Palliative care — an essential component of cancer control

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Abstract

Unlike in other nations, in Canada palliative care has its origins in university hospitals. It has subsequently developed in a few Canadian schools as an academic discipline closely linked with oncology programs. Although this model is successful, other faculties of medicine and cancer centres have been slow to emulate it. Today, the situation is rapidly changing, and both palliative care and oncology professionals are re-examining the manifest need for collaborative efforts in patient care, research and education. Palliative care must be regarded as an essential component of cancer care; its principles must be applied throughout the course of the illness and, as in other phases of cancer control, palliative care should be regarded as an exercise in prevention — prevention of suffering. This article discusses practical applications that flow from acceptance of these concepts.

For more than 2 centuries hospitals have not been regarded as welcome havens for patients in the last days of their lives.1,2 Interest in biology and therapies directed at reversing disease have outweighed emphasis on care of the dying. Although the imbalance between care and cure is not a 20th-century phenomenon, the increasing emphasis on the biology of disease and the ability to treat disorders with often-complex therapies have skewed the focus of medical care. Thinking of options for management in terms of disease reversal has caused us to overestimate our successes and perhaps even misconstrue the benefits of therapy. For example, cancer chemotherapy prolongs lives to only a modest extent in adults with most forms of metastatic cancer, but until very recently assessment of such treatment has concentrated on outcomes such as patient survival, change in tumour size and the toxic effects of the drugs. Trivial but statistically significant improvements in survival have been enthusiastically heralded, whereas the effects of therapy on patients’ symptoms and quality of life have been ignored.

Modern palliative care dates back to 1967, when Dame Cicely Saunders responded to what she perceived to be a deficit in the care of dying patients by opening St. Christopher’s Hospice in London, England. She based her model of humane care for the dying on a sound educational and research base. Since then, thousands of palliative care programs have been established in many communities in the West-
ern world, particularly Great Britain, Canada, the United States, Australasia and Scandinavia. Other developed countries have been slow to establish formal palliative care programs, but most Western European nations are now introducing palliative care into their health care systems.

As in other English-speaking countries, palliative care in Canada has been heavily influenced by the work of Saunders. However, unlike in other nations, the first Canadian palliative care programs began in university hospitals. In 1974 Dr. Balfour Mount and Dr. Paul Henteleff opened inpatient care units at the teaching hospitals of McGill University in Montreal and the University of Manitoba in Winnipeg respectively. Although palliative care continues to struggle for recognition in many Canadian medical schools, the early work of Mount and Henteleff has had a major influence on its academic development in Canada.

The following definition of palliative care, developed by Palliative Care McGill, is based on the model definition of the Canadian Palliative Care Association:

Palliative care is a philosophy of care and combination of therapies intended to support persons living with life-threatening illness. Palliative care strives to meet physical, psychological, social, and spiritual needs, while remaining sensitive to personal, cultural, and religious values. Palliative care may be needed at any time in the disease trajectory, and bereavement. It may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care. Care is delivered through the collaborative efforts of an interdisciplinary team including the individual, family, and others involved in the provision of care. Where possible, palliative care should be available in the setting of personal choice.

As exemplified by this definition, in a palliative care program, the focus of activity has shifted from efforts to prolong life or cure diseases to approaches that aggressively address psychosocial and physical problems.

Patients who are not beset by physical problems such as pain or nausea and vomiting are better equipped to deal with the myriad psychosocial issues commonly encountered as chronic illness advances. For palliative care professionals to assist patients and their families with these problems, they must operate within a coordinated program that gives team members full authority to employ their skills. Physicians must be sensitive to social, psychological and spiritual distress, but they must also be prepared to accept help from those with perhaps greater skills in these areas (e.g., nurses, social workers, psychologists and pastoral care workers).

Palliative care does not end with the death of the patient. Although not all families require sophisticated follow-up, a palliative care program must offer bereavement counselling. Physicians and oncology nurses trained to deal with families in distress can help them link up with the palliative care group.

**Palliative care — current relevance to oncology programs**

Although palliative care has flourished in many settings, faculties of medicine and cancer centres have been slow to offer a place for its nourishment and growth. Issues related to the care of the dying have not been regarded as topics of academic interest. The concerns of oncology training directors in the US about the reduction in the number of applications for residencies in medical oncology demonstrate this: "Programme directors acknowledge that critically ill patients, having few or no therapeutic alternatives, can have a negative impact on House Staff and students. They urged an exposure to outpatient oncology, where treatment successes are more frequently found."

A paradox is immediately apparent. Whereas the administration of chemotherapeutic agents according to strict protocol guidelines is regarded as intellectually exciting, the holistic management of metabolically compromised, often elderly, cancer patients with a range of symptoms is somehow seen as an uninteresting exercise. Most such patients have an average of 8 to 11 symptoms, but many have twice this number. The management of these symptoms, which requires complex drug therapies that are difficult to administer to patients with advanced illness, represents one of the most challenging areas of medical care and requires the full armamentarium of medical wisdom. Melding exemplary medical care with considerations of humane ethical and psychosocial concerns surely represents the apogee of a health care professional's work. Why then would it be regarded as depressing, uninteresting or of little intellectual value?

Ironically, the way both patients and physicians view illness is influenced by the way the health care system is organized and, particularly in the US, by the way health care bills are paid. Compare the care of 2 patients, one with congestive heart failure and the other with metastatic cancer. Often the patient with cancer is perceived to be in a "battle" — a battle that is considered lost when the desired response is not achieved or relapse occurs. Once the battle is "lost," the patient is viewed as qualitatively different and is often no longer treated within the oncology system but "returned" to the care of a family physician who may have lost contact with the patient, may lack experience and often needs continuing advice from a specialist. Only the cancer care system devalues symptom control as an end in itself, one that is worthy of a specialist's attention. In the US, the care of patients with advanced cancer is further complicated by the fact that patients qualify for care not only on the basis of their suitability for treatment but also on the basis of the payment system — Medicare covers palliative care only for the estimated last 6 months of life.
Recent reports have given us the welcome news that age-adjusted cancer mortality rates are slowly decreasing. As the population increases and grows older, the total number of people dying may stabilize but probably will not decrease. This total, on which end-of-life priorities are predicated, rose an estimated 13.3% between 1990 and 1996, although it remained stable from 1996 to 1997.

Although cancer will no doubt ultimately prove to be a curable disorder, for years to come tens of thousands of Canadians will die of this disease, and each death will be accompanied by its own burden of suffering. Many of the elements of this suffering could be successfully addressed today if our cancer centres would take responsibility for the full continuum of care.

Concepts of palliative care have great community appeal, and our medical organizations and public bodies agree on their importance. Influences are now coalescing to raise the profile of palliative care in academic centres.

• Recent public interest in euthanasia and physician-assisted suicide: It is generally agreed that death cannot be ethically sanctioned if a patient has not had access to the best possible care.

• Changing ethical perspectives: The principle of autonomy currently governs Canadian and US ethical thought. Today, the concept of duty — one's duty to another — and a rebalancing of power among institutions, professionals and patients are coming to the forefront. As a result, institutions may begin to realize that they, and those in their employ, have an ethical responsibility not only to honour the autonomy of those within their care, but also to establish systems to relieve the suffering of the patients and families who depend upon them.

• The recognition by the oncology community that studies of symptoms associated with advanced cancer and related psychosocial issues are promising lines of enquiry: This change is reflected in the establishment of a Palliative Care Committee by the American Society of Clinical Oncology, the publication of Approaching Death. Improving Care at the End of Life by the Institute of Medicine (National Academy of Sciences) and the sponsorship of workshops on symptom control by both the Canadian and US National Cancer Institutes. The interest of these associations may have arisen in part from studies on cancer pain, the results of which represent one of the major advances in clinical cancer research in the last 10 years, despite relatively modest funding.

Cancer centres stress the importance of coordinated programs of cancer control. Logically, cancer control should encompass the continuum of cancer care, including easing the suffering of patients with advanced disease.

Palliative care, like other aspects of cancer control, should be regarded as an exercise in prevention. A corollary of this tenet is that the principles of palliative care should underlie the continuum of care for patients with life-threatening illnesses.

**Palliative care — an exercise in prevention**

Cancer control can be seen as an exercise in prevention with 4 phases:

* preventing disease by eliminating environmental causes or correcting genetic abnormalities
* identifying precancerous conditions or treating small, curable cancers at the earliest possible moment
* treating to cure, to rehabilitate or to prolong the lives of patients with invasive cancer
* preventing suffering by recognizing and treating symptoms associated with cancer as early as possible.

Since the genesis of problems at the end of life is often related to symptoms that were unexplored or ill-addressed early in the course of the disease, it is logical to assume that end-of-life care could be enhanced if problems were addressed at the earliest possible moment. Preventing pain rather than reacting to established pain is critically important. There is evidence from animal studies that chronic pain left untreated results in changes in the central nervous system’s mediation of pain impulses, which increases the severity of the pain.

Recently it has been demonstrated that pain can actually be prevented in certain forms of advanced cancer: prophylactic bisphosphonates have been used to prevent adverse skeletal events in patients with multiple myeloma and breast cancer. And yet preventive exercises are not always as highly valued as new chemotherapy drugs. It is puzzling that the consistent demonstration in level 1 studies of the prophylactic role of bisphosphonates has not led to changes in public policy to ensure that patients have access to these agents.

Pain is not unique in this regard; similar data are emerging for other critical symptoms, including confusion and malnutrition. Moreover, it is likely that emotional and psychosocial issues not addressed during the early stages of an illness will be more difficult to deal with during the final days of life.

Adopting this viewpoint should lead to a substantive change in the way our cancer programs are organized.

*This section is adapted from:


However, as we frame our organizational structure and use language to describe our actions, so will we interpret events of the present and risk freezing our vision of the future.

Fig. 1 represents a conventional view of the continuum of cancer care currently in use. In the early stage of the disease, curative efforts are made and life-prolonging therapies are administered. If these therapies become futile, care becomes palliative during the remaining months of life.

Although the model seems rational, working within it may limit the acceptance of new ideas. It is illogical to emphasize the control of symptoms at the end of a patient's life, when these symptom patterns are already well established. If identified and well managed in the early stages of illness, many of the symptoms that afflict dying patients could be either eliminated or diminished.

This principle is represented in Fig. 2. Even though this model is an improvement on that shown in Fig. 1, palliative care is still distinct from curative efforts and life-prolonging therapies. In this model of care, which is used occasionally, chemotherapy is still regarded as being an entirely different order of activity from and having a very different importance than therapies directed at relieving symptoms. Indeed, terms such as “active palliative care” and “palliative care” are employed to describe seemingly distinct therapeutic approaches that, in reality, provide similar probable outcomes. For example, consider the current realistic aims of chemotherapy for metastatic non-small-cell carcinoma of the lung and carcinoma of the pancreas. A review of recent clinical trials provided no evidence that chemotherapy substantially prolongs life. Presumably, the major benefits of chemotherapy are that it relieves pain and dyspnea, improves appetite and helps maintain function.

Relieving symptoms might do more than ease suffering. Unrelenting pain may compress disease progression, decreasing life expectancy and the period of time a patient is free of pain. Chronic pain has an adverse effect on the immune system and on a patient's functioning. In fact, patients with inadequate management of postoperative pain have higher mortality and morbidity rates. Since the early observations of Warren it has been accepted that the cachexia-anorexia-asthenia syndrome does not just affect functioning and dependence, it may actually kill the patient. Maintaining adequate appetite and function for a longer period preserves patient independence — with consequent economic benefit — and may also slow the progression of an ultimately fatal disorder.

The model illustrated in Fig. 3 reflects the ideal interaction that should exist among the various therapies that can be used to care for patients with cancer. Inherent to this system is the need to clearly identify the goals of treatment throughout the course of illness. These goals
may be straightforward, as in the case of a patient with pulmonary metastases from an embryonal cell carcinoma of the testicle, or they may be more complex, as in the treatment of a patient with metastatic non-small-cell lung cancer. The therapy may have a modest effect on survival, but another goal of therapy, be it with cisplatin or morphine, is to relieve pain and other symptoms. In this model, the goals of treatment are reviewed and possibly changed as the illness evolves.

Those comfortable with this model will also see the merit of a non-reductionist approach to cancer control. A cancer centre based on this model would give a balanced priority to all phases of cancer prevention, would include palliative medicine divisions or departments to consult in the management of complex symptoms, and would take a leadership role in palliative care research and education.

Education in palliative care*

Palliative care is not well represented in academic centres throughout the world. Although the first palliative care programs in Canada were established in university hospitals, a recent survey has revealed that the way faculties of medicine teach palliative care at the undergraduate level varies considerably from school to school (Canadian Palliative Care Education Group: unpublished data). In Canada there are now 3 designated chairs in palliative medicine and 7 recognized academic divisions or groups within the 16 medical schools. Two of the chairs are held by people who lead academic divisions of palliative medicine within departments of oncology.

In every country where surveys have been carried out (with pain as an indicator) physician education and oncologists’ knowledge have been judged inadequate, and patient outcomes have been rated as “unacceptable.”25–28 Although excellent educational material on palliative care is available in books and journals, most of these do not come to the attention of oncologists, whose major textbooks, journals and meetings devote a disproportionately small amount of space and time to end-of-life issues.

What we choose to assess sets our agenda and priorities. It may be that those of us whose careers date back to the first 2 decades of medical oncology did a disservice to our younger colleagues and their patients by choosing and accepting narrowly conceived assessment measures. If, in concert with establishing measures of tumour anatomy, patient survival and the toxic effects of treatment, we had set criteria for therapeutic benefit that included measurements of symptom response and patient suffering, our training methods and research initiatives might have evolved along different lines. This is a matter of historical conjecture but is also of importance for the future of oncology education and research.

Palliative care specialists have developed and routinely used a series of easily administered assessment tools that evaluate symptom control, patient functioning and global quality of life.29 These tools may also serve to refocus training for both trainees and their mentors. Physicians in training are compassionate people — once they are aware of the degree to which their patients suffer, surely they will demand to be taught how to respond appropriately.

Educational goals

A set of assessable program goals, examples of which are provided here, could easily be formulated for oncology training programs without burdening the health care system or disrupting other aspects of oncology education.

• All residents should have to demonstrate their familiarity with the basic literature about pain and symptom control through an in-house evaluation by experts in this area.

• All residents and fellows should be expected to rotate through an academic palliative care program.

• All residents and fellows participating in clinical research should have the opportunity to consider programs dealing with pain and symptom management and with the broader issues of palliative care within their academic setting.

• All programs should include oncologists with special training in palliative medicine who can act as consultants, develop educational programs and demonstrate leadership in clinical research.

• All oncologists should be tested on the basic principles of palliative medicine in their qualifying exams. When the first Canadian oncology examinations were established, 5% to 10% of the questions related to palliative medicine in their qualifying exams. When the first Canadian oncology examinations were established, 5% to 10% of the questions related to palliative medicine, a standard that continues to this day.

This outline of program goals is not complicated, and some of the elements have already been introduced into a number of Canadian oncology programs. A major attitudinal change is required, however, for these simple measures to become generally accepted. This may happen more readily if instruction on relief of suffering is viewed as an ethical issue.

*This section is adapted from:
Working document presented to the Committee on Care at the End of Life. Washington: Institute of Medicine; 1996.
Research in palliative care*

Progress in a particular field depends on its research base. The recruitment of competent young professionals to a field is affected by both the existence of mentors and the availability of financial support. Studies on problems in end-of-life care have lagged. Consequently, role models to stimulate students’ enthusiasm are rare, and students therefore fail to appreciate the value and potential of palliative care research. If this self-fulfilling spiral of neglect does not change, lack of interest will continue to translate into research barriers, which in turn will lead to an even greater lack of interest. This is particularly troublesome today, when many research leads for work that might improve the care of dying patients are apparent.

Opportunities

The lack of interest in palliative care research makes no sense. Although there has been little emphasis on this topic over the past 20 years, the modest investment that has been made has paid substantial dividends. Recent advances in clinical cancer research have been made in the following areas:
- managing cancer pain
- managing nausea and vomiting associated with chemotherapeutic drugs
- using adjuvant chemotherapy, radiation therapy or both
- introducing successful techniques for bone marrow transplantation
- emphasizing quality-of-life studies in clinical cancer trials
- introducing several new classes of chemotherapeutic agents.

Three of these advances have led to improved symptom control and psychosocial well-being. Much of this work was completed with little financial support. For example, the observation that opioids and other symptom-controlling drugs can be administered subcutaneously when parenteral administration is required has, in many instances, simplified patient care and eliminated the need for institution-based intravenous or intramuscular therapies.

Biomedical research depends on the interaction between basic scientists and their clinical colleagues. Advances in the management of pain and improvement in our understanding and treatment of chemotherapy-induced nausea and vomiting illustrate this point. It is likely that similar success could be achieved in the management of other symptoms afflicting cancer patients if existing research methods were applied to those symptoms. Expertise in pain assessment and the design of clinical trials might be successfully transferred from pain to other symptom complexes. Recent recognition of the importance of chemical mediators of pain generated in response to a tumour, or by the tumour tissue itself, provides pathophysiologic lessons that will improve our understanding of mechanisms of dyspnea, cachexia–anorexia, confusional states and other major symptoms.

Barriers

Table 1 lists the factors limiting palliative care research. Many of these barriers are products of the current lack of emphasis on research in academic centres. If major granting agencies and academic leaders begin to recognize the relevance and potential of symptom research, many of these problems could be resolved. For example, a consortium of major centres with appropriate research funding could work to overcome the limited research base and the lack of common classification systems.

Table 1: Factors limiting palliative care research*

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<tr>
<th>Logistic and demographic factors</th>
<th>Academic factors</th>
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<tr>
<td>Small population base, isolated (rather than coordinated) programs</td>
<td>Lack of association with academic units</td>
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<tr>
<td>Lack of training in research techniques</td>
<td>Where an association exists, lower priority in comparison with oncology and other disciplines</td>
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<td>Need to balance workload and research opportunities</td>
<td>Lower priority from perspective of granting agencies</td>
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<tr>
<td>Problems in controlling variables in rapidly changing patient populations</td>
<td>Unrealistic expectations, which lead to excessive targeting and funding of certain work such as cancer chemotherapy trials</td>
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Academic factors
- Lack of internationally recognized classification and assessment systems
- Absence of multi-institutional groups
- Lack of tie-in between basic science and palliative care
- Absence of support from large pharmaceutical firms
- Semantics (What is “palliative therapy”?)

*Adapted, with permission of the publisher, from MacDonald.

*This section is adapted from:
tems. The interest of leaders might encourage competent students to become interested enough in palliative care research to master the research techniques needed, both in the lab and at the bedside.

Some may question whether palliative care research is important. After all, shouldn’t our research priorities always aim toward a cure? Maybe not. I challenge that view for the following reasons.

Palliative care cannot continue to count on adapting advances from other medical fields, yet studies on the problems of dying patients are not given priority by the cancer research establishment in any country. Reviews of major meetings and journals dealing with cancer research reveal a disproportionate emphasis on cancer chemotherapy relative to symptom control and psychosocial issues. Of the abstracts published for the 1997 meeting of the American Society of Clinical Oncology, only 20 were on cancer pain, 4 on cachexia–anorexia, and 3 on dyspnea; however, in contrast, 190 (9.5% of all studies submitted) were on a new chemotherapy agent, paclitaxel.

“Evidence-based medicine” will increasingly influence the decisions of policy-makers responsible for setting priorities and supporting health care programs. Palliative care will be unfairly hampered if research in the field is not supported and the lack of research is then used as a reason not to support palliative care initiatives.

Because of the lack of interest in palliative care research, there are many promising yet unexplored opportunities for research in the field.

In some cases, patients with advanced chronic illness are disqualified from participating in clinical research that may improve their situation and provide meaning to their lives. This situation is fundamentally unjust.

The priority given to medical research should be proportional to the importance of the problem. Whether one health care issue gets priority over another should depend on:
- the size of the problem
- the likelihood that research will result in a useful intervention
- the degree and duration of beneficial interventions
- the cost of following a research lead

When these points are considered, cancer pain clearly stands out as an area in which research would be cost-effective and beneficial. Similarly, the major physical symptom of patients with advanced cancer, the cachexia–anorexia–asthenia syndrome, lends itself to a concerted research initiative. To be successful, basic scientists and clinicians must be encouraged to work together to address other substantive palliative care problems, in a manner similar to that which has advanced the field of pain research.

### Palliative care organization

Today in Canada, the number of people with chronic life-threatening illnesses is increasing, and societal expectations for access to excellent care are rising. At the same time, health care professionals must adjust to and plan for the continuing downsizing of the health care system. The number of physicians and other health care professionals is decreasing, as is their compensation. Holistic patient care is stressed in our professional faculties, but it is time consuming and may be regarded by some planners as inherently inefficient, in part because of the time required for in-depth discussions with patients and their families.

Health care must be cost effective, and special attention should be given to the use of beds in acute care hospitals. The full application of palliative care approaches will enable us to increasingly move the care of the chronically ill from the institution to the home setting. However, in order for this to come about, sophisticated palliative care programs must be in place. Without comprehensive palliative care services, it is unlikely that a successful shift from institutional to home care can be achieved.

There are 4 essential components of a cancer centre or community palliative care program:
- A comprehensive 24-hour home care program that is linked to a cancer centre palliative care day hospital for consultation and respite care, a specialized inpatient palliative care unit with both acute- and chronic-care beds, an ongoing educational program for family physicians in the community and an easily accessed palliative care physician consultative group.
- Consultative palliative care groups located in community and university hospitals and cancer centres, which would offer consultative services to both inpatients and outpatients and which would interact with each other for educational and research purposes.
- Inpatient palliative care units located in designated community hospitals and drawing from all other hospitals patients with severe physical or psychological distress not readily managed at home or in another hospital.
- Administration that is unified under one director who would also serve as the director of the university division of palliative medicine and who would coordinate community services and establish a research and educational base.

A comprehensive palliative care program such as this needs the support of the regional health authority. This support is likely if officials understand the toll of advanced, chronic, life-threatening illness in their community and realize the opportunity to provide humane care by reducing expensive hospital care and shifting resources to home care.
Conclusion

Modern palliative care should be viewed as the prevention and relief of suffering by identifying, assessing and treating both physical and psychosocial symptoms as early as possible in patients with incurable medical problems. This concept has been recognized in a recent policy statement on the reorganization of cancer services in Britain.14 The report states:

Palliative care is required for many patients early in the course of their disease, sometimes from the time of diagnosis. It should not be associated only with terminal care. Palliative care teams should integrate in a seamless way with all cancer treatment services to provide the best possible quality of life for the patient and their family.

In several Canadian centres, palliative care grew out of and was nurtured by well-established oncology programs. Because of the structure of both our health care system and our provincial cancer care networks, Canada is in a particularly strong position to offer cancer patients a truly integrated cancer care system. Modest changes in awareness, attitude and the criteria for setting priorities will yield large dividends.

References