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# Palliative Care Is More Care, Not Less

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## Case Study

### Palliative Care Is More Care, Not Less

by Rachel Selby-Penczak, MD

#### Educational Objectives

1. Discuss the origins of hospice and palliative care.
2. Compare and contrast Curative, Palliative, and Hospice Models of Care.
3. Identify when palliative care is appropriate.

#### Background

Both palliative care and hospice share a similar background and purpose, making it difficult to discuss one without the other.

The word “hospice” derives from the same Latin root as “hospitality” and can be traced back to medieval times, referring to a place of shelter and rest for weary or ill travelers on a long journey. It was first applied to specialized care for dying patients by Dame Cicely Saunders, a physician who began her work with the terminally ill in 1948 and went on to create the first modern

hospice, St Christopher’s Hospice, almost two decades later in a residential suburb of London.

Dr. Saunders introduced this concept of care to the United States in 1963, during a visit to Yale University. Her lecture to medical students, nurses, social workers, and chaplains about the concept of holistic hospice care included photos of terminally ill cancer patients and their families, showing the dramatic differences before and after symptom management. Although her lecture served as the launching pad of a long chain of events that eventually resulted in the development of hospice care as we know it today, the U.S. Congress did not make the Medicare Hospice Benefit permanent until 1986.

The word “palliative” derives from Latin *palliare*, meaning to “cloak, conceal or alleviate symptoms without curing,” and can be found in documents traced back to the late 14th century in Elizabethan and Indo-European traditions.

Modern day use of the term palliative care first occurred in 1974, by Canadian surgical oncologist and

Saunders student, Dr. Balfour Mount, as a means to help French speaking Canadians accept the concept of holistic care for people with chronic or life limiting diseases, while dispelling the poor reputation and negative connotation of destitution that had become affiliated with hospice institutions in France.

Books including *On Death and Dying* by Dr. Elisabeth Kubler-Ross published in 1969, demonstration projects funded by the Robert Wood Johnson and John A Hartford Foundations, grants supported by George Soros’ Open Society Institute, the 1997 report from the Institute of Medicine entitled “Approaching Death: Improving Care at End of Life (M.I. Field and C.K. Cassel, editors), and consumer awareness efforts through Last Acts, and the Bill Moyer’s Series “On Our Own Terms” (2000) have all played important roles in bringing to the public the concept of “total care” for any patient, adult or child, diagnosed with life-limiting illness, as well as those who are dying, and in many cases, influencing policies both in the U.S. and elsewhere around the world.

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As of 2006, Hospice and Palliative Medicine became a recognized subspecialty by both the American Board of Medical Specialties (ABMS) and the Accreditation Council for Graduate Medical Education; since 2008, physicians who qualify have been able to take examinations that certify their expertise in this important area of medicine.

### Curative versus Palliative Care

Healthcare in the U.S. has a strong tendency to focus on cure, which, while important, can also lead to patient and family suffering, cause patient and family goals to be overlooked, and quality of life to be mistakenly considered as less important.

Curative care tends to focus on cure. In the process of focusing on the disease itself, the goal often becomes eradicating or slowing progression of disease, during which the patient may be viewed as a collection of parts or organ systems, with the body often differentiated from the mind. It places high values on measurable data, such as labs and radiology reports, and in general views death as the ultimate failure.

On the other hand, palliative care focuses on the relief of suffering for the patient and his or her family. It looks to treat symptoms, rather than viewing them as clues to diagnosis. Data may be considered part of the picture, but it's the subjective, often difficult to quantify, information provided by the patient and the family that's given the highest value. Palliative care looks to control symptoms and relieve suffer-

ing, whether or not the underlying disease can be eradicated or slowed, and views the patient as a whole, basing treatments on the values, beliefs, and concerns of the patient and the family. Success is viewed as enabling the patient and the family to live as fully and comfortably as possible until death, whenever it may come.

### Palliative Care Defined

The World Health Organization formally defined the term palliative care in 1989, and published a revised definition in 2002:

*“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”*

*“Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; and is*

*applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemo-therapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”*

Medicare has also recognized palliative care as important, noting that it should be part of overall care management based on *need*, not *prognosis*.

Through education, the public has begun to view palliative care for what it really is: a team-based approach to care that will improve quality of life, provide an extra layer of support, and can be given to any person, at any age, and at any stage of the serious illness alongside curative treatments. Palliative care can be provided in any setting, including home, hospitals, clinics, and nursing facilities and applies to any number of chronic and life limiting illnesses, including, but not limited to: cancer, cardiac disease and heart failure, kidney failure, cirrhosis of the liver, lung disease, multiple sclerosis, Alzheimer's and other dementias, Parkinson's disease, HIV, and drug-resistant tuberculosis. When first diagnosed with a chronic illness, the focus may be mostly curative, but as time goes on the amount of curative and palliative interventions may fluctuate and gradually shift towards a progressively more palliative approach.

One of the most well-known randomized controlled studies of the benefits of palliative care is by Temel and colleagues (2010). It demonstrated that those patients

with newly diagnosed metastatic non-small cell lung cancer who received early palliative care alongside standard cancer care had improved quality of life, reduced depression, and longer survival, compared to those patients receiving standard care alone, even though the former received less aggressive interventions.

Although hospice and palliative care share similar goals and focus, they are not the same, and despite studies to the contrary, patients are not the only ones to associate, mistakenly, the term palliative with death or hospice. Studies (Fadul, 2009; Dalal, 2011) have shown that clinical providers and oncologists were more likely to embrace the use of and consult palliative care services if the name were changed from Palliative Care to Supportive Care.

It is important to mention that while Medicare has a distinct payment system for hospice services, currently there is no equivalent payment system to easily facilitate palliative services delivered in a complete and coordinated interdisciplinary package.

### **Hospice Defined**

Hospice is a group of services and the largest provider of palliative care in the country. It is a comprehensive and holistic approach to treatment that recognizes that the impending death of an individual warrants a change in focus from curative to palliative care for relief of pain and symptom management, providing compassionate patient and family-centered care for those who are terminally ill.

The goal is to help terminally ill individuals continue life with minimal disruption to normal activities, while remaining primarily in the home.

Hospice is an interdisciplinary approach to deliver medical, nursing, social, psychological, emotional, and spiritual services with the goal of making the individual as physically and emotionally comfortable as possible; the expectation is that the care plan will shift over time to meet the changing needs of the patient and the family, while viewing both the patient and the family as a single unit of care.

However, unlike the palliative model, in the United States, Medicare has determined that a person is only eligible for hospice if in the terminal phase of the disease, with a life expectancy of six months or less, and if willing to give up curative treatments. That being said, some treatments such as radiation, chemotherapy and dobutamine may still be allowed by some hospice agencies if they are specifically for comfort and symptom management and are consistent with the goals of the patient.

Hospice is considered a skilled service, and most often occurs where the patient lives; however, unlike with Medicare Home Health Services, the patient does not have to be homebound.

The Medicare hospice benefit does not end at the patient's death and includes bereavement services to the family for up to 13 months after the patient dies.

### **Case Study #1**

Joan is a 48-year-old single mother of three daughters ages 17 to 20 years old. She works as a book keeper and volunteers at a local museum. She presented to the ER with abdominal pain, nausea, and constipation. She has a history of ovarian cancer diagnosed two years earlier which was treated with surgery and chemotherapy resulting in successful resolution of the primary tumor. She is started on opioids for pain, anti-emetics for nausea, and admitted to the palliative care unit for further symptom management. An aggressive bowel regimen results in relief of constipation. CT scans of her abdomen and pelvis reveal new tumor recurrence. Oncology is consulted, and while she is no longer considered a surgical candidate, she may be a candidate for further palliative chemotherapy as an outpatient, once her acute symptoms resolve and if her functional status remains stable.

Despite being in pain, each morning she greets the staff with a smile, and before she is willing to answer questions about her own symptoms, she insists on expressing her appreciation of the care she is receiving, and her hope that the members of the medical team are doing well.

Although her nausea improves, her pain remains poorly controlled. She is seen by the palliative social worker, chaplain, and psychologist.

Customary measures for pain control, including escalating doses of opioids, opioid rotation, and epigastric nerve block performed by interventional radiology, have little

impact on her abdominal pain. Throughout the hospitalization, Joan's code status has been Full Code, meaning that should her heart stop beating or should she be unable to breathe on her own, she would receive CPR, be intubated, and placed on a ventilator if medically indicated. A discussion about the risks and benefits of potential atypical pain medications led to talking about code status, and the normally calm Joan became, stating "I don't want to talk about that. Just go get the medication."

With Joan's permission, her daughters are invited to a family meeting during which the palliative care nurse and physicians work together with Joan to address goals of care. Upon listening to Joan discuss her clear understanding of her medical problems, hearing her goals to remain independent and pursue palliative chemotherapy in hopes that it will enable her to attend her daughter's high school graduation, and having the opportunity to see Joan interact with her daughters, it becomes obvious that although Joan has physical reasons for symptoms, her uncontrolled pain may, in large part, be due to existential sources of suffering.

Dr. Rose kneels down at bedside, looks Joan in the eyes and asks if she can share some thoughts that might be upsetting. Joan agrees. Dr. Rose expresses her admiration for Joan's strength and grace, informing her that as a mother of three herself, Dr. Rose doesn't know if she would demonstrate the same virtues in a similar circumstance. She explains her suspicion that Joan may be avoiding discussions about certain topics such as code status in

an effort to protect her daughters and prevent them from mistakenly believing that she has given up. She informs Joan that, given her advanced cancer for which she is not a surgical candidate, she is also not a good candidate for cardiopulmonary resuscitation; it would be unlikely to work, would not change the underlying cancer, would add to burden and suffering at end of life, and would bring her further away from her stated goals. Dr. Rose added that, by not specifically expressing her wishes to her daughters now, there may be increased suffering for her daughters later, if they had to make clinical decisions for their mother if she became unable to make decisions for herself. Joan thanks Dr. Rose for her candor and calmly tells her daughters that should her heart stop or end of life draw near, she would not want to receive CPR or be placed on artificial means of life support but rather would want to be kept comfortable and die with dignity. After responding to the daughters' questions, the palliative team gives the family private time alone.

The next morning, Joan appears brighter and reports much less pain. Over the next few days, her opioid regimen is gradually reduced, she engages in more open discussions with the palliative interdisciplinary team, and is seen by physical and occupational therapy. She is discharged home on much lower doses of opioids, with improved pain control, and plans to follow up in the outpatient Palliative Care Clinic for continued symptom management, and with outpatient oncology for palliative chemotherapy.

## Case Study #2

Michael is a 58-year-old father of three grown children. He has strong family and social networks, and religion is an important part of his life. A mechanic, he was diagnosed with colon cancer in February 2009. He underwent surgical removal of part of his colon and received chemotherapy that was completed in September 2009, after which he was feeling good and able to return to work. Almost a year later, he was found to have regional recurrence of his colon cancer. Extensive surgery resulted in bladder and prostate removal, and a colostomy. Despite another six months of chemotherapy, he was diagnosed with a second local recurrence; the regimen was discontinued, as it interfered with the anticoagulant he was taking for treatment of blood clots. He received pelvic radiation which was completed in May 2012.

In July 2012 he developed abdominal pain and vomiting due to small bowel obstruction for which he was hospitalized twice at a local hospital and managed medically with bowel rest and IV hydration. When his symptoms recurred a third time, he presented to a tertiary medical center for a second opinion and was hospitalized once again. His primary oncologist, Dr. Turner, was contacted by the inpatient medical team and she informed them that, despite aggressive treatment, Michael's cancer had progressed to the point that recurrent partial small bowel obstructions would likely continue. She was concerned about Michael, and stated that at their last visit he and his wife Sheila were having a hard time accepting the information

given to them and were understandably tearful when they left. She recommended focusing on symptom control as the best option. At the time of his discharge in early August, his symptoms had resolved and he was tolerating a normal diet.

In late August, he had an outpatient appointment with Dr. Smith, an oncologist at the tertiary medical center, for a second opinion. Dr. Smith discussed possible treatment options, including the risks, benefits, and possible toxicity from further chemotherapy, pointing out that any treatment at this point would be palliative, with possible extension of life, but without cure. Michael and his wife decided to pursue this route.

Chemotherapy was delayed by insurance issues, and over the next two months he was hospitalized three more times. CT scans of his abdomen and pelvis were compared to those done a month earlier and revealed new metastatic disease to his lungs and soft tissue. Laparoscopic exploratory surgery was offered which Michael initially declined in favor of more conservative management with total peripheral nutrition (TPN) and symptom medications.

Michael was seen by the Palliative Care Chaplain and expressed concerns about his body image, should he proceed with further surgery. The Palliative Care Psychologist also met with him, providing education and teaching him breathing and other relaxation techniques, as a means to help manage stress and anxiety related to his health problems and inability to work for the past two years.

In late October, Michael was taken to the operating room for laparoscopic surgery with extensive removal of adhesions and removal of his distal small bowel. His post op course was complicated by delayed return of bowel function and fever related to intraabdominal abscesses for which he was started on broad spectrum antibiotics.

He was transferred to the palliative care unit for further symptom management. Despite aggressive medical treatment and improved symptom management with help of the Palliative Care Interdisciplinary team, it became clear that he would no longer be a candidate for palliative chemotherapy and that the risk of continuing TPN outweighed the benefits, given the persistent infection and sepsis. With his poor prognosis and life expectancy of two to four weeks, Michael chose to return home to focus on quality of life with his family.

He was enrolled in home hospice in late December 2012. Over the next nine months, the hospice team helped manage Michael's symptoms at home. Despite continued weight loss and periodic low grade fevers, he was able to enjoy time with his family, go fishing with his wife, and avoid further hospitalization. He died peacefully at home in early September 2013.

### **Conclusion**

The concept of both palliative and hospice care has been around for centuries. While scientific and technological advancements have provided the means for cure and prolongation of life to those with chronic and life limiting illness,

such measures may also contribute to increased symptom burden, add to suffering, and detract from quality of life. The biggest mistake patients, families, and clinicians make is believing that one must choose between cure and comfort, waiting too long to ask for a palliative care referral. Regardless of disease stage, it is never wrong to treat symptoms and make sure that all medical interventions pursued are consistent with patient and family goals. Although the cases discussed here highlight two patients with cancer, palliative care can and should be provided for all patients, at any stage of any chronic or life limiting illness or disease, as studies have shown that doing so may result in improved length and quality of life, better patient and family satisfaction, and lower costs at end of life.

### **Study Questions**

1. What are the differences between curative and palliative care?
2. When should one receive hospice instead of palliative care?
3. Which types of symptoms can be addressed by palliative care and who are the typical members of a palliative care team?

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