

A NURSING PERSPECTIVE ON END-OF-LIFE CARE: RESEARCH AND POLICY ISSUES

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Our health care is primarily designed to deal with patients' treatment in a cure rather than comfort mode.¹ Nursing can make a major contribution in adjusting this imbalance. Effective end-of-life care is informed by scientific evidence and best provided by an interdisciplinary team that shares a common philosophy and set of values about how to care for dying patients and their loved ones. Helping patients and families achieve their concept of a "good death" is an essential part of health care, respecting the values and choices of patients and those close to them. This article addresses current and emerging issues in end-of-life care, the role of nursing on an interdisciplinary team, and the contribution of nursing research. Part I discusses nursing research and its contribution to end-of-life care by focusing on autonomy, informed consent, and advance directives. Part II debates the financial aspects of end-of-life treatment, including many health care providers' over-aggressive treatment of dying patients. Part III addresses future challenges the nursing profession will face. Finally, Part IV highlights some of the studies related to end-of-life research.

BACKGROUND

The technological advances of our health care system in extending the lifespan of Americans leads to a downside: we're living longer and dying longer.² The quality of dying is not what most Americans want or expect.³ Advances in medical technology over the

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1. See Ronald Carson, *Drugs and Pain*, WASH. POST, Aug. 21, 1998, at A22.

2. See Joanne Lynn, *Measuring Quality of Care at the End of Life; A Statement of Principles*, 45 J. AM. GERIATRIC SOC'Y 526, 526 (1997).

3. See Virginia P. Tilden, *Dying in America: Ethics and End-of-Life Care*, 31 COMMUNICATING NURSING RES. 39, 39 (1998).

past few decades have radically changed the demographics of dying,⁴ resulting in ethical dilemmas that challenge the most capable ethicists. Thus, the dying process is extended because medical treatments can manage previously life-threatening secondary complications that accompany chronic illness.⁵ As Dr. Lynn explains, "Dying slowly while old is much to be preferred over dying young, but it presents its own challenges, which the care system is just beginning to overcome."⁶

End-of-life care is most effectively provided by an interdisciplinary team that shares a common philosophy and set of values about how to best care for dying patients and their families. Caregivers from all disciplines may be involved in deciding on the duration and intensity of treatment to be offered to patients with terminal diseases.⁷ In many parts of the country, lawyers specializing in health law or elder law are considered an essential part of this team. Professional nursing is one of many disciplines that provide palliation,⁸ communication, and support, three essential elements of effective end-of-life care.

Nursing's role in palliative care began with Florence Nightingale's work during the Crimean war. Her work was based on a philosophy of caring for the physical, emotional, spiritual, and environmental needs of the dying patient, believing that nursing's role was "to put the patient in the best possible position for nature to act upon him."⁹ Nightingale also encouraged research on facilitating the natural healing process.¹⁰

In the early 60's, the nursing profession subscribed to Maslow's theory of hierarchy of needs and integrated this into its philosophy of caring.¹¹ Maslow's theory purports that basic physical and security needs must be met before one can turn one's attention to the higher cognitive needs.¹² This principle is particularly applicable to the care

4. *See id.*

5. *See* Deborah J. Cook, *Health Professional Decision Making in the ICU: A Review of the Evidence*, NEW HORIZONS, Feb. 1997, at 15.

6. Lynn, *supra* note 2, at 526.

7. *See* John F. Hermann & David S. Ettinger, *The Final Dilemma: End-of-Life Treatment Decisions*, CANCER PRAC. 57, 57 (1998).

8. "Palliative care . . . is therapy designed to relieve or reduce the intensity of uncomfortable symptoms, but not to produce a cure." Margaret A. Varnell, *Palliative Care: A Patient's Right*, 1 ADV. FOR NURSES 29, 29 (1999).

9. Kathleen M. Light, *Florence Nightingale and Holistic Philosophy*, 15 J. HOLISTIC NURSING 25, 33 (1997).

10. *See id.*

11. *See* ABRAHAM H. MASLOW, *MOTIVATION AND PERSONALITY* 97-104 (Wayne G. Holtzman & Gardner Murphy eds., 2d ed. 1970) (1973).

12. *See id.* at 98-99.

of the dying. It can be hypothesized that: (1) relief of suffering must be attended to before higher level needs are addressed, and (2) patients and families will have difficulty in decision-making if these basic physical and comfort needs are not first met.

Another major influence on nursing's philosophy of caring was the work of Virginia Henderson, the first theorist to consider that nursing's role included care of the dying.¹³ She described a nurse as someone who "assists the individual, sick or well, in the performance of those activities contributing to health or its recovery, or to a peaceful death, that he would perform unaided if he had the necessary strength, will, or knowledge."¹⁴

A contemporary theoretical influence on the "caring" aspects of nursing is the work of Patricia Benner. Benner's focus on the phenomenologic view helped gain a fuller understanding of the meaning of events, the person, the concept of caring, and the context of care delivery.¹⁵ In their commentary on the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT), Oddi & Cassidy refuted the tenet that "a nurse is a nurse."¹⁶ Furthermore, for patients and families who need end-of-life-care, masters-prepared nurse practitioners and clinical nurse specialists were deemed best qualified to provide this specialized nursing care.¹⁷

I. NURSING'S PRIMARY FOCUS ON END-OF-LIFE CARE

Research findings have identified two areas where nursing has a major impact on end-of-life care: (1) communication and support in decision-making and (2) relief of suffering through pain and symptom management.¹⁸ The remainder of this paper focuses on these essential areas and identifies how nursing research can expand its contribution to end-of-life care. A discussion of communication and decision-making must encompass the principles of autonomy, informed consent, and advance directives.

13. See generally A VIRGINIA HENDERSON READER: EXCELLENCE IN NURSING (Edward J. Halloran ed., Springer Publishing Co. 1995).

14. *Id.* at 357.

15. See PATRICIA BENNER & JUDITH WRUBEL, THE PRIMACY OF CARING: STRESS AND COPING IN HEALTH AND ILLNESS 57 (Addison-Wesley Publishing Co. 1989).

16. LOYIS F. ODDI & VIRGINIA R. CASSIDY, *The Message of SUPPORT: Change Is Long Overdue*, 14 J. PROF. NURSING 165, 167 (1998).

17. See Patricia Hinton-Walker, *Care of the Chronically Ill: Paradigm Shifts and Directions for the Future*, 8 HOLISTIC NURSE PRAC. 58, 58 (1993).

18. See Tilden, *supra* note 3, at 40.

A. *Autonomy, Informed Consent, and Advance Directives*

In the United States health care system, the principle of autonomy has been a central force in guiding treatment or treatment withdrawal,¹⁹ and it has been the underlying ethical tenet guiding the development of advance directives²⁰ and the Patient Self-Determination Act of 1990 (PSDA).²¹ The PSDA requires that all persons admitted to facilities receiving Medicare or Medicaid funding be given information regarding their right to establish advance directives on admission to the facility.²² Advance directives were intended to move the locus of decision-making toward patients and their families, empowering patients to exercise control of their care.²³ However, before patients can be empowered they must be informed with knowledge. The consenting-adult autonomy paradigm follows this algorithmic approach:

If the patient has the capacity to decide, provide full information, ask for a decision, and respect it. If the patient lacks capacity, seek advance directives and follow their guidance when possible. If the patient has left no advance directives, close friends and family members are the next source of guidance although their authority is sharply limited in many states. If the person is 'unbefriended', to use Joanne Lynn's term, guardianship or an alternative to it may be necessary.²⁴

While this algorithm appears fairly straightforward, it is deceptively complex. Each of the steps in this paradigm raises questions that remain unanswered and, according to Finucane and Harper, may be unanswerable.²⁵ In responding to these difficult issues, the nurse is often the first person who is asked to address these questions, serving

19. See Thomas E. Finucane & Michael Harper, *Ethical Decision-making Near the End-of-Life*, 12 CLIN. GERIATR. MED. 369, 375 (1996) (defining the current standard of autonomy as being "lawyerly" where the fully-informed patient and physician develop a specific contract of medical decision-making).

20. There are two types of advance directives. The *instructional* type specifies in advance what kinds of life-sustaining treatment the patient accepts or declines. See *id.* at 372. The *appointment of a health care agent* delegates the patient's authority to make such decisions to a third party. See *id.*

21. The Patient Self-Determination Act of 1990, Pub L. No. 101-508, §4206(a)(2), 104 Stat. 1388 (1990) (codified as amended at 42 U.S.C. §1395cc(f)).

22. See *id.*

23. See *supra* notes 18, 19 and accompanying text; Theresa S. Drought et al., *Advance Directives: Changing Our Expectations*, 110 CHEST 589, 589 (1996).

24. Finucane & Harper, *supra* note 19, at 370.

25. See *id.* at 371.

as interpreter to the patient and family or relaying information to the physician on the patient's behalf.²⁶

B. Advance Directives: Success or Failure?

How we judge our progress in the area of advance directives is related to our expectations; many viewed advance directives as quick and easy decisions that would result in enormous medical cost savings.²⁷ However, almost a decade after the PSDA was enacted, the research showed disappointing results. In the absence of a definitive study, existing data suggested that hospice and advance directives could only save between 25 and 40% of health care costs during the last month of life.²⁸ While this is less than expected, hospice and advance directives should be encouraged given that costs were lowered while still respecting the patient's choice.²⁹

Several factors may explain why advance directives have not met their promise. The report by Tilden supports the assumption that life-sustaining treatment decisions do not conform to individual patients' specific preferences.³⁰ The number of individuals who have completed advance directives remains relatively small, and efforts to increase the prevalence of advance directives have had limited success.³¹ Meier et al. noted that advance directives completed in the ambulatory care setting are rarely available when patients are admitted to the acute care hospital.³²

On the positive side, Meier and colleagues found that counseling from hospital patient representatives improved recognition and execution of advance directives in the acute care hospital.³³ Research on barriers to completion of advance directives in the ambulatory care setting suggest that although patients may be informed about advance directives, they believe that physicians should initiate discussions about such documents.³⁴ In a study of nursing home patients, only

26. See Tilden, *supra* note 3, at 41.

27. See Drought, *supra* note 23, at 589, 591.

28. See Ezekiel Emanuel, *Cost Savings at the End of Life: What Do the Data Show?*, 275 JAMA 1907, 1907 (1996).

29. See *id.*

30. See generally Tilden, *supra* note 3.

31. See Duane E. Meier et al., *Marked Improvement in Recognition and Completion of Health Care Proxies*, 156 ARCH. INTERNAL MED. 1227, 1232 (1996).

32. See *id.* at 1228.

33. See *id.*

34. See *id.* at 1227-28.

35% with advance directives had their directives transferred with them to the acute care hospital.³⁵

There is the assumption that people want choice, certainty, and control when approaching death, yet studies reveal that those who complete advance directives are a homogeneous group: college-educated, privately insured, white females who are financially secure and have a serious chronic illness such as cancer or pulmonary disease.³⁶ Not all cultures share the same perspective on end-of-life care. For example, in Japan an open discussion of treatment options during terminal illness is rare and would be considered unethical.³⁷ In China, the family often does not wish the physician to bear full disclosure to the patient.³⁸

Jeffreys expands on the barriers to use of advance directives.³⁹ One barrier is that health providers lack basic knowledge about advance directives.⁴⁰ Moreover, they are provided with little or no training in how to counsel and advise patients on the formulation of such documents.⁴¹ A second barrier is that physicians continue to believe that such directives are unnecessary for young, healthy patients.⁴² Such attitudes are remarkable given the role of litigation involving formerly young, healthy patients like Karen Quinlan and Nancy Cruzan in creating the impetus for advance directive legislation.⁴³ The third barrier is economic. Physicians and hospitals are not compensated for the time expended in working with patients on advance directives, informed consent, and related issues.⁴⁴ Health care professionals should be compensated reasonably for activities that are con-

35. See Marion Danis et al., *A Prospective Study of Advance Directives for Life-Sustaining Care*, 324 *NEW ENG. J. MED.* 882, 884 (1991).

36. See, e.g., Laura C. Hanson & Eric Rodgman, *The Use of Living Wills at the End-of-Life: A National Study*, 156 *ARCH. INT. MED.* 1018, 1021 (1996).

37. See Finucane & Harper, *supra* note 19, at 370.

38. See Barbara A. Koenig & Jan Gates-Williams, *Understanding Cultural Difference in Caring for Dying Patients*, 163 *W. J. MED.* 244, 245 (1995).

39. See Jo-Anne H. Jeffreys, *Advance Directives: Are They Worth the Paper They're Written On?*, 190 *N. J. LAW.* 17, 17 (1998).

40. See *id.* at 17-18.

41. See *id.* at 19.

42. See *Cruzan v. Director Mo. Dep't of Health*, 497 U.S. 261 (1990).

43. See generally Sandra H. Johnson, *Trends in Health Care Decision-making: The Changing Nature of the Bioethics Movement*, 53 *MD. L. REV.* 1051 (1994) (discussing the growth of bioethics and the resultant impact on legislative initiatives after the pivotal cases, *In re Quinlan*, 355 A.2d 647 (N.J. 1976) (recognizing the right to refuse medical treatment under common law and federal and state rights to privacy) and *Cruzan*, 497 U.S. 261 (1990) (recognizing the right to refuse medical treatment in certain circumstances on the basis of an individual's liberty interest under the Due Process Clause of the Fourteenth Amendment. A surrogate decision-maker may exercise this right in certain situations.)).

44. See Jeffreys, *supra* note 39, at 18.

sidered essential to the discharge of their responsibilities to patients. Nevertheless, it is important to work with their patients to achieve sound advance care planning, whether or not those activities and time are reimbursed.

Another barrier to advance directives is that many physicians take the position that death is not an appropriate outcome of care.⁴⁵ Despite the increased discussion of the concept of medical futility and physicians' increasing concern that scarce health care resources are being spent on hopeless cases, we are a long way from eliminating the technological imperative from the intensive care unit.⁴⁶ One reason why clear and comprehensive advance directives are critically important in changing the culture of intensive care is that they convey, albeit more subtly than the recent rise in public support for the legalization of physician-assisted suicide,⁴⁷ the powerful message that patients do indeed have a concept of a medical fate worse than death. The burden upon each care provider should be, through the assistance of advance directives, to understand and appreciate each patient's preferences for end-of-life care.⁴⁸

Other barriers include the use of ambiguous terminology in directives and conflicts between the directive and the wishes of one or more family members.⁴⁹ While contrary to law, Jeffreys notes that health care professionals operate on the belief that they have more to fear by ignoring the potentially litigious relative than they do by ignoring the patient's previously expressed wishes.⁵⁰ No advance directive instrument can be effective in influencing care so long as it is created and maintained in isolation from the patient-physician relationship.

C. *Advancing Advance Directives*

Research tells us that the public is not indifferent or opposed to advance directives, and that advance directives are not inherently unworkable.⁵¹ Expectations about advance directives must be realistic and should be approached with regard to individual and cultural pref-

45. See U.S. GAO LETTER REP. NO. HEHS-95-135 (reported to Congress Sept. 1, 1995) at 16 (citing N.S. Jecker, *Knowing When to Stop: The Limits of Medicine*, HASTINGS CTR. REP., May - June 1991, at 5-8).

46. See Cook, *supra* note 5, at 15.

47. See, e.g., Jennifer Cole Popick, *A Time to Die? The Legality of Physician-Assisted Suicide*, 24 PEPP. L. REV. 1327, 1343 (1997) (noting that voters in California, Oregon, and Washington unsuccessfully attempted to introduce measures legalizing physician-assisted suicide).

48. See Jeffreys, *supra* note 39, at 19.

49. See U.S. GAO, *supra* note 45, at 15.

50. See Jeffreys, *supra* note 39, at 18.

51. See, e.g., Finucane & Harper, *supra* note 19, at 369.

erences.⁵² Advance directives should also be viewed as an ongoing process of negotiated decision-making over the course of the patient's illness trajectory. The process should focus on shared decision-making at the patient-proxy-physician level rather than on overall life-sustaining treatment utilization. Cost savings can be realized without sacrificing quality of life for the patient and family and without sacrificing the patient's quality of dying. The legal profession can play a vital role in the development of advance directive policies that support the goals of the patient and family.

Commentators addressing the results of the SUPPORT study have spoken with a unified voice for major changes in the training, enculturation, and practice of health care providers, addressing the imbalance between the technological imperative and the personal aspects of care for the dying.⁵³ Some policymakers have recommended strong legal and economic incentives to push providers toward the caring model versus the technological imperative, noting that health providers should help design the incentives since outside imposition will only invite subversion.⁵⁴

II. MAKING THE PARADIGM SHIFT FROM CURE TO CARE

The "technological imperative" ethic, defined as the need to do everything regardless of potential adverse effects, costs, or benefits, still drives many care providers toward overaggressive treatment of dying patients. Concern about legal repercussions may promote this practice of "defensive medicine."⁵⁵ Physicians are reluctant to admit patients to hospice care until they are convinced that treatment will no longer benefit the patient.⁵⁶ Also, patients, families, and providers are often concerned that early referral to hospice care may diminish the level of hope for the patient and family.⁵⁷ As a result, patients are now often enrolled too late to achieve the full benefit of hospice care.⁵⁸

The Health Care Financing and Administration (HCFA) reimbursement structure, Medicare, requires a prognosis of six months or

52. See Drought, *supra* note 23, at 590.

53. See Daniel Callahan, *Once Again, Reality: Now Where Do We Go?*, 25 HASTINGS CTR. REP. S33, S34 (1995).

54. See *id.* at S36.

55. See Cook, *supra* note 5, at 15.

56. See Nicholas A. Christakis, *Predicting Patient Survival Before and After Hospice Enrollment*, 13 HOSPICE J. 71, 73 (1998).

57. See *id.* at 74-75.

58. See Christakis, *supra* note 56, at 73.

less and a terminal illness for admission to hospice care.⁵⁹ This is problematic. For many types of terminal and end-stage chronic diseases, prognosis is often difficult to predict within six months. Practitioners are the first to admit the difficulty in predicting survival time, especially in end-stage chronic diseases such as congestive heart failure and obstructive pulmonary disease.⁶⁰ Our reimbursement system does not allow for the hospice philosophy to be applied earlier than at six months prior to death. Patients with such severe, disabling chronic illnesses and their families are the ones who are most often in need of "palliative" care.

Pressures to control public and private health care costs will continue to intensify as the health care industry changes in its organization, delivery, and financing. In the absence of good methodologic studies, under a "best case scenario," hospice and advance directives have a potential cost savings of 25 to 40% for terminal hospitalizations.⁶¹ However, when the time analyzed is expanded, the potential cost savings decrease to 10 to 17% over the last six months of life, and then decrease further to less than 10% over the last 12 months of life.⁶² Theoretically, a greater use of hospice and advance directives could produce a savings of approximately 10 billion per year for medical costs incurred during the last year of life.⁶³ However, this estimate is based on an "idealized world" scenario and actual savings are likely

59. See 42 U.S.C. §1395(dd)(3)(A) (stating that an individual is terminally ill if the medical prognosis for that individual is a life expectancy of 6 months or less); 42 U.S.C. §1395(a)(7)(A)(i) (allowing payment for hospice care if the individual's attending physician, and the medical director or physician member of the interdisciplinary group of the hospice program providing or arranging for care, each certify in writing that the individual is terminally ill as defined by §1395(dd)(3)(A)).

60. Chronic Obstructive Pulmonary Disease (COPD) is a disorder characterized by reduced maximal expiratory flow and slow forced emptying of the lungs. See Vince Mak, *Chest Medicine On-Line* ¶1 (visited Feb. 8, 1999) <<http://www.unet.com/priory/cm/definiti.htm>>. COPD comprises two related diseases, chronic bronchitis and emphysema, with one rarely occurring without the other. *Id.* The rate of progression of COPD varies from person to person. See *The Lung Association Breathe Easy, A Guide to Living with COPD* ¶1 (visited Feb. 8, 1999) <<http://www.lung.ca/copd/intro/progression.html>>. Congestive heart failure occurs when the heart is unable to maintain adequate circulation of blood because of a dysfunction in the pumping action of the heart. The heart loses the ability to pump because the cardiac muscle loses the ability to stretch and contract, or the heart's chambers do not adequately fill with blood between beats, or the valves regulating flow allow the backflow of blood. See *Medical College of Virginia Hospitals Congestive Heart Failure Program* ¶4 (visited Feb. 8, 1999) <<http://www.views.vcu.edu/chf/chf.htm>>. Death may occur predictably as the heart muscle continues to weaken or, if a disturbance in heart rhythm occurs, it may occur suddenly and unexpectedly. See *id.*

61. See Emanuel, *supra* note 28, at 1913.

62. See *id.*

63. See *id.*

to be less.⁶⁴ Indeed, the “best case scenario” annual savings is estimated at substantially less than the billions of dollars in savings predicted by some advocates of advance directives.⁶⁵

There are several reasons why advance directives may not produce the cost savings envisioned by some proponents. Perhaps the most significant limitation is the unpredictability of death. For most patients, it is difficult to predict in months, weeks, or even days, which patients will benefit from intensive interventions and which ones will receive ‘wasted’ care. Moreover, many advance directives, especially living wills, often do not address situations in which wasted resources are directed to the elderly.⁶⁶ In most cases, advance directives have not guided medical decision-making for the seriously ill with hoped-for precision.⁶⁷ Furthermore, even where such precision is found, it might not point to less treatment.⁶⁸ A significant minority of patients want aggressive medical treatment even in the face of a poor prognosis.⁶⁹

Contemporary scholars suggest that providers, regardless of health care setting, must be made aware of the many factors affecting palliative care,⁷⁰ including: predicting death and anticipating the need to change the goals of care as therapeutic trials fail; anticipating and treating bothersome symptoms of dying patients; recognizing that family support and contact between the dying patient and family facilitate decision-making and acceptance of death; and facilitating the coordination of care and the development of alternative care teams in order to optimize end-of-life care. The success of hospice has been a catalyst for integrating palliative care into traditional models of care delivery.⁷¹ Additional models are needed for conveying the hospice philosophy to nursing homes, assisted living facilities as well as other innovative end-of-life care models, such as “MediCaring,” that are able to demonstrate quality care while controlling costs.⁷²

64. *See id.*

65. *See id.* at 1907.

66. *See S. Elizabeth W. Mallory, Beyond Misguided Paternalism: Resuscitating the Right to Refuse Medical Treatment*, 33 WAKE FOREST L. REV. 1035, 1055 (1998) (estimating that between ten and twenty-five percent of American adults complete formal advance directives).

67. *See Callahan, supra* note 53, at S33.

68. *See id.*

69. *See id.*

70. *See Dianne Rosen, A Hospice Primer*, 190 N. J. LAW. 12, 13 (1998).

71. *See American Association of Colleges of Nursing, Peaceful Death* ¶ 2 (visited Feb. 25, 1999) <<http://www.aacn.nche.edu/deathfin.htm>>.

72. The MediCaring project provides comprehensive treatment and services for chronically ill patients near the end-of-life. *See generally* Andrew Scolnick, *Medicaring Project to Demonstrate, Evaluate Innovative End-of-Life Program for Chronically Ill*, 279 JAMA 1511, 1512

III. THE CHALLENGES AHEAD

Nursing is in a special position to serve as advocate for the patient and family, helping patients and families cope with uncertainty and supporting their communication and decision-making in face of this uncertainty. As the time period between execution of the advance directives document and its implementation may become an issue, all advance directives should be reviewed regularly and modified as needed. The nurse must be knowledgeable about the patient's health care wishes and facilitate ongoing communication with the patient, family, and physician to ensure understanding of and compliance with the advance directives. The advance directive document is only as good as the health care representatives who implement it. Above all, health care professionals are there to act on behalf of the patient to ensure that the patient's wishes are honored.

Fundamental changes will be needed to alter society's views on dying. Patients, families and health care workers must be provided with accurate information to help cope with the dying process and death. A number of ways to remove barriers to effective end-of-life care have been proposed, from gender issues to the health care culture itself.⁷³ On a more sophisticated level, people must demand a higher standard from their health care providers, attorneys, hospitals, and health plans.⁷⁴ For example, when choosing a health plan, people must inquire about the plan's track record in honoring do-not-resuscitate orders and other advance directives, including pain control or coverage of home care.

The following case study illustrates some of the ethical issues and challenges facing providers of end-of-life care: *A 90 year-old white male in the intensive care unit is receiving vasopressor and mechanical ventilation. The physician has evidence to believe he will die soon from septic shock and multiple organ system failure. The physician thinks he should withhold cardiopulmonary resuscitation (CPR) because he believes it will be ineffective. Legally, the physician is obligated to rouse the patient long enough to let him know that CPR will be withheld when he dies. The physician instructs the nurse to explain to the patient and his 89 year-old wife that CPR will be withheld. The spouse is hard of hearing and has periods of transient memory loss. Advance directives were completed six months ago by the patient's wife when he was admitted to a nursing home following a brain attack that left him with a*

(1998). Services are tailored to the needs of the individual patient and eligibility is based on the severity of the disease. *Id.*

73. See Callahan, *supra* note 53, at S33-S34.

74. See generally *id.* at S34, S35.

right hemiplegia. At that time, the advance directives indicated that he desired CPR.

Finucane and Harper raise the fundamental question regarding the consenting adult or autonomy paradigm, "[I]s it always right to require frail, elderly dying persons to consider the details of their illness, the possible treatments, and then ask them to choose among tragic, disastrous alternatives?"⁷⁵ Other questions arise in the above case: Whose responsibility is it to communicate to the patient and his wife? How can we best evaluate the decisional capacity of the patient and spouse in this case? In some countries, such as Japan, physicians would solve the problem in this case by exercising the "therapeutic privilege," bypassing informed consent in order to avoid overburdening a gravely ill patient and a spouse who already has a great burden to bear.⁷⁶ Nurses have a critical role to play in these types of situations, often interpreting for, and providing observations about the patient and family to the physician that help guide the course of treatment or treatment withdrawal.

As our population ages, we will continue to face the challenges of older hospice patients and their caregivers. Since many patients in hospice care are over 65 years of age, as are their caregivers, there is a need for models of communication and decision-making that consider the special needs of elders receiving end-of-life care. Many women outlive men and face terminal illness alone. Many hospices, however, will not admit patients who do not have primary caregivers. This policy needs to be examined.

In view of these challenges, many believe that if better pain relief and patient/surrogate communication are provided, thus restoring the public's faith in the health care system, patients would approach the dying process differently and not opt for drastic measures such as assisted suicide or euthanasia. In a recent survey, it was found that physicians who complied with a request for lethal injection often asked a nurse to administer it.⁷⁷ A total of 38 physicians reported a recent experience with lethal injections: 43% gave the injection and 57% requested that the nurse give the injection.⁷⁸ In all cases, the physicians involved believed they had honored the patients' wishes.⁷⁹

75. See Finucane & Harper, *supra* note 19, at 370.

76. See *id.* at 371; see also Koenig & Gates-Williams, *supra* note 38, at 246.

77. See Charles L. Sprung & Arieh Oppenheim, *End-of-Life Decisions in Critical Care Medicine: Where Are We Headed?*, 26 CRIT. CARE MED. 200, 202 (1998).

78. See Dianne Meier et al., *A National Survey of Physician-Assisted Suicide and Euthanasia in the United States*, 338 NEW ENG. J. MED. 1193, 1196 (1998).

79. See *id.* at 1197, 1199.

Interdisciplinary educational efforts are needed to prepare health care providers with confronting family and patient requests to hasten death. Practitioners are often called upon to assess the mental state of the patient and the adequacy of the palliative care before responding to such a request.⁸⁰

IV. CONTRIBUTIONS FROM NURSING RESEARCH

The National Institute of Nursing Research (NINR) at the National Institutes of Health (NIH) issued several program announcements calling for studies related to end-of-life research.⁸¹ These programs have been focused in two key areas: bioethics and symptom management at end of life. Some of the findings from these studies are highlighted here to demonstrate nursing's contribution to the field of palliative care research.

A. *Research on Communication and Decision Making*

Nurses who work in palliative care are positioned to facilitate decisions in support of the patient's preferences and values by promoting discussions between the patient, family, and physician. If used properly, advance directive discussions may even reduce family conflict.⁸² Moreover, spousal caregivers of patients who had died expressed a desire for more concrete discussions of patient preferences.⁸³ Numerous anecdotal accounts document that either through direct statements to physicians while competent, or through an unambiguous written directive, patient refusals of life-sustaining interventions have been disregarded in response to demands from a relative.⁸⁴

Another challenging area for research is determining preferences of patients who are cognitively impaired. A recent study on this issue found that in 66% of the cases studied, surrogates correctly predicted the wishes of patients for particular treatments in specific scenarios.⁸⁵ Results suggest that health care professionals should urge

80. *See id.* at 1196.

81. *See New Directions in Pain Research I*, (visited Feb.1,1999) <<http://www.nih.gov/grants/guide/pa-files/PA-98-019.html>>.

82. *See* Virginia P. Tilden et al., *Decisions About Life-sustaining Treatment: Impact of Physicians' Behavior on the Family*, 155 ARCH. INT. MED. 633, 638 (1995).

83. *See id.* at 636-37.

84. *See id.* at 633.

85. *See* Daniel P. Sulmasy et al., *The Accuracy of Substituted Judgments in Patients with Terminal Diagnoses*, 128 ANN. INT. MED. 621, 621-29 (1998).

patients to talk with their families about end-of-life care and their specific desires early in the course of treatment.

Increasingly important in our pluralistic society are cultural preferences. One of the few studies in this area concluded that efforts to use racial or ethnic background as simplistic, straightforward predictors of beliefs or behavior will lead to harmful stereotyping.⁸⁶ This study suggests more meaningful ways to assess cultural variation in end-of-life care to account for the patient's unique culture and history.⁸⁷ Other cultural research stresses the need for further studies about the ways in which decisions are made and the ways families from diverse cultural backgrounds interact in the health care setting.⁸⁸

B. Research on Pain and Symptom Management at the End of Life

Along with improved communication, patients and families expect that end-of-life care will help relieve suffering and improve their quality of life. Palliation of difficult symptoms such as pain, nausea, fatigue, and shortness of breath has been a major area of focus for nursing. In 1997, a research workshop on "Symptoms in Terminal Illness" was convened at NIH and led by NINR and cosponsored by the National Institute of Allergy and Infectious Diseases (NIAID), the National Cancer Institute (NCI), the National Institute of Dental Research (NIDR), the National Institute on Drug Abuse (NIDA), and the Office of Alternative Medicine (OAM).⁸⁹ Subsequently, a program announcement was issued soliciting research addressing symptom management at end-of-life.⁹⁰ While research exists on the end stages of diseases and the physiological bases of symptoms and symptom relief, current knowledge and understanding are inadequate to guide the practice of evidence-based symptom management at the end-of-life.

The knowledge base to guide evidence-based practice is scarce. For example, even though we have the technology to control and manage pain, it has been reported that of those hospice patients who

86. See Koenig & Gates-Williams, *supra* note 38, at 244.

87. See Koenig & Gates-Williams, *supra* note 38, at 248 (arguing that a physician must understand the patient's cultural background in order to deal properly with end-of-life decisions). However, because individuals are not merely vessels of their culture, "... culture is only meaningful when interpreted in the context of a patient's unique history, family constellation, and socio-economic status." *Id.* at 244.

88. See Eugene Hern et al., *The Difference That Culture Can Make in End-of-Life Decision-making*, 7 CAMBRIDGE Q. HEALTH CARE ETHICS 27, 37, 39 (1998).

89. See *Symptom Management Workshop*, (Sept. 1997) <<http://www.nih.gov/ninr/end-of-life.htm>>.

90. See *id.*

are conscious, approximately 50% still die in pain.⁹¹ State medical boards must consider that providers should be free to provide pain relief without fear of losing their license to practice. More projects are needed such as the Mayday Scholars Program, established by the American Society of Law, Medicine & Ethics.⁹² The Mayday program is an innovative research project to determine legal, regulatory, and financing policies that affect access to effective pain relief. More interdisciplinary research like this would help further develop the scientific basis for practice and health policies that facilitate high quality care at end-of-life.

C. Future Research

Examining research conducted over the last decade permits identification of gaps in our knowledge and delineates areas of promise for the future.⁹³ Most of these are best addressed through the use of interdisciplinary approaches:

- Research on the management/treatment of pain at the end-of-life;
- Epidemiology, pathogenesis, and clinical management of symptoms common at the end-of-life;
- Strategies that facilitate patients and families to negotiate high-quality care;
- Methods of communicating that permit open discussion and identification of patient and family preferences and incorporate variable decision-making styles;
- Innovative structures and processes to help patients and families transition among varied care settings; and
- Clinical information systems that capture data about the wide range of issues affecting care at the end-of-life.

In summary, building a strong knowledge base to guide evidence-based practice and developing sound end-of-life policies will require continued interdisciplinary collaboration. Together, we can help patients and families achieve their concept of the "good death." Since a major focus for the discipline of nursing is on comfort and relief of suffering, we must step up our efforts to conduct research that provides the evidence for practice to improve care of the dying.

91. See INSTITUTE OF MEDICINE, *APPROACHING DEATH: IMPROVING CARE AT THE END-OF-LIFE* 5 (1997).

92. See American Society of Law, Medicine & Ethics, *Announcing Mayday Scholars Program* (visited Feb. 11, 1999) <<http://www.aslme.org/pain/scholars.htm>>.

93. See National Institute of Nursing Research, *Request for Application: Research on Care at the End-of-Life* (visited Feb. 11, 1999) <<http://www.nih.gov/ninr/PARFApage.htm>>.