

Dying for Care

Quality End-of-life Care Coalition

Status Report

June 2004

Executive Summary

The Senate of Canada has released two reports on end-of-life care: *Of Life and Death* in 1995 and *Quality End-of-Life Care: The Right of Every Canadian* in 2000. The 2000 report noted little progress had been made in this area and made a number of strong recommendations to ensure that Canadians have access to appropriate, high quality, end-of-life care.

In December of 2000, a group of 24 national stakeholders met in Toronto to discuss the reports and how to move forward on achieving the goal of quality end-of-life care for all Canadians. They formed the Quality End-of-Life Care Coalition (QELCC), a coalition formed to work in partnership to achieve this goal and developed *A Blueprint for Action*, a discussion paper which identified a number of areas for action required to achieve the goal of quality end-of-life care for all Canadians. Since then, the Coalition has developed an annual workplan to provide a framework for education and advocacy activities aimed at advancing the end-of-life care agenda across Canada at both the national and provincial/territorial levels.

In 2004, a key activity of the Coalition was to assess the status of end-of-life care in Canada through a survey of all provinces and territories. In January 2004, a letter was distributed to each provincial and territorial ministry of health asking a number of key questions on the funding and delivery of hospice palliative care services, including research on hospice palliative care. The survey received a very strong response, with all provinces and territories responding with the exception of Manitoba and Nunavut.

FINDINGS

In analyzing the responses of provinces and territories it is important to note the limitations of the data: not all provinces and territories responded to all survey questions, and the survey itself did not address waiting times for services; the question on “non-prescribed therapies” elicited confusion, given the lack of a common understanding of this term; finally, given the range of provincial, territorial and regional program funding envelopes through which hospice palliative care services are delivered, responses may not provide a comprehensive overview of all services available in a jurisdiction.

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Nevertheless, analysis of the responses to the survey provides a solid basis for understanding the current status of hospice palliative care in Canada with several key themes emerging:

Definition of Hospice Palliative Care Services

There was significant consistency in how provinces and territories defined the hospice palliative care services delivered in their jurisdiction, with common elements including active and/or supportive compassionate care as defined by the dying individual and family aimed at improving the quality of life, and care that addresses the physical, psychological and spiritual needs delivered by a multidisciplinary care team in the home, long-term-care or acute-care setting.

Funding

No province or territory was able to provide a complete answer to the question regarding the level of funding for hospice palliative care services in their jurisdiction, with Quebec providing the most comprehensive response. The reasons for this include the regionalization of health care service delivery (and the funding responsibility that accompanies it) to regional health authorities in most provinces and territories. Secondly, even in provinces with a more centrally delivered health care system, hospice palliative care services are delivered through a variety of programs and funding envelopes. As a result, identifying precise funding levels is very difficult.

Inconsistent Access to Hospice Palliative Care Services

A diverse array of hospice palliative care services are provided with varying degrees of accessibility and coverage, depending on the jurisdiction. Some provinces and territories cover both professional and support services related to hospice palliative care, some jurisdictions cover only professional services, with support services provided as means-tested supplementary programs. Some provinces also require a medical assessment to receive full coverage.

Inconsistent Access to Respite Care Services

Although most jurisdictions indicated some kind of respite care was available, mostly in the form of homemaking services and/or day programs, few provided details on how those programs were accessed or whether a means or income test was applied to be eligible for them. Quebec noted it had amended provincial legislation to allow for up to 104 weeks of leave from work for a parent to care for a seriously ill child, but this did not appear to cover other caregiving situations. Again, from the information supplied, it appears that the type of program offered, if any are offered at all, varies significantly among jurisdictions.

Non-Prescribed Therapies and Prescription Drug Coverage

A few provinces and territories cover 100% of prescription

drug costs, provided the individual is eligible for a provincial/territorial drug card. Some provinces apply deductibles or will cover 100% of drug costs only if the individual receives a medical assessment that indicates he or she has less than six months to live. Other provinces do not have specific drug plans for palliative care clients, who must access standard drug plans and pay any associated deductibles or co-payments.

Provinces and territories were not clear on what was meant by “non-prescribed therapies” and generally only indicated whether or not they provided and covered the cost of home oxygen therapy. Almost all provinces indicated they covered the cost of this therapy if it was medically indicated. However, prescription drug coverage, like other health services required for hospice palliative care, was not covered consistently or through similar mechanisms among the 11 responding jurisdictions.

Palliative Care Research

Larger provinces indicated a dedicated health research capacity, both through their ministry and external funding agencies, but none were able to identify specific funding levels, although a few did indicate specific research projects. Some of the smaller provinces and the territories indicated very little research funding capacity.

Best Practices

Most provinces and territories with regionalized health services delivery systems indicated integrated regional palliative care teams as their “best practice” models. Others included specialized hospices or rural/remote pilot projects.

FEDERAL INITIATIVES

Health Canada, announced \$1 million in 2001 to support a Canadian Strategy on End-of-Life and Palliative Care which will focus on a number of strategic objectives and priorities, although funding in subsequent years has been reduced and current funding levels are unavailable. Human Resources and Skills Development Canada also recently implemented the new Compassionate Care Benefit, delivered through the Employment Insurance Program. It provides up to six weeks of paid leave for someone who is caring for a terminally ill child, parent or spouse.

Also of note is the palliative care initiative announced recently by the Canadian Institutes of Health Research and the Institute of Cancer Research to provide over \$7,000,000 to build research capacity, enhance research resources and fund research on palliative care.

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CONCLUSIONS

- Provinces and territories are unable to provide meaningful funding data on hospice palliative care services delivered in their jurisdiction
- Access appears to be limited by fragmented and inconsistent hospice palliative care programs in some jurisdictions, while others have reasonably comprehensive programs
- Access appears to be limited by fragmented and inconsistent respite care programs in some jurisdictions, while others have reasonably comprehensive programs
- Access appears to be limited in some jurisdictions by financial charges levied for some services, including medically necessary support services, prescription drugs and other necessary supplies and equipment for terminally ill patients
- There is limited or nonexistent research funding on hospice palliative care outside of the Canadian Institutes of Health Research
- Support through the Employment Insurance program is limited by a relatively short duration and a restrictive eligibility criteria

RECOMMENDATIONS

1. All provincial/territorial governments work with the federal government to provide quality end-of-life services that enables Canadians to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice.
2. All provincial/territorial governments fund a comprehensive, coordinated and integrated set of end-of-life services that would include access to:
 - Hospice palliative care professionals and volunteers 24 hours a day/7 days a week
 - Home care services including home support
 - Care for the caregiver often referred to as respite care
 - Compassionate leave for the caregiver (financial assistance)
 - Prescription medications
 - Non-prescribed therapies
3. All provincial/territorial governments work with the federal government to create a “basket of services” at end of life that include the six listed above. This would then assist in having a universal, equitable and transferable set of services across the country.
4. All provincial/territorial governments create a mechanism to track (i.e. funding, volume of usage) what end-of-life services and programs are available throughout their province or territory.



Introduction

In 2000, the Senate of Canada issued the report, *Quality End-of-Life Care: The Right of Every Canadian*. The report was an update of the Senate's landmark 1995 report, *Of Life and Death*. In the 2000 report, the Senate report noted that little progress had been made on recommendations contained in the original 1995 report. As a result, the 2000 report made a number of strong recommendations to ensure that Canadians have access to appropriate, high-quality, end-of-life care, beginning with a Canadian strategy on end-of-life care.

In December of 2000, a group of 24 national stakeholders met in Toronto to discuss the recommendations contained in the Senate report and to lay the groundwork for the development of a Canadian strategy for end-of-life care. The meeting resulted in the creation of the Quality End-of-Life Care Coalition (QELCC). The Coalition believes that all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice. The Coalition also believes that to achieve this goal there must be a well-funded, sustainable national strategy for palliative and end-of-life care. The mission of the Coalition is to work together in partnership to achieve this goal.

The Coalition developed a discussion paper for future work in this area, *A Blueprint for Action*. The paper identifies a number

of key areas for action required to achieve the goal of quality end-of-life care for all Canadians, including access, professional education, family and caregiver support and public education and awareness. Since then an annual workplan has been developed, based on this action plan, to provide a framework for education and advocacy activities aimed at advancing the end-of-life care agenda across Canada at both the national and provincial/territorial levels. The current workplan can be found at www.chpca.net.

The Coalition is comprised of a diverse range of national organizations devoted to supporting the principle of quality end-of-life care for all Canadians (see *Appendix A: QELCC Members* for a full list of Coalition members). Through its members, the Coalition is broadly representative of Canadians and includes professional and family caregivers, volunteers, health care professionals, Canadians with terminal illnesses, their families and other Canadians with an interest in end-of-life care. The Canadian Hospice Palliative Care Association (CHPCA) agreed to act as secretariat for the Coalition and has provided ongoing financial and administrative support for its activities.

Background

As indicated previously, since its inception in the fall of 2000 the QELCC has established an annual workplan to map out key activities aimed at achieving its goal of a national palliative care strategy with sustainable funding.

As a key component of its 2004 workplan, the Quality End-of-Life Care Coalition prepared this status report on end-of-life care in Canada. This report provides a national overview of end-of-life care in Canada. Because the delivery of health care services, including end-of-life care, is delivered provincially and territorially, the Coalition distributed a letter in January 2004, surveying each provincial and territorial ministry of health on a number of key questions related to the funding and delivery of hospice palliative care services, including research on hospice palliative care. A copy of the letter distributed by the Coalition is attached as Appendix B to this report.

In March 2004, the Coalition sent a follow-up reminder letter to all jurisdictions which had not yet responded to the original letter. Ultimately the Coalition received a very strong response to its survey, with every province and territory responding with the exception of Manitoba and Nunavut.

LIMITATIONS OF SURVEY

It is important to note that findings to any survey are limited by the quality of responses; not all provinces or territories answered all of the questions posed by the survey, and at least one question (on "non-prescribed therapies") elicited some

confusion as to the meaning of the term. As a result, the question regarding non-prescribed therapies most often elicited a response only on the example provided: home-based oxygen therapy. This is therefore the only non-prescribed therapy that can be reasonably assessed on a comparative basis among jurisdictions. Significant deficiencies or discrepancies in responses are indicated in the next section, which outlines key findings from the survey.

Although the Coalition received a very strong response to its survey, waiting times for hospice palliative care services were not addressed in the survey or the responses. This additional factor limits the findings, since waiting times for specialty services may vary widely among jurisdictions and among different geographic areas within a single jurisdiction.

Finally, given the range of provincial, territorial and regional program funding envelopes through which hospice palliative care services are delivered, responses may not provide a comprehensive overview of the range of home and institution-based hospice palliative care services available in a jurisdiction - an important caveat to keep in mind when reviewing the findings of this report.

Findings: Provincial/Territorial Survey

This section documents the current state of end-of-life care in Canada, based on provincial and territorial responses to the QELCC survey. The section is organized into the key issues or themes that emerged following analysis of the responses. It is worth noting that in May 2004, Quebec launched a major policy initiative on end-of-life care, the *Policy on End-of-Life Palliative Care (Politique sur les soins palliatifs de fin de vie)*, which provides the guiding principles for structuring Quebec's action in this area in each of the settings where end of life care is delivered: hospitals, home, long-term care facilities (*center d'hébergement et de soins de longue durée*) or community centers (*centres locale de sante communautaire*). No other jurisdiction appeared to have as coordinated an approach to hospice palliative care services or a framework for future activities.

The federal government, of course, plays a key role in this arena, in funding provincial and territorial health services through the Canada Health and Social Transfer (CHSA), in funding its own initiatives in this area (including direct funding of First Nations health services), and in administering the Canada Health Act (CHA), the federal legislation which establishes the criteria by which provinces and territories receive federal funding for provincially and territorially administered health services. Federal initiatives related to end-of-life care are covered in the next section, but it is important to remember in reviewing the provincial and territorial responses that the federal government continues to play a key role in health through its financial and administrative powers under the CHA.

DEFINITIONS

In order to establish whether or not provinces and territories agreed on a baseline definition of what was meant by hospice palliative care services, the survey first asked jurisdictions to provide a definition. Responses were remarkably consistent from the majority of respondents, with several citing the definition from the 2000 Senate report or developing their own description based on the report or other sources such as the Canadian Hospice Palliative Care Association (CHPCA) or (in the case of Quebec) the World Health Organization (WHO) definition. Following is a summary of the key characteristics indicated by the respondents:

- Hospice palliative care refers to “active and/or supportive compassionate care as defined by the dying individual and family” aimed at improving the quality of life for individuals
- Hospice palliative care services are provided to address the physical, psychological and spiritual needs of the individual and their family/caregivers
- Hospice palliative care services are provided by a multidisciplinary team (including, but not limited to, physicians, nurses, dieticians, clergy/spiritual advisors, counsellors, pharmacists, physiotherapists and volunteers) and delivered in the home, long-term-care or acute-care settings

In summary, there was significant consistency in how each

province and territory defined hospice palliative care services. Confirming a baseline standard as outlined above will assist national, provincial and territorial end-of-life care stakeholders in ensuring governments meet that definition in its operational delivery of services.

FUNDING

No province or territory was able to adequately answer the question related to the amount of funding dedicated to hospice palliative care services, although Quebec was able to provide the most precise figures: \$35 million for palliative care services delivered in the home through CLSCs and \$3.35 million provided to the 14 hospices responsible for delivering hospice palliative care in Quebec. There are a number of reasons for why jurisdictions found this question so challenging, but two key factors emerged from the responses:

ESTABLISHMENT OF REGIONAL HEALTH AUTHORITIES

With the notable exceptions of Ontario and Quebec, the majority of provinces have devolved responsibility for health services delivery to regional health authorities. This means that provinces generally provide block funding for the delivery of health services to regional authorities, and regional health authorities then determine how those resources are allocated across the spectrum of community-based and institutional health care services. While this approach to health services delivery has some benefits, it makes it very challenging to determine exactly how those resources are spent, in the absence of provincially/territorially predetermined funding envelopes for specific health services. Most jurisdictions, when responding to the question of funding, noted that only the regional health authorities could identify specific budgets related to palliative care services and referred the Coalition to the regional health authorities for additional information.

The Coalition did not survey regional health authorities for information given that provinces and territories have responsibility under the CHA for health services delivery. It would also pose significant logistical challenges to try to reach the dozens of regional health authorities established in provinces and territories. It is worth noting that hospices and home-based health care fall under “Extended Health Services” under the CHA and are therefore not subject to the same funding criteria as hospital and physician services.

FRAGMENTED APPROACH TO HOSPICE PALLIATIVE CARE SERVICES

For those provinces that do provide direct funding and delivery of hospice palliative care services, it is difficult to establish funding estimates given that those services encompass a broad spectrum of health services funded through a variety of programs. In Ontario, for example, different components of palliative care are funded through the network of Community Care Access Centres (CCACs), the Ontario Drug Benefit (ODB) and Home Oxygen Programs. Although not indicated in the response, hospices such as Casey House Hospice or other institutional-based hospice palliative care services are funded through other funding programs. Again, this approach to

hospice palliative care services makes determining the level of funding, or even providing an accurate overview of provincial or territorial hospice palliative care services, very difficult.

Some provinces also fund specific agencies to provide palliative care services. Nova Scotia, for example, indicated that Cancer Care Nova Scotia and IWK Health Centre (for pediatric care) are also funded to deliver palliative care services in addition to regional health authorities. Until provinces and territories establish better systems to track palliative care expenditures (through regional health authorities or individual programs) it will continue to be difficult to establish current Canadian funding levels for these services.

It should be noted that very few jurisdictions responded to the question about how services were provided in rural/remote areas, perhaps assuming their response to the primary question regarding health services delivery mechanisms also adequately addressed rural/remote issues. Yukon Territory noted that community nurse practitioners provide care in rural/remote areas, with additional support provided through home support workers from the Ministry of Social Services.

INCONSISTENT ACCESS TO SERVICES AMONG JURISDICTIONS

Access to appropriate end-of-life care services has been an ongoing challenge for individuals who are in the end stages of life and for their caregivers. In assessing this critical issue based on the responses, a number of factors must be considered including: financial cost of services to the individual; assessments required to access services (e.g. means-tested programs); and the integration of those services in the provision of hospice palliative care. Because pharmaceutical coverage for pain and symptom management is such a critical component of hospice palliative care, it is addressed separately in this section. However, it should be noted that drug coverage for home-based and some institutional care remains an important factor in determining accessibility.

INCONSISTENT ACCESS TO HOSPICE PALLIATIVE CARE SERVICES

Analysis of the responses indicated a diverse array of services and programs with varying degrees of accessibility and coverage. It is important to note that a few jurisdictions (including Quebec) included hospices and other facility-based hospice palliative care services in their responses, although the question asked specifically about home-based palliative care services.

Some provinces and territories, including Ontario, Quebec, Prince Edward Island, Yukon and the Northwest Territories cover both professional and support services, provided the individual is eligible for provincial or territorial health insurance. Other jurisdictions cover only professional services, with support services provided as an income-tested supplementary program (such as in British Columbia, Nova Scotia, and Newfoundland and Labrador). The response from Alberta noted it had recently removed the \$3,000 maximum cap on home care; Alberta currently provides full funding for professional services but support services are, like its drug program, income-tested.

It is important to note that some provinces (e.g. Saskatchewan)

require a medical assessment that indicates the patient is at “end-stage” palliation (defined in Saskatchewan as “longer than a few weeks or as short as a couple of days”) in order to be eligible for full coverage of the range of home-based palliative care services provided. If the individual is not assessed as being at end-stage, fees are applied in institutional as well as homes and health centres. Ontario noted it offers a “short stay” program where palliative care clients may stay up to 60 days in a long-term care facility.

INCONSISTENCY IN RESPITE CARE SERVICES

Almost all respondents indicated they provided some type of respite care which ranged from homemaking services to day programs. Again, many jurisdictions provided little detail on respite programs or on whether they were fully funded or income tested. Ontario noted that it funds 75 volunteer visiting hospice agencies to provide respite specifically for the caregiver of the palliative client. Quebec’s response referenced an amendment to the *Loi sur les norms du travail*, passed in December 2002, which provides up to 104 weeks for the parent of a seriously ill child to be absent from work. This legislation does not appear to apply to other caregiving situations. Again, there was a wide discrepancy in what jurisdictions reported as available in respite care through a variety of agencies and funding programs, with many once again deferring to the determination of regional health authorities for responsibility in assessing and funding individuals for respite care.

NON-PRESCRIBED THERAPIES

As indicated earlier, several jurisdictions indicated they were unclear as to what was meant by “non-prescribed therapies” and generally limited themselves to responding to the example of home oxygen therapy. Like other medically required therapies, home oxygen therapy was generally addressed in the same way as other palliative care services, (e.g. coverage of such therapy depended on a medical assessment or designation of an individual as “palliative”). Again, most home oxygen therapy is delivered through regional health authorities who authorize it. Some jurisdictions (Yukon, Saskatchewan, and Newfoundland and Labrador) indicated they also cover nutritional supplements at no charge.

PRESCRIPTION DRUG COVERAGE

As noted previously, prescription drugs are a critical component of end-of-life care and are a significant factor in determining accessibility for hospice palliative care services. Pain and symptom management are primarily, although not exclusively, addressed by prescription medications such as opiate painkillers. In analyzing the responses, once again there is significant inconsistency among jurisdictions in both the extent of coverage and the mechanisms for accessing it.

GAPS IN HOME-BASED PRESCRIPTION DRUG COVERAGE

Prescription drugs for acute-care hospitals are fully covered by provincial and territorial drug formularies. However, not all long-term, nursing or continuing/chronic care facilities provide such coverage and prescription drug coverage is even more fragmented when health care services are delivered in the home as a component of palliation. Some provinces and

territories such as Ontario, Yukon, and Nova Scotia, cover 100% of prescription drugs for home-based palliative care (Ontario requires a \$2 co-payment for each prescription). Other provinces employ various means-tested assessments or clinical criteria to determine eligibility for coverage. Alberta, for example, applies a \$25/prescription deductible to a maximum of \$1000, after which Alberta Health and Wellness covers 100% of the prescription drug costs. The British Columbia Palliative Care Benefits Program will cover 100% of prescription drug costs and other medically necessary equipment and supplies only if the patient is assessed as having six months or less to live. Saskatchewan requires a medical assessment that a patient is designated as palliative in order to be eligible for full coverage. Other provinces do not have specific palliative care drug programs and patients or clients must access coverage through other provincial or territorial drug plans. This may mean paying relevant deductibles or co-payments. And in Newfoundland and Labrador, unless you are 65 years of age or require income support, no prescription drug coverage is available.

It is not possible to fully assess the level of prescription drug coverage in long-term care facilities such as nursing homes or chronic/continuing care facilities. However, it is likely some of the same issues would apply in this context for individuals requiring prescription drugs as a component of their palliative care.

In short, there are significant problems in accessing prescription drug coverage as a component of home-based palliative care depending on where in Canada you live.

PALLIATIVE CARE RESEARCH

There was a wide disparity among jurisdictions in the level of support and funding of research on hospice palliative care. Some jurisdictions, such as Yukon and the Northwest

Territories, indicated no support or funding for palliative care research. Other provinces, such as Nova Scotia, indicated only “in-kind” support in the form of advice and information. British Columbia and Alberta each cited two research projects focusing on hospice palliative care and Ontario and Quebec indicated both support and funding through their ministry, but did not provide any additional information on the level of funding or on specific projects.

None of the responding jurisdictions attached a financial figure to their level of funding for research on hospice palliative care; with some (such as Saskatchewan and Quebec) noting that research funding is delivered through another agency or council. Provincial and territorial funding for research on hospice palliative care is clearly either extremely limited or completely nonexistent.

BEST PRACTICES

Not all jurisdictions provided information on examples of best practices in hospice palliative care. Some, such as British Columbia, cited previously mentioned programs that included assessment criteria and/or income-testing. Those that did provide examples of best practices, including Alberta, Prince Edward Island and the Northwest Territories, frequently cited the establishment of regional palliative care teams which integrated multidisciplinary palliative care services that included pain and symptom management. Several jurisdictions also cited education initiatives, such as Ontario’s education of interdisciplinary service providers and family physicians.

Quebec referenced the *Maison Michel-Sarrazin* in Quebec City, a hospice that provides comprehensive care as well as a day center for caregivers. Nova Scotia cited the Rural Palliative Care Pilot Project as a best practices model for delivering integrated palliative care services across the continuum of care in a rural/remote location (northern Nova Scotia).



Federal Initiatives

As indicated earlier, the federal government has a significant role in health and health care, including, among other functions, its funding of provincial and territorial health services delivery (as well as directly funded health programs for First Nations communities). It has also, more recently, launched initiatives related specifically to end-of-life care. The Canadian Strategy on Palliative and End-of-Life Care was announced by the federal government in 2001. The strategy was funded at \$1 million in 2002-2003 and somewhat less in 2003-2004. Funding levels for 2004-2005 have been further reduced. The strategy involves three key stakeholder groups:

- External Stakeholders
- Federal Departments and Agencies
- Provinces/Territories

Through work with these stakeholders, the strategy focuses on achieving four strategic objectives:

1. Client-centred care provided by a well-trained interdisciplinary team in the most appropriate setting
2. Canadians awareness of and making decisions around their choices and responsibilities in life and death planning
3. Supporting continuous quality improvement of care based on research into key questions
4. Sustainability and cost-effectiveness

The Strategic Priorities identified to deliver on these objectives are:

1. Quality care: standards and accreditation
2. Caregivers: formal and informal
3. Research: capacity and evidence
4. Surveillance: performance evaluation
5. Public Awareness: empowerment

Although home care and pharmacare have been on the agenda for the federal government for some time, aside from the establishment of the secretariat within Health Canada and related funding, there have been few major initiatives on the part of the federal government related to palliative health care



services. It is worth noting that the initial \$1,000,000 earmarked for the palliative and end-of-life care secretariat in 2001 has since been reduced.

One significant initiative, of course, is the recent implementation of the new Compassionate Care Benefit delivered through Human Resources and Skills Development Canada's Employment Insurance Program. Initially announced in the January 2002 Speech from the Throne, the benefit was implemented on January 4th 2004. It provides up to six weeks of paid leave for someone who is caring for a terminally ill child, parent or spouse.

Also of note is the palliative care initiative announced recently by the Canadian Institutes of Health Research and its Institute of Cancer Research along with multiple partners to provide over \$7,000,000 to build research capacity, enhance research resources and fund research on palliative care.

As well, Health Canada through the Health Human Resources Fund is funding the Educating Future Physicians in Palliative and End-of-Life Care Project (EFPPEC) for \$1.25 million dollars over five years.

Conclusions

The following conclusions summarize the key findings of the provincial/territorial survey and include an assessment of the federal role and recent initiatives in hospice palliative care. Significant progress has been made; the consistency in cross-jurisdictional understanding of the definition of hospice palliative care is important in providing a baseline understanding against which health services can be measured; best practices in this complex care area (including a multidisciplinary team that address the physical, psychosocial and spiritual aspects of care) are broadly understood by care providers and reflected in responses across jurisdictions; recent financial supports for family caregivers through the Employment Insurance Compassionate Care Benefit will help family members provide support to dying loved ones; and a significant research investment was recently announced by the Canadian Institutes for Health Research.

However, the responses also revealed significant gaps in a number of key areas related to hospice palliative care, particularly in home-based care. Below are the major gaps and concerns by this analysis:

- Provinces and territories are unable to provide meaningful funding data on hospice palliative care services delivered in their jurisdiction

- Access appears to be limited by fragmented and inconsistent hospice palliative care programs in some jurisdictions, while others have reasonably comprehensive programs
- Access appears to be limited by fragmented and inconsistent respite care programs in some jurisdictions, while others have reasonably comprehensive programs
- Access appears to be limited in some jurisdictions by financial charges levied for some services, including medically necessary support services, prescription drugs and other necessary supplies and equipment for terminally ill patients
- There is limited or nonexistent research funding on hospice palliative care outside of the Canadian Institutes for Health Research
- Support through the Employment Insurance program is limited by a relatively short duration and a restrictive eligibility criteria

Recommendations

In order to assess and grade how Canada is doing in providing quality end-of-life care for all Canadians the Coalition recommends that:

1. All provincial/territorial governments work with the federal government to provide quality end-of-life services that enable Canadians to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice.
2. All provincial/territorial governments fund a comprehensive, coordinated and integrated set of end-of-life services that would include access to:
 - Hospice palliative care professionals and volunteers 24-hours-a-day/7-days-a-week
 - Home care services including home support
 - Care for the caregiver often referred to as respite care
 - Compassionate leave for the caregiver (financial assistance)
 - Prescription medications
 - Non-prescribed therapies

3. All provincial/territorial governments work with the federal government to create a “basket of services” at end of life that include the 6 listed above. This would then assist in having a universal, equitable and transferable set of services across the country.
4. All provincial/territorial governments create a mechanism to track (i.e. funding, volume of usage) what end-of-life services and programs are available throughout their province or territory.

Appendix A: Quality End-of-Life Care Coalition Members

ALS Society of Canada	Canadian Medical Association
The Arthritis Society	Canadian Nurses Association
Canadian AIDS Society	Canadian Pharmacists Association
Canadian Association for Community Care	Canadian Society of Palliative Care Physicians
Canadian Association of the Deaf	Caregiver Network Inc.
Canadian Association for Pastoral Practice and Education (CAPPE/ACPEP) / Association canadienne pour la pratique et l'éducation pastorales	CARP: Canada's Association for the Fifty-Plus
Canadian Association of Social Workers	Catholic Health Association of Canada
Canadian Breast Cancer Network	Childhood Cancer Foundation (Candlelighters)
Canadian Cancer Society	The GlaxoSmithKline Foundation
Canadian Caregiver Coalition – La coalition canadienne des aidantes et aidants naturels	Heart and Stroke Foundation of Canada
Canadian Healthcare Association	Huntington Society of Canada
Canadian Home Care Association	National Advisory Council on Aging
Canadian Hospice Palliative Care Association	National Council of Women of Canada
Canadian Lung Association	VON Canada



Appendix B: QELCC Survey Letter

Quality End-of-Life Care Coalition Coalition pour des soins de fin de vie de qualité

January 22, 2004

Name
Address
Address
Postal code

Dear Honourable Minister,

Currently in Canada, comprehensive information regarding the status of hospice and palliative care across the nation is sparse and incomplete. The Quality End-of-Life Care Coalition (QELCC) seeks to remedy this situation by creating a status report on end-of-life care from a national perspective. This status report will be instrumental in measuring the progress of end-of-life care and will shed light on many areas that require further development.

The QELCC is a group of 29 national organizations that represent a broad cross section of stakeholders in the health and social sectors. The QELCC and each member organization individually support the creation of a Canadian strategy for end-of-life care. This strategy will bring value to the millions of Canadians represented by our Coalition member organizations.

The QELCC firmly believes that the provincial and territorial governments have a critical role in the development of a Canadian strategy to ensure all Canadian citizens have access to quality end-of-life care. In developing this national strategy, the QELCC is compiling a status report regarding hospice and palliative care across Canada. We are requesting that your ministry provide information regarding the following issues:

1. How does your province define Hospice Palliative Care Services? Describe what services are considered hospice palliative care in your province?
2. Describe the level of funding and other support provided by the provincial health ministry for access to hospice and palliative care in your provinces? In rural and remote areas?
3. Are palliative home care services delivered to the palliative care patient provided as a fully funded health care service in your province? Are they partially funded (income tested)? Please provide a list of fully funded and partially funded services?
4. To what extent does your provincial health ministry provide support for informal (family and friends) caregivers? This could include respite programs among other services.
5. Does your province cover the cost of prescribed medications for home-based care? If yes, to what percentage and maximum ceiling?
6. Does your province cover the cost of non-prescribed therapies (this could include oxygen) for home-based care? If yes, to what percentage and maximum ceiling?
7. To what extent does your ministry support research for hospice and palliative care?
8. Does your province fund research in hospice palliative or end-of-life care?
9. Every province has a number of end-of-life programs that they feel are exceptional; please provide an example of your best practices.

We would greatly appreciate a response by March 1, 2004. All responses should be sent to the Secretariat for the QELCC at the Canadian Hospice Palliative Care Association, 43 Bruyère Street, Suite 131Y-C, Ottawa, Ontario, K1N 5C8. The email address is sbaxter@scohs.on.ca.

The Quality End-of-Life Care Coalition will ensure that you receive a final copy of the status report on end-of-life care in Canada by mid-April 2004.

We would like to take this opportunity to thank you for participation in the initiative.



Yours sincerely,

Sharon Baxter
Executive Director, Canadian Hospice Palliative Care Association
for the Quality End-of-Life Care Coalition

Appendix C: Hospice Palliative Care Fact Sheet

*At some time, in some way, we must all face the end of life. And most of us share a common hope – that when death comes to us or to a loved one, it will be peaceful and free of pain. We hope to face death surrounded by those we love, feeling safe, comfortable and cared for.*¹

THE GROWING DEMAND FOR HOSPICE PALLIATIVE CARE IN CANADA

- Canada's population is aging: over the next 40 years demands for hospice palliative care (end-of-life care) will dramatically increase
- Each year more than 220,000 Canadians die, with an estimated 160,000 needing hospice palliative care services
- Each death potentially affects the immediate well being of an average of five other people, or more than one million Canadians each year
- Hospice palliative care programs allow patients to gain more control over their lives, manage pain and symptoms more effectively and provides support to informal caregivers²

ACCESS TO HOSPICE PALLIATIVE CARE SERVICES IN CANADA

- Between 5% - 15% of Canadians have access to hospice palliative care services
- Canadians living in remote and rural areas, or those living with disabilities, have severely limited access to hospice palliative care services
- As a result of health care restructuring, the number of institutionally-based palliative care beds has been cut and care has devolved to community-based agencies
- Government funding of community-based hospice palliative care has not increased proportionately, leaving a significant gap in the health care system
- Inadequate government support for hospice palliative care programs results in a significant additional burden on informal caregivers
- A recent poll indicated that 90% of Canadians wish to remain in their own homes during the final stages of life, yet only 6% of informal caregivers feel they can adequately care for their loved ones without hospice palliative care support
- 75% of deaths today still take place in hospitals and long-term care facilities
- Only two provinces cover the cost of medication for home-based care, leaving a significant gap in health care and increasing the financial cost to caregivers
- Billing schedules under provincial health plans focus on clinical procedures and discourage physicians from practicing palliative care

TRAINING AND EDUCATION

- Canada has only 160 palliative care physicians, including those working full and part-time (Canadian Society of Palliative Care Physicians)
- Not all of Canada's 16 medical colleges offer a palliative care certificate program. Lack of funding discourages medical colleges from offering similar programs
- Only 12 of the 142 schools of nursing offer palliative care as part of their curriculum
- In April 2004 the Canadian Nurses Association will begin to offer Hospice Palliative Care Certification

¹ *Living Lessons® – About quality of life for the last stages of life – The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association (2001)*

² **Informal Caregivers** are family members, loved ones, or friends and neighbours who provide support or care for the dying family member, loved one, or friend. The CHPCA's *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice (2002)* defines Informal Caregivers as, "not members of an organization. They have no formal training, and are not accountable to standards of conduct or practice. They may be family members or friends."

for nurses

- Much of Canada's end-of-life care is provided by family physicians, many of whom lack adequate training in pain management and other required skills
- Training is equally underfunded for other disciplines involved in hospice palliative care, including nurses, social workers, psychologists, and spiritual counselors

RESEARCH

- There is an acute need for research into more effective pain and symptom management, psychosocial aspects of palliative care, and effective methods of delivering hospice palliative care services and programs in the health care system
- Palliative care research has been poorly supported in the past. A palliative care research strategy is required to ensure a coordinated approach to this issue
- The Canadian Hospice Palliative Care Association (CHPCA) has produced the *Canadian Agenda for Research in Palliative Care*. Recommendations include the need to build research capacity in Canada by establishing more fellowships in palliative care for researchers in the early stages of their careers

THE ROLE OF INFORMAL CAREGIVERS

- With the devolution of care back to the community and the home, families are facing an increased burden to care for loved ones with little formal support.
- As of January 2004 Human Resources Development Canada will begin to offer 6 weeks of paid leave to eligible workers to care for a gravely ill or dying parent, spouse or child under the new Compassionate Leave Benefit.
- 70% of informal caregivers acknowledge that providing care is stressful and 70% indicate that they need a break from this responsibility
- Whether or not the informal caregiver has a choice in taking on this role is a significant factor in the degree of stress and disruption they experience
- Formal support is important, but does not seem to reduce stress
- Most informal caregivers perform 'light' duties such as medications, finances and transportation rather than 'heavy' duties such as lifting, bathing and dressing

THE ROLE OF HOME CARE

- The supply of formal home care depends on public funding. There has been an increase in demand for services without an increase in funding
- This affects the need for volunteer and informal caregivers
- There is a shortage of home care workers in rural and remote areas
- It is projected that by 2046 there will be twice as many people who require home care as in 1996
- The Canadian Home Care Human Resources Study indicates that 65% of informal caregivers are under 50 years of age and 64% were working full time, part-time or self-employed
- Emerging trends indicate a shift from acute care to home care and the need for sustainability of public funding to home care

FUNDING FOR HOSPICE PALLIATIVE CARE PROGRAMS

- Hospice palliative care programs rely disproportionately on charitable giving; two-thirds of the cost of programs is provided by private donors, restricting the size, scope and access of programs
- Only four provinces have designated palliative care as a core service under their provincial health plans. In other provinces, palliative care may be included in home care or other health service budgets, leaving it vulnerable to cutbacks
- The final report of the Commission on the Future of Health Care in Canada recommends the commitment of \$89.3 million annually to the Canadian health care system to address hospice palliative care needs

RAISING AWARENESS

- Public awareness programs are critically important in helping Canadians face end-of-life issues and raising the awareness of the current gaps in service
- The CHPCA has established the Quality End-of-Life Care Coalition (QELCC), a group of 29 national associations and organizations with an interest in end-of-life care issues.
- The CHPCA and the QELCC support the full implementation of the June 2000 Senate report *Quality End-of-Life Care: the Right of Every Canadian*
- Through its partnership with The GlaxoSmithKline Foundation, the CHPCA provides a bilingual toll-free national information line and other public education services.

CANADIAN STRATEGY ON PALLIATIVE AND END-OF-LIFE CARE

- Less than \$1 million dollar (per year) commitment – expired March 31st, 2004
- Three (3) Focus Areas;
 - Community
 - Inter-Department (at the Federal level)
 - Federal/Provincial/Territorial
- There are currently five working groups;
 - Research
 - Surveillance
 - Public Information and Awareness
 - Education of Formal Caregivers
 - Best Practices

Statistics are from *Quality End-Of-Life Care: The Right of Every Canadian*, Standing Senate Committee on Social Affairs, Science and Technology, June 2000 and *Living Lessons®– About quality of life for the last stages of life*, The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association



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