Pergamon

European Journal of Cancer Vol. 31A, Suppl. 6, pp. S18–S21, 1995
Elsevier Science Ltd
Printed in Great Britain
0959–8049/95 $9.50+0.00

0959-8049(95)00492-0

A Proposed Matrix for Organisational Changes to Improve Quality of Life in Oncology*

N. MacDonald

Educational and institutional changes are needed to improve the care of dying patients. There are four phases to a cancer control programme, and each phase stresses prevention. The fourth phase of a cancer control programme is concerned with the prevention of suffering, through impeccable management of physical and psychosocial distress. In practice, cancer control is usually addressed primarily as a biological problem, with less emphasis placed on behavioural aspects and the alleviation of suffering. The principles of symptom control and the management of psychosocial issues have been defined by the palliative care movement. However, this body of knowledge tends to be cocooned within palliative care programmes and associated journals and textbooks. As exemplified by recent advances in cancer pain management, symptom control research is a promising area for development. However, the promise is not matched by priority assignment and idea implementation. This article offers proposals for specific changes in the structure of university and cancer programmes, and revision of legislative policies which will enhance the care of patients who depend upon our interest in the fourth phase of cancer control, the prevention and relief of suffering.

Eur J Cancer, Vol. 31A, Suppl. 6, pp. S18–S21, 1995

> *No moral impulse seems more deeply embedded than the need to relieve human suffering. It is a basic tenet of the great religions of the world. It has become a foundation stone for the practice of medicine, and it is at the core of the social and welfare programmes of all civilized nations* [1].

ONCOLOGISTS ARE compassionate people. One presumes that most of us would subscribe to the view expressed above by Daniel Callahan. We would agree that quality of life issues should strongly influence the agenda for cancer control programmes. However, to date, we have failed to fully achieve this goal in any country. This paper will address educational and institutional initiatives, whose goal is to bring about attitudinal changes in medical oncologists which will improve the care of patients with advanced cancer. The strategies considered are also relevant to AIDS patients, and to others suffering from illnesses associated with a crescendo of physical and psychosocial problems towards the end of life.

Cancer control programmes should encompass four interrelated phases:

1. Prevention of cancer through elimination of environmental causes.
2. Early diagnosis through identification of precancerous conditions, or treatment of small, curative cancers immediately after malignant transformation.
3. Treatment to cure or prolong the lives of patients with invasive cancers.
4. Prevention of suffering through impeccable management of symptoms associated with cancer [2].

In practice, cancer control is usually addressed as a biological problem, with less emphasis placed on behavioural aspects and the alleviation of suffering. Although mortality rates for cancer continue to rise, relatively little importance has been assigned by medical schools, oncology programmes or cancer centres to studies on the problems of dying cancer patients. Until recently, published reports on the efficacy of chemotherapy have not reported on the impact of these therapies on cancer pain or other symptoms [3]. Quality of life analysis is now a component of many clinical trials. Nevertheless, as reflected in a review of the abstracts describing phase II–III clinical trials in certain categories of incurable advanced cancers at this meeting (the European Society of Medical Oncologists (ESMO), Lisbon, Portugal, 1994), quality of life considerations continue to be subservient to anatomical–biological alterations in tumour activity.

One may expect that yet another combination of chemotherapeutic agents will have only a modest impact on the survival of patients with advanced melanoma, cancer of the pancreas or renal cell cancer. Table 1 outlines an analysis of the assessments reported in chemotherapy studies published in the 1994 ESMO Proceedings, involving patients with the above group of disorders. While I would expect many of the patients enrolled in these studies to suffer from pain or other symptoms, relief of which would be a welcome outcome regardless of change in life expectancy, as reflected in the study reports, investigators continue to prioritise biological endpoints above quality of life concerns. Evidence is gathering that chemotherapy can produce

---

Correspondence to N. MacDonald at the Center for Bioethics, Clinical Research Institute of Montreal, 110 Pine Avenue West, Montreal, Quebec H2W 1R7, Canada.

* Parts of this paper are based on a monograph chapter "Teaching Palliative Care—A Structural Overview", published in "*Teaching Palliative Care: Issues and Implications*", edited by R. D. MacLeod and C. James (Patten Press, Newmill, Penzance, 1994).

Table 1. *Reported assessments of phase II–III chemotherapy trials in pancreas, renal cell, melanoma (abstracts reviewed include* 298, 314, 315, 316, 317, 345, 353, 357, 367, 375, 377, 404, 405, 406, 411, 421, 431, 927, 978)

	Studies	Survival	Tumour response	Toxicity	Quality of life (symptoms)
Pancreas	7	4	7	7	2
Melanoma	2	1	2	2	0
Renal cell	10	4	10	10	0
Total	19	9	19	19	2

symptom relief, independently of major objective tumour regression [4]. Nevertheless, the majority of studies continue to ignore this important therapeutic outcome.

STRATEGIES FOR PRIORITISING QUALITY OF LIFE ISSUES

The effective care of patients with advanced illness is demanding. Since, in most developed countries, at least 50% of our patients go on to die of their disease, medical oncologists should not only be well trained in the analysis of disturbed physiology and the biological effect of therapy, but must also possess excellent communication skills, understand patient–family dynamics, and skilfully address pain, other symptoms and psychosocial issues. For a medical oncologist to concentrate on pharmacotherapy, and to expect someone else—anyone else—to address other problems of cancer patients, is somewhat akin to "a gastroenterologist claiming expertise exclusively in conditions affecting the upper gastrointestinal tract" [5].

Our current system of training medical oncologists may not sufficiently emphasise the importance of symptom control. Recent studies which touch on this point include:

- the lack of studies concerning the effects of chemotherapy on pain and other symptoms (v.i.)
- evidence of the inappropriate management of pain by clinicians in a cancer centre [6]
- evidence of defects in knowledge about cancer pain by oncologists in a major co-operative group [7]
- defects in appreciating the functional status of patients and their quality of life status [8, 9].

Part of the reason for these undesirable outcomes may rest with the modest time assigned to issues relevant to advanced illness in oncology training programmes. For example, it would appear that the control of suffering is not regarded as an exciting and positive aspect of medical oncology training in American programmes. In a recent editorial entitled "Training in Medical Oncology: Regaining the Luster", drawing from the response to a survey of medical oncology programme directors, it is stated that "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 [10]. In a world where so many cancer patients will inevitably die, what do we regard as a success? Should not the skilled management of patient distress qualify?

Carving out a substantial block of teaching time is not likely, in itself, to prove of much benefit. Nor will it suffice to merely provide trainees with the wealth of educational material currently available on symptom control in the expectation that self-learning activities will lead to mastery of pain and symptom management. It is not sufficient to simply preach; rhetoric which is not accompanied by specific, assessable, and clearly delineated proposals for programme change will not do the job. One person's current views on the components of the matrix needed to affect attitudinal change in our oncology trainees follow (see also Table 2).

(1) **An academic base** which supports the palliative care component of cancer control must be nurtured. This will be achieved when cancer centres assign a high priority to issues related to death and dying. Tangible examples of their commitment can be demonstrated through the creation of Divisions of Palliative Medicine within the cancer centre or a university Department of Oncology. In some settings, academic Chairs in Pain Management and Palliative Medicine have been established within cancer centres and university departments. Colleagues holding these appointments should meet the same rigorous academic standards as their peers in cancer centres. This challenge is not daunting; the lack of prior educational and research initiatives relevant to symptom control means that an abundance of promising lines of enquiry exists [11].

(2) "The acquisition of new knowledge requires the experience of a positive examplar" [12]. **Role models** who skilfully manage pain and other symptom issues in balance with the emotional components of illness, must be in frequent contact with staff and students on the wards, in the clinics, and in the patients' homes. This goal will be advanced if our cancer centres support the formation of palliative care consult teams, who demonstrate on a day-to-day basis the skilful management of the problems of the dying.

(3) **Cancer control priorities** must be reset. Major improvements in the mortality rate of cancer are unlikely to occur in

Table 2. Matrix for change

1. An academic home in oncology for palliative medicine
2. Role models
3. A restructuring of cancer control priorities
4. Educational objectives for trainees to include principles of palliative medicine
5. Assessment of symptom control—quality of life as routine components of cancer care
6. Expansion of interdisciplinary teaching
7. Regulatory issues — hospice accreditation
   — professional examinations
   — professional audit
8. Recognition of community interest
9. Research priority—issues in palliative medicine

the near term. Even if cancer programmes increasingly recognise their responsibility for the 50% of patients who go on to die of their disease, they must avoid compartmentalising these programmes within their centres. Rather, systems should be in place that enable the principles of impeccable symptom control to be applied earlier in the patient's trajectory of illness. Problems occurring in the last days of life may be prevented or ameliorated if addressed earlier in the course of illness. For example, cancer pain must be controlled at the onset, because inadequately managed chronic pain can induce changes in neurotransmission which lead to the lowering of the pain threshold, and the development of relative resistance to analgesic agents [13]. Although less clearly defined, social research indicates that the genesis of psychosocial issues faced by dying patients and their families often lies in earlier, unresolved problems. The World Health Organisation stresses that principles for the care of the dying should be applied as early in the course of illness as possible [14]. Organisational structures that further this objective include the employment of experts in symptom management, and palliative care within comprehensive cancer centres.

(4) **Educational objectives** should be specifically stated. The attitudes, skills and knowledge-base which physicians should possess to care for dying patients and their families can be detailed. Examples of this approach include the Pain Curriculum of the American Society of Clinical Oncology [15], the Canadian Palliative Care Curriculum (aimed at a general physician audience) [16], and the Palliative Medicine Curriculum of the Association for Palliative Medicine of Great Britain and Ireland [17].

(5) **Assessment techniques** measuring patient–family distress should be regarded as routine components of cancer care. If physicians are clearly aware of the details of patient suffering, they must respond. The assessment of quality of life in cancer chemotherapy programmes is a current topic of major interest, but the techniques employed remain locked away in research protocols, and have not influenced routine clinical practice. The emphasis on refining psychometric issues, and finding the "perfect instrument" in a clinical trial setting, may have a freezing effect on application of quantitative instruments for symptom analysis in routine clinical practice. There are a number of published simple assessment tools that can be readily used in the office or on the wards [18, 19]. A major initiative by our professional organisations recommending the introduction of "user friendly" instruments to our clinics would be both timely and welcome.

(6) **Interdisciplinary teaching** should be expanded. The care of dying patients will remain fragmented if physicians and other health professionals do not work in concert. It is paradoxical that we do not encourage interdisciplinary education in the course of training when, upon completion of training, we expect professional groups to adopt a team approach to the management of the dying patient. For example, nurses have excelled in advancing the home care of patients. The inclusion of patients and families as "members of the team" has more than symbolic value when tangible programmes for harnessing personal resources through the use of first-rate instruction, often provided by nurse-educators, are in place.

(7) **Regulatory issues**, which can both impede and enhance the care of dying patients, require review. The role of regulatory bodies controlling patient access to opioids has been the topic of many recent studies in the United States [20, 21]. Unfortunately, the emphasis of many regulatory agencies appears to be on policing opioid control, rather than on ensuring that cancer pain relief is not impeded by bureaucracy. However, regulatory groups can have a major positive impact on physician practice. Examples of useful approaches include the following.

(a) An accreditation process for hospital facilities which demands that their stated mission, goals and commitment recognise their responsibilities to provide just and equitable care for all cancer patients. With this approach, it would be possible to establish simple, uncomplicated criteria to improve the institutional climate for advanced cancer patients and their families. For example, as Ferrell states, CPR training is mandatory; why not orientation training in pain management, and documentation of pain and other problems relevant to dying patients? [22].

(b) The inclusion of pain and other identifiable issues relative to death and dying can be readily introduced into hospital **Quality Assurance programmes**. The principles of audit in the care of dying cancer patients have been outlined; a number of audits of this nature have been published [23–25].

(c) The examination content of professional examinations strongly influences both trainees and training directors. At the end of the day, our trainees divine our priorities through the fashion in which we set the examinations that determine their rites of passage. When Canada first introduced the specialty in Medical Oncology (1986), the Chief Examiner, Dr. David Osoba, emphasised the importance of including questions on pain and symptom control. For some years, the examination comprised between 8–10% of its questions on these topics.

Audits of the content of professional qualifying examinations for Medical Oncology can provide telling evidence with respect to whether we back up our interest in quality of life issues by setting appropriate standards for the young men and women who follow us.

(8) **Community pressure** can be employed to reset professional priorities. As witnessed by recent experience in Oregon, it may be that a community may assign different priorities to health care issues than professionals [26]. Direct contact with the community can stimulate health care programmes; the cancer pain initiatives now active in many states in the United States provide examples of joint professional–community educational initiatives [27]. Lay members of the community have participated as members of our research assessment and ethics committees for many years. In this role they provide a necessary community perspective, and ensure that a narrow professional interest does not inadvertently lead to a flawed research initiative. To paraphrase Clemenceau, the education of health professionals is probably too important to be left solely in the hands of physicians and health administrators. Given the success of introducing the community to our research efforts, their inclusion on our curriculum and training committees should also prove to be a step forward.

(9) **The priority for research**—the status of a group within a cancer centre is dependent in some part on its research base and the demonstrated research accomplishments of staff members. Relatively little research support has been directed towards the problems of dying patients. While

research in this area is often regarded as "soft", and lacking in intellectual rigour, ironically, here we note advances outstripping many other areas of cancer research in the past decade. If one reviews the major clinical advances in the management of cancer over the past 10 years, one person's opinion would list the following:

- management of cancer pain
- control of nausea and vomiting associated with the use of chemotherapeutic drugs
- the use of adjuvant chemotherapy and/or radiation therapy in selected cancers
- the introduction of successful techniques for bone marrow transplantation
- the emphasis on quality of life studies in cancer clinical trials [11].

Three out of five advances are concerned with symptom relief. One simple set of studies, demonstrating that opioids and other symptom control drugs can be administered subcutaneously, have dramatically increased opportunities for home care of cancer patients [28–30].

Providing an incentive for clinical research on cachexia-anorexia and pain, among other symptom complexes, will not only pay a dividend with respect to the development of new approaches to these problems, but will also create an exciting research base for educational and service programmes.

The current thrust of cancer research in the Western world has little relevance for developing countries. Bone marrow transplantation and complex immunotherapy–chemotherapy regimes will not ease suffering in the Third World, regardless of our success in North America and Europe. Indeed, successful high technology research will further widen the gap between the haves and the have-not countries. If one accepts the thesis that Western cancer centres should direct part of their educational and research initiatives to problems relevant to the Third World, a powerful reason for supporting symptom control research emerges.

CONCLUSION

Diffusion, acceptance and tangible application of ideas follow the endorsement of these concepts by credible leaders in the field, trainee contact with influential role models, and supportive changes in the structural matrix of a programme. The rising toll of cancer mortality and the relevance of the principles of symptom control and palliative care to other advanced chronic illnesses provide reasons for cancer programmes to review their priorities and redress the balance of support for the fourth phase of cancer control, the relief of suffering.

---

1. Callahan D. *The Troubled Dream of Life: in Search of a Peaceful Death.* New York, Simon & Schuster, 1993, 94.
2. MacDonald N. Palliative care—the fourth phase of cancer prevention. *Cancer Detect Prevent* 1991, **3**, 253–255.
3. MacDonald N. The role of medical oncology in cancer pain control. In Hill CS, Fields WS, eds. *Advances in Pain Research and Therapy.* New York, Raven Press, 1989, Vol. 11.
4. MacDonald N. Oncology and palliative care: the case for coordination. *Cancer Treat Rev* 1993, **19** (Suppl. A), 29–43.
5. Bruera E. Personal communication.
6. Portenoy R. Pain in ambulatory patients with lung and colon cancer. *Cancer* 1992, **70**, 1616–1624.
7. Cleeland CS, Gonin R, *et al.* Pain and its treatment in outpatients with metastatic cancer. *N Engl J Med* 330, **9**, 592–596.
8. Fossa SD, Aaronson NK, Newling D, *et al.* Quality of life and treatment of hormone resistant metastatic prostatic cancer. *Eur J Cancer* 1990, **26**, 1133–1136.
9. Slevin ML, Plant H, Lynch D, *et al.* Who should measure quality of life, the doctor or the patient? *Br J Cancer* 1988, **57**, 109–112.
10. Mayer RJ. Training in medical oncology: regaining the luster. *J Natl Cancer Inst* 1991, **83(12)**, 806–807.
11. MacDonald N. Priorities in education and research in palliative care. *Palliat Med* 1993, 7 (Suppl. 1), 65–76.
12. Calman KC. New methods of teaching and evaluation of teaching. In Twycross RG, ed. *The Edinburgh Symposium on Pain Control in Medical Education.* Royal Society of Medicine, 1989, 175–178.
13. Dubner R. Neuronal plasticity and pain following peripheral tissue inflammation or nerve injury. *Pain Res Clin Mgmt* 1991, **4**, 263–276.
14. World Health Organisation Expert Committee Report. *Cancer Pain Relief and Palliative Care.* Geneva, 1990, Technical Report Series 804.
15. The Ad Hoc Committee on Cancer Pain of the American Society of Clinical Oncology. Cancer pain assessment and treatment curriculum guidelines. *J Clin Oncol* 1992, **10**, 1976–1982.
16. MacDonald N, Mount B, *et al.* The Canadian palliative care curriculum. *J Cancer Educ* 1993, **8**, 197–201.
17. Palliative Medicine Curriculum. Association for Palliative Medicine of Great Britain and Ireland, 1992.
18. Foley K. Pain assessment and cancer pain syndromes. In Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine.* Oxford, Oxford University Press, 1993, Section 4.2.2, 148–165.
19. Bruera E, Kuehn N, *et al.* The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliative Care* 1991, 7–2, 6–9.
20. Joranson DE. Availability of opioids for cancer pain: recent trends, assessment of system barriers, new World Health Organization guidelines, and the risk of diversion. *J Pain Symptom Mgmt* 1993, **3**, 353–360.
21. Agarola RT, Joranson DE. Pain and public policy. *APS Bulletin* 1993, **3**, 2011–2013.
22. Ferrell B. Personal communication. November, 1993.
23. Bruera E, MacMillan K, MacDonald N. Palliative care in a cancer center: results in 1984 versus 1987. *J Pain Symptom Mgmt* 1990, **5**, 1–5.
24. Higginson I, McCarthy M. Measuring symptoms in terminal cancer: are pain and dyspnoea controlled? *J R Soc Med* 1989, **82**, 264.
25. McCarthy M, Higginson IJ. Clinical audit by a palliative care team. *Palliative Med* 1991, 5, 215–221.
26. Hadorn DC. The Oregon priority-setting exercise: quality of life and public policy. *Hastings Center Report* 1991 (May–June).
27. Weissman DE, Dahl JL, *et al.* The cancer pain role model program of the Wisconsin cancer pain initiative. *J Pain Symptom Mgmt* 1993, **8**, 29–35.
28. Russell PSB. Analgesia in terminal malignant disease. *Br Med J* 1979, **1**, 1561.
29. Campbell CF, Mason JB, *et al.* Continuous subcutaneous infusion of morphine for the pain of terminal malignancy. *Ann Intern Med* 1983, **98**, 51–52.
30. Storey P, Hill HH, *et al.* Subcutaneous infusions for control of cancer symptoms. *J Pain Symptom Mgmt* 1990, **5**, 3341.