

SECTION 1

Introduction to the fourth edition: facing the challenges of continuity and change

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The fourth edition of the *Oxford Textbook of Palliative Medicine* reflects the continuity, development, and evolution of the art and science of caring for the incurably ill and dying. The editorial board of the textbook reflects this same theme of continuity and evolution. Professor Geoffrey Hanks, a stalwart of all three previous editions has led the editorial team. He has been supported by Nathan I. Cherny (an editor from the previous edition) and by an international team of new editors including Marie Fallon (Scotland), Russell K. Portenoy (USA), Stein Kaasa (Norway), and Nicholas Christakis (USA).

The *Oxford Textbook of Palliative Medicine* has evolved to increasingly become a truly international text. We now have 193 contributors from 16 countries and 6 continents. This new edition is a major reworking of the textbook with multiple new chapters and new authors. The book has been substantially restructured with new sections on the interdisciplinary team, geriatric palliative medicine, disease modification in advanced cancer, and a section devoted to specific neoplastic diseases. Additionally, some of the pre-existing sections have been restructured. This is particularly true for the subsection on pain in which there are now new chapters on bone pain, neuropathic pain, and breakthrough pain.

As much as we would like to call our contributor list the best and the brightest, we are well aware of the depth of talent and thoughtfulness that exist in the world of palliative medicine. It is in this sense of humility that we invite you to be reviewers and contributors to help make this textbook a very real and living endeavour by taking time to write back to the editors with your feedback about the book or its individual chapters. This information will be used for the development of subsequent editions. To this end we invite you to send feedback to editors@OTPM4.org

As editors, we are well aware of the tensions in the palliative care world regarding the evolution of palliative medicine. We embrace this tension as a challenge to address issues of continuity, development, and change as a theme of this edition.

Continuity: cardinal concepts underlying the philosophy of palliative medicine

Palliative medicine asserts boldly and optimistically that even in the face of overwhelming illness suffering can and must be relieved. This assertion is derived from a rights ethos. There may be pragmatic, economic, geopolitical, or social reasons that make it difficult to provide palliative care, but these do not diminish from duty of care to seek the adequate relief of suffering of persons with incurable illness.

The factors that motivate palliative medicine practitioners to do what they do in the face of great challenges are the underlying axioms of our endeavours. Beyond intuition we believe that it is important to articulate why we make the personal and professional investment in attempting to address intense human suffering in the context of incurable illness and impeding death.

Care, compassion, and empathy and justice

Care is the recognition that the well-being of others is a matter of consequence. As an integral part of the human experience, it is a motivating force that influences the nature and dynamic of interpersonal behaviours. Compassion is that aspect of care that recognizes the emotional dimension of the human experience.

Empathy, the ability to perceive and to understand the emotional experience of others and to relate to it a meaningful and appropriate

manner, predicates care and compassion. In the clinical context, an empathic connection occurs when the carer understands what their patient is experiencing, and when this is communicated (verbally or non-verbally) such that the patient feels that they are understood. The empathic connection is often therapeutic in itself. Beyond that, it is a motivating bond which also facilitates the trust necessary to forge an effective therapeutic relationship.

There is a linear relationship between empathy, care, and perception of justice. The rights claim to adequate relief of suffering is derived from the empathic experience; i.e. that unnecessary suffering is a profound matter of consequence and that it demands a constructive response. Empathy, care, and compassion motivate sensitivity, respect, compassion, concern, charity, generosity, altruism and, sometimes, self sacrifice. The absence of care implies that the well-being of the other is inconsequential and, in its absence, human interaction is often characterized by insensitivity, neglect, or negligence.

Resilience

In taking on the task of palliative care, we, as health-care providers willingly expose ourselves to physical, emotional, and existential distress on a daily basis. Caring for patients and their families in this context day after day (and, in many cases, for years on end), challenges us. We are challenged as professionals and as individuals; each with our own families, needs, and outside stressors. We are challenged as health-care teams; the differential stressors borne by members of the care team can strain and challenge even the best of collaborative relationships.

As caregivers, resilience is the quality that enables us to withstand and to develop despite the tidal surge of suffering that we dare to confront with skills, dedication, and good intentions. As teams, resilience is the flexible, binding matrix that keeps us working constructively together despite forces of team stress, conflict, interpersonal frictions, and grievances that would potentially fragment or undermine our ability to deliver care.

By virtue of self-selection, clinicians choosing to enter into a career of palliative care often have a strong perception of personal resilience. In most cases, palliative care clinicians have chosen their career paths and are thus self-interested partners in developing and preserving their ability to function, to contribute, and to rise above the suffering we help relieve. Not all, however, who work in palliative care, do so by choice. Interns, resident staff, nursing students, administrative and support staffs are often find themselves in palliative care by consignment rather than by choice. For those without innate resilience or good supports, this can be a high-stress challenge that can only be endured if given support understanding and an environment that helps foster coping and resilience.

The patients and families we seek to help have not chosen their fate. How they cope, or are helped to cope, hinges on both meticulous care and on the fostering of resilience in the patient, the individual family members, and of the family as a unit. Some patients come with rich sources of personal and family resilience; many, however come to us overwhelmed and bereft. Beyond the relief of physical symptoms, the processes of adaptive coping and of psychological and spiritual healing all demand the nurturing of coping and courage.

Courage

For the incurably ill, fear is a part of life. There is just so much to fear; death, physical distress, and debilitation, dependency, and so

many losses. Loss of potency, of beauty, of control over biologic function, of mental faculties, of future hopes, of separation, of and of life itself.

Courage takes many forms in the lives of our patients. Finding the courage to seek meaning in a life to be foreshortened and to be able to savour the available life whilst, at the same time, grieving the hopes and dreams, that cannot and will not be fulfilled. Courage to confront difficult decisions about treatment options that have both the potential to either improve quality of life or possibly to undermine it. No one wants to live with a gastrostomy, to wear a diaper, to have an intercostal catheter, to have limb amputated, or to undergo endoscopic stent insertion. In making such benevolent recommendations, we ask a lot of the patients' resources. Yet, for many of our patients, the courage to submit to such procedures will ultimately allow them to live better than they did without.

We often ask of our patients to make the switch from seeking more and better life to accepting the inevitability of impending death. Not only is their courage in choosing the activist or interventionist option 'to do'; there is courage, sometimes even greater courage, in making decisions to desist from, to forgo, or to withdraw treatments or interventions.

Humility and audacity

The magnitude of the issues that our patients confront challenge the limits of the art and science of palliative medicine. Understanding the limits of what can be reasonably expected from our care, treatments, and interventions emphasize the need to present treatment plans with both hope and humility. Often, there will be no one best management option, and, in presenting therapeutic options, we need to explain not only what we know, but also the uncertainties involved.

An excess of optimistic and overconfident hubris regarding the anticipated outcome of treatments risks undermining credibility. This affects the way in which we present anticipated outcomes from treatment recommendations. Desisting from saying some intervention or treatment 'will help', rather, invoking the contingency 'may help', a commitment to vigilant monitoring of outcomes with a readiness to readdress the treatment plan project an honesty and a commitment to care that encourages and fosters trust.

Honest and humble evaluation of what we can reasonably expect from our care outcomes make us aware of the limits of resources, therapeutic efficacy, and of knowledge that limit our ability to provide optimal outcomes for all. It is this critical element of humility that provides the impetus to programme development, political activism to improve resource allocation and, importantly, research to improve the knowledge base of palliative medicine.

For all of its inherent wisdom, there is a tension between palliative medicine and the humility of the Serenity Prayer. The Serenity Prayer asks us to 'Accept the things we cannot change, to change the things we can and to have the wisdom to know the difference'. The importance of the issues that we confront in palliative medicine impels us to seek ways to shift the boundaries between the 'things that cannot be changed' and those that are amenable to intervention and change. This is the dimension of audacity and the imperative of research.

Sensitivity to differences

There is no one best way to deal with life-threatening illness and indeed cultural, religious, and interpersonal factors strongly affect

individual approaches. Individualized care needs to recognize and address a range of potential responses to the issues and decisions faced by our patients and their families.

While cultural sensitivity is important, it is equally important to recognize the heterogeneity with different cultural and religious communities. Indeed, reductionist anthropological approaches with cultural stereotyping are best avoided in favour of a more individualized approach that explores the values and goals of the individual patient and their family.

Trust

Through empathy, compassion, honesty, humility, sensitivity, and diligence, we aim to develop a bond of trust. We aim to build a trust that is sufficiently robust such that patients and their families feel secure in their care to facilitate effective care planning and delivery, courage, and resilience despite the profound difficulties of their circumstances.

Development: education, service delivery, availability, and therapeutics

Education

The maturing of palliative medicine as a profession has been accompanied by the ongoing development of palliative medicine education and educational resources all over the world.

Increasingly, medical schools around the world are recognizing the importance of undergraduate training in the principles of palliative care. It is widely recognized that palliative care is an excellent format for modelling the principles of the bio-psycho-social model of health care that is now widely accepted as the standard of care. Curricula have been developed and published by multiple countries, universities, and individual faculties and there are a plethora of teaching models and aids that have been published and disseminated.

Advanced training in palliative medicine has taken multiple strides forward since the publication of the last edition of the Textbook. The outstanding development has been the recognition, in 2007, of Hospice and Palliative Medicine as a sub-specialty by the American Boards of Medical Specialties. After years of intense effort by a dedicated core of clinicians and researchers, this is a landmark achievement that is likely to impact on similar licencing authorities around the globe. Indeed, palliative medicine is now a recognized medical specialty or sub-specialty in 16 countries, and in others application for specialty or sub-specialty accreditation are underway or pending.

There is no consensus as to how to best train palliative medicine specialists. The content and duration of advanced training programmes varies greatly around the globe; 1 year in the United States, 3 years in the United Kingdom and Australia. Some programmes insist on a research component and others make no such demand. Given that the level of training not only affects competence and service delivery, but also impacts on the function and well-being of specialist clinicians working in the field, the issues of the adequacy of training are salient. How best to adequately equip specialist palliative care clinicians remains an open question worthy of further evaluation and research.

Worldwide, there is an increasing recognition that almost all physicians need some degree of proficiency in palliative medicine. This is specifically true for specialists working in high-mortality

fields such as oncology, intensive care, geriatrics, neurology, nephrology, cardiology, and internal medicine. In all of these named specialties there have been important developments over the past 10 years. These are reflected in curricula development, training initiatives, publications, and research. Despite this, actual changes in training in practice have been, at best, inconsistent and at worst, disappointing. Overall, progress is evidenced but, in most of these specialties, the development of a high level of skill and understanding of palliative medicine remains a goal that has yet to be achieved.

Research in palliative care

Basic, clinical, sociological, and psychological research are all critical to expand the boundaries of knowledge in order to optimize patient care. This truism is valid for the medical endeavour in general, and is particularly relevant for palliative medicine in which the evidence base of practice is still relatively underdeveloped. The proliferation of research relevant to the care of the incurably ill has been a critical part of the maturation of palliative medicine. Research findings have sharpened our understanding of the mechanisms of symptoms we seek to relieve, helped define the limits of old approaches, and have uncovered new approaches to challenging and difficult problems that have previously been refractory to older approaches. Indeed, this edition of the Textbook is replete with multiple new approaches and insights that have been derived from these research endeavours.

By its nature, research in palliative medicine is very broad in its scope. Social science and psychical research are as important in our field as are basic science and therapeutic studies. The care of the incurably ill and their families is a 'complex system' challenge requiring multiple inputs, resource allocation, pharmacotherapeutic and psychological skills, and social understanding. All of these factors are increasingly represented in the growing research culture that we seek to encourage and cultivate.

Funding for palliative care research remains a challenge. Because many of the agents used for palliative care are not under patent, industry sponsorship is not widely available. In recent years, we have witnessed the development of research consortiums in palliative care that have been able to (successfully) submit grant proposals for complex interdisciplinary research endeavours. There is ongoing need to advocate for better funding for palliative care research.

Service delivery

The past decade has seen a flourishing of palliative medicine services in different settings worldwide. This has been well documented and monitored by the International Observatory of End of Life Care Project. There is not a region in the world that has not observed growth in palliative medicine services in the past 10 years. While there are areas where penetration and integration are tremendous, there are others in which programme development is still evolving and, sadly, many in which services are scarce and rudimentary. Programmes promoting education and service development, such as those championed by the Open Society Institute, the National Cancer Institute of the United States, and the European Society of Medical Oncology have made a substantial contribution in many countries with less developed services.

There are now a great many models of palliative medicine service delivery: inpatient and home-based hospices, hospital consultation

services, acute palliative care wards and day hospitals, ambulatory clinics, and mobile clinics. Although the underlying principles and philosophy are consistent, the spectrum of observed problems may be profoundly different in different care settings.

This is particularly true with the increasing movement towards ‘upstream palliative medicine’ in which palliative medicine is being delivered at an earlier stage of the trajectory of illness. The issues confronted by clinicians working in early stage palliative medicine units, such as those in acute palliative medicine units, are often quite different from those confronted by clinicians who are providing immediate end-of-life care. The goals of care are different with a greater emphasis on function and, often, life prolongation (even in the face of incurable disease). In such cases, the duration of care will be prolonged and the fluctuating status of illness (with treatment-induced remissions and relapses) may involve rapidly changing care needs with changing problems lists and priorities.

Journals

There are now more than 10 peer-reviewed journals dedicated to issues of palliative care (Table 1.1). Additionally, the major journals of many other sub-specialties have increasingly embraced the palliative care issues which now feature ever more prominently. Dedicated palliative care sections in general journals, such as have appeared in the *British Medical Journal* and *JAMA*, bring palliative care to a wider audience and are particularly commended.

Table 1.1 Palliative care journals

<i>American Journal of Hospice and Palliative Care</i>
<i>BMC Palliative Care</i>
<i>Death Studies</i>
<i>European Journal of Palliative Care</i>
<i>International Journal of Palliative Nursing</i>
<i>Journal of Psychosocial Oncology</i>
<i>Journal of Pain and Palliative Care Pharmacotherapy</i>
<i>Journal of Pain and Symptom Management</i>
<i>Journal of Palliative Care</i>
<i>Journal of Palliative Medicine</i>
<i>Omega</i>
<i>Palliative and Support Care</i>
<i>Palliative Medicine</i>
<i>Progress in Palliative Care</i>
<i>Psychooncology</i>
<i>Supportive Care in Cancer</i>
<i>Journal of Supportive Oncology</i>

Evolution: change and challenges in palliative medicine

One of the early axioms of palliative care is that it sought to provide an alternative to ‘aggressive’ or ‘highly technical’ medical care. Indeed palliative care was often presented as ‘strong’ on care and ‘low’ on technology. In the sixties and early seventies, when these

concepts were initially articulated, low-technology options were often indeed the very best that could be offered to help relieve patient distress. At that time there were very few truly effective palliative anti-tumour options beyond radiotherapy, and endoscopy and interventional radiology were in their absolute infancy.

The extraordinary development of non-curative, but potentially beneficial, interventions to address so many of the conditions, symptoms, and complications confronted by patients has created new opportunities, new tensions, and new dilemmas for palliative medicine clinicians.

New therapeutic opportunities

The last 20 years have seen dramatic changes in the non-curative treatment options for many of the conditions we encounter, particularly in cancer and HIV. With the introduction of a widening repertoire of treatment approaches, the natural history of advanced cancer and HIV infection have seen radical changes. While many, if not most of these, interventions are not curative, they have created new opportunities to control the ravages of disease, thus reducing symptoms and also by changing the natural history of the disease. Some interventions may add months, others, possibly years to survival.

Whereas previously it was often the role of the palliative medicine clinician to present a counterpoint to the high morbidity and low likely benefit of chemotherapy, the recent developments in the field of palliative anti-tumour therapies have added a whole new outlook for many patients. These developments have necessitated a change in the relationship between palliative medicine and medical oncology.

Furthermore, in order for palliative medicine clinicians to maintain credibility, they now need a far greater sophistication in the understanding of palliative approaches that change the course of the underlying disease: be it in cancer care, retroviral care, or in the management of other degenerative conditions where disease modification is available.

New palliative interventions exist not only for specific disease states but for also for specific disease complications and symptoms. Endoscopic interventions and interventional radiology have radically broadened the range of options in the cases of obstruction of luminal structures (GI, GU, vascular, and respiratory). These approaches have altered the management of intestinal, biliary, ureteric, and bronchial obstruction, venous compression syndromes, and in select cases pain management. Surgical approaches have made major changes to the management of complications of cancer such as spinal cord compression, brain metastases, and impending fractures (see sections 10 and 11).

Palliative medicine clinicians are challenged to take an increasing role in the development and evaluation of these sorts of interventions.

New tensions

Concern is often expressed that the increased availability of technical interventions to relieve distress somehow diminishes from the ability to care, or from the heart of palliative care. It is sometime asserted that palliative care is being excessively ‘medicalized’.

However, just as there is a romantic image of the 19th-century physician at the bedside of his patient dying of TB offering possibly a tincture of opium but predominantly as a source of comfort, there is also a tendency of romanticizing the days of palliative

care when many of these new palliative interventions were not yet available.

Interventional palliative care needs to be used judiciously. When it is considered among the possibly appropriate treatment options, it needs to be discussed with patients in an appropriate perspective: presenting likelihood of benefit, risks, and alternative approaches. Given the choice, many patients are interested in approaches that offer the possibility of life prolongation or symptom relief through these interventions. However, compassionate patient-based care or interventional palliative care should never be presented as ‘either or’ options.

Many dying patients are not in a rush to die and their desire for life-prolonging treatments is often appropriate. Although the WHO definition of palliative care includes the statement that palliative ‘intends neither to hasten nor postpone death’, one must recognize that there is a difference between prolonging dying and prolonging a life in the face of incurable illness. Unfortunately, this is often confused, leading people to believe that non-curative disease-modifying drugs or other high-tech palliative interventions are not part of the palliative care. The consequence of this confusion is substantial: and indeed some patients are denied palliative care services because they are interested in these interventions or treatments, and others are denied access to treatments that would otherwise serve their goals of care because they are in a palliative care clinical pathway.

New challenges

Many of the service delivery models for palliative care were developed with the aim of offering a more cost-effective way of managing patients with incurable illness. Indeed, this was not only the advertised advantage, but programmes were budgeted based on assumptions of great savings for the health-care funders.

How are palliative care services, whose budgets are based on the assumption that palliative care is cheaper, going to manage with these new technologies? This is a major challenge that is not well answered. Many hospices are forced to limit or even preclude the accessibility to palliative interventions, many restrict access to patients who are no longer receiving disease-modifying treatments, some are financially compromised in their valiant attempts to provide all of the potentially helpful options for patients who are needing palliative care services over a longer time frame (by virtue of disease modification).

How different health-care systems cope with the changing face of palliative care is going to have to be part of the next edition. We don’t yet have the answers.

In conclusion

Although we may now be professional carers, at some times in our lives our loved ones or we ourselves will be the people needing the care that we espouse and deliver. Professor Balfour Mount would express this in his widely quoted aphorism that ‘we are all in the same boat’. As palliative carers too, we are all in the same boat: despite our varying settings and circumstances, we are challenged by the same spectrum of problems, challenges, and questions.

In this text you will find some of the answers to many of the questions. Humility demands that we recognize that, with what we know, not all of the questions can yet be answered. Indeed, often the best that can be offered is a range of suboptimal options to be considered and possibly tried on a sequential basis. This underlies the imperative to work together to push the boundaries of what we know, and how we apply it to the care of the incurably ill.

We hope that this Fourth Edition of the *Oxford Textbook of Palliative Medicine* will help in that endeavour.

