

## THE INTERFACE BETWEEN PALLIATIVE MEDICINE AND OTHER HOSPITAL SERVICES\*

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The man we honour today, Dr Sydney Watson Smith, was a native of Dundee who graduated from the University of Edinburgh in the early part of the century. Practicing both in Dundee and in Bournemouth, he gained a reputation as a skilled consultant in general medicine and dermatologic disorders, while also contributing to the medical affairs of his day—culminating in his presidency of the British Medical Association in 1934.

On reviewing Dr Smith's biography, one notes that he was a consultant with a singular understanding and empathy for family practitioners. Recognizing that primary care physicians and nurses continue to carry the major medical burden of care for dying patients and their families, assisted by consultant palliative care colleagues, Dr Smith's exemplary practice is germane to our discussions today.

The modern palliative care movement owes its origin to the default in the care of dying cancer patients, perpetrated by our leading hospitals and cancer centres. It is fashionable to ascribe this seeming dereliction of duty by hospitals to our late-twentieth century overemphasis on pharmacological and technical treatments aimed at altering the course of disease, with a resultant reduced concern for global humane care. Looking at the hospital systems of the eighteenth and nineteenth centuries, however, one may conclude that the tradition of acute care hospitals was never one of offering humane, dignified, whole-patient care. While our cancer centres of today may be fascinated by molecular biology, our forebears in the nineteenth century had an equal fascination with disease; they concentrated on gross pathology and, latterly, bacteriology.

Acute care hospitals have not been regarded as welcome abodes in the last days of life. Nineteenth century literature offers us many examples of the so-called 'good death', usually at home, surrounded by family and, strangely, in view of the probable incidence of cancer in that society, usually devoid of accounts of agony. These 'good deaths' commonly occurred in the absence of a physician. As Thomas Lacqueur states 'It was part of the doctor's job to know when to call the priest', and then, one presumes, to exit. In contrast, Lacqueur, a medical historian, describes hospitals of today as complex institutions with elaborate rules, offering a technology which, by its nature, defines medical care as a challenge to nature, a combat, a technology creating difficult circumstances for the all too human process of dying.<sup>1</sup>

The language we use mirrors, or perhaps presages, our hospital attitudes. Rita Charon of Columbia University analysed discharge summaries, and reminds us that the language employed in our hospital discourses reinforces a cold, clinical approach. An excerpt from a case record on an elderly man with a cancer of the

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bladder: 'He was noted to have Cheyne-Stokes respirations. He was seen acutely by neurology—an EEG was scheduled following their recommendations. A family conference went over all the complications that had occurred over the past few months and it was elected not to pursue heroic treatment. The patient was found pulseless and unresponsive with no blood pressure, at 6.50 a.m.'<sup>2</sup> She calls our attention to the '... extensive and bizarre use of the passive voice to explain human events'. We commonly use the third person singular to refer to patients, but uncommonly employ the first person singular to refer to ourselves and our interactions with the patient. As such, the way we write about patients reinforces remoteness and distance.

The clinical language at the turn of the century was more personal, but not necessarily indicative of a more humane interest in the patient. In an article in the *British Medical Journal* of 1901 the author describes a patient with a truly horrid tumour which has devoured the patient's face. He states '... if it had not been for the pain, I should have lost a valuable and interesting experience.'<sup>3</sup> Two physicians conveniently dismissed the problem of suffering in a large proportion of their patients in the following manner: 'In the lower classes, the sensation of pain is felt in a much less degree than in those of highly intellectual temperaments.'<sup>4</sup>

Thus it may be argued that the traditions of the academic acute-care hospital have neither reinforced nor emphasised the humane care of dying patients. The modern palliative care movement has had thirty years to influence and humanise hospital care. Have we? The evidence in Britain and North America suggests yes—to a modest extent. A recent article in the *British Medical Journal* describing the deplorable care of the dying in four Scottish hospitals eleven years ago (1984),<sup>5</sup> stimulated a lively letter response. Most correspondents stated that the rapid growth of hospital-based palliative care support teams has changed the situation—but another said 'no', that major problems still exist; while a recent survey of hospital patient experience revealed that pain is still poorly addressed in many hospitals.<sup>6</sup> In North America, palliative care functions mainly within a culture all its own; its wealth of information and model practice often remain cocooned outside the mainstream, with little influence on hospital practice.

Using management of cancer pain as a marker, some recent evidence to the point includes: (1) Surveys on pain management by medical oncologists in a large American cooperative trials group illustrate that generally accepted principles of pain management are not fully applied, while assessment of the patient's pain is inadequate,<sup>7</sup> (2) A similar study of oncologists in a leading American cancer centre illustrates the same point<sup>8</sup> and (3) Data from a recent survey of Canadian physicians indicates that they view cancer pain training as often only fair or, indeed, poor.<sup>9</sup>

Because our acute care hospital tradition is one of excellence in disease diagnosis and interventional management, with whole-person care seemingly an issue of lower priority, some have posited that the palliative care movement should simply give up on the acute-care hospitals. In this scenario, palliative care would continue to expand and flourish as a community service, offering hospice care for those who must be institutionalised, and impeccable home care for others. Those whom I have heard expressing this view point out that acute hospital systems are in trouble in every country, and subject to forces that will only further limit the delivery of compassionate care. For example, in the United

States, insurance payments relate to disease and procedures. A hospital is paid according to the disease the patient has, and norms are set for the time that the patient can stay in hospital—longer stays are penalised. There is no disease-related payment code for dying. Therefore, the dying patient may not be welcome in a hospital. While there is something repugnant about profiting through restricting needed care for another—this could be the ultimate outcome of a private-insurance-based medical care system.

In Canada, we are undergoing an extraordinary closure of acute care hospital beds as part of our approach to reducing our substantial national debt. As the toll of chronic disease rises and bed availability decreases, there will be increasing pressure not to welcome the dying patient into our hospitals, except possibly at the very end of life. This may be an appropriate scenario for those with both the personal financial means and family support to stay at home throughout their trajectory of illness, but no longer possible for the increasing number of people, generally elderly, without a supportive nuclear family.

There is no doubt that there are many forces working against the humanisation of hospital care. Should the palliative care community wash its hands of acute care hospitals, and attempt to pick up the pieces in the community? As attractive as this option may sound, it represents a default of responsibility; palliative care must achieve a high profile within our cancer centres and our leading acute care hospitals. There are compelling reasons why this is the case.

#### MORALITY OF CARE

Daniel Callahan, an American ethicist, states the following to be the essential core of medical care: 'No moral impulse seems more deeply embedded than the need to relieve suffering . . . 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 civilised nations.'<sup>10</sup> Dr Callahan's concept may not be reflected in actual hospital practice today. Rather, in the ascendancy is the model which may be termed the 'efficiency model', the rationale of which relates primarily to the bottom line, the money spent on health care. Jane Fulton, an economist at the University of Ottawa, states 'Canadians love the concept of the hospital as a hotel. We have to give them the feeling the hospital is a muffler shop where you drive in and drive out.'<sup>11</sup> In truth, we don't look for compassionate total care, either for our cars or for ourselves, at Mr Muffler. But what are the implications of this concept of hospital function for dying patients?

In contrast to the 'efficiency model', whose governing principle is reduction in cost, with other features of health care subservient, one may posit an alternative 'ethics based' model whose organising principle holds that the prevention and subsequent relief of suffering remains the primary role of health care.

Advocates of both systems will share the understanding that health care costs must be contained; we must all agree with that objective. The priorities to reach this goal within these two systems are likely to be radically different.

Where the efficiency model is pre-eminent, arbitrary budget targets are normally set which must be reached within an arbitrary period of time. Because of the short time available for planning, and the conduct of the planning process by those already in power, this approach tends to favour the preservation of existing strong institutional programmes. As many nursing and medical leaders in positions of authority are not fully cognisant of the principles of palliative care,

they may regard palliative care as a fundamentally new addition to a health care system, which may add cost during a time of financial stringency.

Palliative care concepts should underlie all of humane nursing and medical practice, but administrators may not recognise that putting these principles into action through supporting palliative care programmes does not necessarily add to health care costs. Rather, the introduction of palliative care programmes should result in the sensible application of funds which are already expended in the care of dying patients and their families, often in unacceptable fashion.

Can it be proved that the introduction of a comprehensive palliative care system both improves the care of the dying, and cuts costs? Studies to prove this point are arguable—in part because we have yet to achieve a fully comprehensive community system. There is no doubt, however, that elements of palliative care programmes have been proved to be cost-effective. An example is the use of subcutaneous medications. The research demonstrating that most opioids and other symptom controlling drugs can be administered via the subcutaneous route enabled patients to return home who previously would have required institutional based intravenous or intramuscular parenteral therapy.<sup>12</sup>

While most health managers and administrators believe that trimming waste from the system will eliminate cost, the Hastings Group point out that it is not our failures, but our partial successes, which drive up health care costs.<sup>13</sup> We may eliminate administrative waste, but this will not reduce the expense of dealing with increasing numbers of patients with metastatic cancers whose only partially successful therapy will lead to a further crescendo of hospital admissions, physician contacts and medications.

It is ironic that the bottom line approach to health care planning is closely related to business practices of the eighties which, today, tend to look greedy, soulless, and are often regarded as bad business. While the health industry, which views itself as a bastion of ethical behaviour, stampedes towards the efficacy model, as described in a recent article in the *Harvard Business Review*,<sup>14</sup> the business world is now finding that using an ethical base for decision-making happens to make very good business sense. The author of that article quotes several examples of companies which got into terrible financial problems because of their stress on the bottom line—a single-minded thrust that stimulated employees to cut corners, with consequent customer dissatisfaction and expensive legal suits. Conversely, the Martin-Marietta Company, a defence contractor operating in what is ordinarily thought to be a 'dirty' area of business, re-developed its business strategy on a framework stressing ethical conduct. This proved to be a highly successful strategy, resulting in customer trust, happy, productive employees, and profits.

To conclude, palliative care is not yet another subdivision of medical practice simply clamouring for its rights and privileges—our hospital system needs to adopt a palliative care mode of practice for sound ethical reasons, with consequent overall improvements in care and, not necessarily, an increase in costs.

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## PALLIATIVE CARE: AN EXERCISE IN PREVENTION

A fundamental tenet of medicine holds that prevention is preferable to reaction to disaster. Clearly, the major advances in medical care have come about through preventive efforts, notably in the fields of public health and primary prevention of disease. This concept should inform chronic disease programmes of every country. Using cancer control as an example, we may look upon it as an exercise in prevention, with four 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 and (4) Prevention of suffering through impeccable management of symptoms associated with cancer.<sup>15</sup>

Palliative care first emerged as a programme addressing the needs of dying patients; a system graphically similar to that shown in Fig 1 has emerged.<sup>16</sup> However, this system does not adequately encompass our opportunities to prevent suffering. For example, it is not logical to leave people in pain while they are receiving anti-cancer therapy, and then only address their needs for pain control in expert fashion when the focus of care changes to palliation at a later date. Our neurophysiology colleagues and our own experience tell us that prevention of pain, rather than reaction to established pain, is not simply a rhetorical concept. We now know that because of the neuroplasticity of our central nervous systems, uncontrolled pain stimuli lead to changes in neuro-transmission whereby previously silent pathways become transmitters of the pain message, excitatory neurotransmitters become prominent, with lowering of the threshold for pain, and the development of pain of such a nature that it becomes increasingly difficult to control with drugs.<sup>17</sup>

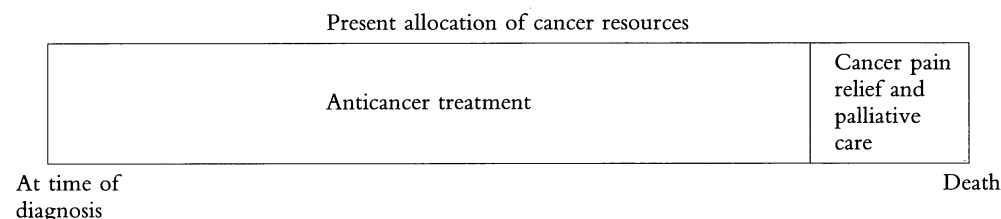


FIGURE 1

Adapted from Figure 2 in Reference 16

Pain is not unique; emotional and psychosocial issues not addressed during the early trajectory of illness may be partially difficult to deal with in the last days of life. More evidence to this point, with another symptom, the acute confusional state so common at the end of life, comes to us from Dr Bruera's group at the University of Alberta in Edmonton.<sup>18</sup> This group analysed their experience with patients presenting with agitated impaired mental status over a two-year span (1988-89), and compared it with the incidence of this problem in a subsequent two-year span (1991-92) during which a number of preventive techniques were introduced. These included the routine use of the Folstein Mini-Mental Status Exam to diagnose the onset of confusion at the earliest possible moment, the increased use of hydration to reduce the risk of failures in drug clearance

contributing to confusional states, and more frequent rotation of opioids. The data outlined in Table 1 illustrate the improved pattern of agitated impaired mental status associated with these preventive measures.

Prevention is at the heart of medical practice. Therefore, palliative care must be strongly represented not only in the community, but within our acute care hospitals, where we can emphasise the importance of symptom control and other aspects of whole patient care early in a patient's illness.

TABLE 1  
Results

	1988-1989 (N=117)	P	1991-1992 (N=162)
Impaired mental status	37 (32%)	NS	67 (41%)
Agitated IMS	30 (26%)	<0.001	17 (10%)
Hydration use	37 (32%)	<0.01	118 (73%)
Opioid rotation	23 (21%)	<0.001	67 (41%)

Adapted from Bruera E *et al.* Changing pattern of agitated impaired mental status in patients with advanced cancer: association with cognitive monitoring, hydration, and opioid rotation. *J Pain Sympt Manag* 1995; **10** (4): 289 (Table 2).

## HOSPITAL CARE VERSUS HOME CARE

*'A man's castle is his daughter's workhouse and his wife's prison'*

George Bernard Shaw

The thrust in every nation to cut down on hospital admissions, and to care for patients in their homes or in community-associated hospices is commendable. However, many patients with advanced chronic illness will spend many of their last days in hospital. This demand for hospital access is created both by the increasing incidence of chronic ultimately fatal disorders, and by changing social conditions which produce additional strains on patients and caregivers in the home.

Using cancer as an example, all countries are noting an absolute increase in mortality. For example, the total number of Canadians who died from cancer increased substantially between 1988 and 1994.<sup>19</sup> While there has been slow progress in the treatment of the disease, and substantial progress, at least for males, in preventing tobacco-associated cancers, an absolute decrease in cancer mortality is unlikely to occur within the next 5-10 years. In developing countries, major increases in cancer mortality are anticipated. Individuals included in these statistics may no longer have the support of a large nuclear family where one member (often a female spouse or daughter) is in a position to sacrifice personal fulfillment and other responsibilities in order to care for a loved one. This is not a selfish concept—there are fewer children to share the burden. Other community institutions such as churches and fraternal organisations may not be as prominent as in the past. Family members may live at a distance, or have other responsibilities which cannot be readily discharged. For those who do take on home care responsibilities, the technical demands are often awesome and expensive.

We can shift our ventilators and our pumps to the home-care setting, but at a substantive cost, both financially and in terms of the technical and emotional demands placed upon family caregivers.<sup>20</sup>

Those with means, both in terms of money and education, will be more likely to spend their days with dignity in a home care setting. A recent study by Higginson demonstrated that in London, deaths at home correlated directly with social status.<sup>21</sup> Studies by Cleeland's group in the United States show that age and low social status correlated with poor pain control.<sup>22</sup> These are the people most in need of sophisticated access to good palliative care, access which may not be as readily achieved in their homes as in the homes of the wealthy.

Palliative care patients must continue to have access to the honed technical skills of the acute care hospital for special problems. Two recent examples in my practice:

Mrs L, with metastatic breast cancer and leptomeningeal involvement, was receiving excellent care in her home community. She was on regular opioids which controlled her pain and allowed her to continue her life as a mother and community leader. The pain in her left hip became severe, and her family physician steadily increased her dose of opioids, to the point where she was still in severe pain, but stuporous. X-rays of her bones did not suggest that she had any recent damage. Nothing else seemed to have happened. She was afebrile, and her white count had not changed; nor had her haemoglobin dropped. This lady needed the services of an acute care hospital and, when she was transferred to such a hospital, CT Scans and ultrasounds of her pelvis revealed that she had a pelvic abscess. She had been on steroids, which may have dampened the usual signs of infection. The abscess cavity was drained, the patient was placed on antibiotics, and she returned home in good pain control, alert on her previous dose of opioids.<sup>23</sup>

Mrs LA, with metastatic breast cancer for 12 years, had three demonstrated episodes of epidural cord compression, had received radiation, and had undergone two spinal operations, with laminectomy and stabilisation. She remains able to walk, carry out her own shopping, and enjoy life in the city. She presents again with radicular pain and investigations demonstrate that she has recurrent epidural cord compression. An artful orthopaedic surgeon is able to carry out a laminectomy in a previously radiated area adjacent to a prior area of spinal stabilisation and, again, with cement and wire to stabilize the spine, keeps this woman independent and able to walk and function.

Mrs LA's pain management in the community was impeccable, but access to a gifted surgeon was necessary to preserve the quality of her existence. These two patients are examples of the benefits arising from the linkage of a palliative care-home care programme with an acute care hospital. At any given time, patients may need access to sophisticated diagnostic procedures and interventions. Conversely, a system enabling smooth flow between home and hospital will assuage patient-family concerns about losing hospital access. They may bear the burden at home more readily if they know back-up help is always available.

#### EDUCATION

At an earlier education meeting in Edinburgh, Dr Kenneth Calman reminded us that '... the education of a physician requires a positive exemplar'.<sup>24</sup> Medical school and resident training establish a mould for our lifetime practice. Wilder Penfield, in his Oslerian address to my McGill class, reminded us that we must always have heroes—those whose command of the art and practice of medicine causes us to admire and to follow their patterns of care. At the time of that address, Dr Penfield was 66, and arguably the leading neurosurgeon of his day; nevertheless, he continued to hark back to the exemplary practitioners of an earlier time, whose practice he attempted to follow.

Medical education is attempting to escape from the total grip of the teaching hospital where, for generations, students have learned. There is an increased emphasis on students moving out into the community, but the reality of the

situation is that they move out into the community attached to a string firmly controlled by the academic teaching centre. Students still spend most of their time within these teaching hospitals. Who are to be their positive exemplars?

Palliative care is not well represented in our North American medical schools. A recent survey in Canada revealed that few formal hours are assigned to palliative care (Table 2) and, perhaps understandably, our graduates are not pleased with their exposure to a signal palliative care teaching component, cancer pain control (Table 3). In Canada we have three designated Chairs in palliative medicine, and six recognised academic divisions or groups of palliative medicine within our sixteen medical schools. In the United States, a recent survey did not reveal one Chair, or one university academic division, although a number of major American cancer centres, notably the Memorial Sloan-Kettering Cancer Centre, the Cleveland Clinic, the Mayo Clinic, and the MD Anderson Hospital, have established strong academic palliative care groups.

TABLE 2  
Dedicated palliative care hours

	University	Hours
High	McGill	20
	Dalhousie	16+
	McMaster	15.5
	Calgary (pain lectures)	11
Low	British Columbia	
	Queens	1-3
	Western	

Adapted from survey of Canadian medical schools—  
Canadian Palliative Care Education Group—1994.

TABLE 3  
Satisfaction of 2,474 physicians with pain education  
in medical school

	Graduated < 12 years (per cent)	Graduated > 12 years (per cent)
Excellent	5	5
Good	32	22
Fair	43	36
Poor	19	33

Adapted from The Canadian Pain Questionnaire,  
1994.

Assuming that the academic teaching hospital will remain the mother house of medical education, then we must be strongly represented in that mother house as professors, Chairs, divisional heads and, ultimately, heads of departments and deans. From our vantage point as insiders, we must not only teach and provide a model for practice through our patient contacts, but also institute tangible programmes for change in educational perspective.

#### RESEARCH

Ironically, while the vector of support for clinical cancer research has been directed elsewhere, one person's review of substantive advances in clinical cancer

research over the past 15 years includes:<sup>25</sup> 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 and the emphasis on quality of life studies in cancer clinical trials.

Three of these five issues involve improvements in symptom control and concerns for patient-family social and emotional well being. The success achieved with one symptom problem, pain, causes one to posit that directed research on other symptom problems offers an attractive research target.

And yet, research involving dying patients lies at the opposite end of the biomedical research spectrum from the basic sciences, where specially trained colleagues working full time in a research environment can conduct rigorous studies, where variables and the vagaries of chance can usually be controlled. In contrast, in a palliative care programme, we usually encounter a physician- or nurse-scientist whose primary responsibility lies in patient care. They may not be trained in methodology, and have probably chosen to work with dying patients for reasons other than research. They may work in isolation from colleagues, and may not be part of research networks. When they attempt to organise a clinical trial, they must recognise the ethical implications manifest in asking dying patients and their families to take part in research programmes. Even if they are successful in launching their trials, they may be diverted by the crisis of the moment and have little control over the environment of the trial.

Some may question the need for a research arm in a palliative care programme. If studies on the problems of dying patients were well represented within the complex cancer research network, perhaps palliative medicine could concentrate on offering the best care of the moment, borrowing its advances from other areas of medicine. To date, however, as reflected in our oncology publications, grant awards and meeting presentations, research on issues critical to the care of dying patients does not flourish. Studies on drug or biological attempts to alter the course of incurable cancer, where only modest progress has been made in advancing life expectancy, or to correct the adverse effects of these therapies, stands in contrast to the paucity of studies on quality of life, social and emotional issues in cancer care, and symptom control.

Therefore, palliative medicine must develop an identifiable research base. Otherwise, promising leads in the management of the cachexia-anorexia syndrome and dyspnoea may never be properly exploited.

#### RELEVANCE OF SYMPTOM RESEARCH

A recent editorial in the *British Medical Journal* stated, 'evidence-based medicine is a phrase that is currently familiar to only a few doctors, but we will all know it by the millennium'.<sup>26</sup> Clinical research aims to prevent or control illness, to improve the quality of human life and experience, and to build a knowledge base for our current intellectual satisfaction and future research endeavours. But, increasingly, it will inform policy makers and guide them as they prioritise and implement health programmes. If we are not active in research, in the era of evidence-based decision making, palliative care may suffer.

As one works with patients who are progressively closer to the moment of death, the ethical issues become more complex. Amongst others, three issues stand out: (1) obtaining a truly informed consent is problematic in a group of

patients where confusional states are common, (2) adherence to a rigid protocol must be subservient to the exigencies of patient-family care and (3) both the schedule and the invasive qualities of regular testing may add to suffering unless carefully planned and considered.

Nevertheless, palliative care research is normally aimed at finding an immediate improvement in suffering, and our patients with advanced chronic illness should maintain the right to participate in a research programme that may benefit themselves or others. To serve as a teacher for others, and to employ one's suffering for the common good may be a powerful incentive for research participation. If our patients are to have this option it is more likely that they will benefit from symptom control trials which are launched earlier in the trajectory of their illness—at a time when they are located on the wards or the out-patients' clinics of our acute care hospitals and cancer centres.

What are some of the critical areas for stimulation of research? General surveys indicate that an individual patient may encounter as many as 23 symptoms at one time. The mean number of symptoms in a recently studied New York population was 11.<sup>27</sup> Nevertheless, there is a subset of prominent symptoms of particular import, both because of incidence and the possibility of research-based improvement in management, which can be identified. Currently, the cachexia-anorexia syndrome, with its component features of weight loss and asthenia to the point where patients can no longer care for themselves, is the major symptom complex afflicting patients with advanced incurable cancer.

Selecting cachexia-anorexia for a moment's consideration, a brief review can demonstrate both the intellectual challenge and a promise inherent in research.

Until recently, cachexia-anorexia seemed to be accepted as an inevitable price associated with end-stage disease. We exhibited little curiosity about the syndrome's causative mechanisms or potential therapies, even though this symptom complex, more than any other, causes patients to be dependent on others, with consequent strain on family resources, and requirements for institutional care for prolonged periods prior to death.

Borrowing from work often conducted in hospital laboratories by surgeons and people concerned with sepsis, it is now apparent that the cachexia-anorexia syndrome is probably induced by chemical factors produced as part of a host response or, on occasion, by similar factors produced by tumours.<sup>28</sup> While injection of a number of cytokines, including tumour necrosis factor, Interleukins 1 and 6, and Interferon Gamma produce abnormalities which closely mimic the cachexia-anorexia syndrome, it is likely that an interactive cascade involving multiple cytokines is responsible for the syndrome in humans. If selective cytokines cause anorexia and weight loss, it may be possible to use specific inhibitors to control the syndrome. There are many avenues worthy of investigation.<sup>29</sup>

Therefore, it remains my thesis that the acute care hospital should remain an integral part of the mosaic of palliative medicine practice in the future. This view does not belie the importance of expanding community efforts in home care because this is where the vast majority of patients will be treated. An ideal home care system must be linked to hospices and acute care hospitals in a system which regards the components as part of a continuum, not as competing factions.

During their final days in home or hospital, our patients wish to have family surrounding them and offering solace, in the most comfortable surroundings. They may more readily achieve this state of grace if our acute care hospitals are also



infused with the principles of palliative care, and our medical leaders equally respect our bright technological future and the tenets of compassion and prevention which underlie our traditional physician's role.

## REFERENCES

- <sup>1</sup> Lacqueur T. Working paper: Project on death in America. Sponsored by Open Society Institute, Soros Foundation. January 1995.
- <sup>2</sup> Charon R. 'Examining the Language of Death', Working paper: Project on death in America. Sponsored by Open Society Institute, Soros Foundation. January 1995.
- <sup>3</sup> Paul FT. A clinical lecture on a case of chronic cancer of the face. *Br Med J* 1901; Feb 9: 321-3.
- <sup>4</sup> Gould GM and Pyles W (1895). Anomalies and curiosities of medicine. New York: Saunders, 475—as quoted in 'Bark, blisters and the bathe: some problems of pain relief in former times'. *J R Society Med* 1982; 75: 812-9.
- <sup>5</sup> Mills M, Davies HTO, MacRae WA. Care of dying patients in hospital. *Br Med J* 1994; 309: 583-6.
- <sup>6</sup> Bruster S, Jarman B *et al.* National survey of hospital patients. *Br Med J* 1994; 309: 1542.
- <sup>7</sup> Von Roenn JH, Cleeland CS, Gonin R *et al.* Physician attitudes and practice in cancer pain management. A survey from the Eastern Cooperative Oncology Group. *Ann Intern Med* 1993; 119: 121-6.
- <sup>8</sup> Portenoy RK, Miransky J, Thaler HT *et al.* Pain in ambulatory patients with lung or colon cancer. Prevalence, characteristics and effect. *Cancer* 1992; 70 (6): 1616-24.
- <sup>9</sup> MacDonald N. Canadian Pain Survey. 1995.
- <sup>10</sup> Callahan D. *The Troubled Dream of Life: In Search of a Peaceful Death*. 1993; New York: Simon & Schuster, 94.
- <sup>11</sup> Fulton J. As quoted in *The Gazette* June 4, 1995.
- <sup>12</sup> Bruera E, Brennais C, Michaud M *et al.* Use of the subcutaneous route for the administration of narcotics in patients with cancer pain. *Cancer* 1988; 62: 407-411.
- <sup>13</sup> Gaylin W. Faulty Diagnosis. *The New York Times*. Sunday, June 12, 1994; Section 4A:1.
- <sup>14</sup> Paine LS. Managing for organizational integrity, *Harvard Business Review* 1994; March-April: 106-117.
- <sup>15</sup> MacDonald N. Palliative care—The fourth phase of cancer prevention. *Cancer Detection and Prevention* 1991; 15: 253-5.
- <sup>16</sup> Cancer pain relief and palliative care. Technical Report Series 804. World Health Organisation, Geneva 1990.
- <sup>17</sup>Coderre TJ, Katz J, Vaccarino A *et al.* Contribution of central neuroplasticity to pathological pain: review of clinical and experimental evidence. *Pain* 1993; 52: 259-85.
- <sup>18</sup> Bruera E, Franco JJ, Maltoni M *et al.* Changing pattern of agitated impaired mental status in patients with advanced cancer: Association with cognitive monitoring, hydration, and opioid rotation. *J Pain and Symptom Control* 1995; 10 (4): 287-291.
- <sup>19</sup> National Cancer Institute of Canada: Canadian Cancer Statistics 1994; Toronto, Canada, 1994.
- <sup>20</sup> Arno PS, Bonuck KA, Padgug R. The economic impact of high-technology home care. Special Supplement, *Hastings Center Report* 24 1994; 5: S15-S19.
- <sup>21</sup> Higginson I, Webb D, Lessof L. Reducing hospital beds for patients with advanced cancer. *Lancet* (Letter) 1994; 344 (8919): 409.
- <sup>22</sup> Cleeland CS, Gonin R, Hatfield AK *et al.* Pain and its treatment in outpatients with metastatic cancer. *N Engl J Med* 1994; 330 (9): 392-6.
- <sup>23</sup> Mackey JR, Birchell I, MacDonald N. Occult infection as a cause of hip pain in a patient with metastatic breast cancer. *J Pain and Symptom Manage* 1995; 10 (5): 1-4.
- <sup>24</sup> Calman KC. New methods of teaching and the evaluation of teaching. In: Twycross RG, ed. *The Edinburgh Symposium on Pain Control and Medical Education*. *R Soc Med* 1989; 175-80.
- <sup>25</sup> MacDonald N. Priorities in education and research in palliative care. *Palliat Med* 1993; 7 (Suppl 1): 65-76.
- <sup>26</sup> Morrison I, Smith R. The future of medicine. Editorial *Br Med J* 1994; 309: 1099-1100.
- <sup>27</sup> Portenoy R, Thaler HT, Kornblith AB *et al.* Symptom prevalence, characteristics and distress in a cancer population. *Quality of Life Research* 1994; 3: 183-8.
- <sup>28</sup> Alexander HR, Norton JA. Pathophysiology of cancer cachexia. In: Doyle D, Hanks GWC, MacDonald N eds. *Oxford Textbook of Palliative Medicine*. London: Oxford University Press 1993; 316-29.
- <sup>29</sup> MacDonald N, Alexander HR, Bruera E. Cachexia-Anorexia-Asthenia. *J Pain and Symptom Manage* 1995; 10 (2): 151-5.

## LESSONS FROM A SYMPOSIUM ON PALLIATIVE MEDICINE HELD IN THE COLLEGE ON 8TH MARCH 1995\*

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The most effective intervention to improve the provision of palliative care would be to employ effectively the knowledge already available. This symposium furthered that goal by not only expounding and exploring important facets of our knowledge of the subject, but also examining the scope for, and obstacles to, disseminating that knowledge to all health professionals and facilitating effective palliative care for all patients.

### Palliative medicine services

Palliative care is that of a patient with active progressive and far advanced disease with a limited prognosis for whom the focus of care is the quality of life (rather than quality of death). Patients die; the recognition of this as a natural process is central to the ethics and practice of palliative medicine. All health professionals should acknowledge this fact.

It is important to separate specialist palliative care services from palliative techniques (e.g. ostomies, stenting, orthopaedic procedures, etc.) which are provided by appropriate specialists from the palliative approach (basic caring) which is within the scope of all.

Palliative care services may take several forms: a hospital support team, a ward in a general hospital, a hospice within a general hospital complex, or a freestanding hospice. Each has its own problems. One of the best ways to provide palliative care is to employ an effective hospital-based palliative care support team. This provides an interdisciplinary advisory and supportive service to patients within a general or specialist hospital without having overall responsibility for patients or beds. Although the number of such teams has dramatically increased in the UK the vast majority are unidisciplinary (usually nurses) and are therefore far less effective.

The proportion of people dying at home is currently dropping by 1 per cent per year but patients still spend 90 per cent of the last year of life at home and 90 per cent of symptoms start at home. Home care teams are therefore an essential component of the palliative service. They work by integrating and bridging gaps between the primary care team, community resources and the hospital. They have had no effect on the social trend towards dying in institutions but do enable patients to remain at home longer.

Everyone has the right to receive good palliative care and all professionals have a duty to provide it. The aims for the provision of care are: palliative care for all; appropriate palliative procedures available and accessible to everyone; and specialist services for those few who need them.

\*A list of speakers and the titles of their papers presented at this symposium is recorded in *Proceedings*, Vol. 25, p. 354.