in the availability of palliative care or end-of-life care across Canada. Who pays for palliative care currently largely depends on whether the client is in hospital or at home. Palliative care provided in hospital is usually paid by provincial health plans where the costs of care, drugs, supplies and equipment are covered. Residents in long term care facilities often have to pay part of the costs of palliative care. Some provinces pay for palliative care at home but often the costs of drugs and equipment used at home are not publicly funded. Moreover, provincial home palliative care programs may place limits on the amount of services paid for publicly. [12]

The British Columbia government, in response to the increasing medicalization of death, which took dying in the home and moved it to the hospital, and the use of the most expensive form of health care (acute care hospital beds), is developing a provincial strategy for end of life care. In its October 2002 discussion paper,[13] the BC government committed to expanding home care and palliative care services for chronically and terminally ill patients. These services provide supportive home environments as an alternative to hospital care. The government has also committed to providing patients living at home, in palliative care, or in long term care with the same drug benefits they would receive if they were in hospital, and to providing better home support and home care services. The BC Palliative Care Benefits Program[14], which became effective on February 1, 2001, has two components: Palliative Care Drug Plan and the Medical Supplies and Equipment Benefits. The Palliative Care Drug Plan provides palliative care patients free prescription drugs and selected over-the counter (OTC) drugs needed for care and treatment at home. Eligible medications currently available under the BC Palliative Care Drug Plan include supplies needed for medication administration such as needles and syringes, and intravenous therapy supplies such as hydration solutions, tubing, catheters, syringes and needles.

Alberta has provided home palliative care since 1984. Home care regulations have been changed to exempt palliative care clients from the dollar limit for home care services. In 1999, Alberta

[11] CHPCA, Submission to the Commission on the Future of Health Care in Canada. November 2001.
[12] Canadian Hospice Palliative Care Association (CHPCA). http://www.chpca.net/menu_items/faqs.htm#faq_whopays
[13] Ministry of Health Services, Government of British Columbia, 2002. Discussion Paper on a Provincial Strategy for End-of-Life Care in British Columbia.
[14] Ministry of Health and Ministry Responsible for Seniors' Affairs, BC, 2001. BC Palliative Care Benefits Program. Program Description. February 1, 2001.

implemented a Palliative Care Drug Program to support medication costs for palliative care clients outside of hospitals. A number of the Regional Health Authorities have undertaken pilot projects to improve accessibility, integration and quality of palliative care.

Saskatchewan has a palliative care program for patients who have a life expectancy of a few weeks or months. In 1998, the province decided that end stage palliative individuals would not be charged fees for home care services. The Palliative Care Drug Plan Program provides access to free coverage of drugs on the province's drug formulary.[15] In 2002, Saskatchewan decided that home care and palliative care be part of core primary health care services to be delivered by Regional Health Authorities on a 24/7 basis.[16]

Manitoba's home care program includes palliative care but its availability varies by region. To address this, Manitoba increased funding to the Winnipeg RHA (which serves the largest population) for improvements in palliative care services that include a 24 hour on-call team of physicians and nurse specialists, and the hiring of palliative care coordinators.[17] In 2002, Manitoba's Pharmacare program included coverage of end-of-life patients regardless of setting (hospital, home, LTC residence). Costs are completely covered for eligible drugs.[18]

Ontario indicates that its home care program includes palliative care but does not expand further. There have been a number of palliative care pilot projects in the province, including a Hospice for the Homeless in Ottawa, the first of its kind in Canada. The Hospice Palliative Care Network Project which ran between 1999 and 2001 offered access to a network of support for persons with an advanced illness who wished to remain at home or live in a LTC institution and their families. The team of providers include palliative care physicians, nurse consultants, coordinator consultants and hospice volunteers.[19] Regarding palliative drug coverage, there is no specific program. However, through its Drug Benefit Plan the costs of drugs for all home care clients who are in the receipt of home professional care are covered. There is a user charge attached to this program.[20]

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[15] http://www.health.gov.sk.ca/ps_palliative_care.html
[16] Saskatchewan Health, 2002. *The Saskatchewan Action Plan for Primary Health Care*. June. http://www.health.gov.sk.ca/ph_phs_publications/phs_action_plan_for_primary_health_care.pdf
[17] Canadian Home Care Association, 2003. Home Care and Palliative Care: Recommendations to Increase Awareness, Access and Integration. A Review of Provincial/Territorial Programs. March 2003.
[18] http://www.gov.mb.ca/health/guide/2/pharmacare.html
[19] Canadian Home Care Association, 2003. Home Care and Palliative Care. *ibid*.
[20] http://www.health.gov.on.ca/english/public/pub/drugs/section8.html

Quebec has specialized services such as intravenous therapy, home chemotherapy and palliative care coordinated by its Local Community Service Centres (CLSC). Between 1998 and 2000, the Health Transition Fund supported a palliative care initiative, Toward a Continuum in Care and Services for Terminally Ill Adult Users.[21] A partnership of five Montreal CLSCs provided on-call nursing, medical and drug services, home care services, a dedicated phone line, and psychological, social and bereavement support. Some of these services were available around the clock. Patients had access to day hospitals as well. These CLSCs prior to the project had about 5%-10% of their terminally ill clients receive palliative care, the majority of whom were cancer patients. One result of this project was that 30% of cancer patients received palliative care. Moreover, over 50% of patients died at home, a rate much higher than the provincial rate. The project produced much better quality of life and physical health for family caregivers. The project demonstrated the benefits of comprehensive palliative care services delivery by multidisciplinary teams.[22] [23]

New Brunswick's Extra-Mural Program provides patients discharged from hospitals with acute home care and palliative care. About 4-5% of EMP caseload receives palliative care. A physician referral is required for admission to the program. The EMP provides professional services and arranges support services on a short term basis. Clients who are in receipt of home health care services can access supplies and equipment. The EMP is the payer of last resort for drugs.[24]

Both Nova Scotia and PEI have large rural populations. The Health Transition Fund supported a pilot palliative care project, A Rural Palliative Home Care Model: The Development and Evaluation of an Integrated Palliative Care Program in Nova Scotia and Prince Edward Island.[25] The pilot took place in three sites. Seventy-six percent of clients surveyed indicated that they preferred to spend their last days at home rather than in an institution, suggesting that home-based palliative care should be considered an essential core service. The financial burden on some caregivers suggested a need for some form of income assistance and/or job security for those providing palliative care at home to a family member. Clients and caregivers were generally

[21] Health Transition Fund, *Toward a Continuum of Care and Services for Terminally Ill Adult Users. http://www2.itssti.hc-sc.gc.ca/B_Pcb/HTF/Projectc.nsf/*
[22] Canadian Home Care Association, 2003. Home Care and Palliative Care. *ibid*
[23] Health Transition Fund, *ibid.*
[24] Government of New Brunswick, http://www.gnb.ca/0051/0384/pdf/1985e.pdf
[25] Health Transition Fund, A Rural Palliative Home Care Model: The Development and Evaluation of an Integrated Palliative Care Program in Nova Scotia and Prince Edward Island. http://www2.itssti.hc-sc.gc.ca/B_Pcb/HTF/Projectc.nsf/FactSHeets_e/5A8306836FBFA3358525660900418DA2

satisfied with the care provided, and especially its improved coordination. Factors that contributed to the success of the model included: collaboration among disciplines and agencies; common standards for care; a single access point for services; a clinical team with expertise in palliative care; and coverage for medications in cases of financial need (Nova Scotia site only). Barriers to developing a fully integrated program included a lack of 24-hour access to referral services; funding for respite and nursing visits (Prince Edward Island sites only); a funding formula to reimburse physicians for palliative-care services; and an integrated information system.

In addition to the Rural Palliative Home Care Model project, PEI has implemented West Prince Telehospice, a pilot project, which is to provide support to a dying person at home 24 hours per day. Using a telephone line and fully interactive audio visual equipment, nurses and other health professionals can monitor and assess the health/vital signs of clients and provide education to clients living at home. Results have shown a 76% decrease in days that dying clients were hospitalized, a 20% reduction in emergency room use, and 15% reduction in physician office visits.[26]

The province and territories of Newfoundland and Labrador, Northwest Territories, and the Yukon all indicate that they have palliative care services within home care, but further information was not available.

In 2001 the Secretariat on Palliative and End-of-Life Care was established by the federal government to coordinate the development of a national strategy on end-of-life care. In March 2002, the Secretariat brought together 150 national, provincial and territorial key stakeholders to consider 7 priority areas: availability and access to services; ethical, cultural and spiritual considerations; education for health care providers; research; surveillance; support for family, caregivers; and public education and awareness programs. Work towards a national strategy continues.[27]

Despite the variation, there appears to be impetus both at the national and provincial/ territorial level to improving end-of-life care. There is considerable innovation at the local level. A number

[26] Canadian Home Care Association, 2003. Home Care and Palliative Care. *ibid.*
[27] Health Canada, Palliative Care. http:www.hc-sc.gc.ca/English/care/palliative_secretariat.html, accessed 12/10/03, 6:12 pm.

of pilot projects outlined above provide models for the delivery of integrated, quality palliative care. Model elements that appear to contribute to cost-effective, accessible, quality care with greater client satisfaction include 24-hour access to multidisciplinary provider teams, and full coverage for drugs, supplies and equipment. The use of technology in the home also needs further exploration.

Compassionate Care

Although the vast majority of Canadians indicate that they would prefer to die at home, and family members want to provide care to their ill relation, the lack of job and income protection for family caregivers and lack of home care services have made this difficult to achieve. According to the Conference Board of Canada, 48% of family caregivers indicated that it was difficult to balance personal and job responsibilities in providing care for a family member. The hidden costs of family caregiving include a great deal of stress in juggling roles, a lack of sleep and minor health problems.[28] The most significant indicator of caregiving stress is the lack of choice in taking on this role.[29]

A national survey done for Health Canada[30] indicates that approximately 4% (933,000 individuals) of adult Canadians are providing care to a relative in 2002. The care responsibility is not evenly distributed across the population. Seventy-seven per cent of family caregivers are women and typically older (70% are 45 years of age or older). A little more than 20% are employed full-time and approximately the same number are employed part-time or self-employed. Although caregivers can be found in all income groups, two-thirds report a household income below the national average ($45,000).

One-quarter of caregivers indicated that they are in their roles because of a lack of home care services and one-third indicate that no one else is available to provide the care. Impacts on employment are reported by more than one in four caregivers. Leaving a job entirely is disproportionately reported by women. Added to this financial burden is the out-of-pocket costs

[28] Conference Board of Canada, 1999. Caring about Caregiving: The Eldercare Responsibilities of Canadian Workers and the Impact on Employers.
[29] Decima Research, 2002. National Profile of Family Caregivers in Canada - 2002. Final Report prepared for Health Canada.
[30] Decima Research, 2002. National Profile of Family Caregivers in Canada - 2002. *ibid.*

most are faced with to provide care to their family member. Most common expenses include transportation, prescription and non-prescription drugs, medical supplies and equipment.

Caregivers indicated a strong interest in more workplace supports to balance the demands on their time. A little over 40% would like flexible work hours and a similar proportion would like to see short term job and income protection through the Employment Insurance (EI) program.

On January 4, 2004, Canadians became eligible for the new federal compassionate care benefits.[31] Bill C-28, the *Budget Implementation Act, 2003* amended the *Employment Insurance Act* and the *Canada Labour Code*. The benefit will provide a maximum of 6 weeks of employment insurance for employees who need to be absent from work to provide care or support for a family member who is gravely ill with a significant risk of death (within 26 weeks). The family member may live in or outside Canada. A medical certificate is required to testify that the ill family member needs this care and support and is at significant risk of death within the 26 weeks. Some critics have suggested that family members may be unwilling to ask a physician to make such a determination and that family physicians may be unwilling themselves to make such a declaration. In contrast, amendments to Quebec's *An Act respecting labour standards* only requires, in the instance of a sick child, that the child has "a serious and potentially mortal illness to qualify for palliative care leave.[32]

The Health Canada survey referred to above showed that recipients of family care are most likely to be a spouse/partner (38%), a parent (33%), or a child (34%). A small minority are siblings (5%) or other extended family (8%).[33] The Compassionate Care Leave benefit defines family members as:

- the individual's child or the child of his/her spouse or common-law partner (person living in a conjugal relationship with the individual for at least a year);
- the individual's wife/husband or common-law partner;
- individual's father/mother; or
- the wife of the individual's father/ the husband of the individual's mother;
- the common-law partner of individual's father/mother.

[31] Human Resources Development Canada, Compassionate Care Benefits. http://www.hrdc-drhc.gc.ca/ae-ei/menu/faq/compassionate_care.html#Definition. Accessed 1/14/04, 8:09 a.m.
[32] Watson Wyatt Special Memorandum. New compassionate care leave benefits program introduced. December 2, 2003. http://www.hrpao.org/Knowledge_Centre/kc_s12020306.asp. Accessed 1/3/04, 10:49 a.m.
[33] Decima Research, 2002. National Profile of Family Caregivers in Canada - 2002. *ibid.*

These benefits will be paid to all workers who are entitled to Employment Insurance (EI) Benefits, including those who are unemployed and on employment insurance. To be eligible for the benefits, individuals must demonstrate that their regular weekly earnings from work have decreased by more than 40% and that they have accumulated 600 insured hours in the last 52 weeks (similar to other EI benefits) or since the start of the last claim. As defined, these benefits are not available to unemployed persons who are ineligible for EI or self-employed persons. The six weeks of EI may be shared with other family members who must also apply and be eligible for the benefits. Because applications must be done either on-line or in person at the local HRDC office, persons in rural or remote areas are at a disadvantage if they do not have the technical capacity or capability of internet access.

No doubt anticipating criticism that the benefit period is too short, the federal government has stated that the 6 week benefit was set based on medical information, best practices in the public and private sectors, and the fact that most Canadians who have taken time off from work to provide care or assistance to a gravely ill family member did so for 6 weeks or less. This latter fact may greater reflect employees' inability to afford additional time without income or their fear for job and benefits security, rather than the fact that further time for care was no longer needed. Moreover, the length of the benefit assumes that individuals and their physicians are able to predict when the ill family member is likely to die and therefore, when the individual should take time away from work. Although individuals may break up their 6 week benefit period, the benefits must be taken within 26 weeks of their commencement and it requires a judgment of the individual which weeks would be most beneficial to claim.

The basic benefit is 55% of the individual's average insured earnings and the maximum benefit is $413 weekly. Higher benefit rates are available for low-income families (income less than $25,921) with children. Individuals receiving compassionate care benefits are only able to earn $50 or 25% of their weekly benefits, whichever is higher. Money earned above the limit will be deducted dollar for dollar from the benefits. The $50 or 25% of weekly benefits can be from employment wages/commission, workers' compensation, group insurance income for sickness or loss of income, accident insurance, and pension income. Employers are allowed to include compassionate care benefit payments in their supplementary unemployment benefit and these payments will not be deducted from EI payments to a claimant.

The first two weeks of caring for the family member must be unpaid such that earnings from vacation pay or severance pay will be deducted from the actual benefits. If the benefit is being shared amongst a number of family members, only one member is required to wait the two weeks. This stipulation serves as a form of deductible. Payment of benefits are likely to take approximately 28 days which means that the individual will be without income for almost a month. Benefits end either when the 6 weeks of EI have been paid, the ill family member dies or no longer requires care, or the 26 week period has expired.

Finally, amendments have been made to the Canada Labour Code to establish an entitlement to a period of leave of up to 8 weeks (6 weeks of benefits plus the 2 week waiting period) with job protection within a 26-week period for the purposes of providing compassionate care. This means that federally regulated employees taking advantage of the benefits will not risk losing their jobs and are entitled to the same rights regarding seniority, pension, health and disability benefits. Unless provincial governments make similar amendments to their employment standards legislation, non-federal government employees will not have the same job protection, and as a result, the uptake of the benefit may be lower than expected.

A review of provincial/territorial jurisdictions indicate policy movement in this area. Quebec has legislation that will allow individuals to take up to 12 weeks of unpaid leave to care for a family member because of a serious illness or accident. The leave is available to employees with at least 3 months of uninterrupted service. In addition, employees may take up to 104 weeks to care for a minor child with a serious and potentially mortal illness.[34] As a result, Quebecers may take advantage of the federal program with out risk.

In December 2003, Manitoba amended its *Employment Standards Act* to provide unpaid compassionate care leave and improve job protections. The effect of this legislation will provide Manitobans with the job security to apply for federal benefits. The leave may be broken into 2 periods. At the end of a leave, the employer must reinstate the employee to the position he/she held or a comparable position, with at least the same wages and benefits that applied before the leave began. For the purposes of pension and benefits, the employment of the individual with the same employer before and after a leave is deemed to be continuous.[3536] In the same month New

[34] Watson Wyatt Special Memorandum. New compassionate care leave benefits program introduced. December 2, 2003. *ibid.*
[35] Legislative Assembly of Manitoba, 2003. *The Employment Standards Code Amendment Act*. (Bill 4). http://web2.gov.mb.ca/bills/sess/b004e.php

Brunswick and PEI made similar amendments to their *Employment Standards Act*. [37] [38] In November 2003, Nunavut followed suit with a similar amendment to its Act.[39]

A number of provincial/territorial governments have indicated their intention to change their employment standards' legislation in support of the federal legislation. On October 1, 2003, the Nova Scotia government introduced amendments to the Labour Standards Code to permit unpaid leaves of absence for employees caring for seriously ill family members.[40] The new Ontario government intends to introduce the *Family Medical Leave Act* to provide up to six weeks of job-protected unpaid leave to help employees care for seriously ill family members that parallels the federal legislation.[41] Similarly, the Yukon government is considering amending its *Employment Standards Act* to include job protection for compassionate care leave.[42]

While heralded as a positive step, reactions to the federal legislation have raised some concern. Employers are faced with potential difficulty in backfilling positions for employees on compassionate leave, and the added responsibilities of benefits administrators. However, the federal legislation provides an opportunity to employers to improve staff relations and to become more competitive; such as, topping up the federal leave coverage by providing extra paid leave time, and reviewing and amending their pension and benefit plans to provide continued coverage during compassionate care leave periods.

From labour's perspective, the leave period may be too short and a significant number of workers (particularly women) are ineligible for the benefit because they do not qualify for EI. The program, moreover, offers no support to individuals who must interrupt their employment to care for an ill family member who is not at risk of dying but who has a serious illness or has had a debilitating procedure.

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[36] HRinfodesk. Compassionate Care Leave Receives Royal Assent. December 2003. http://www.hrinfodesk.com/index.asp. Accessed 1/3/04, 11:10 a.m

[37] Legislative Assembly of New Brunswick, 2003. *An Act to amend the Employment Standards Act*. http://www1.gnb.ca/legis/bill/editform-e.asp?ID=223&legi=55&num=1

[38] Legislative Assembly of Prince Edward Island, 2003. *An Act to amend the Employment Standards Act.* http://www.assembly.pe.ca/bills/onebill.php?session=1&generalassembly=62&number=19

[39] HRinfodesk, Compassionate Care Receives Royal Assent. http://www.hrinfodesk.com/search.asp?artno=11301&libview=TRUE

[40] Mercer Communiqué, October 2003. Nova Scotia Proposes Compassionate Care Leave. http://www.hrinfodesk.com/search.asp?artno=11260&libview=TRUE

[41] HRinfodesk, 2003. Compassionate Care One Workplace Priority for New Ontario Government. http://www.hrinfodesk.com/search.asp?artno=11310&libview=TRUE

[42] Department of Community Services, Yukon, 2003. Compassionate Care Leave. http//www.gov.yk.ca/depts./community/labour/compare.html. Accessed 1/3/04, 10:47 a.m.

While the compassionate leave benefit is a key advancement in policy, it should be viewed as a first step toward the development of a comprehensive package of supports for caregivers. In most jurisdictions caregiver supports and respite continue to be viewed as a residual policy issue. According to the Caledon Institute respite should be understood as an outcome derived by the caregiver as a result of relief from caregiving duties or direct support for his or her needs. These services should include, for example, a temporary break, adult day care, personal emergency system, information on care receiver needs, adult daycare, housekeeping, outdoor home maintenance, counselling and peer support.[43] The sustainability of the health care system depends in part on the participation of unpaid caregivers. Provinces should nurture this resource by developing policies that support caregivers and amend their employment legislations to provide greater job and benefits security.

Challenges

Provinces and Territories report a number of challenges they face in providing home and community care to their populations.[44] These include:

- limited health care dollars
- increasing demand for services due to shorter hospital lengths of stay and growth of the proportion of seniors in the population;
- the growing acuity (increasing health needs) of home care clients which require more intensive and professional services;
- shortages and problems in recruitment and retention of trained professional and support personnel;
- projected decrease in family caregivers due to changes in family structures
- geographic disparity in service availability and differential access to service;
- rising costs;
- inadequate data system to plan and manage services; and
- rising consumer expectations of services and choice.

[43] S Torjman, 2003. What are Policy Makers Saying about Respite? Ottawa: Caledon Institute of Social Policy. February 2003.
[44] Canadian Home Care Association, 2003 *Portraits of Home Care: A Picture of Progress and Innovation.*

Conclusion

More and more care that was formerly provided in hospitals and by physicians is being provided in the home. Although significant progress has been made in the growth of home care funding and services, variability across the country indicates the need to modernize our notions of health care. The health care system needs to be brought into line with Canadian values by implementing a national standard in the area of home care.

The shift of acute care from the hospital to the home has resulted in the shift of costs from the public to the private purse. The federal and provincial/territorial governments must get on with the work of defining a core basket of publicly funded home care services that is universally available to Canadians. Palliative care must be considered one of these core services and should include the cost of drugs, supplies and equipment.

All provinces should immediately revise their employment standards legislation to ensure that all workers can take advantage of the federal compassionate care benefits. These benefits should be viewed as a good first step. In keeping with our value of equity, the benefit must be expanded to cover all workers and not just those eligible for employment insurance. With experience with the program, consideration should be given to extending the length of the benefit to accommodate those situations where it is warranted. Governments should respect family caregivers as an essential component of care provision. As such, they should develop policies that nurture and support this resource.

Finally, it is difficult for governments to plan, manage and evaluate the effectiveness of publicly funded services and to be accountable to their citizenry without well-defined, standardized and reliable data. While data systems' development do not provide direct service improvements, they are essential for moving forward in the right directions.

Table 1: Summary of Services Available (funded fully or in part) through Home Care Programs Across Provinces and Territories

	BC	Alberta	Saskatchewan	Manitoba	Ontario	Quebec	NB	NS	PEI	Nfld	Nunavut	NWT	Yukon
Assessment & Coord.	y	y	y	y	y	y	y	y	y	y	y	y	y
Nursing	y	y	y	y	y	y	y	y	y	y	y	y	y
Rehabilitation Services (PT, OT, & to some extent SLP)	y	y	y	y	y	y	y		y	y		y	y
Personal Support	y	y	y	y	y	y	y	y	y	y	y	y	y
Homemaking		y	y		y	tax credit for seniors	y	y	y	y	y	y	y
Respite	y					y				y			
Social Work	limited	y		y	y	y	y		y	y		y	y
Dietetics	limited	y			y	y	y		y	y		y	
Respiratory		y		y		y	y	y		y			

Source: Canadian Home Care Association, 2003 *Portraits of Home Care: A Picture of Progress and Innovation*

Table 2: Summary of Provincial/Territorial Home Care Programs in Canada

	BC	Alberta	Sask	Man	Ontario	Quebec	NB	NS	PEI	Nfld	Nunavut	NWT	Yukon
Income Test	Home support, respite, residential	Home support	Fees charged after 1st 10 units of service for meals, homemaking, home maintenance.	None	None for CCAC services	None for CLSC services	Long term supportive & residential care	For homemaking Personal care and oxygen services	For home support (respite, personal care) based on income and # living in home	Home support	None	None	None
Direct Fees	Supplies (after 2 wks) Home support, Drugs	Home supp., supplies, equipment & meds.	No fees for palliative care	Adult day care, meals on wheels, facility respite	$2 co-pay for drugs, support services	None for HC services; some fees for those under 65 for home supp.	None for EMP prof. services; fees for home support	Based on income, family size; fees for homemaking, personal care & home oxygen.	Clients pay for supplies, equipment, medication	Medication	None	None	None
Service Limits	No maximums	HC not required to provide service if there are insufficient $ or staff. $3k/mo for prof. services & personal support except for palliative care	When HC costs reach the level of nursing home individual reassessed	Upper cost limit based on formula for equivalent institutional care.	Personal Supp./ Homemaking – 60 hrs/mo Nursing – 48 hr/wk	Public funding for HC until costs approximate LTC facility care	Public funding for HC until costs approximate LTC facility care. $2040 limit for home support	Acute –up to $4000/mo excluding drugs. No charge for medication. Chronic- up to costs for LTC facility placement.	Total services cannot exceed 3 visits or 4 hr/day (28hr/wk) unless authorized.	No limit on professional services.	None	None	Acute care for clients needing < 12 wks of care; wound supplies provided for 2 wks if no income or insurance. Max home support is 35/wk.
Supplies	2 weeks free		Medications, some nursing supplies covered by DHB	An approved range available	Some supplies provide outside of ADP	Equipment provided; supplies not uniformly provided	EMP related supplies and equip are insured; some drug coverage	Medical supplies for home nursing; medical equip not thru HC		Some supplies provided	Yes-some	Supplies not provided; loan cupboard for equip	Short term supplies and loans
Palliative/End of Life	(6 mo.) N, HS, R, drugs for pain & symptom mgmt, medical supplies & equip. free		Life expectancy of a few weeks or months	Palliative care available, palliative drugs only available after 2002 separate from HC	yes	yes	yes	HC does not have a formal program. But does provide services.	Yes – palliative care pilot implemented- Palliative care coordinator, expansion of palliative care; program across prov. in 1 yr	yes	yes	?	yes
Wound Care	yes		yes	yes	yes	yes	yes	May be provided	yes	yes	?	?	?

Source: Canadian Home Care Association, 2003 *Portraits of Home Care: A Picture of Progress and Innovation*

Table 3: Summary of Provincial/Territorial Home Care Expenditures in Canada

	BC	Alberta	Sask	Man	Ontario	Quebec	NB	NS	PEI	Nfld	Nunavut	NWT	Yukon
SC 2001 population	4,077,047	2,974,807	1,019,466	1,119,583	11,410,046	7,237,479	755,391 (2002)	943,025	138,434	536,344	26,745	37,360	28,674
Expenditures $ Mill.										n/a			
1997-98	306				938			60.8					
1998-99				136.7	1033	457.9		74.4				4.2	
1999-00	364	199.8	75.5	149.2	1064	508.7		90.4	5.79			2.8	1.4
2000-01	412	243.7	80.4	165.8	1148	577.8*		96.5	6.20		2.9	2.8	1.4
2001-02	457	287.4	86.5	176.3	1143	633.3*		102.5	6.55		5.4	2.8	1.7
2002-03	507				1167		114.7	126.6			5.7		
% Increase 1999-00 to 2001-02	25.6	43.5	14.5	18.1	7.4	24.4	n/a	14.4	13.1	n/a	86.2[1]	0	21.4
% of Prov. Health Care Exp										n/a			
1997-98								4					
1998-99				6.7	5.5	3.14		5					
1999-00		5.7	3.9	6.6	5.2	3.43		5	2.4			1.76	1.2
2000-01	4.4	6.0	4.1	6.6	5.2	3.57		6	2.4		2	1.58	1.1
2001-02	4.9	6.4	3.9	6.5	4.8			6	2.2		3	1.67	1.2
2002-03	5.3										3		
HC-%Public in 2000-01	75.3	89.8	82.9	92.1	80.2	61.8	82.7	78.8	67.2	78.0	96.9	97.0	91.4
Per Capita HC$ 99-01[2]													
1999-00	90.74	67.65	74.40	130.59	92.47	69.46	n/a	96.81	42.48	98.05	n/a	68.80	45.46
2000-01	102.00	81.10	79.78	144.50	98.24	78.54	n/a	103.33	45.42	118.37	105.46	69.14	46.05
2001-02	112.05	94.02	86.49	153.13	96.07	85.62	n/a	109.93	47.92	135.63	192.17	68.63	56.48
% Per Capita Change, 1999-01	24.4	38.2	16.3	16.8	3.8	22.9	n/a	13.4	12.7	38.2	82.1	0	24.2
1999-00	112.09	96.61	80.16	157.43	140.93	87.50	151.84[3]	117.07	47.29	132.00[4]	201.91	85.46	59.29

1. Data only available for 2000-01 and 2001-02.
2. Data derived from CHCA expenditures and population figures from Statistics Canada for three years, 1999-00 to 2001-02.
3. Data available only for 2002-03.
4. Data is only for home support services.

Source: Canadian Home Care Association, 2003 *Portraits of Home Care: A Picture of Progress and Innovation*

Table 4: Summary of Relevant Provincial/Territorial Home Care Initiatives in Canada

	BC	Alberta	Sask	Man	Ontario	Quebec	NB	NS	PEI	Nfld	Nunavut	NWT	Yukon
Initiatives	Better-End-of-Life Care –developing a provincial strategy	Between 1999-02, $40 million added to home care; training initiatives	Supports for children with complex care needs; direct funding to consumers to manage their own supportive services.	Palliative Drug Access Program 2002 to provide deductible free coverage for eligible drugs (not part of home care); computerized scheduling in some regions; tele-monitoring home care pilots	Establishing CCACs as statutory corporations of the government; implantation of RAI-HC across province; implementation of MIS reporting standards and automation	Home chemotherapy program being piloted, considered for expansion across prov. Collaboration between hospitals and CLSCs in urban areas to develop specialty services	Development of palliative care strategies; telehealth; Health Charter of Rights and Responsibilities; expansion of service delivery models to include support personnel; HR strategies.	Developing a provincial approach to a palliative care program; adoption of common assessment tool; single access to home care	Integrated Palliative Care- access to necessary clinical and support services regardless of care setting. Stay at home with pain and symptom mgmt. Tele home care;	Most home support outside urban centres involve direct funding of client to deal with issue of staff shortages; LTC and Supportive Services Strategy	First Nations and Inuit Home and Community Care Initiative to enhance home care program.	Palliative Care initiative – training workers and professionals in end of life care; home care coordinator designated as public guardian in some areas	Implementation of electronic health record and client database.
Challenges	Inappropriate utilization of acute care as a substitute for home care; RHA fixed budgets; rising consumer expectations; potential decrease in un paid caregivers.	Funding and service delivery needs; human resource and skill shortages; increasing demand on formal and informal system; higher costs and expectations; geographic disparity	Geographic disparities due to limits in resources, personnel.	Growing acuity of clients; recruitment & retention of staff,; shifting from facility to home; improvement of data info systems; expanding use of in-home medical technology.	Shortage of professional and support personnel; geog. disparity; increasing demand for service due to shorter LOS and aging; info automation	Most rapid growth of seniors in Canada; shortage of personnel; inconsistency of services across prov; rising costs and use of meds.			Regional disparity in data management.	Absence of data; differential access; population is shrinking and aging which makes it a challenge to get trained staff; need for hard and software; self managed care program too time consuming	Shortage of personnel and training; need to improve data collection; access only by air transportation and costs, absence of telephones	Personnel shortage; training and certification; data collection	Shortage of therapies outside Whitehorse; service limitations especially in palliative care.

Source: Canadian Home Care Association, 2003 *Portraits of Home Care: A Picture of Progress and Innovation*