CARING FOR THE DYING: THE IMPORTANCE OF NURSING

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It was an honor to participate in the University of Maryland's symposium, "Caring for the Dying: Reexamining Our Approach," and to contribute to the discussions about how we might better care for those who are dying. While nursing is integral to providing health care to individuals at every stage of life, this article will specifically address the importance of nursing care for those who are approaching the end of life.

I. THE ROLE OF NURSING AND NURSING RESEARCH

The normative role of the nurse is to provide health care services, either directly or by collaborating with other professionals as indicated, to help the patient cope with progressive illness. In most circumstances, the nurse is responsible for:

- Ongoing assessment of the patient's physical and emotional status,
- Developing a plan of care,
- Working with physicians and other disciplines to initiate and modify medications and other therapies directed toward the treatment and personal goals of patients and families,
- Educating family members about how to avoid problems and what to do if a problem occurs,
- Arranging additional help as needed,
- Being available as a resource for information and support.

The nurse provides health care as both generalist and specialist, a communicator and a team collaborator, and as a caring presence and a vigilant professional. Nurses bring a great deal of knowledge, skills, and personal commitment to health care. Nurse researchers develop new understandings and methods of care. Caring for people who are near the end of their lives with palliative, or comfort-oriented care,[1] presents nurses with very particular challenges and concerns.

The National Institute of Nursing Research (hereinafter "Institute") is committed to addressing these challenges and has designated

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1. The goal of palliative care is to provide comfort and a quality of life acceptable to the patient and the family members. *See* Margaret A. Varnell, *Palliative Care: A Patient's Right*, 1 ADVANCE FOR NURSES 29, 29 (1999) (stating that palliative care is defined as therapy designed to reduce the intensity of uncomfortable symptoms, but not to produce a cure).

end-of-life care as an area of major program emphasis.[2] The Institute's research portfolio provides an important base of knowledge for addressing the health care needs of the terminally ill. Some of the Institute's end-of-life areas of research include:

- Management of pain and other symptoms,
- Decision-making processes for incapacitated patients and their families,
- Methods of palliative health care delivery, and
- Development of effective palliative care.

The Institute established these priorities to address the need for improving how the dying are cared for, and is now the lead institute for palliative care research among the Institutes and Centers of the National Institutes of Health (NIH).[3]

Because the research mission of the Institute is not specific to any given disease or condition, the Institute collaborates with virtually all components of the NIH to contribute both the scientific expertise of nurse researchers and the insights of clinical experience. Nursing research strives to ensure that knowledge about health-enhancing and life-conserving interventions is translated into effective health care services. The Institute also works to make this knowledge relevant to people as they live out their lives and as they near the end of their life.

II. NURSING RESEARCH AND END-OF-LIFE CARE

The Institute's emphasis on end-of-life research is timely. The Institute of Medicine (IOM) has reported that while advances in health care continue to increase life expectancy, attention to the quality of life and to the inevitable experience of dying has not kept pace.[4] The IOM report has stressed the need for more research in palliative care.[5] The Institute currently supports studies to understand and ease the symptoms of acute and chronic pain.[6] Research is also being funded to address the bioethical, biological, and behavioral issues that are inextricably a part of dying.[7]

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2. *See National Institute of Nursing Research, Mission Statement*, ¶ 1 (visited Jan. 23, 1999) <http://www.nih.gov/ninr/NINRMission.htm>.

3. *See id.*

4. *See* Caroline McNeil, *Are Changes in End-of-Life Cancer Care Coming? IOM, ASCO Tackle Issues*, 89 J. NAT'L. CANCER INST. 994, 994-96 (1997).

5. *See id.* at 994; *see also* COMMITTEE ON CARE AT THE END OF LIFE, DIVISION OF HEALTH CARE SCIENCES, INSTITUTE OF MEDICINE, APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE, v-vii (M.J. FIELD & C.R. CASSEL eds. 1997).

6. *See National Institute of Nursing Research, supra* note 2, at ¶ 1.

7. *See id.*

Technological advances in health care over the past few decades have created challenges for health care providers, patients, and family members.[8] Those involved must face difficult choices between pursuing cure-oriented, though possibly futile, treatment options, or delivering comfort-oriented palliative care. Arguably, there has been a cultural inclination toward using all means to extend life. From this perspective, palliative care has been considered a concession or a failure, and has not always been regarded as appropriate or as good health care.[9]

While technological advances in health care have extended life expectancy, they have also resulted in people living longer with chronic, often painful and disabling conditions.[10] Our society now faces the dilemma of having the technological capacity to extend life beyond what many consider a reasonable quality of life.[11] The rapid rise in the elderly population presents even more complex challenges to the health care system as it attempts to respond to the needs of frail and incurably ill elderly patients.[12] This challenge also extends to the patients' families and their needs for assistance in managing their burden of care and possible financial hardships.[13] Concern about how people die and the options that are now available to some have led to health care initiatives that emphasize the need for palliative treatment for patients near the end of life.[14] The Institute is committed to supporting research to find ways to improve how we care for those who are dying. End-of-life research does not focus on curing chronic ill-

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8. *See generally* Katherine Morton Robinson, *Family Caregiving: Who Provides the Care, and at What Cost?*, 15 NURSING ECON. 243 (1997).

9. *See* Michael McCarthy, *U.S. Patients Do Not Always Get the Best End-of-Life Care*, 349 LANCET 1747, 1747 (1997) ("Medical culture still tolerates and even rewards the misapplication of life-sustaining technologies while slighting the prevention and relief of suffering.").

10. *See id.*

11. *See, e.g.*, Alan B. Astrow, *Wrong Medicine*, 348 LANCET 1227, 1227 (1996). Doctors receive little guidance on how and when to limit their use of advanced medical technology on dying patients. *See id.* As a result, many dying patients receive aggressive therapies of questionable value. *See id.* Patients who will never leave the intensive care unit will often receive life-extending treatments. *See id.*

12. *See generally* Kathleen N. Lohr, *How Do We Measure Quality?*, HEALTH AFFAIRS 22 (May 1997).

13. *See generally id.*

14. *See* Melinda A. Lee, *Legalizing, Assisted Suicide—Views of Physicians in Oregon*, 334 NEW ENG. J. MED. 310, 310 (1996). There are relevant initiatives that pertain to how people die and the need for better care so patients do not feel as if suicide is their only avenue for pain relief. *See* Assisted Suicide Funding Restriction Act of 1997, Pub. L. No. 105-12, *amending* 42 U.S.C. § 781 (1997) (mandating a review by the General Accounting Office of NIH funding for palliative care and pain management research with the aim of addressing those issues that lead people to consider suicide for relief from an intolerable quality of life).

ness but on managing symptoms of those who are near the end of their life span. The goal of palliative care is to provide comfort and a quality of life acceptable to the patient and the family members.

Presently, the challenge for nurse researchers is to decipher and understand the significant complexity of what has been referred to as the "constellation of symptoms" associated with the end of life.[15] There are substantial gaps in the knowledge of the physiological basis for the symptoms, how these symptoms are interrelated, and how to manage and reduce the impact of these symptoms. The Institute's goal is to help build the knowledge base about effective palliative care for use with those who are dying.[16] As we understand more about how to provide a higher quality of life for those who are dying, patients and families will be able to dedicate their efforts and time to their own personal dimensions at this critical time.

III. SYMPTOM MANAGEMENT RESEARCH

Over the past few years, the Institue has been building on its base of research in symptom management.[17] In particular, Institute-sponsored research includes studies that focus on pain as a prevalent symptom experienced by those who are dying. Pain is a multimillion dollar public health problem and the number one reason for patients to see a health care provider.[18] Pain accounts for 42 million patient visits per year, and crosses the entire spectrum of health, from the neonatal unit to the hospice bed.[19] The Institute supports a number of investigations on pain and its effects on health.[20] The following studies are examples of the Institute's pain management research portfolio.

Family members report that physicians and nurses typically underestimate the amount of pain and other physical distresses, such as nausea and shortness of breath, experienced by terminally ill patients

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15. The phrase "constellation of symptoms" is generally regarded as an apt description of the complexity of end-of-life issues. *See* Russell Portenoy, *Symptoms Commonly Experienced in Terminal Illness: Symptoms in Terminal Illness: A Research Workshop*, ¶1, 7 (visited Jan. 22, 1999) <http://www.nih.gov/ninr/end-of-life.htm>.

16. *See National Institute of Nursing Research, supra* note 2, at ¶ 1 (stating that the Institute, "seeks to understand and ease the symptoms of acute and chronic illness").

17. Symptom management embodies the notion that even in situations where an underlying disease cannot be cured, the symptoms of the disease can be prevented or cured by using drugs or other interventions, thus enabling an individual to achieve a better quality of life. *See Executive Summary: Symptoms in Terminal Illness: A Research Workshop*, ¶ 3 (visited Jan. 22, 1999) <http://www.nih.gov/ninr/end-of-life.htm>.

18. *See id.* at ¶ 2.

19. *See* Dr. Richard Payne, *Pain: Clinical Perspective: Symptoms in Terminal Illness: A Research Workshop*, ¶ 1 (visited Jan. 22, 1999) <http://www.nih.gov/ninr/end-of-life.htm>.

20. *See National Institute of Nursing Research, supra* note 2, at ¶ 1.

in the last week of life.[21] Without accurate measures to assess a patient's level of pain, treatment often can be inadequate. Without adequate pain control, the patient's quality of life and health status may be jeopardized. Severe discomfort from pain can deter a patient from adequate nutritional intake and necessary physical activity, which may compound and lead to other complications. The goals of this study on pain assessment in elderly patients are to establish measures of pain intensity, identify difficulties in optimally responding to measures, and identify criteria for selecting the appropriate and reliable tool for measuring pain in an elderly patient population.[22]

Certain medications given before surgery can actually block the action of medication given to relieve pain after surgery.[23] Nurse researchers are also investigating behavioral interventions that would improve the effectiveness of analgesics by addressing patient-related barriers such as concerns about side effects or fear of addiction, beliefs that can interfere with patient-family-clinician goal of pain control.[24] Another study found evidence of gender differences in response to pain medication.[25] Further study could lead to gender-specific recommendations for pain treatment.

One area of symptom management associated with terminal illness deals with the unique problems of HIV/AIDS patients. Using the Institute's funds, nurse researchers are conducting clinical tests on a dietary intervention to reduce the frequency of diarrhea in AIDS patients.[26] In advanced stages of AIDS, as in other terminal illnesses, this condition can be life threatening. The investigation is being administered at an outpatient clinic serving a low-to-middle-income community.[27] This symptom management research may significantly enhance the quality of life among terminally ill patients in underserved populations.

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21. *See* Virginia P. Tilden, *Family Decision Making for Incapacitated Patients*, 1997, *available in* CRISP, Project No. R01NR03526; *see also* Summary of the Capital Hill Breakfast Briefing on End-of-Life Care, ¶ 9 (visited Dec. 21, 1998) <http://www.nih.gov/ninr/eolbriefing.htm>.

22. *See* Keela A. Herr, *Elder Pain—Assessment of Intensity*, 1997, *available in* CRISP, Project No. R29NR0328.

23. *See* Robert W. Gear et al., *Benzodiazepine Mediated Antagonism of Opioid Analgesia*, 71 PAIN 25, 25 (1997).

24. *See* Sandra E. Ward, *Representational Intervention for Cancer Pain*, 1997, *available in* CRISP, Project No. R01NR03126-04.

25. *See* Jon D. Levine, *Gender and Sex Hormones and Opioid Analgesia*, 1997, *available in* CRISP, Project No. 3R01NR03923.

26. *See* Joyce K. Anastasi, *Testing Strategies To Reduce Diarrhea in Patients with HIV*, 1997, *available in* CRISP, Project No. R29NR04169.

27. *See id.*

Nausea is another symptom that afflicts many terminally ill patients.[28] Current research into the side effects of chemotherapy is expected to produce advances in treating nausea for all chronically ill patients.[29] Nursing studies have found that pre-treatment scores on measures pertaining to the autonomic nervous system active in nausea development predict subsequent chemotherapy-induced nausea.[30]

Cachexia or wasting and profound weight loss are symptoms associated with terminally ill patients and are a major contributor to the death of cancer patients as well as being prevalent in patients with AIDS, bacterial diseases, rheumatoid arthritis, and chronic diseases of the bowel, liver, lungs, and heart.[31] Nurse researchers are studying the complex relationship of calorie intake, nutrient utilization, and malignancy.[32] Preliminary findings indicate that the reduction in food intake in cancer patients may represent the body's deliberate regulatory adjustment.[33] Further research will attempt to determine why the body would consume less at a time when it would appear to need more calories to fight disease. Researchers will also attempt to develop interventions that can improve caloric intake and lessen the complications associated with cachexia.[34] Other studies within the NIH research community have indicated that nutritional manipulations, exercise, and pharmaceutical therapies have had limited success in control of cachexia-related symptoms, including nausea.[35]

Dyspnea, generally described as a shortness of breath or subjective difficulty or distress in breathing, is another symptom associated with patients at the end of life.[36] Nurse researchers are studying the

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28. *See* Dr. Neil MacDonald, *Cachexia or Wasting: Clinical Perspective: Symptoms in Terminal Illness: A Research Workshop*, ¶ 1 (visited Jan. 22, 1999) <http://www.nih.gov/ninr/end-of-life.htm>.

29. *See* Gary R. Morrow, *Predicting Side Effects of Cancer Treatment*, 1997, *available in* CRISP, Project No. R01NR01905.

30. *See* Albert M. Bellg et al., *Autonomic Measures Associated with Chemotherapy-Related Nausea: Techniques and Issues*, 13 CANCER INVESTIGATION 313, 315, 322 (1995).

31. Cachexia is characterized by deterioration of organs and muscles resulting in profound weight loss. *See* MacDonald, *supra* note 28.

32. *See* Eduardo Bruera & Catherine M. Neumann, *Management of Specific Symptom Complexes in Patients Receiving Palliative Care*, 158 CANADIAN MED. ASS'N. J. 1717, 1717 (1998).

33. *See id.*

34. *See* Donna O. McCarthy et al., *The Effect of Protein Density of Food on Food Intake and Nutritional Status of Tumor-Bearing Rats*, 20 RES. IN NURSING & HEALTH, 131, 131-38 (1997).

35. *See* Carlos Plata-Salaman, *Cachexia: Basic Perspective: Symptoms in Terminal Illness: A Research Workshop*, ¶ 13-14 (visited Jan. 22, 1999) <http://www.nih.gov/ninr/end-of-life.htm>.

36. *See* Deborah Dudgeon, *Dyspnea: Chemical Perspective: Symptoms in Terminal Illness, A Research Workshop*, ¶ 1 (visited Feb. 5, 1999) <http://www.nih.gov/ninr/end-of-life.htm>.

causes of this disconcerting respiratory condition.[37] Palliative treatments of dyspnea that are currently being tested include opioids and anti-anxiety drugs.[38] Findings indicate that anxiety compounds the distress of dyspnea, and that further study needs to focus on developing effective interventions for both dyspnea and anxiety.[39] In other studies, behavioral interventions such as altered diaphragmatic maneuvers and other breathing techniques have produced some success in the treatment of dyspnea.[40] One study on dyspnea proposes the development of a model for symptom interpretation.[41] Despite the prevalence of breathlessness in terminally ill patients, measurement and definition are inadequate. The goals of this investigation include the development of methods of defining and measuring dyspnea, and the development of nursing intervention strategies. The results of this research have the potential to decrease the financial, physical, and emotional impact of dyspnea.

Many patients at the end of life experience cognitive disturbances or delirium that are disconcerting to patient and family.[42] Nurse researchers have enhanced the understanding of this symptom by developing new measurement tools. A recent study proposed quality-of-life measurements for patients with Alzheimer's disease based on personality, external support and environment, and health and psychological status variables.[43] The goals of this area of research include the ability to predict the standard of the quality-of-life for patients with symptoms that impede cognitive faculties. Such measures will ultimately lead to enhanced sensitivity to individual patients' health care and emotional needs.

Given the crucial role of family members and other informal (or unpaid) care givers, nurse researchers have dedicated a significant amount of resources to investigating systems and mechanisms for those who directly help in the management of symptoms. As increasing numbers of people elect to leave hospitals to die in a home set-

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37. *See id.*

38. *See* Bruera & Neumann, *supra* note 32, at 1717.

39. *See* Virginia Carrieri-Kohlman et al., *Differentiation Between Dyspnea and Its Affective Components*, 18 WESTERN J. NURSING RESEARCH 626, 627 (1996).

40. *See* Dudgeon, *supra* note 36, at ¶ 1.

41. *See* Paula Meek, *Examining the Symptom Interpretation Process, available in* CRISP, Project No. R29NR04137-03.

42. *See* Jane Ingham, *Cognitive Disturbances: Clinical Perspective: Symptoms in Terminal Illness: A Research Workshop*, ¶ 3 (visited Jan. 22, 1999) <http://www.nih.gov/ninr/end-of-life.htm>.

43. *See* Sandy C. Burgener, *Factors Predicting Quality of Life in Dementia Patients*, 1997, *available in* CRISP, Project No. K07NR00074.

ting[44], family members or compassionate friends must be trained as care givers. Research has identified the need for care givers' training in the areas of health care delivery skills, problem solving, and the utilization of community-based services.[45]

For example, care givers need to be trained in the skills of dispensing opiates as well as in an understanding of the sensitivity to the changing nutritional needs of a dying person.[46] Research designed to enhance the care giving capacities of family members or friends also addresses issues concerned with helping care givers handle stress and maintain their own health.[47] Nurse researchers are developing these educational and training programs for those who care for the dying.

Several of these end-of-life symptoms often occur in combination and are interconnected. For example, wasting affects breathlessness because the chest muscles become weaker. In another example, opioids, a class of drugs used to treat pain, may also lessen dyspnea but worsen cognitive function. This association underscores the need to consider these symptoms as interrelated, as a constellation of symptoms.[48] Furthermore, multi-disciplinary collaborative research priorities within the scientific community will advance our understanding of these complex interactions and debilitating conditions. The Institute continues to encourage and facilitate the collaborative end-of-life research efforts at NIH.

IV. BIOETHICAL AND DECISION-MAKING PROCESSES

In addition to the extensive research portfolio on symptom management, the Institute also supports research on the bioethical issues and decision-making processes associated with terminal illness, including the needs and expectations of dying individuals and their fami-

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44. *See, e.g.*, Lee Bowman, *More Die in Hospitals with More Beds*, PITT. POST-GAZETTE, Oct. 9, 1998, at A20 (citing a recent study that found that 81% of the terminally ill questioned said that they wanted to die at home).

45. *See* Virginia K. Conkling, *Continuity of Care Issues for Cancer Patients and Families*, 64 CANCER 290, 292 (1989); *see also* Frank Smeenk et al., *Transmural Care of Terminal Cancer Patients: Effects on the Quality of Life of Direct Caregivers*, 47 NURSING RES. 129, 134-135 (1998).

46. *See generally* Nat'l Inst. Nursing Res., *supra* note 21.

47. *See id.* (recognizing the extraordinary demands placed on family caregivers and calling for more attention to caregivers' well-being).

48. *See* Carlos Conill et al., *Symptom Prevalence in the Last Week of Life*, J. PAIN & SYMPTOM MGMT. 328, 330 (1997). For example, advanced cancer patients have over six symptoms on average. *See id. See also* Joanne Lynn, *Common Research Issues: Symptoms in Terminal Illness: A Research Workshop*, ¶14 (visited Jan. 22, 1999) <http://www.nih.gov/ninr/end-of-life.htm>.

lies.[49] The impetus for this area of research comes from findings that report great disparities between the preferences of terminally ill patients and their families, and what clinicians think patients and families want.[50] There are many reports in the media that the American public is generally not satisfied with care at the end of life.[51] Several major studies sponsored by such organizations as the Robert Wood Johnson Foundation (RWJ)[52] and IOM,[53] have issued reports on end-of-life issues. These reports document the following:

- Pain is common in most terminally ill patients,
- Discrepancies exist between patient desires and actual treatment, and
- Almost half of the physicians in the RWJ-funded SUPPORT study did not know that their patient's preferences were not to be resuscitated.[54]

The Institute supports research comparing the decision-making processes of patients, their families, and clinicians (nurses and physicians) regarding the ethical reasoning behind decisions to withdraw life-sustaining treatments.[55] This research addresses how family members perceive their responsibility and authority, and what conflicts may arise among family members and between family members and clinicians. Previous efforts to enhance patient and family autonomy through the encouragement of advance directives have not produced consistent results.[56] Health care clinicians, patients, and families lack

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49. *See National Institute of Nursing Research: Areas of Research Opportunity Responding to Compelling Societal Health Concerns End-of-Life Care*, ¶ 1 (visited Jan. 18, 1999) <http://www.nih.gov/ninr/fy98-research-ops.htm>.

50. *See, e.g.*, Joanne Lynn et al., *Perceptions by Family Members of the Dying Experience of Older and Seriously Ill Patients*, 126 ANNALS OF INTERNAL MED. 97, 103 (1997). *See also* Laura C. Hanson et al., *What is Wrong With End of Life Care? Opinions of Bereaved Family Members*, 45 J. AM. GERIATRIC SOC'Y, 1339, 1339-44 (1997).

51. *See Medics Say Dying Often Overtreated*, CHI. TRIB., Jan. 17, 1993, *available in* 1993 WL 11032039.

52. *See National Institute of Nursing Research*, *supra* note 49, at ¶ 5; *see also* SUPPORT Investigators, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT)*, 274 JAMA, 1591, 1591 (1995).

53. *See* COMMITTEE ON CARE AT THE END OF LIFE, *supra* note 5, at v-vii.

54. *See National Institute of Nursing Research*, *supra* note 49, at ¶ 5.

55. *See id.*; *see generally* Tilden, *supra* note 21.

56. *See, e.g.*, Marion Danis et al., *A Prospective Study of Advance Directives for Life-Sustaining Care*, 324 NEW ENG. J. MED. 882, 884 (1991). Medical treatment was consistent with advance directives in 75% of cases. *See id.* Consistency between patient's wishes and treatment was actually less when the advance directive was included with the patient's medical record. *See id.* at 885; *see also* Joan Teno et al., *Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention*, 45 J. AM. GERIATRIC SOC'Y 500, 504 (1997). Patients with advance directives had their prefer-

procedures for determining when aggressive treatment is futile.[57] We also need to provide guidance to family members in understanding treatment options and the goals of palliative care.

In addition to the findings from these studies, Institute-supported researchers also have outlined the following preliminary recommendations on bioethics and health care delivery to those who are dying:

- Families report that clinicians underestimate the level of pain and other physical distress of the patient.[58]
- When health care professionals view death as a failure, it causes considerable distress for family members.[59]
- Abrupt changes in the health care setting, such as being discharged from the hospital to a nursing home, result in discontinuity in services and potential patient/family distress.[60]
- People with inadequate health insurance lack access to good palliative care and are much more likely to rely on expensive hospitalization for symptoms that could have been managed by hospice or home-health nurses.[61]

Not surprisingly, findings show that the families involved in making the decision to terminate aggressive life-sustaining treatments have urgent needs for emotional and educational support.[62] Research shows that nurses, in particular, could take specific actions to reduce the burden on families during decision-making.[63] Possible recommendations include:

- Verifying the accuracy of patients' preferences over time,
- Monitoring staff compliance to patients' preferences, and
- Ensuring high quality comfort care when intervention treatment transitions to palliative treatment.

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ences documented in 38% of cases, while those without advance directives had their preferences documented 33% of the time. *See* Teno, *supra*, at 504.

57. *See* Malcolm McD Fisher & Raymond F. Raper, *Withdrawing and Withholding Treatment in Intensive Care Part 2. Patient Assessment*, 153 MEDICAL J. AUSTRALIA 220, 220 (1990).

58. *See* Summary of the Capitol Hill Breakfast Briefing on End-of-Life Care, *supra* note 21, at ¶ 3.

59. *See id.*

60. *See id.*

61. "Hospice care" can be defined as palliative care provided to the terminally ill and their families. *See* Conrad J. Clemens et al., *Pediatric Home Health Care in King County, Washington*, 99 PEDIATRICS 581, 582 (1997). "Home health care" consists of medical services provided to the ill or disabled in their homes. *See id.*

62. *See* Hanson, *supra* note 50, at 1343.

63. *See Nursing Colleges Point to Needed Skills for End-of-Life Care*, PUB. HEALTH REP., July 1, 1998, at 298, *available in* 1998 WL 15142365.

V. FUTURE DIRECTIONS FOR END-OF-LIFE RESEARCH

As the lead institute for research on palliative care at the end of life, the Institute encourages additional research in this area. As findings from current projects are being issued, the Institute is developing and refining directions for future study. The Institute will continue to support research of common symptoms associated with terminal illnesses.[64] One of these areas will include investigations around drugs and pharmaceuticals, such as reduction of side effects of drugs, developing better-targeted drugs, and improving techniques for drug delivery.[65]

Future symptom management research priorities also include the development of more precise methods and assessment strategies to measure symptoms. As more effective tools and strategies are tested and implemented, clinicians will be better equipped to deliver appropriate palliative care.

The Institute will also continue to examine the ethical issues that affect health care for the terminally ill. The study of the efficacy of advance directives[66] and other mechanisms for establishing and honoring family and patient preferences about symptom management will continue. Researchers will be encouraged to study other issues regarding ethics and decision-making, including autonomy issues for a dying person who is cognitively impaired, barriers to end-of-life research for vulnerable populations, and cultural perceptions and variations that influence patient and family preferences.

Economic issues, such as the direct and indirect costs and burdens of symptoms, represent challenges for future the Institute-sponsored research.[67] Specific economic concerns that have been identified for further study include the issue of transitions from one health care setting to another, and what contexts foster effective and

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64. *See generally* National Institute of Nursing Research, *Request For Applications and Program Announcements* (visited Jan. 20, 1999) <http://www.nih.gov/ninr/PARFApage.htm>.

65. *See generally Symptoms in Terminal Illness: A Research Workshop* (visited Jan. 21, 1999) <http://www.nih.gov/ninr/end-of-life.htm>.

66. There are two kinds of directives. The first is the instruction directive, or "living will," which states a person's preferences regarding the use of life-sustaining treatment. *See* Robert E. Astroff, *Who Lives, Who Dies, Who Decides?: Legal and Ethical Implications of Advance Directives*, 7 WINDSOR REV. LEG. & SOC. ISSUES 1, 3 (1997). The second is the proxy directive, or "durable power of attorney," which designates a particular person to make decisions regarding the use of life-sustaining treatment should the patient become incapacitated. *See id.*

67. *See* Summary of the Capitol Hill Breakfast Briefing on End-of-Life Care, *supra* note 21, at ¶ 2.

cost-efficient palliative care.[68] The Institute anticipates issuing a request for proposals that will include this area of end-of-life research.

The National Institute of Nursing Research is enhancing the base of knowledge and practice for health care professionals and all those who care for the dying. As more is known about how to provide effective palliative care, remaining life can be more meaningful and affirming for those who are dying and for their families. The Institute is committed to investing resources in the development of new tools for assessing symptoms and evaluating treatments. These tools will enable us to clarify the extent of the problem and to set national priorities to improve quality of life for those facing terminal illness.

The end of life is an important phase of life. People have the right to expect the highest quality of care possible and to have their wishes about care respected. They also deserve to have their symptoms well controlled to permit the highest quality of life possible so that they have opportunity to focus on those things that are most meaningful and personal. Nurse professionals and nurse researchers are honored to have a central role in addressing how we might best care for those who are dying.

68. *See* National Institute of Nursing Research, *Transitions in Long-Term Care*, ¶ 28 (visited Jan. 21, 1999) <http://www.nih.gov/ninr/vol13/Transition.htm>.