

## What is Palliative Care?

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... the meaning of a word is its use in the language.<sup>1</sup>

WHEN A CARDIOLOGIST introduces himself to a patient or family member or is asked, "What do you do?" a clear, concise, simple, and readily understood answer might be, "I am a heart specialist." An internist can say, "a physician for adults," and then perhaps specify something about nonsurgical management of nonpregnant adults. But what does a palliative care specialist say? As a hospice medical director for many years, I am familiar with the awkwardness of introducing myself to a new patient or family member. Words like "terminal care" or "death" stick in the mouth, and one searches for euphemisms. Now, as a newly labeled palliative medicine specialist, I continue to struggle with how to explain myself.

Balfour Mount coined the term, "palliative care" around 1973 to describe his new program at the Royal Victoria Hospital in Montreal, modeled on St. Christopher's Hospice.<sup>2</sup> "Palliative care" and the related term, "palliative medicine," have become the labels of choice throughout the world for programs based on the hospice philosophy, and are now being used increasingly in the United States.<sup>3-7</sup> The Institute of Medicine recommends that "Palliative care should become, if not a medical specialty, at least a defined area of expertise, education, and research."<sup>8</sup> "Palliative care" overlaps with "terminal care," "death-and-dying," "hospice," "end-of-life care," "thanatology," "comfort care,"<sup>9</sup> and "supportive

care"<sup>10,11</sup>—this latter term sometimes referred to comfort care, sometimes to support of the compromised host or critically ill patient, particularly those suffering from the adverse effects of cancer treatment. The diversity of meanings of these terms and their unfamiliarity to many persons can bewilder patients, family members, and colleagues in the health professions. A lack of agreement on the meaning of the terms also reflects conflict among palliative care practitioners about the nature of the field. How we label ourselves and how we and others define our work may have profound effects on the future of the hospice movement and on palliative care as a discipline. Although I cannot resolve all of the bafflement and contention that underlie these issues, and certainly do not pretend to any authority in arriving at a final definition, I hope this essay will provide some clarification and stimulate further discussion about the meaning of palliative care.

### DEFINITIONS OF PALLIATIVE CARE

To palliate, of course, literally means "to cloak." Palliation can be viewed disapprovingly as merely covering up problems. However, as currently used in American medicine, "palliative care" is becoming a widely accepted term for an approach to the management of a terminal illness that focuses on symptom control and support rather than cure or life prolongation.

The term "palliative care" currently enjoys two widely cited definitions.<sup>12</sup> Both of them are

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easily criticized, which I interpret as evidence not so much of their coiner's shortcomings but of how the field has evolved, matured, and expanded. One commonly quoted interpretation comes from the World Health Organization (WHO) in its 1990 publication, *Cancer Pain Relief and Palliative Care*: "the active total care of patients whose disease is not responsive to curative treatment."<sup>13</sup>

Try that on one of your patients! Or maybe suggest to your medical colleagues that they only deal with inactive or partial care or with curative treatment! The term "active" is presumably included here to dispel notions that palliative care is passive or focused simply on avoiding interventions, but seems to add little to the meaning of the definition—what is inactive care? We certainly do not want to claim expertise on the vast number of diseases that do not respond to curative treatment. Ideally, our definition should focus on the positive aspects of the work, such as helping patients and families live well or promote their quality of life. Here, the emphasis on failure—"not responsive to curative treatment"—seems unnecessarily gloomy, but perhaps is fairly gentle and acceptably euphemistic about terminal care and death. The common but problematic distinctions between palliation and curative or life-prolonging (or life-extending) treatment (or treatment with "aggressive intent") are not invoked.

One strength of this definition is the assertion that care should address all forms of suffering: "total care." Related terms are "total pain or suffering" or "holistic care." Unfortunately, such claims can sound a bit overinflated or unrealistically ambitious. "Holism" unfortunately is a bankrupt term, a red light that often signals nonsense. It has lost its cache in thoughtful social science circles,<sup>14</sup> and "holistic care" is now regularly used synonymously with "alternative" or "complementary" medicine. A derogatory term, "symptomatologists" has been introduced by Michael Kearney<sup>15</sup> and might be used to describe caregivers who focus on various diseases and problems but do not address the total suffering of the person.<sup>16</sup> "Comprehensive care" is my term of choice, especially because it already has established meaning in health services literature, and it

avoids pretentious or confusing implication of the other terms.<sup>17</sup> Other characteristics of palliative care that might be related to or subsumed by the term "comprehensive" are "interdisciplinary," "coordinated," "integrated," "humanistic," and "accessible" care.

This WHO definition is typically followed by a longer, somewhat awkward attempt at clarification:

Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment.<sup>13</sup>

These additional assertions are helpful,<sup>13</sup> though they do not clearly distinguish our work from that of other clinical fields. Many other clinicians recognize the importance of comfort and support in terminal disease, as well as in nonterminal disease. Arguably, all of medicine can be viewed as seeking the goal of quality of life. Moreover, the association of palliative care solely with cancer is misleading.

A second definition of palliative care, used by the authors of *The Oxford Textbook of Palliative Medicine*, first published in 1993, also has been widely cited: "The study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life."<sup>18</sup> This definition is more concise and more precise than the WHO phrases. By choosing a word like "focus" (or "emphasis" or "concentrate"), we avoid making palliative care a conflicting or totally separate approach from "conventional," "curative," "aggressive" or "life-prolonging" measures. A Canadian Palliative Care Association definition also stresses that palliative care "may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care."<sup>19</sup> We should not be consigned to the final days of life when other approaches are abandoned.

However, this definition is replete with jargon and confusing terminology. What is a "lim-

ited" (or "unlimited") prognosis? Is this designation preferable to "incurable" or "terminal?" Who will attend to the subtle distinction about the disease being both active and progressive? Where is the family in this explication?

None of these definitions are brief or clear enough to answer a patient or family member's questions: "What does palliative care mean?" Or, "What does the palliative care service do?" Indeed, the definitions may be too abstruse and too vague for even clinicians or health-care policy experts who are familiar with the jargon.

These definitions are often accompanied by a host of precepts that I find largely meaningless, silly, grandiose, and even inaccurate, many of which would seem quite out of place in a discussion of another clinical specialty, regardless of its scope or sense of mission. We should be mindful of Derek Doyle's admonition "never to believe that we have a monopoly on care, concern or compassion," and of hospice's tendency to "self-righteousness."<sup>20</sup> Some terms and phrases—for instance, "patient-centered care," "care versus cure," "treating the person, not the disease," "compassion," "skill," "dignity," "recognition of patient values," or "culturally sensitive services"—may suggest standards distinguishing good from bad palliative care, but do not constitute essential parts of a definition. They seem to imply that palliative care has a special claim on such virtues. The use of such terms can muddy the waters and, for me, engender misgivings. For instance, although palliative care should certainly be tailored to the needs and wishes of the patient and family, this feature does not distinguish us from other fields of medicine any more than do skill or compassion. Quality of life is a concern in all areas of medicine, and any intelligent approach to assessing it begins with an understanding of patients' knowledge about their condition and potential management strategies, their values, and their personal cost-benefit calculations. Here, also, the term "dignity" is often used, although it seems vague and potentially laden with care providers' values.

We also often read that hospice or palliative care "affirms life and regards dying as a normal process." But what does it mean not to affirm life? Do other clinicians disapprove of life

or really regard dying as an abnormal process? Theology seems to be attempting to impose itself on clinical work. Certainly, palliative care may not always view death as a failure or as an inevitable enemy, and may see positive opportunities for growth and reconciliation in the face of dying. A more distinguishing characteristic of palliative care would be that it openly acknowledges dying.

Similarly, we regularly read that hospice or palliative care "neither hastens nor postpones death," which appears to be a statement of ideology, reflecting perhaps an aversion to euthanasia and, tellingly, to life-prolonging treatment. This maxim may reflect some of the religious orientation of the hospice movement, but does not seem appropriate for defining a field of health care. Regardless, the statement certainly does not reflect my own sense that I am often postponing or hastening death. For instance, patients who are not eating, losing weight, and becoming progressively weakened but then receive careful mouth care, nutritional support, pain control, and other comfort measures seem to live longer (and wish to keep living longer) with good palliative intervention. Vigorous application of opioid analgesics or sedatives to treat a patient's severe pain or dyspnea may cause drowsiness and reduced intake of food and fluids, as well as predisposing to aspiration, and thus potentially hasten death.

#### **HOSPICE AND PALLIATIVE CARE: A PARTING OF WAYS OR A NEW COALITION?**

Competition is greatest between those who occupy the same position in the economy of nature.<sup>21</sup>

Palliative care embraces the hospice philosophy of care and seeks to bring this approach to a wider group of patients than currently served by hospice programs in this country. It also seeks to integrate the hospice approach into clinical practice. I do not believe that most palliative care practitioners have forsaken hospice, but rather are trying to apply the model more broadly and also more sensibly than currently

fostered by hospice regulations and reimbursement in the United States. I view all hospice care as a segment of palliative care.

In the United States, hospice has come to mean primarily a governmentally regulated organization or program for dying persons and their families,<sup>22</sup> typically focusing on home care, and limited to patients with:

1. An expected prognosis of 6 months or less
2. A focus on comfort measures—this is sometimes (but not always) defined by hospice programs as a desire to forego a variety of “aggressive” and often expensive management approaches (usually including cardiopulmonary resuscitation, blood product replacement, and some forms of radiotherapy, surgery, chemotherapy, and acute care hospitalization), at least insofar as these treatment modalities are being used in an attempt to cure or prolong life rather than to palliate symptoms
3. A general preference for care at home (except where inpatient hospice is available and specifically sought)
4. A willingness to sign a form acknowledging that they want to enter a hospice program and focus on comfort care
5. Health insurance that covers hospice

Many hospice programs also require that the patient have a primary care-giver in the home or readily available. Another set of eligibility requirements, which I hear occasionally from patients or family members but which are not embodied in Federal hospice regulations or the Patient Self-Determination Act, is that the patient and family agree not to call emergency services or to be rehospitalized.

Hospice programs in the United States have been increasingly boxed in by these requirements. They have become extremely cautious with admission or recertification in the face of the threat posed by an unsympathetic and perhaps ill-conceived government audit that scrutinizes long-stay patients and those with non-cancer diagnoses. At the same time, health maintenance organizations and insurers have attempted to “unbundle” hospice services, providing and paying for only part of the hospice package (e.g., home nursing without social ser-

vice, chaplaincy, volunteers, or bereavement care). Moreover, as recently documented for home care patients with amyotrophic lateral sclerosis, although hospice staff may be perceived as more knowledgeable and empathetic than conventional home care workers, hospice may provide far fewer hours of formal care.<sup>23</sup> Thus, patients and families are often forced to choose between hospice care with insufficient home health aide support and a conventional home care approach that includes significantly more home health aide hours.

Eligibility requirements that may make sense from a fiscal vantage in designing a hospice benefit or in running a program under the current reimbursement scheme make little sense to a clinician concerned with overall care of the dying and their families. For instance, many patients who are receiving purely comfort care and seem appropriate for hospicelike services can be expected to live for years. Many aggressive or high-technology or simply expensive interventions are appropriate for patients in the very late phases of a terminal illness and should not be foregone just to qualify for comprehensive hospice home care services. The use of antiretroviral regimens or of treatments to prevent blindness from cytomegalovirus in far-advanced AIDS would be common examples. Similarly, patients who may be ineligible for some hospice programs because they do not have a primary care-giver still may want to receive care at home and can benefit greatly from the support offered by hospice. Patients who need the greater home health aide hours offered by conventional home care programs and thus choose to forego hospice enrollment still may wish a palliative care approach. Patients who are averse to the word “hospice” or who are reluctant to sign forms that redefine their insurance benefits or who have difficulty acknowledging that they are imminently facing death may benefit from and should be able to receive palliative services.

Hospices rightly object to terms such as “hospicelike” care because so many conventional home care programs have claimed to provide services that are equal to that of hospice but, in fact, do not offer many of the standard benefits of hospice, including interdisciplinary care, specially trained and supported clinicians, vol-

unteer and bereavement services, and free medications and durable medical equipment. At the same time, some hospice programs are establishing "bridge" or pre-hospice programs that may facilitate early admission and avoid some of the difficulties posed by hospice admission or recertification requirements. Bridge programs represent an effort within hospice and home care organizations to extend hospice services to patients and family that currently are not receiving such services, as well as to facilitate earlier and more appropriate transfers to hospice. The bridge programs may be presented as hospicelike, but they have not been systematically studied in such a way as to assess their impact or allow a meaningful comparison with hospice care. Similar questions arise with palliative care services, which lack meaningful standards of care or appropriate accreditation of providers. Bridge programs and palliative care programs both exemplify, in part, an attempt to extend the hospice philosophy of care to more patients and families while sidestepping the regulatory constraints of certified hospice programs, as well as the current constriction of hospice services.

Hospice clinicians have asserted that palliative care is an attempt to avoid the negative connotation of the word, "hospice,"<sup>24</sup> but I think they misperceive, underestimate, or simply overlook problems with hospice programs, which provide some of the motive behind using an alternative term. I personally do not believe that "hospice" is a bad word in my community. I continue to foster my identification with hospice, and I feel free to use the term in describing my work, past and present. At the same time, having switched recently from being a hospice medical director to a palliative care service director who regularly refers to hospice, I have been struck with how hospice programs can confuse referral sources and tarnish their reputation through a lack of relatively uniform standards of care and by seeming to show greater concern, at times, for their program goals and financial constraints than for the needs of patients, families, and referring clinicians. Clinicians, who may not distinguish one hospice program from another, may be told that one program does not provide continuous care or respite or does not accept patients who

lack a primary caregiver or are receiving palliative radiation, and then generalize this rule to all hospices. From both within and outside of hospice, I have frequently witnessed that many hospice nurses communicate poorly with physicians and hospital-based colleagues and do not appreciate potentially appropriate "aggressive" management approaches. Hospice staff often lack a sense of collegiality with non-hospice health-care providers, apparently believing that only hospice truly "cares." "Letting go" of various treatments or hopes for cure or prolongation of life becomes a weird virtue, a holy state, the only right way to die. Physicians, particularly, become a butt of criticism and are treated in a manner that seems at least subtly demeaning, sometimes overtly hostile. In my community, a frequent emphasis on exclusionary criteria ("We can't provide around-the-clock care. . . . Have they given up chemotherapy yet? . . . Where will he go if he gets sicker?") has conveyed a withholding, negative attitude among hospice staff about sharing in the care of dying patients and families.

Finally, much to the dismay of palliative care providers, hospice in the United States has become a program for imminently dying persons, caring for many patients only in the last few days or weeks of life.<sup>25</sup> Only a small proportion (roughly 20%) of dying persons are cared for by hospice programs in this country. Palliative care seeks involvement with patients and families as soon as the diagnosis of a life-threatening illness is confirmed, occasionally even earlier. Palliative care is not just for the imminently dying, nor should be hospice.<sup>26</sup>

In the United States, the greatest threat to hospice from palliative care would seem to be the possibility that the hospice philosophy will be distorted and supplanted by the newer programs. Insofar as palliative care appears to be more academic, scientific, doctor driven, inpatient based, inclusive of specialists, and consultative, rather than community based, patient centered, nurse driven, generalist and primary care dominated, psychosocially and spiritually oriented, and committed to comprehensive, interdisciplinary services, these fears seem well founded. A pain or symptom control team that does not provide comprehensive, interdisciplinary care to patients and families may provide

a needed service but it should not be confused with palliative care. Until clear standards are established for palliative care programs, including valid, professionally recognized credentialing of clinicians, and accountability for standards of quality of care, apprehension is inevitable about diluting or distorting the hospice philosophy and reversing the gains from the establishment of certified hospice programs in this country over the past 15 years.

Many opportunities remain for cooperation among palliative care programs and hospice. Briefly, hospice is the home care program of choice for eligible patients and families. Palliative care programs provide a conduit for wider education about and earlier referrals to hospice. Insofar as many palliative care services are based in hospitals, they are generally better able than hospice programs to participate in the key treatment decisions, including the transition to comfort care, which often occur in the inpatient setting. Palliative care programs tend to be based in academic institutions and can provide broader training of physicians and other health-care professionals and students about good end-of-life care, which includes hospice care. Few academic palliative care programs will want to start their own home hospice programs, and most will want to work closely with hospices in a variety of communities to assure continuity of excellent care when patients go home. Hospices are needed as training sites for students in the health professions.<sup>27</sup> Additionally, although a great strength of hospice in the United States has been its emphasis on quality home care and the management of chronic, progressive, fatal disease, palliative medicine can contribute to care in a variety of other settings—the acute care hospital, including the intensive care unit and the emergency ward, as well as offices and extended care facilities—and has a role in deaths from acute conditions.

#### A NEW SPECIALTY OR GENERALISTS WITH AN AREA OF SPECIAL COMPETENCE?

Where do palliative care physicians fit in the panoply of generalists and specialists in this

country? The answer to this question is part of defining ourselves and may have important implications for reimbursement in the age of managed care. Although I will not offer a conclusion on the difficult question of whether palliative medicine should become a specialty or an area of exceptional competence within existing fields, part of the justification for a new field is to address unmet patient and family needs, offer expertise with difficult cases and unfamiliar treatment methods, train medical students and graduate physicians, and carry out research, all of which pertain to palliative medicine.

An early and ongoing distinction among kinds of doctors is based on the type of technology they principally use in their treatment—between physicians who primarily use medication and those that perform surgery. Palliative care teams do have a treatment method that differs from most (but definitely not all) other fields of care: comprehensive care and case management by a specially trained and supported interdisciplinary team. Notably, none of the definitions of palliative care cited earlier in this essay include interdisciplinary care as a basic feature.

If we are specialists, we cannot delineate our work as follows:

1. Organ or organ-system based (nephrologists principally take care of the kidney, neurologists the nervous system),
2. Disease based (oncologists principally take care of cancer)
3. Age based (pediatricians provide general medical care to children).

Palliative care is end-of-life care, directed to dying persons and their families. It cannot be a subset of oncology or any other specialty because we deal with a broad range of terminal illnesses. Similarly, although palliative medicine may be developing primarily as hospital consultation services,<sup>28</sup> and might be viewed as an inpatient specialty, analogous to “intensivists” or “hospitalists,” the bulk of patients requiring palliative care are outpatients. A focus only on institutional care would undermine our comprehensive focus and contribute to further fragmentation of end-of-life care.

Therefore, it might make sense to call ourselves generalists, providing comprehensive, accessible, first-line care, but only to a subset of patients and their families—those facing a terminal illness. This approach is similar to how geriatricians may define themselves as generalists for the elderly. However, both specialists and generalists populate the field of palliative care, and various medical subgroups may have different attitudes about and training for specialized consultation versus comprehensive, interdisciplinary primary care.

Regardless of our orientation as specialists or generalists, I believe that we need to interface effectively with patients, families, and health-care providers who have a variety of needs, wishes, and resources. We need to work closely and comfortably with our clinical colleagues who provide the bulk of preterminal care. For instance, when a skilled, dedicated primary care provider is managing a case, we might act solely as consultants, providing advice directly to the referring physician. Only part of the palliative care team (e.g., the social worker or chaplain or volunteer) might become directly involved with the patient or family, complementing the work of the primary care doctor. On the other hand, if the patient is being observed, for instance, by a neurosurgeon who views his or her job as largely completed after recovery from surgery, patients, families, and health-care providers may prefer that the palliative care team assume a primary care role, taking responsibility for not only the management of the terminal illness but also for coordinating the input of the specialists, assuring good communication and overseeing general medical management. For a patient undergoing chemotherapy or radiation for cancer, we may want to co-manage care with the oncologist or radiation therapist, sharing some responsibility for symptom management, but perhaps taking a dominant role in supervising home care services or providing psychosocial and spiritual support.

Thus, in my view, palliative care in the United States must be flexible and collaborative yet retain responsibility for assuring coordination of comprehensive care and, at times, providing a full range of appropriate services. I believe that palliative care programs must

have the capability of offering a range of consultative and primary care services. A simple consultative approach that focuses on symptoms, particularly physical symptoms, without addressing broader psychosocial and spiritual aspects of patient and family suffering—exemplified by some pain services or pain and symptom control teams—is neither state-of-the-art symptom control nor true palliative care.

### ELEMENTS OF A DEFINITION

Palliative care is characterized as follows

1. Limiting itself to a particular clinical condition: terminal illness or care at the end of life. Unlike hospice, as currently regulated in this country, we do not need to specify a prognosis. In describing ourselves as caring for the dying, we want to avoid euphemisms, but also not be so blunt as to frighten patients and their families (e.g., speaking about “incurable” or “terminal” disease), nor be so kindly as to become hopelessly vague (e.g., describing patients as “advanced”). With our health-care colleagues, “terminal illness” is a relatively clear notion and allows us the flexibility to participate in the earlier phases of “active, progressive” fatal conditions that eventually become “far-advanced.” For patients and families, “life-threatening illness” may be the most appropriate descriptive term, though it includes conditions, such as acute trauma, that are not typically within our domain.
2. Employing a distinct method of evaluation and management, a special expertise: (a) comprehensive and (b) interdisciplinary (or collaborative) care.
3. Directing care to the patient and the family and, by implication, extending care into the period of bereavement.
4. Focusing on a specific management goal: promoting quality of life (or living as well as possible). This goal includes alleviating suffering, providing support, and making the best of remaining time, but need not exclude other goals, including cure or remission. Alternative terms that may be more acceptable to patients and families are “com-

fort care" or "supportive care," although I find that the former tends to imply passivity and withholding, as suggested by "comfort measures only," whereas the latter also can mean treatments clearly aimed at prolonging or sustaining life.

Hence, palliative care is comprehensive, interdisciplinary care, focusing primarily on promoting quality of life for patients living with a terminal illness and for their families. Key elements for helping the patient and family live as well as possible in the face of life-threatening illness include assuring physical comfort, psychosocial and spiritual support, and provision of coordinated services across various sites of care.

This explication, which still is a mouthful, does not mention anything about supporting the service providers, an essential feature of any palliative care program, yet one that does not seem to deserve inclusion in a brief definition statement. The definition also does not specifically address the components of an interdisciplinary team and, like other definitions above, does not specifically mention volunteers or bereavement services.

### WHAT DO YOU SAY?

For statements that are intended primarily for clinicians and other health professionals, I speak of "comprehensive care, provided by an interdisciplinary team, for patients and families living with a life-threatening or terminal illness, particularly where care is focused on alleviating suffering and promoting quality of life." I might then go on to clarify: "Major concerns are pain and symptom management, information sharing and advance care planning, psychosocial and spiritual support, and coordination of care, including arranging for excellent services in the community."

In talking with patients, I might say, "Palliative care is a special service, a team approach to providing comfort and support for persons living with a life-threatening illness and for their families. We are a nurse, social worker, chaplain, and physicians who work with your current health-care team to assure

that you and your family receive excellent pain control and other comfort measures, get the information you want to participate in decisions about your care, receive emotional and spiritual support and practical assistance, obtain expert help in planning for care outside the hospital, continue getting good services in the community, and overall enjoy life as best you can, given your condition. We try to coordinate and tailor a package of services that best suits your values, beliefs, wishes, and needs in whatever setting you are receiving care."

### CONCLUSION

Throughout the world now, palliative care is developing as an area of special clinical competence. As a fledgling field, it now can boast of multiple clinical centers and training programs, a variety of fine textbooks, journals, and educational conferences, and a small research enterprise. Palliative care has attracted clinicians from disparate backgrounds and interests, and hence the field currently embraces a diversity of views about its scope, goals, and methods. This diversity is a virtue. Where different viewpoints and expertise are shared, cross-fertilization occurs, and untested assumptions are challenged. However, diversity implies disagreement or conflict within the field, and hence confusion for those trying to understand us. Critics will easily find opportunities for derision. Diversity also can mean lack of meaningful standards. Our challenge is to avoid orthodoxy yet move ahead with greater unanimity about the nature of the field.

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