

Preface

We are pleased to collaborate with *The Gerontologist* to present this series of articles on end-of-life research with a focus on older populations. The articles are an outgrowth of the Integrative Workshop on End-of-Life Research, which was held in Bethesda, MD, on October 22–23, 2001. This invitational workshop was organized by the Trans-Department of Health and Human Services End-of-Life Research Interest Group and was sponsored by the Fetzer Institute, the National Institute of Nursing Research, the National Institute on Aging, the National Cancer Institute, and the National Center for Complementary and Alternative Medicine at the National Institutes of Health (NIH); the Agency for Health Care Research and Quality; and the Health Resources and Services Administration. A list of planning committee members and workshop participants is appended at the back of this special issue.

The primary purpose of this workshop was to define the current state of the science for end-of-life in older people and to identify future directions for NIH research initiatives. The workshop was organized according to four themes related to end-of-life research:

1. The Experience of Dying—Spirituality
2. End-of-Life Organizations, Settings, and Transitions
3. Methods and Measurement in End-of-Life Research
4. Ethical Implications of End-of-Life Research

Prior to the workshop, experts were commissioned to write articles on selected topics, and discussants prepared written reactions to the articles. These articles provide the content for this special issue. At the workshop, the articles and comments were presented to a multidisciplinary panel who then discussed each topic and identified future research directions.

The following summary provides a brief synopsis of the articles contained in this issue and proposes future research directions.

Theme 1: The Experience of Dying—Spirituality

Article 1—The Experience of Dying: An Ethnographic Nursing Home Study

In this article Kayser-Jones reviews the literature on the experience of dying and presents data from a larger, ongoing ethnographic study of dying in nursing homes. Her review of the literature disclosed that research on the experience of dying is limited; most of the studies have been conducted in acute care hospitals among people who were dying of cancer. The ethnographic study found that lack of attention to cultural needs, cognitive status, inadequate staffing, and

inappropriate and inadequate communication between health care providers and nursing home residents and their families were the predominant factors that influenced the experience of dying.

A Commentary: The Role of Religion and Spirituality at the End of Life

Koenig argues that patients who are dying and their families need to have physical, psychological, social, and spiritual needs comprehensively addressed during their final days of life. None of these areas should be neglected either in clinical care or in scientific research. When these needs are addressed in a compassionate, sensitive, and patient-centered way, this increases the likelihood that the dying process will be experienced as both comfortable and meaningful for patient, family, and health care providers. More research is needed to better understand the spiritual needs of dying persons, to determine when religion contributes positively and when it contributes negatively to the dying process, and to decide what role the religious community can play in providing the kinds of support patients and families need as they depend less on the formal health care system.

Article 2—A Biopsychosocial-Spiritual Model for the Care of Patients at the End of Life

Sulmasy notes that people live their lives as human persons. They die their deaths as human persons. The fundamental task of medicine, nursing, and the other health care professions is nothing other than to minister to the suffering occasioned by the empirically necessary physical finitude of human persons, in their living and in their dying. A patient is a human person in relationship—biologically, psychologically, socially, and transcendentally. Illness disrupts all of the dimensions of relationship that constitute the patient as a human person, and, therefore, only a biopsychosocial-spiritual model can provide a foundation for treating patients holistically. The biopsychosocial-spiritual model proposed in this article suggests an approach to research that accommodates the many dimensions of the human person.

A Commentary: Hospital Experience and Meaning at the End of Life

Examples from an ethnographic study place *meaning* within the complex cultural worlds of persons and in the rules and norms of institutions in this commentary

by Kaufman. Meaning resides not only in the patient but also in the family, health provider, and the communication among them. It is expressed in negotiations about care. What constitutes the religious or spiritual may be indistinguishable from moral convictions, desperate hopes, or the expression of fear and confusion. Family perspectives may challenge the societal ideal of humane dying. Health professionals who are concerned with making death better can seek meaning in multiple locations, including the patient's life course and cultural world, the family's hopes and moral understandings, the health professional's convictions, and the institutional pathways where decision making is conceived.

Research Recommendations for The Experience of Dying—Spirituality

1. Develop instruments for measuring existential meaning and value, spiritual states, spiritual histories, religious coping, spiritual well-being, and spiritual needs of those who are mourning.
2. Study the interactions between the measurable dimensions of spirituality and more traditional health variables.
3. Design and measure the effectiveness of spiritual interventions, such as prayer and systematic use of groups.
4. Assess the spiritual significance of patient-professional relationships, the impact of the health professional's own spirituality on end-of-life care, and the influence of the dying person on the caregiver.
5. Evaluate the positive and negative contributions of spirituality to the dying process and the role of religious communities.
6. Evaluate the contribution of the humanities—what words mean and how people interpret words.
7. Design interventions to alleviate existential suffering (as opposed to pain).
8. Identify whose role it should be to help patients examine and address their spiritual needs.
9. Evaluate interactions between spiritual domains and traditional medical phenomena, symptom perception and management, and quality of life.
10. Assess spirituality after death, including bereavement research and how the spirituality of the patient impacts the family.
11. Determine the impact of care providers who are nonreligious but spiritual and individuals outside Judeo-Christian backgrounds.
12. Identify what is important to individuals at the end of life and their expectation of a good quality of life.
13. Define how hope for a cure affects patients' and families' decisions about the use of technology to extend life.
14. Define the clinical pathways of dying and important influencing variables such as duration, patterns, and comorbidities.

Theme 2: End-of-Life Organizations, Settings, and Transitions

Article 1—What Is Known About the Economics of End-of-Life Care for Medicare Beneficiaries?

This literature review by Beeuwkes Buntin and Huskamp suggests two fields of future inquiry. First, researchers need to fill critical gaps in their knowledge about how to design an end-of-life care system that better meets the needs of older populations. The most critical gaps are in researchers' understanding of how end-of-life care decisions are made and their consequences for patient satisfaction, care costs, and care outcomes. Second, researchers should study what can be done to improve the care available to dying patients under Medicare's current financing rules. One thing about the future seems certain: The need to understand and improve end-of-life care will become more pressing. The baby boom generation is caring for aging parents and beginning to think about their own retirement and old age. The demands they will place on the health care system will be large in financial terms and in terms of expectations for rationality and responsiveness. America's current system of care for the dying is not likely to meet those demands.

A Commentary: Social and Cultural Determinants of End-of-Life Care for Elderly Persons

This article by Berger and colleagues reviews the literature regarding the social, cultural, and economic determinants regarding the settings where elderly individuals in the United States die. Given the paucity of data on this subject, the review includes research conducted over the past 20 years. The problem with this approach is the profound economic and technological advances that have occurred in the health care delivery system that have affected how and where people spend their last days of life. The model used to structure the discussion is that of Mor and Hiris (1983), which outlines possible factors that influence the settings at the end of life: (a) patient sociodemographic characteristics, (b) types of available support networks, (c) measures of functional characteristics and degree of dependence on support network, and (d) health system and institutional factors.

Article 2—What Impact Do Setting and Transitions Have on the Quality of Life at the End of Life and the Quality of the Dying Process?

According to Mezey and associates, demographic factors, diagnosis, and health resources influence where older people die. In turn, the setting at time of death exerts a direct impact on the quality of life (QoL) at the end of life. Setting affects the philosophy of care; the types and intensity of services; who controls these services; the relationships among the persons delivering care and the dying person; caregiver expectations, skill, and availability; and financing to sustain care. Care provided in settings such as home, residential facilities, and prison is not easily reconciled

with a vision of comfort and quality at the end of life. Goals of care, expectations, training and availability of providers, and regulatory and financing structures are often at odds with good end-of-life planning. Most transitions of a dying older adult from home, assisted living facilities, skilled nursing facilities, and prisons are to the hospital, where 49% of deaths occur. This article provides a portrait of care in these settings and highlights the influence of setting and transitions on the quality of dying.

A Commentary: Where to Live While Dying

To provide end-of-life services, Lynn argues that funding for in-home services and regulations will need to be changed. Those reforms will be best if informed by data throughout the process of change. Rather than pursuing an ideology, even one that scorns nursing homes or celebrates hospice, practitioners would do well to settle on measures of success and to constrain their reforms to those that serve to accomplish their aims. Without evidence to the contrary, people who are sick enough to die should only rarely be in hospitals, although they may often live in institutions like nursing homes. Emergency transitions between other settings and hospitals should almost always be seen as a serious threat to patient safety. Planned transitions among settings need to be carried out with grace, redundancy of information and accountability, and patient and/or family involvement. Very good care would include institutional long-term care, and that type of care would be seen as desirable and supportive.

Research Recommendations for End-of-Life Organizations, Settings, and Transitions

1. Conduct prospective studies to quantify the consequences of end-of-life decision making, including comparisons of persons with different types of insurance and exploration of geographic variations in care patterns.
2. Evaluate the effect of costs on access for high-cost versus low-cost patients.
3. Identify how respect for cultural differences is operationalized in terms of the setting of death.
4. Describe the experience of dying in diverse cohorts, such as the aging gay and lesbian communities and newly arrived (undocumented) immigrants.
5. Evaluate how the family caregivers' physical, psychosocial, financial, and spiritual needs affect where the patient dies.
6. Test models for incorporating pain and palliative care in long-term facilities.
7. Describe factors that determine the family members' preferences as to place of death and how these preferences change over the course of the dying process.
8. Identify how differing care delivery systems and processes affect the QoL at end of life and during the dying process.

9. Assess organizational and economic obstacles that impede reliably excellent care at the end of life.
10. Conduct epidemiological studies of families who are involved in hands-on caregiving for a dying family member.
11. Analyze model programs both within and outside the United States that provide end-of-life care to identify features that can be replicated.
12. Assess the impact of the demographics of the baby-boom generation on caregiving for the following generation.
13. Test system changes that support mixed models of palliation and supportive services throughout the disease trajectory.
14. Identify processes that smooth transitions when a chronically ill person is transferred from home to hospital to nursing home.
15. Identify the ways in which our current health care system affects outcomes for patients.
16. Define the relationships among nurse-patient staffing ratios, quality of care, and the experience of dying.
17. Conduct population-based, epidemiology studies and monitoring of community-wide experience with end-of-life issues.
18. Evaluate the effect of changes in professional education about pain and palliative care on the advice given to patients and the place of death.

Theme 3: Methods and Measurement in End-of-Life Research

Article 1—Measurement of Quality of Care and Quality of Life at the End of Life

Although substantial progress has been made in the past decade on the psychometric measurement of variables central to end-of-life care, Tilden and colleagues note that demand is intense for better indicators of quality of care and QoL at the end of life. Complex challenges complicate psychometric measurement at the end of life whether for research or quality improvement. Challenges include difficulties in defining end-of-life time periods to delineate the denominator for statistical analyses, controlling for extraneous influences or other interactions on the variability of constructs, minimizing subject burden while maximizing robustness of a scale, and using proxies as respondents for a patient population that is largely incapacitated at the final stage. Challenges of measurement are especially intense with elderly persons, where frailty, dementias, and diminished vision and hearing, among other factors, affect validity, reliability, and utility of measures. This article offers recommendations for advancing the science of measurement at the end of life.

A Commentary: Cross-Cultural Quality-of-Life Assessment at the End of Life

Saxena and colleagues recommend that social and cultural factors need to be taken into account during

the measurement of QoL at end of life. Cross-cultural applicability of instruments is a major limitation for their widespread use. The World Health Organization's Quality of Life Instrument (WHOQOL) is a cross-cultural measure, which may be particularly useful for measurement of QoL across different areas. In particular, the development of two modules, one for persons who are living with HIV and another that measures Spiritual, Religiousness, & Personal Beliefs may have particular usefulness for assessment of QoL at end of life. The nature of the items reflects the needs of persons living with a life-threatening illness. The process followed in developing WHOQOL as well as the domains, facets, and items may be good starting points for a closer look at QoL at end of life.

Article 2—Research Design in End-of-Life Research: State of Science

Research on death, dying, and end-of-life care has exploded over the past decade, as discussed in this article by George. Although we have learned much, the research exhibits many of the conceptual and methodological problems characteristic of developing research traditions. This article reviews the quality of end-of-life research, focusing on limitations and ways of improving future research. The most fundamental problems are conceptual and include failure to define dying; insufficient attention to the distinctions among QoL, quality of death, and quality of end-of-life care; and an overly narrow focus. Methodologically, the highest priority for future research is longitudinal studies that examine trajectories of dying. Suggestions are offered for piggybacking end-of-life studies onto existing longitudinal studies. Gaps in the research are identified and include insufficient attention to psychological and spiritual issues, presence of psychiatric disorders among dying persons, provider and health system variables, social and cultural diversity, and the effect of comorbidity on trajectories of dying.

Commentary on "Research Design in End-of-Life Research: State of Science"

Researchers can learn much about the dying process by focusing on the symptom experience, rather than the condition(s), as set forth in this article by Tennstedt. Symptom characteristics and associated distress affect a patient's daily functioning and QoL. Most end-of-life research has been limited to Caucasians and African Americans, and it must be extended to other populations and subgroups. Other important avenues of investigation include the effects of health care providers, health care systems, supportive services, complementary or alternative therapies, and telemedicine. End-of-life research must be designed with sufficient scientific rigor to ensure that a worthwhile question can be answered and avoid exposing a vulnerable population to a protocol that yields little or no useful information. Longitudinal study designs will require handling subject attrition. Unlike other fields of research, death is an expected outcome, but

functional attrition is likely. Advances in analytical procedures will minimize bias associated with traditional analyses.

Research Recommendations for Methods and Measurement in End-of-Life Research

1. Test the utility of the WHOQOL in measuring QoL at the end of life.
2. Test conceptual models using sophisticated statistical analyses to determine the pathways among predictive, causal, and dependent relationships of key variables in end-of-life care.
3. Identify modifiable conceptual domains at end of life.
4. Study symptom clusters, specify covariant relationships between symptoms, and develop or modify measures that can most effectively index symptoms within clusters.
5. Develop and test culture-specific measures of variables important for end-of-life care.
6. Study measurement issues related to settings of care, differences in dying trajectories, fluctuations in symptom exacerbations, and validity of proxy data at different time points.
7. Develop and test newer and more sensitive measures of QoL outcomes.
8. Define appropriate methods for studying grief and bereavement.
9. Identify culture-specific research questions and methods such as approaches to investigating the concept of autonomy in Native American populations.
10. Evaluate the effects of comorbidities in end-of-life studies.
11. Test approaches to measuring provider effects, including communication skills, time spent talking with patients and families, and willingness to discuss end-of-life issues.
12. Define approaches for testing complementary and alternative medicine used during end-of-life care.
13. Develop measurement to describe the experiences of end of life.
14. Define how to measure change over time at (or very near) the end of life.

Theme 4: Ethical Implications of End-Of-Life Research

Article 1—What's End of Life Got to Do With It? Research Ethics With Populations at Life's End

Although end-of-life research does present important ethical and moral challenges and should be scrutinized carefully by institutional review boards (IRBs), Phipps notes that special guidelines are not required to promote and ensure the ethical conduct of research at life's end. Research at the end of life is diverse in methods, approaches, and goals and focuses on a vulnerable time for individuals and people in their lives. Arguments for imposing special requirements for

research at the end of life focus on this vulnerability. Special requirements would help ensure a more focused IRB review so that additional burdens are not placed on participants. Arguments against special requirements focus on the need for ethical standards to apply across all research with human subjects. Special guidelines would create different standards for research that would be difficult to justify. Although there are important and compelling reasons why additional attention should be paid to research at the end of life, they are not enough to warrant special requirements.

A Commentary—Institutional Review Board Approval and Beyond: Proactive Steps to Improve Ethics and Quality in End-of-Life Research

In this article Haley notes that three important steps can be taken to directly improve the ethical practice and indirectly improve the feasibility and quality of end-of-life research. One step is to develop educational programs and materials for end-of-life researchers. Experienced researchers have likely found effective ways to conduct studies, and their materials could be disseminated to new investigators. A second step is to develop model policies and guidelines for settings such as nursing homes and hospices, which may ease access and protect participants. A third step is educating staff and caregivers about the benefits of research and assuring they receive feedback about projects so they can apply research to practice. New rules for IRBs will not be effective in maximizing the ethical practice of research on the end of life.

Article 2—“Choice” in End-of-Life Decision Making: Researching Fact or Fiction?

It is rare in our society to leave this life without encountering biomedicine. Drought and Koenig report that it is now widely accepted that when death seems truly inevitable, the only measures that should be undertaken are those addressing comfort. However, we require the individual to choose that approach. The authors propose that the choice model manifest in the ethics of end-of-life care is fundamentally flawed. The problems recognized in the care of people at the end of life—poor symptom management and inadequate palliative care, provision of expensive but ineffective interventions, social isolation of the dying and their caregivers, a lack of resources for basic custodial care—can, in most cases, be traced back to the illusion of patient choice. Paradoxically, for patients to choose end-of-life care they need to understand that there is no choice in the matter. Outside the narrow confines of the hastened death debate, dying is simply not a choice. Patients need to understand—in more than a cognitive sense—that they are at the end of life.

A Commentary—Putting Autonomy in Its Place: Developing Effective Guidelines

For many cultural and historical reasons, autonomy has come to have an important place in Ameri-

can culture. In this provocative article, Callahan suggests that although it is an important principle, it is not the only principle, or value, to be brought to the bedside of the dying patient. It is especially important, moreover, that one particular interpretation of autonomy be excised from our moral reckoning: autonomy as the foundation of human dignity. The value of a human life ought never to be confused with the right or capacity to make choices. Patients come to critical moments in their health, including the threat of death, with a variety of needs: cognitive, emotional, relational, and valuational. It is vital to determine, from discussions with them and their families, just which needs are most important. For some, it will be vital that they make as many decisions as possible; they want their autonomy respected. For others, their emotions, or their relationships with families and friends, or a desire to place their trust in their physicians' discretion, may be more important. Every effort should be made to determine which needs are most important to patients, and their care should proceed accordingly.

Research Recommendations for Ethical Implications of End-Of-Life Research

1. Identify the values (beyond respect for autonomy) in end-of-life care for both patients, families, and providers.
2. Define a *meaningful sense of control* for the patient at the end of life and the applicability of the concept across cultures.
3. Test the utility of bioethical practices in clinical practice, including the legal and policy enshrinement of do-not-resuscitate orders and the impact of regulation on end-of-life care.
4. Measure the effect of ethical regulations and processes in different clinical settings.
5. Test how the choice of words one uses affects the informed consent process and willingness to participate in research.
6. Identify other principles or values besides autonomy and informed choice that influence decision making at the end of life.
7. Test approaches to conducting research with people with altered levels of capacity.
8. Study the consent process for patients who are competent but are in the process of becoming incompetent.
9. Test the effect of emotion in decision making at the end of life.

Overarching Research Topics

1. Patients' and families' perceptions of needs
2. Cultural issues
3. Effective communication
4. The experience of caregiving for families
5. Dying around a stigmatized issue (e.g., alcoholism)
6. Health provider differences
7. Provider decision making
8. Palliative care

Specific Suggestions

1. Piggyback end-of-life studies onto existing trials to eliminate the problem of access to subjects. This would provide collaboration and opportunities to collect longitudinal data.
2. Use the Small Business Innovation Research program to create incentives for new models of end-of-life care.
3. Develop Centers of Excellence in end-of-life research.
4. Use the research project cooperative agreements mechanism to form networks that would be useful in end-of-life research, consisting of a number of sites with access to patients, supported by a data coordinating center.

We hope this special issue will both inform readers

and stimulate them to generate new research projects based on recommendations set forth at the Integrative Workshop on End-of-Life Research.

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