



**Canadian Strategy for Cancer Control:
Palliative Care Working Group**

Final Report

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INTRODUCTION

Palliative care, according to the World Health Organization, is the “active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable in the course of the illness in conjunction with anti-cancer treatment.” Palliative care is needed through out a cancer journey. “Terminal care” refers to care delivered at the end of life and reflects only a portion of all of palliative care.

From onset, cancer often causes physical, emotional and social distress. Recently, the assessment and management of pain and other symptoms that are prevalent in the cancer population has improved. Despite these advances, the burden of suffering for Canadians with cancer remains high. With an increasing number of Canadians expected to develop cancer over the next few decades, the magnitude of this problem will be increasing.

Across Canada there has been a shift in the focus of cancer care from tertiary care centers back into the community. Consequently, the patient’s family and community now share a higher burden of cancer care.

Further, the cost of cancer care to the public purse is increasing rapidly. The public expects that therapeutic advances will be readily available as treatments, irrespective of their cost. With cancer drug budgets far outstripping growth potential for what the health care system will be able to afford, cancer programs have been forced to make hard decisions. For example, should third line chemotherapy, often of modest or uncertain benefit, be made standardly available or should palliative care programs receive expanded support?

Palliative care is relatively inexpensive and affirms primary health care delivery as part of an integrated health care system. Although funding for community based palliative care often comes through provincial Ministries of Health, these programs must integrate better with other aspects of the cancer care system. Indeed, palliative care delivery could become a model of integrated, quality care that is community based but allows a patient to ready access to specialty level pain and symptom expertise at cancer centres, as needed.

In order to guide the Canadian Strategy for Cancer Control, the palliative care Working Group based its recommendations upon the following tenets, which it takes as axiomatic:

- Palliative care is a core component of cancer care and should be integrated throughout the cancer illness
- Cancer control involves strategies in three interconnected core processes: generation of new knowledge, transformation of knowledge into practice, and provision of care.

- The process of creating an improved, integrated model of cancer care entails the adoption of new or revised programming into existing structures, both within cancer organizations and within the larger community of health care services
- All cancer patients should be able to access consistent and effective approaches for the relief of their symptoms whether they are in a tertiary cancer center or their home community.

The palliative care working group has identified four key directions of change that a national cancer control strategy would need to address in order to improve palliative care for Canadians living with cancer. The recommendations that are listed within this report, although developed independently, closely parallel recommendations made by the June 2000 Senate final report on Quality end of life care, chaired by the Honourable Sharon Carstairs:

<http://www.parl.gc.ca/36/2/parlbus/commbus/senate/com-e/upda-e/rep-e/repfinjun00-e.htm> If implemented, the four key directions of change we recommend will result in:

1. Improved integration of palliative care delivery within existing cancer care and other health care delivery systems (Program Delivery)
2. Affirmation of palliative care as a fundamental component of cancer control (Cancer Control)
3. Improved pain and symptom control for patients through improved education for health professionals (Education)
4. Enhanced capacity for palliative care research in Canada (Research)

I. PROGRAM DELIVERY

ISSUE

Challenges in palliative care program delivery are due to three major issues:

- access to care
- variation in practice
- coordination and integration of care between various health care systems

CURRENT STATUS

Palliative care, while often stated to be a component part of a cancer control system, is commonly not found as a key program within an integrated, population-based cancer control strategy. Notwithstanding the recommendations by The Expert Panel on Palliative Care, in its report to the Cancer 2000 Task Force (1991), a reasonable allocation of cancer resources to palliative care has not occurred. The majority of cancer patients in Canada will die of their disease following a period of illness characterized by the presence of pain and other symptoms, physical disability and varying degrees of emotional and spiritual distress (Scott

1992). Cancer centres frequently care for patients with complex and severe psychosocial problems but direct relatively modest resources towards dealing with these patient care issues.

There are many gaps in palliative care delivery throughout the country, including: the lack of population based programs offering coordinated care; poor access to expert consultants; and the unavailability of continuing education for caregivers, particularly family physicians (Macdonald, 1992 and 1993). There is a national shortage of palliative care physicians. The complex funding and accountability systems in regionalized health care systems can result in barriers to coordinated and integrated palliative care delivery. The question of how to integrate a primary care based model of palliative care delivery with secondary and tertiary palliative care expertise remains a challenge in most jurisdictions. While the shift to community-based care may be seen as appropriate, the concurrent shift of cost and suffering to patients and their families, the lack of adequate reimbursement for family physicians providing palliative care, and a general lack of evaluation of the outcome of community based palliative care have largely not been addressed.

DESIRED STATUS

Palliative care will be accessible to all patients and families with a cancer diagnosis, in a timely manner, throughout the entire duration of their disease. The care will be patient-centered, needs-based and provided according to established standards that are evidence-based, through health care systems that are coordinated and integrated to ensure continuity of care.

RECOMMENDATIONS

GOAL

To reduce suffering and improve the quality of life of people living with cancer by providing access to consistent and effective approaches for the relief of their symptoms, whether the symptoms are the result of tumour progression, treatment related side effects, or due to other related problems. This emphasis on palliative care throughout the cancer care process, integrating excellent symptom control and attention to quality of life, may impact on the course of cancer, will greatly reduce end of life suffering, and, will improve preparations for end of life decision-making and bereavement.

TARGET

1. Building on both the regionalization of the health care system and the existing provincial cancer control systems in Canada, comprehensive, cost effective palliative delivery will be available to all persons living with cancer regardless of their place of residence. Formalized partnerships, networks and processes will be in place with the primary health care system and palliative care services in the community to ensure a well-integrated, comprehensive continuum of care for patients and their families. Palliative care networks will link cancer centres with community palliative care resources including tertiary

palliative care units, community hospital palliative care units, home care palliative care services and other hospice services. Evident by 2005.

2. Care processes within cancer centres will be redesigned to ensure integration of symptom management and palliative care throughout the course of illness. Care planning will reflect therapies to treat both the disease and symptoms, shifting in goals of care as the illness abates or progresses. This will be monitored through consistent use of assessments to measure well being, function and patient and family social well being; the establishment of referral processes amongst programs and services; and the monitoring of clinical outcome, patient and family satisfaction, and organizational performance. Evident in all cancer systems by 2005
3. Dedicated resources will be available to support expert interdisciplinary teams for consultation and direct care within each cancer centre and in the community setting. Cancer centre teams will provide leadership in setting the research and education agenda and be an expert resource available for the community. Evident in all tertiary cancer centres by 2003.
4. Cancer agencies, in collaboration with the community, will develop processes that outline the process of transfer of care to the community for end of life care. Evident by 2002.
5. Patients and families in the community receive palliative care services according to national palliative care service standards, based on need and choice. Primary palliative care services are appropriately funded at the home care, hospice, family physician, acute care and continuing care level. Patients and families have access to tertiary level support as required. Community models of palliative care will depend on their patient population and community needs, but will contain principal functions of palliative care. Evident in communities by 2004.
6. The cancer control system will be responsive to the special needs of hard to reach populations (individuals in rural regions), populations with diverse needs related to multicultural issues (with particular attention to First Nations peoples), and the pediatric population. This will necessitate research to better understand issues associated with these patient populations in the various care contexts. The cancer care system will participate in the development and evaluation of specialized palliative care services (e.g. quick response team, daycare programs, respite programs). Ongoing process
7. There is sufficient capacity within the health care system such that appropriately skilled physicians, nurses, other health care professionals and volunteers are available to meet clinical needs. Ongoing process.

ACTIONS

1. Provincial Ministries of Health, Health Canada, CCHSA, the Canadian Palliative Care Association and CAPCA (the Canadian Association of Provincial Cancer Agencies) to work together to support the final development and implementation of national palliative care standards in cancer agencies and the community.

2. Ministries of Health to work collaboratively with CAPCA, the Canadian Cancer Society, the Canadian Palliative Care Association, the Canadian Society of Palliative Care Physicians and other key stakeholders in the development of a national vision for the integration of palliative care within the cancer control system.
3. CAPCA to provide leadership and support in the development of national and provincial linkages at the inter-ministerial levels in government, regional health care system level provincially, and at the local agency level, to ensure integration and coordination of services, including hard to reach and diverse populations.
4. CAPCA to provide leadership and work closely with Ministries of Health in developing an approach to organizational assessment and design of integrated processes. This would involve developing an inventory of best practices across the country and internationally and facilitating dialogue amongst cancer agencies and related health care systems.
5. Ministries of Health and the cancer agencies, in supporting the national standards for inclusion of palliative care in a cancer control system, will fund and facilitate the existence of expert interdisciplinary teams available to cancer patients and their care teams both in cancer centres and in the community.
6. Individual cancer agencies to collaborate with their community partners to define protocols and create networks to facilitate smooth transition to the community for end of life care by fall 2002.
7. Ministries of Health, through consultation with CAPCA, work to address national manpower shortages in professionals involved in palliative care delivery in order to enhance capacity within the health care delivery system. Ministries of Health support the development of physician reimbursement programs for palliative care services in all provinces with their respective medical associations.
8. CAPCA to provide leadership and support, working in collaboration with Ministries of Health and the Canadian Palliative Care Association, in the development of a national cancer system accountability framework that includes palliative care.
9. Cancer agencies provide leadership in the developments of outcome and performance indicators and capacity for ongoing monitoring. Cancer agencies to collaborate with community partners in the development and evaluation of care delivery models.

EXPECTED OUTCOMES

- All cancer patients and their families will have access to palliative care.
- Symptom management and palliative care is an integral component of cancer care services in all provincial cancer agencies.
- There is evidence of regular palliative care assessments that are documented, addressed through a plan of care, and reassessed over time.

- Mechanisms for referral of patients for palliative care services from within and from outside of the Agency are in place.
- Clinical outcomes indicate effective symptom management, with decreased suffering and improved quality of life for patients and their families.
- Patients and families express satisfaction with the transition of care between the cancer agency and community palliative care services.
- Within the dedicated resources for palliative care, an interdisciplinary team is identified to provide consultation services for patients and families regardless of setting.
- Different palliative care services will be available to meet the range of needs of individuals requiring palliative care at various stages of their illness.
- Integration of palliative care within the cancer control system will reduce cost to the acute care sector of the health care system.
- Reimbursement schedules will be provided to primary care providers for providing palliative care closer to home.
- The contribution of and cost incurred by family members providing care will be analyzed and strategies will be developed to mitigate against this burden.
- Palliative care services will be responsive to cultural and spiritual beliefs and practices of individuals, families and communities from different cultural and diverse backgrounds.

II. CANCER CONTROL

ISSUE

Progress in any particular field of health care is dependent on its research base and subsequent translation of knowledge into practice. The relative lack of interest in palliative care research, scarcity of trained investigators and relative lack of funding support from granting agencies compound the problem. (Macdonald 1998). As a consequence, the paucity of evidence-based strategies will continue to negatively influence policy makers, and palliative care programs and patient care will continue to be characterized by great variations in practice.

CURRENT STATUS

Cancer control in every province is the responsibility of the provincial cancer agencies. A core component of cancer care, palliative care is identified in most provinces under the mandate of the health ministries. Operationally, cancer care is often artificially divided into two separate spheres of activity: active treatment (radiation, surgery or chemotherapy), and palliative care at the end of life. This schism limits patient and family access to palliative care expertise during the earlier course of illness when symptoms first present and could be readily alleviated or prevented. This

schism can create a lack of continuity of care as patients are “ discharged” from cancer agencies into the community.

The Canadian Palliative Care Association is working on standards to guide palliative care but the work is not completed. The lack of widely used standards to guide care and inconsistent application of clinical management tools for assessment allows for variable quality of care. The result is that many patients continue to suffer.

DESIRED STATUS

Full integration of palliative care services in the cancer control system, through formalizing and integrating national, provincial and regional palliative care and symptom management standards and guidelines into the care processes of a cancer control system.

RECOMMENDATIONS

GOAL

Palliative care will be a core service that is supported by all provincial Ministries of Health and developed according to national standards.

Palliative care will be an integral component of the cancer control system and each cancer control agency. New knowledge and development of practice standards will result in helpful interventions. Comprehensive databases profiling the patient population will generate new research questions resulting in effective and efficient care.

TARGET

1. Principles and standards of palliative care are endorsed and accepted by Health Canada, Ministries of Health, and CAPCA as national standards in palliative care for Canada. The standards set out by the Canadian Palliative Care Association may serve as a model worthy of adoption. Evident by 2003.
2. Cancer agencies mission statements, core services and priorities reflect a mandate in palliative care. Consequently, palliative care is identifiable within the formal organizational structure with associated dedicated funding. Evident by 2005.
3. Cancer agencies provide leadership and collaborate with community partners in setting the research and education agenda for palliative care. Evident by 2003.
4. Cancer agencies and acute care facilities consistently apply clinical management tools, communicate the results of these on an ongoing basis to the community for consistent patient care, and are leaders in the development of clinical practice and guidelines in collaboration with the community. Evident by 2005.
5. Databases within cancer agencies include agreed upon palliative outcome indicators with linked communication to community services. Evident by 2005.

6. CAPCA to provide leadership and support in the development of a comprehensive database related to workload, nature and scope of corresponding resources, clinical and system performance measurements. This would be utilized to establish standards and best practices for palliative care in oncology. Evident by 2005.
7. Cancer agencies participate in and provide leadership for quality assurance initiatives and outcome assessment studies to evaluate the quality of palliative care delivered to their patients as identified by national palliative care standards. Outcome assessment studies include measure of pain and symptom management. Evident by 2005.
8. The accreditation process for cancer services delineates standards for the full integration of palliative care into the cancer control system and monitors compliance with standards consistent with the underlying quality dimensions of responsiveness, system competency, and client/community focus. Evident by 2003.

ACTIONS

1. Health Canada, National Cancer Control Strategy, CAPCA and Ministries of Health endorse and support the Canadian Palliative Care Association in the completion of palliative care standards in 2000.
2. CAPCA requests cancer agencies to address palliative care within the cancer agencies mission and infrastructure thereby ensuring services receive the required resources by spring, 2002.
3. Ministries of Health collaborate with CAPCA, addressing issues of continuity of care, data requirements, and in the development/enhancement and application of clinical assessment and guidelines and performance indicators and outcomes. A mechanism for collaboration is identified by fall 2002.

CCHSA, CPCA and CAPCA collaborate in the refinements of standards for palliative care cancer services and in facilitating the accreditation process. Enhance standards drafted for 2003.

EXPECTED OUTCOME

- National standards for palliative care are available to outline principle functions that cancer patients and families can expect throughout the cancer illness, across the spectrum of organizations and programs involved in the care of cancer patients, including but not limited to: tertiary cancer centres, acute care hospitals, hospices, home care and the voluntary sector.
- Comprehensive palliative care is included as an integral part of the mission and funded as a core service within each cancer agency.
- There is evidence of palliative care representation at the executive level in cancer agencies.

- There is evidence that patients are being asked about their pain and symptom management. Clinical management tools addressing pain and symptom control are present upon patient files. Where there is evidence of unresolved symptoms, referrals are made to the palliative consultants.
- Clinical practice guidelines for palliative care are available for care of cancer patients and families regardless of setting.
- Core performance and outcome indicators are identified and collected on cancer patients and families, regardless of setting.
- Databases include palliative care clinical and outcome indicators, providing clinicians and managers with clinical, and outcome information based upon agreed upon elements in palliative care. Information is available regardless of patient setting.

Accreditation processes include palliative care standards consistent with agreed upon performance and outcome indicators, addressing responsiveness, system competency, and client/community focus.

III. EDUCATION

ISSUE

Inadequate palliative care education limits the competency of health professionals, including the Oncology community, in identifying and treating components of pain and suffering in their patients.

CURRENT STATUS

Professional curricula do not appropriately reflect learning needs in palliative care. Once in practice, there is not sufficient encouragement to continue to learn new palliative skills, knowledge and attitudes. Family physicians have limited opportunity to access palliative care education. An overly strong curricular focus on disease management (radiation therapy, surgery and chemotherapy) can result in unmet patient needs. Illness management (incorporating principles of palliative care with traditional cancer therapies) should be the standard of care available to Canadian cancer patients and their families. Role models are critically important in ensuring that educational rhetoric is translated into professional behaviors that will be emulated by trainees and colleagues. Training in communication skills have been recognized as an important component of health care curriculae but current efforts are not yet sufficient. An innovative palliative care fellowship certification program, sponsored by both licensing Colleges, is now available through several medical schools across Canada. Unfortunately, the manpower shortage in palliative care is so severe that a hand full of program in the country will barely begin to meet the clinical need for specialists in the area.

DESIRED STATUS

Proportionate representation of palliative care in the undergraduate, post graduate and continuing education curriculae of health care professionals who are involved the care of cancer patients; regulatory efforts are established to foster an environment that will be supportive of such educational initiatives.

RECOMMENDATIONS

GOAL

Professional education needs in palliative care receive a priority similar to that of other components of cancer treatment within curricula and continuing educational initiatives.

TARGET

1. Each undergraduate medical curriculum in Canada adopt and implement the Canadian Palliative Care Curriculum. By 2005.
2. Each school of nursing adopt and implement a curriculum of palliative care. By 2005.
3. All professional health care schools test for competency in palliative care. By 2005.
4. All CFPC (College of Family Physicians of Canada) and Royal College of Physicians and Surgeons of Canada residency programs that involve care of cancer patients include palliative care in their curricula. By 2005.
5. All professional examinations for health care providers that are involved in the care of cancer patients include testing of competency in pain, symptom control and other aspects of palliative care. By 2005.
6. Accreditation processes of cancer facilities, acute treatment centres and regional health authorities where cancer patients are cared for evaluate the rigor of continuing education programs for their health care professionals. Professionals involved in cancer care should be required to have attended continuing education events involving the teaching of palliative care in order for a centre to be accredited to take care of cancer patients. By 2003.
7. One or more palliative care experts should be formally affiliated with each academic internal medicine teaching unit. By 2003.
8. Medical students should have compulsory rotations or some other formalized mechanism for involvement in palliative care patients. By 2005.
9. An academic division of palliative medicine should be established in every faculty of medicine in Canada, and a division or department of palliative oncology should be established in every tertiary cancer centre in Canada. By 2005.

ACTIONS

1. As part of its implementation strategy, the Canadian Strategy for Cancer Control Steering Committee should contact the Executive Director of the Royal College of Physicians and Surgeons of Canada and formally request that: the teaching of palliative care be required in every patient related clinical specialty; and that competency in palliative care be assessed in the certification examinations for these specialties.
2. The Association of Canadian Medical Colleges (ACMC) adopt a policy requiring pain control and palliative care be a curricular requirement and that competency in pain control and palliative care be evaluated in the LMCC.
3. Faculties of nursing and other health care professional schools adopt palliative care learning objectives within their curricula and test for competency in palliative care.
4. All CCFP and Royal College of Physicians and Surgeons of Canada residency programs that involve clinical care of cancer patients include palliative care in their curricula. All professional examinations for health care providers that are involved in the care of cancer patients include testing of competency in pain, symptom control and palliative care.
5. CCHSA alters the accreditation processes of cancer facilities, acute treatment centres and regional health authorities where cancer patients are cared for evaluate the rigor of continuing education programs for their health care professionals. Professionals involved in cancer care should be required to have attended continuing education events involving the teaching of palliative care in order for a centre to be accredited to take care of cancer patients.
6. ACMC be lobbied to support the principle that an academic division of palliative medicine should be established in every faculty of medicine in Canada.
7. CAPCA support the plan that a division or department of palliative oncology should be established in every tertiary cancer centre in Canada.

IV. PALLIATIVE CARE RESEARCH

ISSUE

Ensuring an adequate research base for palliative care.

CURRENT STATUS

Most palliative care is not evidence-based. Primarily this observation reflects a lack of capacity for research. Few Canadian palliative care centres are research oriented, and capacity building

has not been targeted for support by funding agencies. And yet, where trained people are present and support is available (e.g., Edmonton), research of immediate benefit to patient care has flourished. The lack of a research basis for much of palliative care in practice today stands in contrast to the manifest need to further understand and address components of suffering encountered by Canadian cancer patients. Relevant to other cancer research, two salient points are evident:

- The fruits of palliative care research benefit not only cancer patients, but also control of suffering in other chronic, ultimately fatal disorders.
- Contrary to prior belief, symptom control may not only relieve suffering, but also favorably alter the course of illness.

DESIRED STATUS

- Significant capacity for research exists in a large number of palliative care centres that are closely related to or integrated within cancer centres.
- Palliative care research is interdisciplinary and helps direct programme development
- Strong inter-institutional research initiatives are active in several Canadian academic centres.

RECOMMENDATIONS

GOAL

1. To establish strong comprehensive palliative care research programmes integrated within Canadian cancer centres. In addition to the conduct of research, these centres will train investigators who may successfully compete for support from national granting agencies. It is expected this will require a change in the existing cancer centre culture that, through programmes and actions, seemingly does not recognize the ethical imperative of impeccable symptom control from the time of diagnosis of a cancer that may be expected to proceed to take the patient's life. Acceptance of this concept will enhance control of suffering throughout the duration of illness, and may result in prolongation of life.
2. To establish collaborative research linkages between centres, ensuring the success of multicentre clinical trials.
3. To ensure that the coordinated National Cancer Institute of Canada – Canadian Institutes of Health Research programmes reflect the need for capacity building in palliative care research. This could in part be achieved through sponsored research fellowships or scholarships to build research capacity, the funding of investigator initiated operating grants, the designation of funds ear marked for palliative care research and the creation of dedicated palliative care research review panels.

TARGET

1. An approved programme by NCIC-CIRH for dedicated funds for capacity building in palliative care. Evident by 2003.
2. Provincial cancer agencies establish strong palliative care divisions within each tertiary cancer centre. Evident by 2005.
3. Active palliative care research programmes in most academic cancer centres. If this imperative is accepted, it follows that cancer centres cannot discharge their responsibility in palliative care to “the community”: rather, academic palliative care research programs would partner with cancer centres and community palliative care programs to develop collaborative end of life research initiatives. Evident by 2005.
4. A specific amount of funding should be dedicated by NCIC-CIHR for investigator-driven palliative care research. A dedicated palliative care review panel should be responsible for the review of grants in this sector. Evident by 2005.
5. A strong multi-institutional palliative care research network should be in place. This network should form part of the NCI Clinical Trials programme. Ongoing process.

ACTIONS

A national working group should be established through CAPCA to review the above goals and targets and to develop a business plan for this research agenda and a timetable for achievement. The working group will be guided by the 1999 Canadian Palliative Care Association recommendations on research. This group will also work to see the implementation of the program delivery, cancer control and educational recommendations of this report. Members of this working group will include representatives from Health Canada, the NCIC-CIHR, the provincial cancer agencies, the Canadian Palliative Care Association, the Canadian Society of Palliative Care Physicians and interested community Seniors organizations. In addition to the usual effort to ensure national distribution of members, a particular effort should be made to enlist representatives from multiple disciplines concerned with palliative care. A number of members should be research participants or family members of individuals who have participated in palliative care research.

EXPECTED OUTCOME

- Reduction of suffering of patients with advanced chronic illness will invariably correlate with support of palliative care research.
- In addition to an enhanced quality of life for patients, we hypothesize that improvement in symptom control will also correlate with prolongation of life.
- A measurable example of this could be found in a highly prevalent symptom in cancer and other advanced illnesses, cachexia-anorexia syndrome. Patients, whose cachexia-anorexia

syndrome has been successfully controlled through the application of therapies emerging from research on the syndrome, will utilize fewer medical services. They will remain independent for a longer period, with consequent improvement in productivity and maintenance of dignity. Outcome studies could be undertaken with other controllable symptom complexes such as pain or nausea.

- Cross-disease research initiatives will flourish, as palliative care research outcomes are highly relevant to advanced cardiac disease, renal disease, chronic obstructive pulmonary disease, the rheumatoid disorders, AIDS, and other chronic degenerative disorders of the aged.

Feedback:

Much of feedback received was similar to input and discussions generated in the process of developing this report and has therefore been readily incorporated by minor adjustments to the report.

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