

*Restoring
palliative care
as a surgical
tradition*

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The term palliative care was first coined in the mid-1970s by Balfour Mount, MD, a Canadian urologic surgeon and pioneer of hospice and palliative care, to describe a comprehensive, patient-centered, symptom-treatment approach to caring for patients with advanced illness.¹ The modern origins of his philosophy stem from the work of Dame Cicely Saunders, OM, OBE, FRCS, of Great Britain and her seminal efforts to develop hospice care during the 1950s and 1960s.

One of Dr. Mount's many contributions to the field was his introduction of the hospice concept to the milieu of an acute care multispecialty hospital.² Dr. Saunders's hospice model of care not only lent itself to successful application in different settings but also in the management of illnesses other than cancer. Significantly, it was recognized that this approach to care was compatible with ongoing disease-directed therapy. Surgeons were among the earliest and most steady referral sources to Mount's palliative care unit at Montreal's (QC) Royal Victoria Hospital.

In 1990, the World Health Organization (WHO) defined palliative care as "the active total care of patients whose disease is not responsive to curative treatment."³ By then it was widely appreciated that the palliative model of care could be applied earlier in the course of illness and in conjunction with disease-directed therapy, and the WHO's definition specified this application. Palliative medicine had already been designated a medical specialty in Great Britain in 1987, and recently in the U.S. a plurality of the medical subspecialties not traditionally active in palliative care practice and research, including surgery, have endorsed the principles of palliative care.^{4,5}

The "total care" referenced in the WHO definition can be understood as the caring response to the four domains of human pain or suffering: the physical, psychological (emotional), social (economic), and spiritual. Dr. Saunders defined distress in all four domains as "total pain."⁶ An enduring iconographic image of total pain is seen in Montegna's fifteenth century masterpiece *St. Sebastian*, in which a nearly naked man, lashed to a pillar of stone and with numerous crossbow bolts in his torso and extremities (reminiscent

of a laparoscopic procedure gone haywire) averts his eyes heavenward with a look of profound existential suffering (see image on page 23). In the background, completing the picture of isolation and abandonment, are two distant figures (family? consultants? insurers?) walking away from the sufferer.

In palliative care, no specific therapy is discounted. At the heart of palliative care is the agreement between physician and patient that the expected outcome is relief from distressing symptoms, easing of pain, and improvement in quality of life. The decision to intervene is based on the ability of the treatment to meet the agreed upon goals rather than its effect on the underlying disease. The three foundations of palliative care are: (1) pain and non-pain symptom management; (2) communication between patients, families, and care providers; and (3) continuity of care across a range of clinical settings and services.

Other hallmarks of palliative care include team-based care planning that involves the patient and his or her family with attention to their spiritual, psychosocial, and bereavement issues. Team members who provided care for the deceased may also require this type of support.

It cannot be emphasized enough that the indications for palliative care are based on need, not prognosis. Terminally ill patients and actively dying patients are only subsets of patients treatable using a palliative approach.

New to surgery?

Is palliative care really new to surgery or has it always been an integral part of the surgical tradition but applied under a different name? Until the twentieth century, when the full impact of Descartes and Newton became visible in clinical medicine and its underpinnings and practice became increasingly the result of scientific methodology, the vast majority of medical and surgical interventions were, in fact, palliative measures. These interventions were noteworthy—or notorious—more for reducing symptom burden than for curing disease. Many of these procedures exchanged an imminent demise for a chronic illness. Theodor Billroth's first successful gastrectomy for an advanced, ob-

structing cancer of the pylorus exchanged an imminent demise of the patient from dehydration and starvation for a more peaceful death from anorexia and cachexia from liver metastases several months later. More than a century later, his reflections on this case offer us good guidance on the rules of engagement for surgical palliative care: "Our next care...must be to determine the indications, and to develop the technique to suit all kinds of cases. I hope we have taken another good step towards securing unfortunate people hitherto regarded as incurable or, if there should be recurrences of cancer, at least alleviating their suffering for a time."⁷

W. S. Halsted, MD, FACS, completed the initial series of radical mastectomies not for the mammographically detected lesions of today, but for individuals who were undergoing enough symptom burden to "have nothing to lose" by submitting to what was an enormous surgical undertaking by the standards of his day. More recently, Alan O. Whipple, MD, stated in his 1942 writings about his series of pancreaticoduodenectomies, "the considerable risk (that is, operative mortality) of 30 percent to 35 percent is justified if they (the patients) can be made comfortable for a year or two."⁸ These examples of oncologic treatment proved that prolonged survival and cure ultimately were possible following a pattern seen as well beyond the field of cancer care. There is abundant evidence in the history of surgery to show that the relief of suffering as the first priority of surgical care has never undermined the goals of prolongation of life or cure: on the contrary, it has made them possible. More subtle and lasting variations of this theme are evident today in the surgical management of vascular disease and end-stage organ failure.

Recent voices in surgery remind us that the core principle of palliative care, nonabandonment, is intuitive to us and not an exotic import from the primary care specialties or medical oncology.^{9,10} Nonabandonment should not be interpreted in the strict and literal sense of continuous, scheduled follow-up visits, but as an attitude of willingness to stay engaged in whatever way would be helpful. Examples include facilitating contact or referrals with other health

care professionals, paying "social" visits to a patient now hospitalized under another specialist's care, or making a house call to a bed-bound patient.

Burn care

For surgeons, the most riveting and well-developed paradigm for surgical palliative care is found in burn care. It is more than a coincidence that some of the most eloquent speakers on palliative care, hospice care, and medical ethics in general have had experience with burns, possibly because these individuals have witnessed the intensity of the suffering (or the totality of the threat to a person's wholeness) associated with burns. Burn patients suffer pain at the highest degree, no matter which parameter is used to measure it—physical injury to the body, neuronal injury and the complications thereof, or transformation of an individual's lifestyle, social status, psyche, and spirituality. Burn care has taught us that the first step toward salvaging a patient involves attending to pain control. Burn experience has taught us to respect, not fear, morphine in a way that has ultimately benefited countless individuals suffering from other painful conditions, such as cancer. The threat of physical mortality is only a part of the existential threat resulting from devastating injury because we also exist in social and spiritual contexts. Nowhere else in the practice of surgery is it so obvious as in burn care that existential salvation for patient and caregivers alike begins with the response to suffering.

Barriers

If we all agree that the concept of palliation is deeply rooted in the surgical tradition, that the need for the palliation of illness is widespread, and that fertile areas for growth and application of this idea await, then what are the barriers to implementing a comprehensive approach to palliation in surgical care? As it turns out, there are quite a few. The impediments work at the cognitive, psychological, social, and spiritual levels, making them reflective of the four dimensions of pain identified with suffering.

As surgeons trained extensively in the natural sciences, we highly value information and rea-

soning. The philosophical background of our current cognitive framework is revealing when searching for the reasons for the visceral sense of awkwardness we feel when the boundaries of life and death are obscured, and we are haunted by questions of meaning. The separation of mind and body at the heart of Descartes' philosophy, so influential in modern scientific thinking with its implicit emphasis on the physical, has often blinded us to nonphysical suffering. Intriguing discoveries in physics and the neurosciences increasingly tell us that the Cartesian separation of mind and body was an arbitrary and ultimately doomed conceptualization. The irony here is that Descartes' philosophy evolved as an attempt to accommodate the study of anatomy within the existing doctrine of the Roman Church, and it is the current study of anatomy that is contradicting his philosophy.

In the largely agrarian society that existed before the twentieth century, even lifesaving measures such as amputation were more morbid from a socioeconomic and psychological point of view than from a physical perspective. Yet success in therapy since then has increasingly become a measure of its impact on the individual's physical domain to the exclusion of all other domains. As our understanding of the natural sciences deepened, we were increasingly ready to harness this knowledge to solve physical problems encountered at the bedside, while the other domains were assigned a subordinate status because they were somehow "less real."

Our current deficiencies of language and knowledge to discuss and provide palliative care in the context of surgery is one of the results of scientific materialism, despite the bounty of useful physical interventions we have received as a result of this world view. McCahill and others have shown that formal education or training in palliative care for surgeons is limited, even within a population of medical professionals who have frequently encountered these problems.¹¹ Several reviews of surgical textbooks and articles show little attention, if any, is paid to death and dying or palliative techniques or approaches, using a systematic and interdisciplinary approach.^{12,13}

Language problems pose another cognitive barrier to full integration of a palliative philosophy. We lack the words and phrases to adequately account for the newer thinking and insights that are

rapidly accruing. "Surgical palliative care" is not "palliative surgery," although "palliative surgery" certainly is a subset of "surgical palliative care." Widespread inconsistencies in the use of the words "palliative" and "palliation" exist in the surgical literature.¹⁴ In some cases the word is used to describe tumor positive histologic margins, in other words, a "failed" curative operation; in other instances these terms are appropriately used to describe symptom control, through the eyes of the beholder (the surgeon) but not through those of patient. McCahill's survey demonstrated the extent to which palliation is examined from the surgeon's perspective: 43 percent of surgeons surveyed defined palliative surgery on the basis of the surgeon's preoperative intent, 27 percent defined it on the basis of postoperative findings, and 30 percent defined it based on individual prognosis.¹¹ Even with the best intentions, the current inconsistencies of language defining palliation allow a dangerous gap between the surgeon's and the patient's perception of a given experience. It is genuinely tragic whenever a surgeon, justifiably proud of his or her skill and commitment, discovers a procedure has completely missed the mark of the patient's personal goals.

Other cognitive barriers consist of scarcities and deficiencies in the quality-of-life data in the literature of surgery and surgical oncology. Much work needs to be done, although the field is already in a robust phase of development, leading to the design of better instruments and interpretation of quality-of-life outcomes.

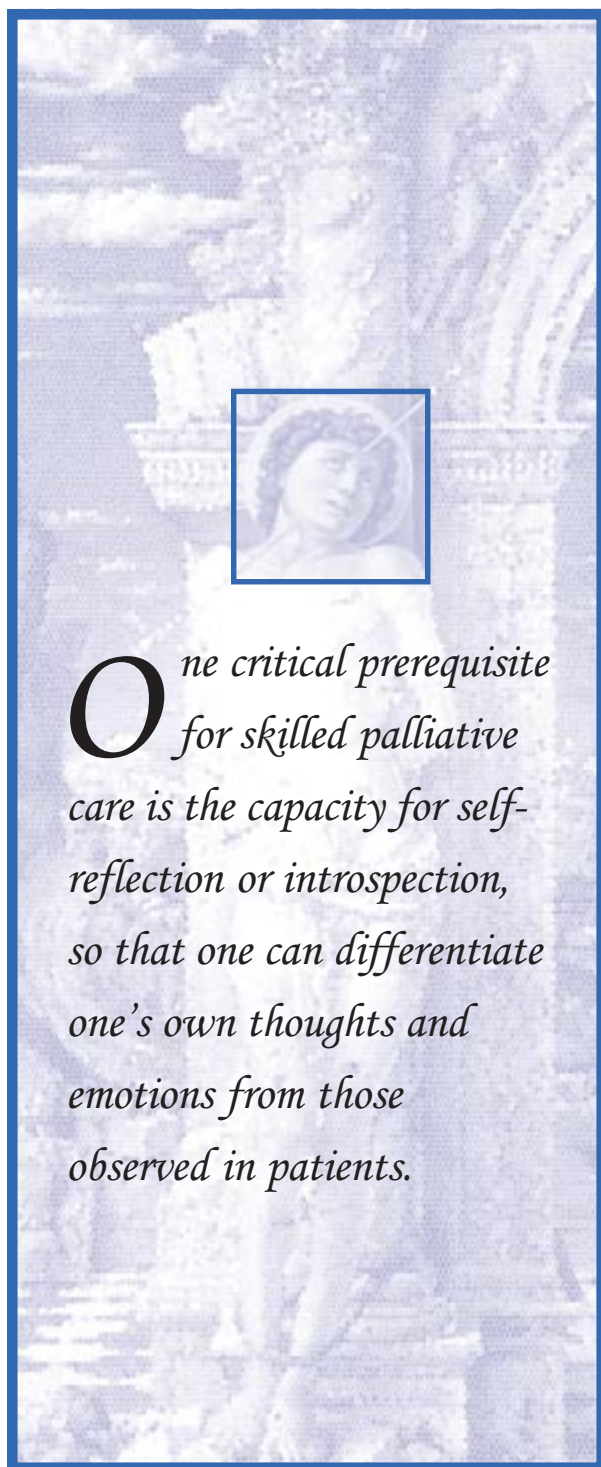
The psychological barriers to palliative care may be more formidable than the cognitive obstructions. Many surgeons, including those who have performed brilliantly and successfully in terms of relieving suffering, still express a fear of "taking away hope" when discussing palliative treatments, especially during direct disclosure of a terminal disease to a patient. These fears often have more to do with the surgeon's own psyche than with the possibility that the patient might actually lose hope when told a truth they have consented to hear. It may seem counterintuitive to some surgeons that disclosure of bad news, if given gently, honestly, and empathetically, can actually engender the renewed trust necessary for rekindling and redirecting hope.

Another potential psychological barrier for sur-

geons is the fear that lack of disease control is lack of *all* control, or, that they are “losing” or, worse, “giving up.” The inevitable reactions (denial, anger, resistance, despair, stoic acceptance, humor, and so on) that accompany any loss of control can profoundly color the outcome for surgeon and patient. As part of examining psychological barriers to palliative caring, the long-held doctrine that the surgeon is the “captain of the ship” in the course of care of the patient will invite ongoing scrutiny. Does being the captain of the ship mean the surgeon is the ultimate undisputed authority on all matters, or, will it come to mean guiding the patient with a lighter hand on the tiller, capable of quickly adjusting to the needs of any particular moment?

One critical prerequisite for skilled palliative care is the capacity for self-reflection or introspection, so that one can differentiate one’s own thoughts and emotions from those observed in patients. This may be more difficult for surgeons than for other physicians because of the nature of surgical disease and the settings (trauma centers, operating rooms) in which it is provided. The acuity and intensity of crisis often do not allow for much reflection, and may provoke a more drastic psychic defense mechanism. Krizek wrote of the phenomenon of “doubling” by surgeons.¹⁵ This process involves a behavioral description first described by Robert Jay Lifton, who wrote about Nazi concentration camp guards who could do murderous things by day and then go home and be kind and loving husbands and fathers.¹⁶ Although the comparison is not a flattering one, it does demonstrate that people have a basic ability to split emotion from behavior when dealing with extreme circumstances such as murder or saving lives. (In the case of the camp guards and others engaged in activity that would provoke an extreme visceral reaction, this behavior was only one of a series of psychological adjustments that ultimately led to profound mental illness and distress later in life.)

Krizek warned of the psychological morbidity to surgeons maturing in a culture that does not offer the necessary support for emotional self-awareness.¹⁷ More mundane counsel related to psychological preparedness for the frequently arduous work of palliative care can be found in many commercial in-flight information cards describing the use of oxygen masks: “Take care of your own needs



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before attending to your child.” Surgeons comprise a culture; that is to say, “an institution in which attitudes, beliefs, customs, traditions, art, and achievements of a society...are passed on from generation to generation.”¹⁸ Any reorientation of perspective, especially if related to basic concerns such as quality of life, will inevitably encounter social or cultural barriers.

The surgical culture in the U.S. and Canada is predominately hierarchical, male, and caucasian. To fulfill its basic mandate of addressing the four dimensions of pain and suffering, palliative care requires a consensual, interdisciplinary, and patient-centered process that is gender and culturally sensitive. Fortunately, the innate response to suffering shared by all surgeons can do much to overcome these differences when they present barriers to effective palliative care.

Other potential social barriers to palliative care include the perception held by many of our nonsurgical colleagues that surgeons are aloof or inaccessible. One of our other cultural institutions, mortality and morbidity (M&M) rounds, will need redirection toward enhancing palliative care. A disincentive remains to operate on patients near death even if another procedure would greatly enhance comfort and function when that patient, due to the stage of illness, is predestined to appear on the M&M list.

Financial and referral considerations also may prevent worthwhile interventions and encourage futile ones. An internist who is unaware of the danger and futility of placing a feeding gastrostomy in a patient with end-stage cancer cachexia syndrome will press the surgeon to perform this procedure, invoking the distress of the individual’s family. It will require more than the surgeon’s principles to exit this type of no-win situation. He or she will need prospective data, support from peers, and, most importantly, the patient’s understanding. The surgeon will need to show that he is protecting the patient’s realistic wishes and not the desires of the referring physician.

The spiritual barriers to palliative care in surgical practice stem from the tension between the most physical and mechanistic of the medical arts and the nature of spirituality, the capacity for transcendent yearning and connection.¹⁹ Evidence shows that patients welcome our interest


in this aspect of their lives, though there is a potential barrier in recognizing these needs if the surgeon cannot distinguish religion from spirituality and his own beliefs from the patient’s.¹⁰

The College’s role

Although palliative care always has been part of surgery, it was not until the late 1990s that it was recognized as a specific philosophy of care with principles in consensus with other medical specialties in the U.S. and abroad. In 1998, the College endorsed the “Statement on Principles Guiding Care at the End of Life,” marking the first specific institutional step in the direction of promoting better understanding of palliative care.⁴

In October 2002, the Task Force on Surgical Palliative Care was organized in the Division of Education of the College. The purpose of the task force is to facilitate introduction of the precepts and techniques of palliative care to surgical practice and education in the U.S. and Canada by bringing together surgeons with demonstrated interest in palliative care to share resources, strategies, and expertise, and in so doing, to act as a catalyst for change.

In October 2003, the task force published its *Recommendations to the Field Summary* with funding from the Robert Wood Johnson Foundation.²⁰ Members of the task force have been contributing to an ongoing series of articles, “The Surgeon and Palliative Care,” in the *Journal of the American College of Surgeons*. In addition, the panel has presented symposia on palliative care issues at College meetings. The task force has proposed a revision of the College’s 1998 “Statement on Principles Guiding Care at the End of Life” that would adapt them to the broader spectrum of chronic illness as an effort to break down the current dichotomy that exists between care for patients at the end of life and all other patients.²¹ Future projects of the task force include surveying surgeons about their beliefs and concerns about palliative care, creation of teaching materials, ongoing conference presentations, and participation in other activities of the College. The task force hopes to inspire and assist the College to use its credibility and influence to provide re-

search opportunities and public education in this rapidly expanding and deeply rewarding field, in which the very best of our past becomes a light in our future. 

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