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THE ROOTS OF HOSPICE

Even though its roots can be traced to the Middle Ages, the modern hospice program did not take shape until the mid-1960s. At that time, the work of two remarkable physicians, Elisabeth Kubler-Ross, and Dame Cicely Saunders, converged to bring the emotional and physical needs of the dying to the forefront.

In 1970, Kubler-Ross' landmark book, *On Death and Dying*,¹ revolutionized the psychologic approaches to patients with terminal illness. After several years of observation and actual interviews with the dying, Kubler-Ross created a theoretic framework describing the psychologic stages of dying and pointed out to health care workers a sobering fact: as dying patients needed more attention and support, they were actually receiving less. Indeed, Kubler-Ross brought death and dying "out of the closet," making health care providers and society in general more aware that death is a part of life and a legitimate part of clinical

care, and that with sensitivity and understanding it can be faced openly and honestly.

In 1967, while Kubler-Ross was working at the University of Chicago Hospital, a British physician, Cicely Saunders, MD, opened the doors of St Christopher's Hospice in London. Trained as a nurse and social worker, she received her medical degree and set about her life's work to improve the care of the dying—and what better background? Some have called Saunders "a whole hospice team wrapped up in one person!"

Saunders' approach to the dying was first and foremost geared to achieving and maintaining comfort. Her approach to pain management has shaped the development of a pain control philosophy that has become a benchmark of hospice care.

Her model, prescribing an interdisciplinary team, communicating effectively, treating symptoms of terminal disease, including the patient and family,² has been replicated in concept over 1,400 times in the United States today.

HOSPICE IN THE UNITED STATES

In the early 1970s, as the work of Kubler-Ross and Saunders became known, individuals in the United States became eager to put their concepts into action. The United States programs, however similar in concept to the British world, were very different in design. The first US hospice,

Hospice of Connecticut (New Haven) began to deliver care to the dying at home, since funding problems forced delays in the construction of a free-standing facility. After 6 years of delays an inpatient unit was christened in 1980 "but its early years as a home care program left an indelible impression on the purposes and practices of the hospice staff and administrators. It provided the country with a new and different model of care for the dying, care focused primarily on patients at home."^{2(p.11)}

As the hospice movement spread across the United States, programs took on various shapes and sizes. In most instances the shape of each hospice was determined by its genesis. For example, if a hospital felt that its commitment included the provision of terminal care, its hospice program would probably be a hospital-based hospice; if a group of active lay volunteers began a program, it might be a consortium model hospice. In all, there are at least six common program designs for hospice.

In an effort to more exactly define this concept, the National Hospice Organization (NHO) and the then Joint Commission on Accreditation of Hospitals (JCAH) developed standards of care to which hospice should adhere. Standards were developed in seven areas: (1) the patient and family as the unit of care, (2) interdisciplinary team services, (3) continuity of care, (4) home care services, (5) symptom control, (6) bereavement, and (7) quality assurance.

Most significant in the creation of uniformity of hospice programming was the addi-

tion of hospice to the Federal Medicare Program in 1982. Maintenance of a certification to deliver hospice care calls for rigid adherence to the standards developed. As we look toward the 1990s, many uncertainties still exist, many questions remain unanswered, such as

- What is the best model for delivery of hospice care?
- Will hospice in the United States face a dilemma as larger programs force out small, community programs?
- Will hospice care be assimilated into mainstream health care, or can it only stand alone?
- Will patients be *forced* to participate in hospice?
- What will be the impact of high technology on the dying process?

CRITERIA FOR ADMISSION

Probably the most crucial in the management of a hospice in today's society is the development of the program's admission criteria. Surely the kinds of support the hospice offers might be well received by any patient and family facing a major illness, but just when during that illness does a patient become eligible?

After years of developing a careful decision-making process, the authors' hospice has developed a fairly rigid set of three criteria for admission:

1. completion of all active, curative treatment
2. patient's awareness of diagnosis and prognosis
3. patient and family's clear understanding of the goals of hospice care.

Clearly these criteria bring to mind grey areas for questioning such as, "What if a patient is receiving palliative chemotherapy?" "What if a patient knows the diagnosis but not the prognosis?" "What if the family is divided about how the patient's illness should be treated?" And more recently, "What if the patient wants no life supports, but does want artificial hydration and nutrition?" These so-called grey areas demand that each patient's application for hospice care is reviewed in depth with the *most* important question: "Are the patient and family choosing supportive care for a terminal disease with the care delivered primarily in the home setting?"

THE INTERDISCIPLINARY TEAM

The essence of hospice care is derived from the multifaceted and comprehensive approach of the hospice interdisciplinary team, whose members look for solutions to a patient's medical, psychosocial, and spiritual problems. The diversity of talent, cultural and ethnic backgrounds, life style, and educational background creates a blend

that can sort out various problems to find the approach most suitable for that individual patient and family. A well-coordinated, confident group of hospice professionals can work together with everyone having equal say in most matters only if each team member is comfortable offering information from his or her experience and knowledge as well as listening to and accepting the differing contributions of others (see Fig 1).

"Role blurring" (overlapping of duties of various professional disciplines) is acceptable and actually encouraged to some extent within hospice programs. Every team member has an area of expertise accompanied by some primary responsibilities but each also must have some knowledge of other disciplines and be sensitive to problems and needs not directly related to the particular area of expertise. A common example of role blurring is when a hospice nurse spends time with family members advising them on how to approach the children about an impending death. There is no need (and often, no time) to wait until the counselor can be called to talk or meet with the family. A well-trained, experienced, and sensitive hospice nurse can

give meaningful and accurate information in this situation. However, the lines must be drawn when the problems require more specific expertise and that team member must defer to another member of the team. Furthermore, sharp distinctions must be made in some areas because of primary responsibility and liabilities (ie, the patient's physician has the final decision in the ordering of medications, treatments, etc). Hospice personnel need to be cognizant of and comfortable with role blurring and to know their boundaries.

THE ROLE OF THE FAMILY IN HOSPICE CARE

In the early days of the hospice program, many held the view that hospice staff was essential to do for the family, to be a substitute for the family in the care of the patient. Hospice, by its very nature, seemed to attract those helpers caught up with the notion of the "rescue fantasy." This, combined with an underestimation of what families are capable of doing, made for much overfunctioning and early warning signs of staff burnout.

As staff members learned together about the nature of family systems and how best to be helpful, they realized that the primary role of the hospice nurse was to be an enabler. When staff members share their competence in caring with families, rather than taking over, families are able to feel as if they did everything they could until their loved one died. One of the highest compliments to hospice staff is the thank-you note that says, "You gave us what it took to be able to do it ourselves. . . ."

PAIN MANAGEMENT

Probably the most valuable contribution to the health care system at large has been the development of the body of knowledge by hospice professionals regarding pain management. Even though only approximately 50% of hospice patients have moderate to severe pain problems, pain is often what patients and families fear most. Some of the most important pain management concepts follow.

- Chronic pain management requires regularly scheduled (not prn) delivery of appropriate analgesia *in advance* of the return of pain.
- Patients do not exhibit signs of drug addiction (ie, drug-seeking behavior, ever-escalating dosages) when placed on appropriate pain management program.
- Various routes of administration (ie, sublingual, rectal, oral) can be equally effective to the IV route when used in equianalgesic ratios (see Table 1).
- Morphine and its derivatives are by far the most useful drugs in the management of intractable pain.
- Knowledge of combinations of drugs such as narcotics with nonsteroidal antiinflammatory drugs can be very effective for bone pain.
- Careful assessment of pain and all of

its components is essential to developing an effective intervention.

Before dealing with some of the more complex psychosocial problems such as loss and grief, the hospice nurse must make a thorough evaluation of all symptoms, particularly pain.

PREPARATION FOR A HOME DEATH

A person dying at home surrounded by family and the familiar smells, sounds, and sights can be an exceedingly beautiful experience. Almost nothing can make family members feel any better about themselves than caring for someone they love and being able to keep the loved one at home for the duration of the illness. For some a home death is the ultimate gift. For others the very thought of someone dying at home is repugnant. A hospice nurse's greatest challenge may be discerning the choice relating to home death for each patient and

family. Some families feel a home death would be wonderful but unmanageable for them, while others may see a home death in much simpler terms than are accurate and are inadequately prepared physically and emotionally. The hospice nurse needs to convey to these families the sense that (1) a home death is manageable for nearly every patient and family if they have proper support; (2) it is important to address needs as they arise, so that a crisis does not occur because of unrealistic or inadequate preparation; (3) not every patient can die at home no matter how much he or she is loved and supported. It is not an indication of failure if an institutional death is necessary or is chosen by the family.

Preparing for a home death is really not too difficult if the professional people supporting the family believe home death is acceptable and are willing to help the family through it. Most patients and families say that they fear not the death but rather the dying. They are concerned about suffering.

First and foremost it must be explained that the physical symptoms will be kept to a minimum, and that the hospice staff and the patient's physician will see to it that enough of the needed medication will be supplied to keep the symptoms at bay. Some families worry about emotional suffering, but most people worry about physical suffering.

The hospice staff must be aware that many families crumble temporarily and need extra visits, telephone calls, and pats on the back to get through that time when they believe they cannot get through it. One of these crises is generally all that is seen, and the sailing is usually much smoother after that. Families may be more intent than ever to achieve a home death because now they know they can.