



Helping Hands

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pain or distress, including transport to the hospital. But if Ophelia died in the home or on route to hospital, the paramedics would not have attempted to resuscitate her.

If Ophelia was transported to the hospital and there was an Advance Directive, the paramedics would pass this information on to the Emergency Department physician for immediate consideration. In this case, after evaluating her condition and treating any symptoms which could make her more comfortable, the physician would have considered returning Ophelia to her home with support at home from her family and a hospice/home care team.

Ophelia's goal of dying peacefully at home might still have been preserved.

Most of the U.S. population is not currently served by an EMS with specific palliative care protocols. Palliative care and end-of-life care training for EMS providers is currently uncommon in most states. However, in NJ, a three-hour training program developed in 1997 (*Editor's Note: by Jeanne Kerwin*) is already being provided to NJ EMS staff. The training covers patients' rights, end-of-life care and sensitivity to the needs of patients near the end of life. Many EMS organizations in NJ include this training as part of their annual educational programs, and the NJ State Department of Health,

Office of EMS, has approved this training for three continuing credit hours for EMS professionals. Evaluation of the training has shown an increase in knowledge about end-of-life care, as well as a significant change in attitude and beliefs about the role EMS professionals can play in such care.

We are currently working with several national organizations and leaders in palliative care to promote EMS training in end-of-life and palliative care nationwide, with the NJ training as a model.

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Welcome

Emergency Departments (ED) and Emergency Medical Services (EMS) (paramedics, ambulance services, mobile intensive care units) are of major importance to the delivery of health care in America. For many in need, financially and otherwise, the ED is the first place to come for help, or the only place care is received.

This is almost always the case for people who feel they are experiencing a health emergency, of which many are psychosocial in nature (stress-related, psychiatric, or from lack of social support). Those who seek help through the ED include many people near the end of life and their families, including people already receiving home-based hospice care. (Families often feel the need for additional support or become fearful and overwhelmed as dying nears.) So the ED/EMS is a vital element in our health care system for so many.

In modern times, emergency care has improved in many ways, and has been a focus for many notable efforts at Overlook and other hospitals, as Dr. Espinosa's article in this issue describes. But as in the rest of the health care system, there still needs to be more attention paid to patient and family suffering.

Palliative care offers EMS professionals a sophisticated body of knowledge in the care of suffering, including pain. In this sense, the emerging relationship between palliative care and emergency care offers a familiar challenge to palliative care professionals: to help transform health care.

Stuart Green, MSW, MA
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Perspective

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Emergency Medical Services includes pre-hospital care by emergency medical technicians and paramedics as well as the recognized specialties of Emergency Nursing and Emergency Medicine. Understandably, Emergency Medical Services has focused on training, techniques and processes designed to save life and limb. But in recent years, EMS has also developed intense interest in the *quality* of life of patients with emergent conditions and in patient satisfaction with EMS care. These changes can be seen clearly in the EMS approach to pain. Where once pain medication was thought to mask illness and delay diagnosis, excellent pain management is now seen as critical to proper diagnosis, healing and well-being.

Leaders in Palliative Care are challenging hospital services to go even further: to appreciate a broader range of patient suffering. Patients can be hungry for air, thirsty for water, looking for connection with family and also needing relief from pain and other distressing symptoms. That's why a typical palliative care service, as at Overlook Hospital, includes social workers, pain physicians and nurses, psychiatrists, clergy and bioethicists. In this issue, the case will be made that Palliative Care services should be integrated with Emergency Medical Services.

EMS already deals with Palliative Care issues. EMS cares for hospice patients who need

additional support in symptom management, and other patients near the end of life. We have developed ways to better understand, identify, and honor patient preferences for care. We have improved procedures for the management of pain and air hunger. But great elements of care do not make a great system of care. Our EMS systems will be increasingly called upon to support the many manifestations of pain beyond those that can be reached with analgesics. To do so, we will have to become experts at identification and care of other kinds of distress, even during emergencies.

As Jeanne Kerwin notes in her article in this issue, the connection between palliative care and EMS may not seem obvious at first. Upon closer examination, however, it's clear that the goals of these two services can be integrated. In fact, in no other setting is there a greater need for palliative care than in a medical emergency.

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Palliative Care in Emergency Medical Systems

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Emergency Medical Services in the United States includes the hospital Emergency Department (ED), as well as ambulance (transport and mobile intensive care units) and paramedical services. The impetus for the development of Emergency Services grew out of a national movement to protect life and limb. In 1966, the National Academy of Sciences published a historic report that described gaps in trauma care in the United States. This led to legislation that funded pre-hospital care vehicles (ambulances), training and services. In time, funding was extended to better means of communication, critical care services, more advanced emergency department services, better documentation, disaster management, links to county, state and federal agencies and the development of Mobile Intensive Care Units (MICU). Overlook Hospital was one of the earliest MICU providers.

Over the last three decades, emergency physicians and emergency nurses became specialists, with associated credentials, societies, and training. Increased public awareness of the skill and effectiveness of emergency services led to greater public trust in and reliance on emergency departments and services for a wider range of problems, on a 24-hour-a-day, 7-

day-a-week basis. And many patients who do not, for various reasons, have their own physicians in the community, rely on emergency departments for the bulk of their medical needs, especially in some urban and underserved communities.

Patients and families have influenced the nature of Emergency Services by providing feedback through patient satisfaction surveys. In response, Emergency Services have become more sensitive to the needs of patients and families in new and important ways. This includes decreasing patient waiting time, reducing delays in providing care, providing more information to and communication with patients and families, and more attention to patient preferences for treatment.

Similarly, emerging research in pain management, for example, along with patients' desires for prompt and effective management of discomfort, has led to new processes for addressing pain in emergency situations. These include protocols (standardized procedures) for quantifying and treating pain, providing pain medications more quickly, and earlier splinting of injuries.

Historically, pain relief was too often seen as a barrier to diagnosing disease, and not as a treatment priority. For example, it was thought that giving pain medication to patients with abdominal pain might prevent proper diagnosis of the underlying problem. But these days, pain medication is often given to patients with abdominal pain, in consultation with the patient's surgeon. The literature shows that rational and prudent administration of pain medication improves the accuracy of diagnosis in many cases. For one thing, patients in whom pain is controlled are better able to communicate and to describe their other symptoms. In many studies, the physical examination findings, and thus the accuracy of diagnosis and safety of the patient, are brought into sharper focus with appropriate pain management.

As the basics of airway management and circulatory support became standardized and routine, ED physicians had more ability to pay attention to other patient problems, such as pain. Pain, rather than pain relief, began to be seen as an impediment to diagnosis, treatment, and healing. In children, for example, undertreatment of pain could actually imprint developing pain pathways in ways that increase sensitivity to pain in later life. We began to understand that adequate pain management in patients who go to surgery was related to better recovery from anesthesia, faster healing times and earlier discharge from the hospital.

The Overlook Hospital Emergency Department began research to better manage acute pain almost eight years

ago. Studies were conducted by a multi-disciplinary team led by Linda Kosnik, RN, presently Overlook's Chief Nursing Officer. As a result, patients with extremity injuries, especially bone fractures, receive comfort measures from the time of their first contact with the ED, including not only pain medication, but also ice, elevation and splinting. Patients with kidney stones are asked to rate their pain at prescribed intervals so that pain medication can be given before pain increases. Similar attention is being given to such diverse conditions as cardiac pain, pain from a foreign body in the eye, and pain from neck and back conditions. More optimal ways of reducing pain in patients with abdominal pain are a current area of study.

As part of Overlook Hospital's "pain as a fifth vital sign" process, all patients are asked about pain and pain is actively addressed. Since patient and family anxiety about illness also increases the experience of pain, an effort is made to provide information about diagnosis and treatment as soon as possible. New radiology equipment planned for the ED will allow physicians to assess and analyze results more quickly.

Through patient satisfaction surveys, patients told us of other sources of discomfort. They did not wish to be isolated from their friends and families. They wanted spiritual support when requested. They wanted more privacy. So family members are encouraged to be with patients, and in the new ED, rooms are larger and made more private and comfortable. Overlook's Pastoral Care chaplains are continuously available to ED

patients. And patient education materials are improved and distributed more actively to patients and families. Nurses and physicians work harder to ensure that patients' families are adequately informed and involved in care, taking patient preferences and confidentiality concerns into account.

As more patients with cancer are identified and treated, more patients have been seen in the ED requesting relief of discomfort from cancer-related causes. In the ED, as in all other healthcare areas, it seemed evident that our ability to extend life sometimes seemed to have moved faster than our ability to understand and reduce suffering. As Diane Meier, MD, of the Center to Advance Palliative Care in Hospitals and Healthcare at Mount Sinai School of Medicine, points out, critically ill patients may suffer profoundly from symptoms common in intensive care settings such as the ED. These symptoms include thirst, fatigue, anxiety, pain, hunger, depression, and shortness of breath. (Nelson, Meier, Oei et al. *Critical Care Medicine* 2001; 29:277-282). Dr. Meier suggests that symptom distress is maladaptive and is associated with poorer outcomes. In addition, she and others point out, death is not as predictable as we might think. If we are not sure who is dying, but we know many critically ill patients are, then palliative care needs to be a part of intensive care for all.

There are predictable challenges in integrating palliative care and EMS care. Effectively addressing patient needs requires clear communication about patient preferences for care. This is not yet

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ideal in healthcare generally and the problem is magnified under the intense time-pressure of EMS care. In addition, EMS care in the United States is now experiencing surges of demand and shortages of key personnel.

A development which will be helpful to the goal of integrating palliative care with ED care is the recent creation, by members of the Overlook Hospital Emergency Department, of a national movement which resulted in the founding of a Section on Geriatric Emergency Services within the American College of

Emergency Physicians. Palliative Care is of natural interest to Geriatric Section members. The increase in visits to emergency departments seen in recent years is the result of overall population growth and increases in the number of seniors who are more subject to severe and chronic illness. Of that group, people 75 years and older had the highest rate of emergency department visits, with 65 visits per 100 persons per year.

[Emergency Department Use Continues to Grow, EM Today Digital, April 25, 2002, ACEP.org]

Palliative care training methods also offer EMS professionals an opportunity for addressing their own needs for support. A major problem for EMS staff is the stress caused by extreme time-pressure and the high level of exposure to injury and death which EMS work commonly involves. An approach which emphasizes the humanity of patients will also inevitably support the humanity of the professionals who provide their care.

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Goals of Care in Emergencies

Palliative Care in the Emergency Department or the Mobile Intensive Care Unit? Paramedics providing palliative care?

The idea seems strange at first glance. After all, the mission of Emergency Medical Services personnel is to respond to medical emergencies and to intervene in sudden illness and/or injury and to preserve life. Heroics depicted on television shows such as ER emphasize CPR, emergency airway intubation,

administration of life-saving medications and other means of resuscitation. Palliative care, on the other hand, is not about aggressive resuscitation and life-saving interventions, but about providing relief of suffering for patients, especially those whose disease cannot be cured. However, upon closer examination of these two areas, we find that their goals can be integrated. In fact, in no other setting is there a greater need for palliative care than in a medical emergency.

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Palliative care is appropriate for all patients: those of all ages, those who suffer from reversible illness or injury, from irreversible chronic diseases, and those near the end of life. Palliation is required for pain, for discomforting symptoms such as nausea and fatigue, and for the relief of anxiety, fear or spiritual loss. Calls for EMS and ED care can occur because of trauma such as accidents or falls, sudden heart attack, medical emergencies such as severe asthma attacks or episodes of

uncontrolled pain, or because a sudden decline in the condition of elderly frail nursing home residents. Each of these conditions may require immediate interventions to preserve life and function. But each of these patients also requires attention to their discomfort and distress, including any increased needs for psychological, social and spiritual support.

So what is different about the 48-year old male suffering from severe chest pain, with no other medical problems, and the 93-year old female nursing home resident with multiple serious conditions who suddenly loses her ability to speak? The answer lies in the goals of care identified for each patient. These goals are identified through diagnosis (the nature of the immediate and underlying problems), assessing prognosis (the likelihood of reversing the problem and restoring function), and determining the wishes and expectations of the patient and his or her family.

A primary goal of care for the 48-year old male would likely be the urgent treatment of his heart attack (if that turned out to be the diagnosis) with angioplasty and/or thrombolytic ("clot-busting") therapies to resolve the blockage to his heart muscle and restore circulation, thereby minimizing the damage to his heart. The expectations of the patient and the medical team would be to preserve

cardiac function and to return him to his normal life activities. Throughout his treatment, however, attention must also be paid to the relief of his pain, reduction of his anxiety and fears, support for him and his family with ongoing information and communication, and psychosocial and spiritual support. These are the core principles of good palliative care.

Upon examination of the goals of care for the 93-year-old female resident of the nursing home, the diagnosis is that she has suffered a stroke and that her medical history reveals previous strokes, congestive heart failure, some kidney failure, dementia, and recurrent pneumonia and urinary tract infections. Her nutritional intake has been poor in the last six months and she suffers from malnutrition. We also find that she expressed her wishes to her family some years ago upon entering the nursing home, and also through an Advance Directive document. She clearly indicated in these various ways that she does not want her life artificially maintained if she is unable to interact with her world and take some care of herself in the nursing home setting. Her family supports her wish not to have aggressive treatment attempts – and its associated discomfort – near the end of life. For this patient, the primary goal of care would be the relief of pain and uncomfortable symptoms, as well as

providing support for her and her family's psychological and spiritual needs.

A large percentage of EMS calls for assistance come from patients with irreversible illnesses at the end of life. They often do not want heroic interventions to artificially prolong life, but relief from suffering, and support in the process of dying. In keeping with concerns about unnecessary suffering at the end-of-life, and the strong voice of Americans saying they want improved care for dying patients, EMS organizations can provide an often-overlooked but critical resource for improving emergency palliative care in our communities.

No patient or family member should ever be told not to call 911 when help is needed because of fear that EMS staff will insist on providing unwanted medical interventions! On the other hand, palliative care will sometimes include emergency pain management or the urgent relief of reversible conditions causing discomfort and suffering – and those are interventions EMS staff can, and should, provide.

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End-of-Life Care Training for EMS: *the NJ Model*

Jeanne Kerwin, MICP, MMH

EMS practitioners are traditionally guided by the principal of implied consent. This principal states that EMS staff may reasonably assume that a person in a life-threatening situation wants action taken which may save their life. Implied consent allows for urgent medical care and life-prolonging treatments to be provided in situations in which the patient's wishes may not be clear or known. While this approach is reasonable, and meets the needs of most patients who have life-threatening medical emergencies, this time-driven approach to all calls for emergency medical assistance affords little consideration for palliative care for those near the end of life.

There are protocols (recommended procedures) which allow Emergency Medical Services staff such as paramedics to be guided by out-of-hospital Do Not Resuscitate (DNR) Orders. These protocols prevent the unwanted provision of CPR (cardiopulmonary resuscitation) in the event of death. However, these protocols deal only with the issue of resuscitation, and therefore do not address the provision of palliative care during emergencies by EMS staff. Another factor

discouraging EMS provision of palliative care is that until recently, no specialized palliative care training has been provided to EMS professionals.

However, there are a significant number of patients seen by paramedics in the community who are near the end of life, or receiving hospice care, or who call EMS because of emergencies related to psychosocial or family distress. EMS staff will typically be first responders, even when patients are otherwise involved with hospice and home care providers. EMS staff, properly trained, can function as mobile and immediate resource centers and interim caregivers for such patients and their families. It is therefore important that in addition to life-saving skills, EMS providers also be able to help patients (and families) who need urgent attention to pain, discomfort and distress. Palliative care training provides such skills.

To illustrate the importance of palliative care provided in the community setting by paramedics and other EMS professionals, let's examine a case in which a patient came into the hospital system through EMS without palliative care.

Ophelia was an elderly 92-year-old lady who had been widowed 15 years ago. She had been a social worker in the New York City Welfare System for 46 years and was a very independent, intelligent and stubborn person. After her husband died, she continued to live on her own in the city. She was active in her church and did volunteer social work in the city. She had 12 siblings and they remained in close contact through the years.

Several years ago, with only three siblings surviving, Ophelia was diagnosed with Alzheimer's Disease. She went to live with a brother, 10 years younger, in his town house in New Jersey. Her brother cared for her in the early years of her dementia. During those years, Ophelia and her brother talked openly about care at the end of life. She told her brother clearly and often emphatically that when she became debilitated and unable to care for herself, she did not want aggressive medical treatment or artificial life supports. She wished to be comfortable and to die at home "in peace." When her disease made it impossible for her brother to care for her by himself, he hired a 24-hour live-in aide to manage her daily care.

Ophelia eventually did not get out of bed. Her eating diminished and she was not communicative. She received total care from her aide but remained at home with her brother. One afternoon when Ophelia's brother was at a doctor's appointment, the aide called 911 because Ophelia spiked a very high temperature and would not speak or eat breakfast. The EMS team responded and found a bed-ridden elderly woman with an elevated temperature, dehydrated and unresponsive. The paramedics started IV fluids and oxygen,

hooked Ophelia up to a cardiac monitor, bundled her up, put her on a stretcher in the ambulance and transported her to the local hospital Emergency Room.

We can imagine that Ophelia opened her eyes in the back of the ambulance and was frightened. She would feel the ambulance sway and jerk through traffic and hear the blaring of the sirens. At the hospital, among the hustle and bustle of emergency room nurses and doctors treating acutely sick and injured patients, she was treated for dehydration and pneumonia. The staff tried to reassure and comfort her but she did not appear to understand. She was admitted to the hospital for further treatment and evaluation. She received IV fluids and antibiotics, and blood was drawn. A patient in her condition would not understand what was happening.

Ophelia's brother, recovering from a total hip replacement, had to wait several hours for a neighbor to drive him up to the hospital to see his sister. When he arrived late in the day, she was in bed on a medical floor and appeared to be resting comfortably. He stayed for a few hours, stroking her hand and talking soothingly to her until she slept. He then left, planning to speak with her treating doctor in the morning.

During the night, Ophelia developed respiratory distress and was having difficulty breathing. Her oxygen levels dropped and the resident on call suggested intubation and a ventilator. He noted her age and diagnosis (end-stage Alzheimer's Disease) and asked the nurse if there was a Do Not Resuscitate (DNR) order or any indication on the chart about her wishes. There was no DNR order and no Advance Directive or indication of her wishes on which such an order could

have been based. Since the patient could not communicate, the resident called her brother in the middle of the night and requested his consent to place her on the ventilator. Her brother was alarmed and unprepared for this question, but when told that Ophelia would die without the ventilator, he consented.

Ophelia was placed on a ventilator and transferred to the Intensive Care Unit. When her brother came in to see her the next morning, he realized with great dismay that Ophelia was in exactly the circumstance she had clearly told him she did not want. He felt he had let her down, and wondered what he could do now. He contacted the doctor who was in charge of her hospital treatment. The physician was a "hospitalist," an expert in managing inpatient care, but who did not know Ophelia or anything about her. He explained to Ophelia's brother that his sister's likelihood of recovery was very poor.

Her brother told the physician of his previous conversations with his sister and of the strong wishes for a peaceful death at home she had communicated to him. He felt as if everything that had happened, starting with the aide's call to 911, was a mistake. Ophelia never wanted any of this! She will be furious with me, he explained.

The doctor assured Ophelia's brother that her wishes could still be followed. He documented Ophelia's wishes, as expressed to her brother, in the chart, wrote a DNR order, and ordered the ventilator to be withdrawn. Ophelia was made comfortable with pain-relieving and other medications and moved to the inpatient hospice room, to be allowed to die with no heroics. She died peacefully the next day, with her brother and a sister at her bedside, as well as the hospital chaplain and social worker.

While no one individual in the case presented above did anything wrong, Ophelia did not receive palliative care (adequate attention to her and her family's suffering and preferences) soon enough. What could have been done to make this end-of-life scenario more compatible with Ophelia's wishes from the start?

Ideally, in addition to her conversations with her brother, Ophelia would have written an Advance Directive (AD), specifying her preferences for end of life care, and naming her brother as her Health Care Proxy (to speak for her when she became unable to make decisions or communicate for herself). Her aide would have been informed of her preferences and given a copy of the AD.

In discussions with her primary physician and her brother, a decision might have been made to refer Ophelia to Hospice. If so, specialist nurses and social workers, with added consultation from a Hospice Physician, would have supervised the care at home, ensuring maximum attention to Ophelia and her family's discomforts and needs. This might have prevented an unnecessary trip to the hospital and allowed her to die at home, as she preferred.

But whether or not Hospice was involved, at any point, a physician could have been asked to write an Out of Hospital DNR (OOH DNR) order. Given a better understanding of Ophelia's wishes, it is possible the aide would not have called 911. But even if she did, when paramedics arrived, the presence of the OOH DNR in the home would still allow the paramedics to assess and provide any emergency care needed for

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