CHAPTER 4

Beyond Symptom Management: Physician Roles and Responsibility in Palliative Care

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Role of the Physician in Caring Beyond Cure

Chronic illnesses are now the most common causes of death in the United States (1). For many patients, medical care can slow the course of the illness and improve quality of life, but as illness advances, continued life-prolonging interventions can impose increasing burdens and offer diminishing returns. Often, there is no clear point of transition. The lack of reliable physiological markers for determining when a patient is “dying” remains an obstacle to research and policy development to improve end-of-life care (2-6).

Despite the inherent uncertainty of identifying when precisely patients are approaching life’s end, physicians must provide care that meets recognized clinical standards and responds to the needs of patients (7). Caring for people approaching death will always draw on the art and humanity of the practitioner. The responsibility of ensuring excellent medical care for the dying patient lies with the attending physician.

Recent studies have documented serious deficiencies in access to and quality of care in the months, weeks, and days before death (1,8-10). Correcting deficiencies and raising practice standards and expectations within the professional culture and developing improved models for end-of-life care delivery are important challenges.

Principles and Practice of Palliative Care

In practice, the transition from life-prolonging to palliative treatment is often gradual and may only be recognized in retrospect. The anonymous 16th-century aphorism, “To Cure Sometimes, To Relieve Often, To Comfort Always” (11), describes an integrated continuum of care that sets a standard for physicians and the health care system to meet. In providing treatment to enhance comfort and support to improve the quality of patients’ lives, physicians who care for patients with progressive illness routinely incorporate a palliative approach to care within their range of practice.

In current usage, “palliative care” also refers to an area of distinct practice delivered by clinicians with particular expertise and by specialized teams, such as hospice programs or hospital-based palliative care services (11). In the United Kingdom, palliative medicine has formal status as a medical specialty. In the United States, the Institute of Medicine recommended, “Palliative care should become, if not a medical specialty, at least a defined area of expertise, education, and research” (1). Whether the term is used to connote a general approach or to refer to an area of specialized practice, palliative care does not represent a departure from the tenets of general medicine. It is, instead, distinguished by its strong emphasis on specific principles, such as alleviation of suffering, symptom management, good communication, and supportive counseling related to illness, disability, and limited prognosis.

Specialized programs of palliative care rely on an interdisciplinary team model composed of professionals and trained volunteers (12). Each member of the team contributes particular skills and areas of emphasis (13). Within this interdisciplinary team dynamic, the physician’s area of concentration includes symptom management, as well as continued, appropriate application of disease-modifying therapy. The patient with his or her family is the focus of care, with “family” being operationally defined as the people who are most important to the patient, and to whom the patient is most important. Dying is regarded as an inherently difficult, but normal, stage in the life of individuals and families. In contrast to problem-based medicine, a patient need not have acute or active “problems” to warrant evaluation and intervention. A diagnosis of progressive, incurable illness or any constellation of medical problems that result in progressive disability or an eventually terminal prognosis are indications for palliative care. By identifying quality of life as a central focus, attention is shifted to patients' subjective experience. During the initial period of bereavement, typically through the first anniversary of the person's death, palliative care offers support for the family and screens for instances of complicated grief requiring referral for formal counseling (Table 4-1) (14-16).

Specialized palliative care services and programs expand the resource base and complete a full spectrum of essential health care services (17). In the United States, hospice is the best-known delivery model for palliative care. The most experienced and skillful hospice programs provide a "best practice" standard against which to assess the quality of palliative and end-of-life care (18).

Relief of physical distress is the first priority for palliative care. Symptom management requires an organized, ongoing approach that is careful, comprehensive, and, when necessary, intensive. Pain is a cardinal symptom associated with late-stages of cancer, advanced HIV infection, and progressive, crippling diseases. However, dyspnea, nausea, profound weakness, and delirium are all common sources of physical distress among dying patients (19-21). Specialists in medical and radiation oncology, anesthesiology, neurology, surgery, and neurosurgery commonly contribute to the team process of palliative care. The "intensive" nature of symptom-alleviating (interventions such as neurolytic blocks for unrelenting neuropathic pain or sedation for management of otherwise uncontrolled terminal agitation) is properly limited only by patient-imposed restrictions.

Suffering for the dying patient often extends beyond physical distress, involving emotional, social, and spiritual dimensions. As function wanes and the activities, roles, and responsibilities that have given meaning to life fall away, a sense of impending disintegration and loss

Table 4-1. Precepts of Palliative Care.

- Ethical decision-making that respects patient autonomy and the role of family or legal surrogates
- Interdisciplinary team approach to care
- Patient with his or her family as the unit of care
- Effective and (when necessary) intensive symptom management
- Dying understood as a time of life; improving quality of life as a primary goal
- Recognition of the importance of the "inner life" of the patient
- Bereavement support to family during initial period of grieving

of meaning may be experienced (22,23). Clinicians caring for patients who are struggling with issues of life closure best serve the dying person and family by staying involved, listening, and expressing a willingness to support the person in exploring his or her own answers (24). Sources of emotional and spiritual distress can be acknowledged, assessed, and effectively responded to without requiring the assignment of psychological diagnoses. Beyond alleviation of physical symptoms and psychoemotional distress, physicians can help patients to live as fully as possible and complete tasks they identify as most important during this poignant time.

CASE 4-1. A 67-YEAR-OLD ATTORNEY WITH NON-SMALL CELL LUNG CARCINOMA, METASTATIC TO THE BRAIN

Mr. Baker is a 67-year-old attorney. Ten months ago he noticed a subtle change in right-sided fine motor control while writing. When his secretary questioned his signature on a letter, he made an appointment with Dr. Jones, his internist. During that week he also became aware of intermittent difficulty with word searching. Dr. Jones noted slight right-sided weakness. A magnetic resonance imaging scan revealed a 2.5-cm left parietal-temporal lesion and a smaller left posterior lobe lesion. Chest x-ray showed a solitary left upper lobe nodule. A transbronchial needle biopsy confirmed the diagnosis of non-small cell lung carcinoma, metastatic to the brain.

Whole-brain radiation was promptly begun and tolerated without problems. Mr. Baker's neurologic symptoms rapidly resolved. A consulting medical oncologist presented the risks and potential benefits of combination chemotherapy for his condition (25,26). Mr. Baker decided against chemotherapy.

Mr. Baker has continued to see Dr. Jones for monthly checkups. He has not had further focal neurologic symptoms or acute problems; however, gradual weight loss, diminished energy, and exercise tolerance have slowly worsened.

Four days ago, Mr. Baker developed significantly increased low back pain and 2 days ago noted bilateral weakness in his legs. Contacted by phone, Dr. Jones sent Mr. Baker to the emergency room of the University hospital, where he was evaluated by Dr. Young and a first-year resident.

After discussion with Dr. Jones, morphine was given for immediate comfort and Mr. Baker was admitted. Dr. Young elicited a report of recent onset of urinary incontinence and "numbness" in his feet, and examination uncovered 3-over-5 lower extremity weakness, abnormal plantar responses, and diminished rectal sphincter tone. An emergency magnetic resonance imaging scan revealed impending lumbar spinal cord compression caused by a metastatic lesion and an additional midthoracic vertebral metastasis. A bone scan detailed another probable lesion in his right proximal femur. High-dose intravenous dexamethasone was administered. Urgent neurosurgery and radiation oncology consultations were obtained and, after discussions with Dr. Jones and Mr. Baker, local radiotherapy to the vertebral metastases and the femoral lesion was begun on an emergency basis (27). Mr. Baker's pain rapidly improves and neurologic symptoms stabilize, but lower extremity weakness persists.

Mr. Baker wants all available information and to make his own decisions. Each day Dr. Jones and Dr. Young review the latest test results with him. Dr. Jones answers all his patient's questions in nontechnical terms. He suggests that it is now time to consider involving the hospice team in his care. Mr. Baker initially bristles, "Are you giving up on me, Doctor?", then bluntly asks how much longer he has to live. Dr. Jones assures Mr. Baker that he is not going to stop caring for him and responds that, though it is always difficult to estimate with certainty, his life expectancy is probably weeks to at most a few months. During the conversation, Mr. Baker reluctantly agrees to a hospice referral.

During the intake interview with the hospice nurse case manager and social worker, Mr. Baker's living situation and social history are reviewed. His law practice has always consumed most of his time. He has been divorced twice and lives alone. He and his first wife, Margaret, maintain contact. Their three children live out of state. A son and elder daughter are each married with young children, and a younger daughter attends graduate school. Mr. Baker's strongest wish is to stay at home until he dies.

Mr. Baker is transferred to a rehabilitation unit while receiving daily radiation therapy. Oral long-acting morphine *controls his back pain. Baclofen is started for leg spasms and lorazepam is available for intermittent anxiety. Occasional nausea is treated with perchlorperazine (28). Dexamethasone is tapered and prednisone 20 mg per day is begun as an adjunct for analgesia and to improve appetite and general well-being (29). Physical and occupational therapy are begun, including transfer skills and the use of assistive devices, so that Mr. Baker can continue to dress and toilet himself.*

Mr. Baker complains little. His most serious symptomatic distress occurs when, because of an oversight, no bowel regimen is prescribed and constipation is overlooked for 5 days, resulting in painful abdominal cramps. Multiple enemas and digital disimpaction resolve the problem. Mr. Baker tells Dr. Jones that the experience is an assault on his dignity. Thereafter stool softeners with stimulant laxatives are prescribed for routine use and doses of oral sorbitol adjusted on a daily basis (11).

Mr. Baker's children arrive from out of town. Before discharge, a family meeting is held. Margaret agrees to participate in his care. Hospice volunteers are assigned to help with household chores, errands, and transportation.

Dr. Jones asks the hospice nurse to administer a quality-of-life survey designed to assess the subjective experience of patients with far-advanced illness (30). Mr. Baker's responses suggest feelings of guilt and low self-worth. These issues are explored by the hospice social worker and in sessions with the hospice chaplain in which, to his family's surprise, Mr. Baker shows great interest.

During a second family meeting, Mr. Baker and his children talk openly about their disappointments and fears. Mr. Baker asserts that, despite his law career, in his heart his children have always been most important to him.

In the weeks that follow, the family spends considerable time visiting. Generalized weakness progresses and Mr. Baker becomes bed-bound. At the chaplain's suggestion, Mr. Baker, with help, tapes several hours of stories from his childhood as a gift to his grandchildren.

On one visit in which Dr. Young is present, Dr. Jones asks Mr. Baker if he feels there would be anything left undone if he *were to die suddenly. After a moment of thought, he smiles wryly and responds, "Oh, I'd like to live 20 more years, but the truth is that everything is in place."*

Two months after coming home, Mr. Baker abruptly becomes confused and unable to speak or swallow. Emergency evaluation by the hospice nurse confirms increased right-sided weakness. In phone consultation with Dr. Jones, the symptoms are attributed to a probable intracranial hemorrhage or other cerebral-vascular compromise. Consistent with Mr. Baker's wishes and the plan of care, no diagnostic workup is initiated. Oral medications are discontinued. A low-dose subcutaneous morphine infusion is administered, to replace oral narcotics, providing for continued analgesia and preventing possible withdrawal symptoms. Additional rescue bolus doses are prescribed pro re nata for signs of discomfort such as grimacing or muscle stiffening on turning. A small dose of subcutaneous midazolam is administered by continuous infusion as an antispasmotic, an anxiolytic, and a prophylaxis for possible seizures (31,32). Dr. Jones is unable to visit but calls Margaret, inquiring about Mr. Baker's status and level of comfort, and reviews the current plan of care and orders with the on-call hospice nurse.

The family gathers at the home. Mr. Baker is mostly somnolent, although he intermittently becomes alert, acknowledging his family. He is often touched, his hand held and his skin cleansed or oiled, while family members talk. They each say goodbye. Mr. Baker dies quietly the next morning with his family present.

Dr. Jones is out of town the day of the memorial service but sends a condolence card. He encourages Dr. Young to attend. During a eulogy given by Mr. Baker's son, Dr. Young is moved to be acknowledged by name.

Dr. Young confides to Dr. Jones that this case has been one of the most profound clinical experiences he has had. Later that spring, Dr. Young arranges to spend a full day attending the hospice interdisciplinary team meeting and making rounds with Dr. Jones. He is surprised by the range of diagnoses among the hospice patients, including several with advanced emphysema and congestive heart failure, two with

> *far-advanced dementia, and a patient with renal failure who had just stopped dialysis. Dr. Young remarks about the appreciation expressed by patients and families for the importance of this time in their lives. He decides to take a month-long elective hospice rotation in his third year.*
>
> *Six months after Mr. Baker's death, the hospice team continues to make intermittent contact with Margaret and his children. Margaret has joined a bereavement support group.*

Discussion

Mr. Baker was fortunate to have a physician who knew him well, was adept at palliative interventions, and who recognized an important role in supporting patients at the end of life. Medical house staff frequently encounter patients who have lacked consistent medical care before an acute hospitalization. Within the context of bedside and specialty rounds, attending physicians typically focus on the disease-modifying treatment and, to an increasing extent, on symptom management. Living situations of patients and families may only be assessed to the extent they impact discharge planning and patient placement. Within teaching hospitals, medical direction for incurably ill patients' care may be delegated to interns and resident physicians. Patients discharged to nursing homes commonly have primary care transferred to physicians covering the receiving institution.

In current practice, the subjective experience of dying patients or their families may only become a priority for treating physicians when suffering gives rise to disruptive or otherwise demanding behavior. Over-reliance on a problem-based approach can lead to an unfortunate constriction in the scope of physician practice. To confine medicine's focus to physiological interventions is to limit the art, and heart, of medicine. A physician who avoids imposing a "hospice philosophy" on patients in order to maintain a value-neutral therapeutic stance is mistaken. Although palliative care is value-laden, it is no more so than prevailing modes of disease-modifying treatment. Limiting patient choices constrains their ability, and their right, to make autonomous decisions.

As Case 4-1 illustrates, life-prolonging and palliative care need not be an "either/or" choice. At the time of diagnosis, no curative treatment was available for Mr. Baker. Care continued and, when symptoms developed, prompt diagnostic workups were conducted, consultants were involved, and appropriate disease-modifying and symptomatic interventions promptly begun. Life-prolonging and comfort measures were provided concomitantly, reflecting the concordant nature of these goals. Mr. Baker's authority to make final treatment decisions was respected.

Dr. Jones' plan of care extended beyond ensuring that his patient was fully informed and providing meticulous symptom management. He directed an organized assessment of the impact of physical discomfort, functional limitations, and awareness of death's approach on Mr. Baker's emotional well-being and his subjective quality of life. He provided anticipatory guidance and mobilized resources to support his patient in adapting to this difficult life transition. And he extended this support to Mr. Baker's family in their caregiving and adjustment to their impending loss.

Dr. Jones helped Mr. Baker identify "things left undone" and identify meaningful and realistic goals. He listened. He related stories of previous patients and families who had used similar times to express mutual forgiveness, reinforce their appreciation and affection for one another, and undertake similar opportunities for closure.

When Mr. Baker was admitted to hospice care, the hospice nurse assumed the role of case manager. Dr. Jones retained leadership of his patient's health care team and final authority for his care.

Dr. Jones was conscious of the learning opportunity that Mr. Baker's care afforded Dr. Young. In his role as clinical instructor, he provided Dr. Young with information and the reasoning behind appropriate symptom-alleviating medications and interventions. He modeled skills in communication, including listening. In treatment and in counseling, Dr. Jones conveyed to Dr. Young the importance of caring for patients as they die. These are important aspects of the role of clinical instructors and warrant consideration in processes of advancement for academic physicians.

Barriers to Palliative Care

Not all patients are as receptive to this type of care and support as Mr. Baker and his family, and not all cases are as well managed. Barriers to providing good palliative care exist (Table 4-2). Perhaps the most obvious barrier encountered by busy physicians is too little time to do all that they would like to do for patients and families. Excellent palliative care requires more than knowledge of symptom alleviation and basic counseling skills; it requires time to impart information and time to listen. Meaningful communication regarding matters of dying and options for care requires time to explore whatever questions patients and family members may have.

Our societal tendency to avoid the subjects of dying and death is another barrier to communicating with and counseling people who are suffering emotional, psychosocial, or spiritual distress related to advanced illness. The life-saving orientation of mainstream medicine also tends to reinforce a denial of death (1). Physicians may be reluctant to refer to palliative care and hospice programs, fearing that patients will interpret the suggestion as abandonment, as Mr. Baker initially did, and patients and families may be reluctant to accept a referral, viewing it as a loss of hope.

Current regulatory and payment structures, epitomized by eligibility criteria under the Medicare hospice benefit, reflect and reinforce a false dichotomy between life-prolonging and palliative care. System-based limitations of this nature impose an unnecessary, "either/or" choice on patients and families and challenge clinicians to combine measures to extend life and interventions to improve the quality of life in a manner that is seamless and at all points consistent with the cultural values and personal goals of the people they serve.

Table 4-2. Barriers to Palliative Care.

- Time limitations
- Barriers within the culture of medicine
  - Life-prolonging and curative orientation of medicine
  - Death as a "bad outcome"
- Clinical barriers
  - Prognostic uncertainty
  - Insufficient knowledge and skills
  - Inadequate prescribing for pain control
- Inadequate physician-patient communication
- Ethnic, cultural, and religious challenges
- Legal, regulatory, procedural, and financial barriers
- Education and training deficiencies

Rather than conflicting, the cultural differences between life-prolonging and palliative care can effectively complement one another. For many patients and families, relentless disease progression and increasing disability gradually erode denial of the approach of life's end. As with Mr. Baker's appreciation of the hospice chaplain's visits, interest in and openness to addressing issues of meaning or spiritual connection often surprises those who knew the patient well before illness. When life-prolongation is exclusively pursued, a discrepancy can arise between clinician goals and plans of care and patient-centered priorities. Physicians who, for instance, assume that mundane details of bathing and transportation or psychosocial tasks are not their concerns, may neglect the needs that patients may feel are most important. Physicians may miss opportunities to suggest involvement of consultants and valuable resources such as home health aides, social workers, and clergy and leave patients and families feeling unsupported in the very issues that most affect their quality of life.

Problems related to health care systems, logistics, and even financing often can be alleviated by individualized, case-by-base advocacy and coordination. These services are, themselves, time-intensive. Although physicians can assist in these efforts, care management is often overseen by a primary nurse or social worker. Clerical staff also may help patients gain access to needed services and coordinate visits, transportation, and home-based care.

Working in their own health systems and communities, physicians can view these barriers as opportunities for institutional and programmatic quality-improvement efforts. Collectively, the medical profession can provide leadership by reducing barriers to excellent, inclusive care for dying patients and their families through professional education, research, clinical quality improvement, policy development, and participation in public education and advocacy.

Preservation of Opportunity: A Clinical Role and Responsibility

Although symptom management and relief of suffering are the first priorities for palliative care, they are not the ultimate goals. The experience of living with a progressive illness affects every dimension of a person's life: physical, social, emotional, and spiritual. Consistent with ethical tenets of medicine, patient and family priorities properly guide treatment priorities reflected in the plan of care. To avoid interfering with an important, a poignant, and a potentially meaningful time in the lives of dying patients and families, whenever possible, expediency in the scheduling of medical tests and delivery of treatments should be subordinated to the personal goals of those being served. Medication schedules can be adjusted, home-based services initiated, and care coordinated among local providers. In hospital and intensive care unit settings, deliberate attention is warranted to minimize blood draws and x-rays and related intrusions and distractions. Routine measures, such as daily weights, measurement of intake and output, cardiac and oxygen saturation monitoring, and blood pressure readings, which no longer contribute to an individual patient's current clinical priorities and goals, may be discontinued. Meals need not be delivered to patients who are not eating. A sign on the door, alerting visitors to check with the patient's nurse before entering, can help preserve a semblance of intimacy for a hospitalized patient and family.

Unlike sudden death, dying of a progressive illness offers the chance to "get one's affairs in order." Financial and legal affairs can be settled. People have a chance to say things that would have been left unsaid if death had come abruptly. They have the opportunity to heal strained relationships. There is a chance to get one's most important interpersonal affairs in order, saying: "Forgive me, I forgive you, Thank you, I love you, Goodbye" (33,34). Relationships can become complete, even if they are not imminently ending.

Dying from a progressive illness presents opportunities for reminiscence and life-review that can facilitate life completion (35-38). Providers can help patients and families use activities to deepen the sense of meaning about the life lived. Story telling can be more than a pleasant pastime, becoming a means to transmit one's special knowledge and wisdom to others (39). Families of patients with advanced, incurable illness can benefit from the chance to express their love in words and through the care they provide. For the patient who desires spiritual exploration, palliative care providers can acknowledge and encourage the process. Patients are well served by clinicians who are willing and able to remain emotionally involved, visiting as time permits, if only to listen in a non-judgmental manner.

Barriers to Life Closure

Although a number of valuable opportunities exist during the time of living identified as "dying," they are just that—opportunities. Developmental assessments must not, however, become criteria on which a patient or family's worth is judged. Some issues of personal and family history will not lend themselves to forgiveness, and extremely difficult clinical or social situations may afford no chance for introspection or the intimate communication required for reconciliation. Sudden death, critical care settings, severe, uncontrolled symptoms, serious family dysfunction, social circumstances, poverty, or psychosocial problems all represent significant challenges to a satisfying sense of life closure (Table 4-3).

Table 4-3. **Barriers to Satisfactory Life Closure.**

- Severe, uncontrolled symptoms
  - Pain
  - Dyspnea
  - Nausea
  - Confusion
- Poverty
  - Housing
  - Transportation
  - Medical care
- Family and social support
  - Family dysfunction
  - Child abuse
  - Physical and sexual violence
  - Active drug and alcohol abuse
  - Mental illness
- Critical care environments
  - Constant activity and noise
  - Traditional emphasis on technology
  - Prolongation of life; relative inattention to suffering
  - Surrounded by others in active fight for life
- Sudden death
  - Lack of preparation; anticipation
  - Often lack of ongoing medical relationships
  - More complicated bereavement

Clinicians are challenged to avoid the nihilism that can undermine valuable opportunities for dying patients and families while averting guilt or recriminations within families when, for whatever reasons, such opportunities remain unfulfilled. Difficult situations and the myriad sources of suffering that people encounter highlight the importance of the collective efforts, and potential synergistic efficacy, of clinical teams (12). The more complex and troublesome a case becomes, the more pressing becomes the need for involving the resources of the palliative care team.

Summary

When cure is no longer possible and life prolongation is a fleeting goal, the ongoing process of care presents an important and potentially satisfying role for physicians. Working with a team of prepared, committed providers, physicians can practice and model care that integrates life-prolongation with comfort and patient-defined goals. In this manner, patients can be helped to live fully and die well.

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