Family Practice Grand Rounds

Hospice Care: Not Available to Everyone

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DR. JONATHAN NOCE *(Director of Behavioral Science)*: When faced with a terminal illness, an increasing number of patients and their families are choosing palliative over traditional medical care, preferring to let the illness run a natural course. When this decision is made, hospice care becomes a valuable option to the patient and the family. However, as more adults choose to remain single or childless and as families become increasingly mobile, we will be faced with an increasing number of difficulties. Almost 70 percent of American hospice patients are older than 65 years. Unfortunately, as they age their chances of living alone increase.[1] The core of the American hospice program is focused on providing family-oriented home care. The primary unit in hospice care has always been the patient and the family or significant other. However, what happens when a patient has no available family or significant other to assume the role of primary care giver? Are there viable options within the traditional home-oriented hospice program? What effects will changing funding patterns have on future hospice care? Today we have a panel of health care providers who will discuss such a patient from the Family Practice Center at Lutheran Medical Center (LMC). Dr. Lorene Lindley, third-year resident, will present the case.

DR. LORENE LINDLEY *(Third-Year Resident in Family Practice)*: The patient, aged 78 years, was first seen in July 1982. Her chief complaint was sores in the mouth for three weeks. She also noted a weight loss of 50 lb, increased weakness, and anorexia over the last two or three months. Her only known chronic illnesses were diverticulosis and chronic pedal edema. She had been last seen by a physician 12 years previously, when she had a right colonic polyp diagnosed. Her family history was pertinent in that her father died of colon cancer and her mother died of endometrial cancer. She had lived alone since her husband died 12 years before. The couple had no children, and there were no close relatives living in St. Louis. Her only income was a social security check of $500 every month.

On the initial visit she was found to be quite pale. There was a large palpable mass in the left periumbilical area about 6 cm in diameter. The stool guaiac was positive and her hemoglobin was 4.7 g/dL. Although informed of the possibility of cancer, the patient refused further workup. A month later she returned to the clinic with complaints of increasing abdominal pain, anorexia, and constipation. She agreed to further investigation and was admitted to the hospital. A barium enema showed a high-grade constricting lesion in the left transverse colon. At surgery a predominately well-differentiated adenocarcinoma was

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found that had perforated the muscularis, forming an abscess. Excision of the transverse colon and splenic flexure with reanastomosis was performed.

She had a slow postoperative recovery but was eventually transferred to a rehabilitation facility. After five weeks she returned home, where she continued to live alone, receiving assistance from visiting home nurses. Initially she appeared to do well and did not seek medical care for the next five months, when she was brought back to the office by her niece, who was visiting from another city. Although she had lost 27 pounds over the five months, when questioned, she denied any symptoms. She was readmitted to the hospital for further evaluation. The tumor had recurred and was almost obstructing the bowel lumen. It was elected not to perform further surgery unless bowel obstruction occurred. The patient did not wish other palliative treatment and was admitted to a nursing home. Two weeks later she was readmitted to hospital for an episode of bloody diarrhea and drop in her blood pressure. The abdominal mass now occupied the entire lower abdomen, although the bowel was still not completely obstructed. It was felt that surgical intervention would not be of benefit. Within a few days she was accepted into the inpatient hospice unit. There was a rapid decline in her health; at times she was lucid, but often appeared anxious, fearful, and repeatedly requested people to sit with her. She died after nine days in the hospice unit.

DR. KAREN HOLMAN *(Residency Program Director)*: Why was she not involved in hospice care earlier in her illness?

DR. LINDLEY: Hospice care was first considered when she was readmitted with recurrent disease, but she was initially ineligible for hospice care because a primary care giver could not be found. Nor was she eligible for inpatient hospice care because she did not meet Medicare requirements for reimbursement. Currently Medicare regulations place a ceiling on the amount reimbursed for inpatient hospice care, and it was thought that she would live for several more months.

DR. HOLMAN: After her second admission she couldn't go home because she was too ill to

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care for herself and she had no primary care giver. However, she was alert, totally oriented, and not in any significant pain. The only alternative seemed to be nursing home placement.

DR. NOCE: With this case in mind, let us review the criteria for hospice care at our medical center and compare them with those in the rest of the country.

MAXINE STEIN *(Coordinator, LMC Hospice)*: The general rules for our hospice are similar to those nationally. The criteria include a life expectancy of six months or less, a need for symptomatic management that may include physical, psychological, emotional, or spiritual support, and the availability of a primary care giver to assume the responsibility for home care. The hospice patient is one who acknowledges that he or she wants only palliative care and does not want any life-extending measures. Hospice philosophy emphasizes home care. An inpatient unit is used primarily as backup to home care for symptom control and offers the primary care giver the opportunity for a respite. Sometimes families will offer to care for someone at home until the very end and then want the patient admitted to the unit.[2] However, with our support we find that families are better able to cope with the patient remaining in the home.

DR. HOLMAN: Of the requirements you just listed, one of the most difficult is the expectation that a physician can accurately predict a given patient's life expectancy.

DR. CHRISTIAN WESSLING *(Third-Year Resident in Family Practice)*: How is a primary care giver defined?

MS. STEIN: Although the exact definition may vary among programs across the country, we define primary care giver as anyone willing to care for the patient, even someone who is hired by the patient. A recent study showed that 67 percent of hospices in this country required a primary care giver. Over one half of the elderly in the United States today live alone even though relatives still exist. Because of the primary care giver requirement, the majority of elderly patients cannot qualify for hospice services.[1]

DR. MIRIAM CHANG *(Second-Year Resident in Family Practice)*: Can you describe these services more specifically?

MS. STEIN: First, the care is given very differently from that given in a traditional medical setting. We function as an interdisciplinary team planning the care together. There is no single discipline in charge of the care. It is physician directed but involves the whole health care team. The health care team members may include social workers, counselors, nurses, and physicians.[3] In addition to these members, our particular program uses music therapists, occupational therapists, dietitians, chaplains, and pharmacists. Volunteers also form an integral part of hospice care. All these team members are available to assist the patient at any time both in the home and in the inpatient unit. Along with these primary services, we use any other discipline needed by the patient.

DR. HOLMAN: How is a patient accepted into the program?

MS. STEIN: Admission is a team decision. A patient's application is first reviewed by the hospice physician, who then contacts the primary physician to verify and clarify information. The application is then reviewed by the rest of the hospice team. We evaluate the patient's and the family's understanding of the diagnosis and their understanding and expectations of the hospice program.

DR. WESSLING: Since the hospice program at Lutheran Medical Center is a part of an acute care hospital, isn't it under financial pressure to take only people whose life expectancy is very short? Also, wouldn't it be better to have hospice as part of an intermediate care facility, or has this been done?

MS. STEIN: No, to my knowledge this has not been done. The problem is whether an intermediate care facility could provide the intense care that is needed in an inpatient unit. Besides, we are trying to get people to think of hospice as a home-based instead of hospital care program. Ideally, we should be enrolling patients much earlier than the present two to four weeks prior to dying. Unfortunately, in the case that was presented today, there was not a family available to provide the patient with hospice home care. As it turned out, she was eligible to come into hospice inpatient unit at the end because her life expectancy was limited.

DR. NOCE: One article in our review of the literature suggested the possibility of a nursing-home-based hospice, but we were unable to actu-

ally find an example of one.[1]

DR. HOLMAN: We had inquired about the possibility of arranging hospice care for the patient in the nursing home, and that could not be arranged. What are the restrictions to sending hospice personnel to other institutions?

MS. STEIN: To have a link to hospice, we can send a volunteer in an unofficial capacity to see the patient. This type of care could provide some psychological support. However, we would not be delivering complete hospice care because we wouldn't be involved in such areas as nursing care or counseling and other areas of symptom management.

PAULA MONTGOMERY *(Physician's Assistant)*: What has been the major roadblock for implementing a hospice program in an institution, such as a nursing care facility, particularly for people who have no other alternatives?

MS. STEIN: Linking a hospice with a chronic care facility would be an excellent idea, and I believe it could be done. As stated earlier, many people don't have spouses, children, or friends to be the primary care giver; therefore, they don't qualify for the hospice program and end up in a nursing home. Again, the problem is nursing homes are designed to provide chronic care, not the intense care required for hospice patients. But the major roadblock has been reimbursement.

DR. HEATHER BEECHER *(Third-Year Resident in Family Practice)*: What are the repayment methods available for hospice care?

MS. STEIN: Medicare and some private insurance companies will reimburse for hospice services, but both have placed limitations on reimbursement for hospice care services.

DR. HOLMAN: There was a recent article by Keller and Bell[4] that outlined current Medicare reimbursement regulations. According to these authors there is an overall ceiling of $6,500 of which no more than 20 percent may be for inpatient care. As I understand it, this amount is an improvement over previous reimbursement for home care services, but severely limits inpatient reimbursement. It is estimated that hospice care is one quarter of the daily cost for traditional hospital care. A savings of up to $50 million is possible during the first year under Medicare reimbursement for hospice depending on the mix of home and inpatient care.[5]

MS. STEIN: In addition, a hospice must be certified as eligible for Medicare funds. The regulations are difficult for most hospice units to meet. We are hoping that the requirements are changed in September 1986, when the law's sunset clause requiring reapproval goes into effect.

DR. LINDLEY: Could a nursing home qualify for Medicare reimbursement?

MS. STEIN: It is unlikely that a chronic care facility such as a nursing home could qualify for Medicare funds under current Medicare regulations without establishing a separate hospice unit that would provide the required inpatient and outpatient services.[2]

DR. HOLMAN: It would be nice if you could redefine primary care giver to include alternatives such as a nursing home. Then hospice services could be provided just as they would be in a private home.

DR. WESSLING: Is it more cost effective to provide care on acute medical care floors or in the hospice unit?

MS. STEIN: Overall the cost of the inpatient hospice unit is slightly higher. The primary reason is the increased staffing requirements and higher medication costs compared with a regular floor. There is an emphasis on home care because it is less expensive.[4]

DR. NOCE: Have you found hospice to be different from nursing homes or medical floor when considering the patient and his family's psychological satisfaction?

MS. STEIN: I think the hospice inpatient unit is different because it is a central place providing psychological support for the terminal patient and his family. There are no visiting hour regulations, and we have places for families to sleep. We cater to preserving the individuality of the patient and helping keep the family intact. A recent study showed that eight out of ten cancer patients surveyed stated they would use hospice services if they were available.[6]

MS. MONTGOMERY: These are the supports that are unavailable for patients who have no primary care giver.

MS. STEIN: Correct. In the past we allowed patients in the unit to remain for long periods of time. In effect we became their primary care giver. Unfortunately, current Medicare regulations do not reimburse for extended stays.

DR. HOLMAN: A hospice in Columbus, Ohio,

studied the utilization and costs of their unit. They noted that 26 percent of those requesting care died before being accepted into the hospice. An additional 16 percent were rejected because they didn't have a primary care giver. Thus almost one half of the people who applied to this particular hospice did not benefit from hospice care.[3] If the government would redefine primary care giver to include other alternatives such as a nursing home and significantly alter reimbursement practices, more of these people could benefit from this important alternative to traditional care.

DR. NOCE: What other funding alternatives are on the horizon for hospice care?

MS. STEIN: Many hospice programs have relied on government and private foundation grants, money from the community, and private resources to continue to provide care.[7] Programs frequently ignore current Medicare regulations for hospice care and instead apply for reimbursement under the acute care reimbursement guidelines. Present Medicare regulations are ineffective and need to be rewritten.

DR. HOLMAN: Today we have briefly reviewed the hospice movement and the problems that one particular patient had in attempting to qualify for hospice care. The requirement for a primary care giver and restrictive Medicare reimbursement policies denied this patient the full benefit of hospice. Broadening the scope of reimbursement regulations and redefining some requirements, such as the provision for a primary care giver, are important. Family physicians should actively lobby to have these regulations modified. I would like to thank everyone for coming today and a special thanks to Maxine Stein for sharing her expertise.

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