Care CEU's
Continuing Education for Nursing Home Administrators

The Science of End of Life and Palliative Care

Structured Abstract

Building Momentum: The Science of End-of-Life and Palliative Care

Objective. This report provides a review of scientific literature published since the 1997 Institute of Medicine report, *Approaching Death: Improving Care at the End of Life*, in an effort to map the nature and extent of published research themes related to end-of-life and palliative care (EOL PC) science, the patterns in federal solicitation and funding of awards, and author acknowledgment of public and private stakeholders who fund this science. The report recognizes the significance of public and private investments to foster the growth of this research in order to better understand and improve EOL PC for patients and their families.

Data Sources. Four databases were used to search published research articles from 1997 to 2010: P*ubMed*®, the *Web of Science*, the *Cumulative Index to Nursing and Allied Health Literature*, and the *Cochrane Database of Systematic Reviews* (CDSR). The National Institutes of Health (NIH) *Query/View/Report* database was also used to search and view detailed information about NIH and related federal agency grant applications and awards from fiscal years 1997 to 2010.

Review Methods. Staff reviewed relevant articles, compiled tables of study characteristics and datasets, appraised target factors, and summarized results. Dataset topics, collection procedures, and evaluations were developed in consultation with advisory experts from the public and private sectors, including experts in research, clinical practice, policy, and evaluation.

Results. A total of 3,155 research publications were categorized for analysis. Funding-source information was contained within 1,258 of these articles. Additional funding-source information was obtained for an additional 216 publications through a follow-up author questionnaire. A total of 37 federal organizations supporting 444 new research grants were identified. More than 500 private, nonfederal organizations were also cited in the literature as sources of research funding.

A review of the datasets indicated significant trends in the growth of published EOL PC research. Scientific publications have tripled since 1997 with the primary emphasis of these publications focusing on topics related to advance care planning, care settings and standards, and pain and other symptom management. Cancer remains the most frequent health condition or disease topic of the published research; however, an increasing number of publications have begun to emphasize research targeting neurologic and respiratory issues in EOL PC.

Gaps in topic areas were identified. There were fewer publications reflecting the changing demographics of EOL PC for individuals with serious advanced illnesses and complex and multiple chronic conditions. Less than 5% of publications addressed EOL PC issues related to advanced renal or liver disease as well as EOL PC topics in advanced HIV/AIDS. Fewer publications

addressed EOL PC issues related to ethnic, cultural, or spiritual needs. EOL PC research focusing on pediatric populations has increased, but represented a small proportion of the publications. The review of the literature also noted trends in research topics that addressed economic, demographic, ethical, and social dimensions of EOL PC.

In terms of research funding, the sources of EOL PC science support are changing. Initially, the private sector was the primary acknowledged source of funding within the published literature. Since 2008, however, private funding acknowledgments have diminished while citations of federal sources of funding have increased. Within the public sector, NIH database information indicated that federal funding support of EOL PC science has increased more than tenfold since 1997; however, the sources for funding of this science by three key NIH institutes has remained unchanged. Since fiscal year 1997, 19 NIH Institutes and Centers have funded 399 new EOL PC research grant awards. The National Institute on Aging, the National Cancer Institute, and the National Institute of Nursing Research accounted for 87% of all federal grant awards and 85% of the associated funding. The Research Project Grant (R01) grant mechanism accounts for 30% of all awards and 51% of the funding dollars. Despite these gains, EOL PC research represents only a fraction of the total funds for biomedical science.

Conclusion. As various public and private organizations look to prioritize future scientific agendas, it is critical to support the continued growth of EOL PC science to address evolving knowledge gaps, identify new models of care, and build the evidence base to guide strategic planning. The findings from this current review point toward several opportunities to foster new science in EOL PC and create new momentum to broaden the existing scope of the field. Through embracing public-private research partnerships, fostering collaborations with new funding partners, creating opportunities to measurably fill evidence gaps, and shifting focus to vulnerable populations and under-researched topics, EOL PC science will continue to meet the challenges and the needs for high-quality and evidence-based advanced illness care.

Executive Summary

OVERVIEW | BUILDING THE SCIENCE OF END-OF-LIFE AND PALLIATIVE CARE

In 1995, the results of the landmark *Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment* (SUPPORT)[1] triggered a national discourse surrounding the serious deficiencies in the care provided to seriously ill and dying patients. Amidst the public outcry to address the study's identified gaps in and dissatisfaction with the experiences of end-of-life care, the report served as an assertion of the significant contributions of evidence-based research to inform and to guide the quality of health care services throughout the entire spectrum of living with and dying from an advanced illness. The *SUPPORT* study prompted a nationwide focus on the impact of research surrounding end-of-life care and became an illustration of how rigorous scientific research profoundly affects what, how, and why end-of-life care is provided. Since that time, numerous publications, reports, and initiatives have exemplified that research is the underpinning for identifying 'best' evidence to ensure that quality decisions are made in the care of those facing advanced illness. The significance of end-of-life and palliative care (EOL PC) science—from building strong integrative research programs to the effective dissemination of results into meaningful health care practices—remains unparalleled in its capacity to ensure the needs of individuals are addressed and that the end of life is fully integrated into the fullness of living.

MORE AND BETTER RESEARCH IS NEEDED TO INCREASE OUR UNDERSTANDING OF THE CLINICAL, CULTURAL, ORGANIZATIONAL, AND OTHER PRACTICES OR PERSPECTIVES THAT CAN IMPROVE CARE FOR THOSE APPROACHING DEATH.

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[1] A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) (1995). The SUPPORT Principal Investigators. *JAMA, 274*(20):1591-1598.

PURPOSE | KEY QUESTIONS ADDRESSED IN THIS REPORT

As a component of reviewing the contributions of the published EOL PC research literature over the past 14 years, this report evaluated information on the sources of funded research, the topics and trends in research themes, and the implications of these data to address existing gaps and priorities for future EOL PC science. The report's focus was to address several of the key1997 Institute of Medicine's *Approaching Death: Improving Care at the End of Life* report recommendations that called on the scientific community to strengthen the research landscape, foster new evidence, and define and implement priorities for increasing the knowledge base for EOL PC.[2] This report, therefore, is an effort to map not only the nature and extent of the trends in published research but also to define the scope of its funding support. The review recognizes the significance of both public and private investments to build this science and to foster the growth of research to better understand and improve EOL PC for all patients and their families. While not an evaluation of the quality of research or its findings, this report addressed several key questions:

- *What are the trends in EOL PC published research?*
- *Are EOL PC research interests and priorities changing over time?*
- *What are the funding sources of EOL PC science?*
- *Who are the stakeholders in EOL PC science?*
- *What opportunities exist for future partnerships to harmonize and strengthen research support for EOL PC science?*

METHODS | HOW DATA WERE COLLECTED AND ANALYZED

Four databases were used to search 1997 to 2010 published research articles: *PubMed®,* the *Web of Science*, the *Cumulative Index to Nursing and Allied Health Literature*, and the *Cochrane Database of Systematic Reviews*. Staff reviewed relevant articles, compiled tables of study characteristics, appraised target factors, and summarized results. Data topics, procedures, and reviews were developed in consultation with advisory experts from the public and private sectors, including experts from research, clinical practice, policy, and evaluation. A total of 3,155 research publications were identified for analysis of topic themes and trends. Research funding source information was contained within 1,258 of these articles. Additional research publication funding information was obtained for 216 publications through an online, follow-up author questionnaire. The National Institutes of Health (NIH) *Query/View/Report IMPAC II* database was also used to search and accrue detailed information about NIH and related federal agency grant applications and awards from fiscal years 1997 to 2010. Within this report, studies that satisfied the inclusion criteria were summarized in data tables and figures. These tables provided information about the study targets and data outcomes. The study sample size offers a measure of the weight of the evidence. The following key findings from this report identify the evolving trends in published topics in EOL PC science, the cited sources of research funding and trends in

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[2] Institute of Medicine (1997). Approaching Death: Improving Care at the End of Life. Committee on Care at the End of Life, Field MJ and Cassel CK (Eds.). Division of Health Care Services, Washington, DC: The National Academies Press.

federal funding, and the existing gaps and critical priorities required to build continued momentum and strengthen collaborations in future research initiatives.

RESULTS | KEY FINDINGS

Questions: What Are the Trends in Published EOL PC Research Themes? Are Scientific Interests and Priorities Changing?

SINCE 1997, THE NUMBER OF PUBLICATIONS IN EOL PC SCIENCE HAS TRIPLED.

The number of research publications consistently increased over the past 14 years.

Data Highlights

- From 1997 to 2010, a total of 3,155 research publications with EOL PC themes were identified.
- From 1997 to 2010, the number of these research publications per year tripled from 97 publications in 1997 to 333 publications in 2010.
- In 2008, 355 studies represented the largest number of EOL PC research publications in one year.

OVER THE PAST 14 YEARS, THE MAJORITY OF PUBLISHED EOL PC SCIENCE FOCUSED ON THREE TOPICS: ADVANCE CARE PLANNING, CARE SETTINGS AND STANDARDS, AND PAIN AND OTHER SYMPTOM MANAGEMENT.

Data Highlights

- *Advance Care Planning* (12.5%), *Care Settings and Types of Care* (12%), and *Pain and Other Symptom Management* (11%) accounted for more than one-third (36%) of all published EOL PC research topic areas.
- While it is imperative to continue research in these areas, the field must also expand to new and contemporary topics that align with changing demographics and needs of the population.

OVER THE PAST 14 YEARS, CANCER HAS BEEN THE PRIMARY HEALTH CONDITION TOPIC OF ALL PUBLISHED END-OF-LIFE AND PALLIATIVE CARE RESEARCH.

Data Highlights

- Cancer was the most frequent focus of all health condition topics in more than two-thirds of all publications reviewed. The frequency and emphasis on cancer as a topic has not changed since the initial 2004 NIH State-of-the-Science Consensus Report.
- Following cancer, neurologic (14%), cardiac (11%), and respiratory (9%) health conditions were the most frequent topics. The proportion of these conditions as publication topics never exceeded 20% of the total research topics in any given year.
- Few publications reflected the changing demographics of serious advanced illness such as complex and multiple chronic conditions. Less than 5% of publications addressed issues in advanced renal or liver disease or in advanced HIV/AIDS.

A LIMITED PERCENTAGE OF PUBLISHED RESEARCH STUDIES HAS ADDRESSED ETHNIC, RACIAL, OR PEDIATRIC POPULATIONS IN ADVANCED ILLNESS HEALTH CONDITIONS AND DISEASE.

Despite recommendations from the 2004 NIH State-of-the-Science Consensus Report, high-quality research in topics of economic, demographic, ethical, and social dimensions is still needed to expand the evidence base.

Data Highlights

- Published research focusing on ethnic, cultural, or spiritual aspects of end-of-life or palliative care represented 3.8% of all publications from 1997 to 2010.
- Less than 10% of all research publications focused on pediatrics.
- Less than 5% of all research publications focused on critical areas such as ethics, caregiving, service delivery models of care, standards of care, and others.
- Only 5.2% of all publications focused on education and training.

Question: What Are the Sources of Funding EOL PC Science?

THE SOURCES OF EOL PC RESEARCH SUPPORT ARE CHANGING.

Initially, the private sector was the primary acknowledged source of funding in the published research. Since 2008, however, private funding acknowledgments have diminished while citations of federal sources of funding have increased.

Data Highlights

- In 1997, 48.5% of all research publications cited private funds as sole support of EOL PC research. In 2010, this percentage decreased to 24.8%.
- In 1997, 24% of all research publications cited federal sources as sole support of EOL PC research. In 2010, this percentage increased to 47.6%.
- More than 500 foundations, academic institutions, professional organizations, and private industries were identified as supporting EOL PC research over the past 14 years.
- The majority of published EOL PC manuscripts did not include a source of research funding.

FEDERAL FUNDING PATTERNS SUPPORTING EOL PC SCIENCE HAVE INCREASED MORE THAN TENFOLD SINCE 1997.

Data Highlights

- A total of $432.93 million has been spent by federal agencies for EOL PC research, from $4.23 million in 1997 to $61.55 million in 2010.
- Since FY1997, there has been a sixfold increase in the number of awards for EOL PC research by federal agencies. Thirty-seven federal organizations supported 444 new EOL PC research grants. These included NIH, the U.S. Department of Veterans Affair, the Agency for Healthcare Research and Quality, the U.S. Public Health Service, the Health Resources and Services Administration, the Centers for Disease Control and Prevention, and others.
- Despite these gains, EOL PC research funding represents only a fraction of the total obligated funds in biomedical science.

NIH FUNDING FOR EOL PC RESEARCH HAS INCREASED MORE THAN TENFOLD. HOWEVER, THE DISTRIBUTION OF FUNDING AMONG NIH INSTITUTES HAS REMAINED UNCHANGED SINCE 1997.

Data Highlights

- A total of $389.59 million in NIH awards has been spent in EOL PC research, from $3.83 million in 1997 to $56.94 million in 2010. Three NIH Institutes accounted for 85% of this funding: the National Cancer Institute (NCI, 37%), the National Institute of Nursing Research (NINR, 26%), and the National Institute on Aging (NIA, 22%).
- Since 1997, 14 NIH Institutes and Centers have awarded 399 new EOL PC research grants. NCI, NINR, and NIA accounted for 86% of these grant awards.
- The R01 mechanism represented 30% of all EOL PC grant awards.

DISCUSSION | BUILDING MOMENTUM FOR THE FUTURE

The findings from this current review point toward several opportunities to foster new science in EOL PC research and to create new momentum to broaden the existing scope of this field. Despite the clear indication of growth in terms of research awards, funding dollars, and scholarly publications, the future of EOL PC science must continue to evolve and parallel the changing demographics of what it means to live with and die from serious advanced illness in today's society. Attention to the spectrum of diversity throughout the life-course and disease trajectory—from awareness of the needs of the youngest neonate to the care needed by the frailest elder—must parallel the changing gestalt of 'approaching death' in the context of advanced and serious illness and complex, chronic conditions. The science must broaden its reach and its relevance to data-driven, equitable, and high-quality EOL PC as well as to strengthen new evidence to reduce gaps in services for all populations and in all health care sectors. Issues related to economics, ethics, and access must be integrated into new research paradigms and attention to culture, ethnicity, and minorities must be made to produce a measurable shift in the focus of research grants, the sources of funding dollars, and the dissemination of meaningful results to inform and educate the public.

EOL PC science originated from the germinal efforts of the private sector, and the value of these endeavors to foster past and current research must not be overlooked. However, new investment in future research must garner the strengths of *both* the public and the private sectors. Efforts to facilitate such collaborations may create new and critical research momentum, bring leadership into the EOL PC community to guide and advise both the NIH and potential stakeholders on the formation of new partnerships and the leveraging of resources, and focus directions for new initiatives to address the contemporary challenges and future needs in EOL PC science.

CONCLUSION | THE SCIENCE OF END-OF-LIFE AND PALLIATIVE CARE

The data in this report draw attention to the past research accomplishments and current achievements that will help shape future directions and continue to build momentum for strengthening the science of EOL PC. Since the 1997 Institute of Medicine (IOM) report's call to action to invest in this important research area and the 2004 NIH State-of-the-Science Consensus Report to recognize the obligation to create a vibrant research agenda, both the public and the private sectors have demonstrated unprecedented stewardship in building the field of EOL PC science. The research establishment has taken the lead to organize workshops, symposia, and conferences fostering consensus on current knowledge and future needs. Agencies and private organizations have focused significant efforts on increasing the number of research solicitations and addressing new issues related to advanced illness care. New clinical guidelines and standards of practice have emanated from a growing evidence base, which has served as a foundation for many new and innovative programs in palliative care and hospice. Further, the dissemination of this science has exponentially increased, resulting in a rich research literature that has provided the public with meaningful information on the high-quality, evidence-based care that is available to those who live with and die from serious, advanced illnesses.

CARE AT THE END OF LIFE . . . IS INFORMED
BY SCIENTIFIC EVIDENCE, VALUES, AND
PERSONAL AND PROFESSIONAL EXPERIENCE.

Clearly, the state of the science has grown over the last 14 years, but as in all research, much more needs to be done. At a time in which there is enormous opportunity to improve the health of the American people through the innovations of science, the findings of this report speak to a new and collaborative *call-to-action* to continue momentum in addressing the benefits of EOL PC research. The science of EOL PC, with its capacity to inform, educate, build better health services, and empower individual-centered choices, must not be overlooked. As such, there is a national mandate to support this science and employ research outcomes to engage the public in meaningful dialogue surrounding the benefits of individual-centered care. As public and private organizations look to prioritize new initiatives, allocate resources, and seek new partnerships, it is important to recognize the significance of research and to create new momentum to fund this science. Such efforts will make certain that all individuals who face the many challenges of approaching the end of a life will be guaranteed the full experiences benefited by the compassionate, high-quality services of palliative and end-of-life care.

Building Momentum:
The Science of End-of-Life and Palliative Care

I. INTRODUCTION

The public debate on end-of-life and palliative care (EOL PC) is fraught with highly charged perceptions, individual values, and fundamental beliefs about life and its meaning. Despite decades of public education initiatives and scientific research, the promise of equitable, compassionate, and dignified care for all individuals in the final stages of life remains a major challenge for much of American society. The need for high-quality, accessible, and person-centered palliative care and end-of-life support is not new, but the ways in which the nation understands these issues, empowers choices, formulates solutions, and engages patients and families is continuously shaped by knowledge.

The science of EOL PC with its capacity to inform, educate, and build the evidence for better health services has played an enormous role in the national dialogue surrounding end-of-life care and has served as a facilitator of the evolution of a spectrum of EOL PC. As a catalyst for change, research substantiates improvements to public policy, provides evidence of what works (or does not), and evaluates strategies for reliable clinical performance within health care systems. Because EOL PC research addresses the cultural-, spiritual-, age-, and disease-specific factors that make each person's experience at the end of a life unique, a robust research enterprise ensures that there is an ongoing process from which to understand serious advanced illnesses and identify evidence-based interventions that are shaped by compassion and a respect for the needs and preferences of each individual.

Whether in facing the inevitability of a serious advanced illness, living with progressive disabling function and diminishing independence, or grieving the loss of a loved one, the continuum of end-of-life care—from early palliative care to later hospice and bereavement support—demands a seamless, comprehensive, and integrated system of health service that reaches all communities, cultures, and practices. It is therefore imperative that as the national dialogue continues to address the important and highly personal issues surrounding end-of-life care, and as new health services are created to meet these needs, the contributions of a strong research agenda are not overlooked. Scientific discovery has historically challenged popular perceptions of end-of-life care and transformed ideas into innovative directives for clinical practice. For example, the 1995 research investigation, *Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments* (SUPPORT), documented serious deficiencies in the care provided for dying patients and their families (SUPPORT, 1995). The implications from the research findings and the subsequent outcry from the public to address EOL PC service delivery gaps heralded a number of scientific consensus meetings and workshop reports undertaken by the National Institutes of Health and private foundations; most notably, the creation of three seminal reports from the Institute of

Medicine (IOM): the 1997 report, *Approaching Death: Improving Care at the End-of-Life*, the 2001 report, *Improving Palliative Care for Cancer,* and the 2003 report, *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. Each of these reports explicitly called for national attention to address, build, and sustain a robust research agenda in EOL PC science.

IDENTIFYING RESEARCH PRIORITIES TO GUIDE EVIDENCE-BASED PALLIATVE AND END-OF-LIFE CARE BECOMES INCREASINGLY IMPORTANT AS OUR POPULATION AGES.

Now, more than 14 years after the first IOM report, it is important to reflect on current perspectives of what it means to approach death in today's culture and the changing landscape of EOL PC science to meet these health care needs. These new health care challenges for EOL PC have arisen from the prerequisites of an increasing aging population with chronic health conditions that impact the entire milieu of symptom management care. Advanced illnesses and health conditions (e.g., cancer) that once provided the template for defining end-of-life care along a distinct continuum now may encompass variable illness trajectories, and where once considered fatal, many diseases and conditions are now managed with the possibility of extended life or even survival. These new paradigms in the trajectories of advanced illnesses shift EOL PC research priorities. Science must not only align with the changing perceptions and contemporary needs of the public, but also continue to set new directions. While there is an ongoing imperative to continue to address pain, fatigue, and related co-morbidities, whether among the very oldest or the youngest of populations, there continues to be public misunderstandings about the implications of end-of-life care, a lack of shared decisions about individual-directed care plans, inequitable access to high-quality care, fragmented transitions across diverse health systems, inadequate reimbursement policies, and ongoing public stigma associated with 'dying' that will shape current and future research priorities. The conduct of EOL PC science must therefore progress to meet these evolving needs by addressing these contemporary issues, incorporating new methodologies into experimental paradigms, and broadening the scientific reach and the impetus for strengthening the scope of this research (George, 2002).

BETTER CARE IS POSSIBLE NOW, BUT WE ALSO NEED BETTER DATA AND SCIENTIFIC KNOWLEDGE TO GUIDE EFFORTS TO DELIVER MORE EFFECTIVE CARE, EDUCATE PROFESSIONALS TO PROVIDE SUCH CARE, AND DESIGN SUPPORTIVE PUBLIC POLICIES.

The following review of the published EOL PC research literature from 1997 to 2010 was conducted to address many of these issues through a systematic evaluation of the trends and gaps in manuscript topic areas and their cited sources of research funding support. The report begins with a review of background material and historical contexts that served to incentivize some of the first solicitations for research by both the public and private sectors. It then describes the evolving scope of the research topics and themes published over the past 14 years, including the extent of funding resources and grantmaking efforts within federal and nonfederal programs. The report provides an analysis of the drivers of these early and germinal research initiatives, as well as interpretations of how many new and contemporary factors in EOL PC will influence research sustainability and benchmarks for scientific capacity in the future. The intent of the review is to provide information as to whether the scope of published EOL PC research has significantly increased since the 1997 IOM report, through what mechanisms of funding support, and the factors that will provide future opportunities for continued momentum to build the science of EOL PC.

II. PURPOSE

As a component of reviewing the published end-of-life and palliative care (EOL PC) research literature over the past 14 years, this report reviewed data on the sources of funded EOL PC research, the topics and trends in research publication themes, and information for consideration of existing gaps and priorities for EOL PC science. The report's focus was to address earlier recommendations from the 1997 Institute of Medicine (IOM) report for the research establishment to strengthen the research landscape, foster new evidence, and define and implement priorities for strengthening the knowledge base for end-of-life care. While not an evaluation of the quality of research or its findings, this report addressed several evaluation questions:

- *What are the trends in EOL PC published research themes and topics?*
- *What are the federal, philanthropic, and other nonprofit funding sources cited in this published research and overall trends for EOL PC science support?*
- *Are EOL PC research interests and research priorities changing over time?*
- *Who are the stakeholders in EOL PC science?*
- *What opportunities exist for future partnerships to harmonize and strengthen research in EOL PC across U.S. funding bodies?*

III. BACKGROUND. HISTORICAL CONTEXTS FOR END-OF-LIFE AND PALLIATIVE CARE SCIENCE

Trends and Dynamics

While death is inevitable, the experiences of serious advanced illness have changed tremendously over the past century. Changes in the extent of the life span, the aging of the population, changes in the leading causes and trajectories of death, and advances in medical interventions and lifesaving technologies have altered the context, the settings, and the course of dying in the United States. At each point, the health care requirements and societal demands of an approaching death affects the social and political landscape and influences consideration of priorities for research as well as the public's interest to support such science. The following section reviews key historical trends and dynamics that have shaped the end-of-life and palliative care (EOL PC) research agenda and how these important areas have swayed priorities, changed definitions, and guided effective clinical practices.

SERIOUS ILLNESS AND DEATH ARE INEVITABLE, BUT THE EXPERIENCE OF ILLNESS AND DYING HAS CHANGED TREMENDOUSLY OVER THE PAST CENTURY.

Changing Demographics. In the last century, few Americans lived past the age of 65, but over a relatively short period of time, life expectancy in the United States has steadily increased from 73 years in 1980 to 78 years in 2009 (Kochanek, Xu, Murphy, and Kung, 2011). Now, the majority of Americans die of chronic, progressive illnesses or degenerative diseases often accompanied by prolonged periods of physical dependency and increasing frailty. In 2010, the five leading causes of U.S. death were heart disease, cancer, chronic lower respiratory diseases, stroke, and accidents (Miniño and Murphy, 2010). The recent rank order of the leading causes of death in the United States also varies according to demographic variables such as age, sex, and race and the impact of these factors in understanding end of life draw attention to a changing national diversity that inevitably shapes contemporary research needs. For example, race is an important consideration in understanding causes of death. The highest mortality rates occur in non-Hispanic black populations followed by non-Hispanic whites (Miniño and Murphy, 2010). While heart disease remains the leading cause of death among non-Hispanic whites and African Americans (Lunney, Flynn, Foley, et al., 2003), Hispanics die more from cancer than any other health condition or disease (American Cancer Society, 2012). Age is also a factor. According to the 2010 NCVHS report, the five leading causes of death for those aged 1 to 24 years include external causes (i.e., accidents, homicide, suicide) followed by cancer and heart disease. This pattern shifts noticeably as age increases. In older age groups, chronic conditions account for more deaths than do external causes of injury. Such chronic conditions (many times *multiple* chronic conditions) in the growing aging population give rise to the need for long-term and continuing health care programs and innovative solutions for resource-intensive, high-cost treatments and/or long-term services and support.

Changing Care. The setting and the manner of care provided to those approaching the end of life are also changing. Today, the health care services that are given to individuals living with and dying from advanced illness are often fragmented among care providers and health service settings. This fragmentation leads to a lack of continuity of care and often impedes the ability to provide high-quality, interdisciplinary care support. In regard to place of care, for most of the past 40 years, the conceptualization of 'end-of-life' care has largely been associated with hospice services even though only 42% of all deaths in the United States occur in hospice settings (Xu, Kochanek, and Tejada-Vera, 2009). Hospice as a program of health service grew out of a philosophy of care aimed at improved approaches to symptom management and emotional and spiritual support for dying patients and their families, and its U.S. origins were closely linked to research support. In the 1970s, the National Cancer Institute (NCI) of the National Institutes of Health (NIH) funded research aimed at implementation of such programs at the Connecticut Hospice in New Haven, Connecticut, and at hospices in Arizona, California, and New Jersey (National Hospice and Palliative Care Organization, 2012). Based on the research findings substantiating that hospice was informed by an ethic of compassion, dignity, and service, a 1978 Federal Task Force report recommended federal government reimbursement of hospice services and, that same year, the Health Care Financing Administration (HCFA), now the Center for Medicare and Medicaid Services of the U.S. Department of Health and Human Services (DHHS), announced that it would support demonstration projects providing health services to persons with terminal illnesses (Committee on Finance, U.S. Senate, 1988). By 1980, under Medicare and Medicaid waivers, HCFA began paying hospice providers for home health services as well as for bereavement counseling and pain-control drugs. Congress authorized hospice coverage under Medicare in the Tax Equity and Fiscal Responsibility Act of 1982 (P.L. 97-248). Clinical practices for end-of-life care, based on a foundation of scientific evidence, were underway.

CHARITABLE FOUNDATIONS WERE SIGNIFICANT IN ADDRESSING THE NEED TO IMPROVE CARE NEAR THE END OF LIFE AND CREATING INITIAL IMPETUS TO SUPPORT EVIDENCE-BASED RESEARCH.

While federally supported research provided the impetus for moving hospice into a reimbursable standard of non-curative end-of-life care, the private, philanthropic sector also played a seminal role in funding research efforts and developing new and additional hospice-related research initiatives. The Robert Wood Johnson Foundation and the John A. Hartford Foundation financed the assessment of HCFA's demonstration program and the W. K. Kellogg Foundation provided funding to the Joint Commission on Accreditation of Hospitals (now the Joint Commission on Accreditation of Health Care Organizations) to prepare hospice standards and an assessment and survey guide (Miller, Williams, English, and Keyserling, 2002). These initiatives helped to bridge research evidence into an evolving health service that resulted in the expansion of both hospice and palliative care programs. For example, the March 2011 *Report to the Congress on Medicare Payment Policy* documented that the supply of hospices increased 50% between 2000 and 2009, growing an average of 5% per year from 2000 to 2008 and 3% from 2008 to 2009. In a 2011 report released to Congress, the *Center to Advance Palliative Care* noted the growth of hospital-based palliative care also increased from 658 (24.5%) programs to 1,635 (65.7%)—a 148.5% increase between 2000 and 2010 (Morrison and Meyer, 2011).

Changing Dialogue. As palliative care and hospice programs became more available, research directives were not untouched by a series of critical events that escalated the public debate surrounding the end of life and a renewed national attention on the need to strengthen the rigor and scope of scientific research. In 1976, the New Jersey Supreme Court decision in the case of Karen Ann Quinlan and the 1989 U.S. Supreme Court case of Nancy Beth Cruzan brought national awareness to the issues of autonomy and decision-making, advance directives, determination of what constitutes death, and the right for compassionate, dignified care for those unable to advocate for themselves. In 1990, the Federal Patient Self-Determination Act 1990, 42 U.S.C 1395 cc (P.L. 101-508) emanated from these issues and legislative hearings prior to its enactment served to identify significant priorities and needs for research.

Adding to the public debate were the findings of the landmark 1995 SUPPORT (*Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments)* research investigation, which documented long-standing and unchanged deficiencies in the care of dying patients and their families. Even with new interventions focused on increased patient-provider communication, the study highlighted that individuals still died in uncontrolled pain, in non-hospice or palliative programs, and without attention or adherence to completed advance directives. The SUPPORT findings spurred major involvement by both private and public organizations to improve care at the end of life (Lynn, 1997) and the subsequent Institute of Medicine 1997 report *Approaching Death: Improving Care at the End of Life* served as a collaborative 'call-to-action' to bring the issues of end-of-life care to the attention of national leaders, policymakers, and the research establishment. As a result, numerous funding opportunities were created by both the public and private sectors to address these needs and create a stronger research base in EOL PC science.

However, amidst many challenges and new evolving issues, the science of EOL PC has a significant role to further the empirical knowledge and address contemporary advanced care issues, discover new solutions for complex and chronic health conditions, test new systems of care, and respond to the needs of an ever-aging and diverse population. Despite dramatic trends and dynamics in conceptualizing what it means to approach death, there remains uncertainty in public understanding of what constitutes the last stages of life and the providers of and boundaries for high-quality and compassionate care throughout its entire trajectory. For example, a recent poll indicated that 36% of respondents continued to erroneously believe that the provisions of the recent 2009 Patient Protection and Accountable Care *Act* allowed a government 'panel' to make decisions about end-of-life care for Medicare recipients (Kaiser Family Foundation, 2012), a misperception that continues to impact early and appropriate referrals to hospice as well as palliative care services. It is clear that effective dissemination of EOL PC information, based on evidence from the research community, can help dispel such misunderstandings and augment public knowledge and subsequent utilization of appropriate palliative and hospice services. As issues of what it means to live with and die from advanced illness continue to evolve, shifting priorities, new policy concerns, practice standards, and public perceptions of the meaning of dying and its processes will continue to press the need for continued research to inform and to clearly define the scope and the quality of EOL PC.

Evolving Evidence-Based Practices

As conceptualization of issues surrounding end-of-life and palliative care (EOL PC) evolved, so too did evidence-based standards of clinical practice. Shifting perceptions of health care providers, primarily in the medical and nursing professions, resulted in significant interests to change existing systems of health services by training and educating practitioners in palliative care and, through this training, bring these important services into the mainstream of medical practice (Bronner, 2003). In April 2009, the *National Consensus Project* issued the *Clinical Practice Guidelines* (National Consensus Project for Quality Palliative Care, 2009), which detailed the core elements of quality palliative care. In 2012, the *National Quality Forum* (NQF) further endorsed 14 quality measures in palliative and end-of-life care, including pain management, psychosocial needs, care transitions, and experiences of care (NQF, 2012). These evolving standards of practice, substantiated by evidence-based research, paralleled the momentum in the growth of hospice and palliative care services.

The dynamic changes in life expectancy and chronic illness also steered the need to garner evidence supporting the benefits of earlier clinical integration of palliative care into traditional health care models as well as earlier and appropriate referrals to hospice care. Educating and training providers in EOL PC through evidence-based practices has resulted in evolving health care service delivery models, new clinical guidelines, and national professional standards that include interdisciplinary training in palliative and hospice care. In addition, following the medical, nursing, and allied health care profession's recognition of hospice and palliative care as a subspecialty, other health care disciplines have expanded their professional boundaries to embrace palliative care (American Board of Medical Specialties). Undoubtedly, as health providers continue to develop the knowledge and skill sets needed to provide quality EOL PC, new evidence-based data will be needed to address not only emerging aspects of evidence-based practice, but also data that guide clinical implementation amidst barriers that continue to exist in access to services, in a sustained workforce, and in issues of reimbursement and care coverage (Armstrong, Hutson, Wachs, and Eckerd Lambe, 2012).

In addition to a renewed focus on evidence-based standards of clinical practice, measuring or assessing patient and family satisfaction with palliative or hospice services is a critical component of quality care and evaluation of quality outcomes. The Family Evaluation of Hospice Care was initially validated in 2001 (Teno, 2001) and in a national mortality follow-back survey in 2004 (Teno, 2004). Family respondents using these tools report how well providers support dying on one's own terms through respect of patient wishes, communication about illness, controlling symptoms, and providing emotional support. As an example of the critical link between science and clinical practice, this research has now been translated into a publicly available tool for implementation and is disseminated by the Agency for Healthcare Research and Quality (*Closing the Quality Gap*, 2011, 2012).

UNDERSTANDING THE HOSPICE BENEFIT

The Medicare hospice benefit is one of the only benefits with mandated interdisciplinary team-based care. Hospice benefits, covered by Medicare, Medicaid, and most private insurers, include areas such as drugs for symptom control or pain relief; doctor, medical, nursing, and health professional services; medical equipment; and supplies. Hospice focuses on caring, not curing. Hospice services can be stopped for any reason but can also continue as long as patients are certified as eligible; if care is required beyond six months, hospice benefits may be extended. If health improves or an illness goes into remission, hospice care can be stopped. The hospice benefits allow patients and their families to stay together in the comfort of their home unless care is needed in an inpatient facility. If the hospice team determines that inpatient care is needed, the hospice team assists with arrangements for short-term stay. Hospice care also is provided in freestanding hospice centers, nursing homes, and other long-term care facilities. In choosing hospice care, Medicare will still pay for covered benefits for any health problems that aren't related to terminal illness.

Definitional Clarity

As knowledge and understanding increased about the dying process throughout the illness trajectory—and as research-based evidence shaped the standards for high-quality clinical practices—the need for definitional clarity in conceptualizing the breadth and depth of the field of end-of-life and palliative care (EOL PC) remained a critical premise for defining the scope of its research. The title of the 1997 Institute of Medicine (IOM) report acknowledged that "approaching death" imparts both a framework for the nexus between research, policy, and practice and the conceptual underpinning of how the public acknowledges and enables the care of those who face serious, advanced illnesses. The language of the IOM report also distinguished that end-of-life care is not defined within the boundary of a specific disease category or health service. Instead, the referent for end-of-life care is a focus on living, and living well, throughout the entire continuum and phases of advanced illness. End-of-life care thus encompasses the period of time when the inevitability of an advanced critical illness is realized; throughout the progression of disabling function and diminishing independence; and during palliation and hospice care, death, bereavement, and loss. As stated in the 2004 National Institutes of Health (NIH) Consensus Panel *State-of-the-Science: Improving End-of-Life Care* proceedings (NIH, 2004):

> *“Research would benefit from characterizing the implications of alternative conceptual and operational definitions of the ‘end of life’ . . . particularly for important conditions.”*

This statement has guided the field of EOL PC science to consider that the processes of care, as one approaches last stages of life, transcend a fragmented system of health service and, instead, demand a seamless continuum of comprehensive integrated and evidence-based care for all communities, cultures, and practices. Subsequent concepts and terms, some old, some new, have been used to define the scope of the research related to this care, often affecting perceptions of need and influencing what is funded. Additional terms have also emerged in both the clinical and research arenas, in part to describe new understanding of the individual experiences and extended pathways of care in the last years of life. These important terms, such as ‘advanced care,’ ‘life-limiting illness,’ ‘life-threatening illness,’ ‘serious illness,’ and others demarcate a changing landscape in defining the complex rubric and sometimes ill-defined trajectory of sudden or last stages of life as influenced by age, gender, beliefs, culture, religion, or ethnicity and underscored by shifting disease conditions, dependence, and frailty.

The ‘science-to-practice’ challenges of and need for definitional clarity were highlighted by a 2001 trans-Department of Health and Human Services *Integrative Workshop on End-of-Life Research* that stressed, in the absence of clear definitions, the use *of research* to inform practice or policy will be limited (George, 2002). A central problem in achieving this definitional clarity is that the scientific evidence lacks conceptual and operational congruence on what constitutes the ‘end-of-life’ or its transitions. The process of approaching the last stage of life can include numerous transitions such as physical, emotional, spiritual, and even financial transitions. Life is a continuum and individuals traverse this continuum facing these transitions amidst increasing dependence and limited functionality. Moreover, advanced illness care can be fragmented by transitions across health systems and exacerbated by the lack of continuity among caregivers, challenges to social support networks, unshared clinical information, and multiple physical locations for care.

> *THE SINGLE MOST DIFFICULT AND POORLY HANDLED ISSUE IN END-OF-LIFE RESEARCH IS THE MISMATCH BETWEEN CONCEPTUAL AND OPERATIONAL DEFINITIONS OF ‘DYING’ OR ‘TERMINAL ILLNESS.’*

The challenges of well-defined concepts and lack of conceptual and operational consistency have often become the center of confusion and debate in describing to the public the focus of EOL PC research and its correspondence to specific practices of care. Too often the terms are conceptually used interchangeably in the research literature and the lack of distinction subsequently mires the translation of findings to the public. Definitional challenges, incongruence in contemporary terminology, and continued misperceptions regarding distinctions in services are underscored in the results of recent public surveys. For example, 86% of Americans recently polled were somewhat familiar with 'hospice care,' 65% were somewhat familiar with 'end-of-life care,' but only 24% of respondents were somewhat familiar with 'palliative care' (National Journal and Regence Foundation, 2011). Physicians also polled expressed that ensuring quality of life at the 'end stage' is important, but they also identified barriers to achieving that goal; almost 25% of polled physicians expressed discomfort in discussing the 'end of life' with patients, and 24% said they were also reluctant to bring up 'palliative care' (National Journal and Regence Foundation, 2011).

LANGUAGE MAKES A DIFFERENCE.
PALLIATIVE CARE MUST BE DIFFERENTIATED FROM HOSPICE OR END-OF-LIFE CARE.

As efforts are made to achieve clarity to both terms and practices, scientific advances in disease prevention, new disease-modifying therapies, and life-saving medical technologies will also continue to shift perspectives on the scope of EOL PC research. It will be critical to regard the recommendation of the State-of-the-Science Consensus Panel that, *"Efforts should be made for further development and consensus about common definitions and constructs as they relate to end-of-life and palliative care."* (NIH, 2004). For the purposes of this report, the following descriptions are offered for consideration in addressing the scope and the definition of the science in end-of-life, palliative, and hospice care:

End-of-Life Care*:* The *2004 NIH State-of-the-Science Consensus Report* defined this as:

"End of Life Care is the care provided to a person in their final stages of life. Also known as: comfort care, supportive care and symptom management." (NIH, 2004)

Palliative Care: The National Quality Forum (NQF) definition of palliative care includes:

". . . patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice." (NQF, 2009)

The World Health Organization (WHO) provides a broader description of the scope of palliative care for adults and delineates differences for care provided for children. In adults, the WHO definition specifies that:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." Within this definition, the WHO also extends palliative care's

focus into aspects of the dying process, inclusive of end-of-life care and bereavement, such that palliative care: *". . .affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated."* (WHO, 2012)

Hospice Care: The National Hospice and Palliative Care Organization defines hospice:

"Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. [. . .]" (NQF, 2006)

Emanating from each of these definitions, and driven by the public's politically charged response to the "*Death Panel*" debate (Meier, Casarett, von Gunten, et al., 2010), more recent and additional terms have been offered to describe the care received during serious illness, terms that continue to represent the shifting demographics and the epidemiology of living with and dying from multiple, complex health conditions and/or diseases. The incorporation of these terms into the mainstream of EOL PC mirrors the evolving nature of chronic illness and the dying process in the United States. These changes, and the public discomfort, even stigma, associated with terms related to *death* or *dying* have all resulted in cultural shifts to create definitional language and hopeful boundaries that focus on the scope of extended, complex chronic illness across the health care continuum in terms of serious or advanced illness. For example, the Coalition to Transform Advanced Care (C-TAC, n.d.) threaded the term 'advanced illness' into the field in an effort to describe, *". . . when one or more conditions become serious enough that general health and functioning decline, and treatments begin to lose their impact. This is a process that continues to the end of life."* (C-TAC, n.d.). On a practice level, the care provided along the advanced illness continuum includes palliative and hospice services. The *Center to Advance Palliative Care* (CAPC) also conducted public opinion market research to further its own definition of palliative care and, using consumer information to describe palliative care, created language that describes palliative care as, *". . . an extra layer of support . . . appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment."* (CAPC, 2011). Concern, however, is that many new terms tend to "over-medicalize" the services delivered and that some do not acknowledge a broader scope of care for people with progressive illness that include complex chronic conditions, increasing frailty, and loss of functional independence (Peres, 2012). For many, the terms "serious illness" and "advanced illness" are not the same; many equate an advanced

THE FUNDAMENTAL PREMISE OF ANY APPROACH TO ADVANCED CARE IS TO PROVIDE NECESSARY AND COMPREHENSIVE QUALITY CARE THROUGHOUT THE ENTIRE TRAJECTORY OF NEED.

illness with the end of life—others do not (CAPC, 2011). For some, the concepts of disease, disability, and frailty are distinct, yet overlapping. Experts reasonably argue that the development of palliative care or advanced illness services extends beyond end-of-life care and that creating inclusive approaches will serve to broaden practices across a continuum of diseases and populations and ensure interdisciplinary and individualized holistic care is implemented early and throughout the entire course of illness.

But despite variations, all terms have, as a fundamental premise, the notion of the need for provision of comprehensive quality care throughout the entire trajectory of need. The terms all draw attention to multidisciplinary and integrated approaches to care; the importance of addressing symptom management; psychosocial, spiritual, and family support; and the need for advance care planning. These are mutually shared themes across terms (Bausewein and Higginson, 2012), and for science and its scope, these constructs will be important in defining future directions. As noted by the 2004 *State-of-the-Science Conference on End-of-Life Care:*

> *"There is no exact definition of end of life; however, the evidence supports the following components: (1) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death. Older age and frailty may be surrogates for life-threatening illness and comorbidity; however, there is insufficient evidence for understanding these variables as components of end of life."* (NIH, 2004)

As definitions and public opinions continue to evolve, it is therefore critical that within the research community, the seminal 1997 IOM concepts of EOL PC and other areas of scientific study are revisited and perhaps reaffirmed to distinguish the definitional scope and reach of current and future research.

THE NATION'S RESEARCH ESTABLISHMENT SHOULD DEFINE AND IMPLEMENT PRIORITIES FOR STRENGTHENING THE KNOWLEDGE BASE FOR END-OF-LIFE CARE.

Building the Foundation for End-of-Life and Palliative Care Science

End-of-life and palliative care (EOL PC) research seeks to understand advanced illness with respect to the needs of the individual patient and family. The historical contexts, changing demographics, and growing evidence-based practices have influenced the scope of EOL PC science. As the field evolved, a growing knowledge base of the processes and experiences of dying and the issues surrounding quality care for seriously ill individuals and their caregivers served to shape resulting systems and standard practices of care. The following section highlights significant issues that began the momentum for building the scientific foundation for EOL PC research in both the private and public sectors.

WITHOUT RESEARCH, PALLIATIVE CARE IS AN ART, NOT A SCIENCE.

The 1997 Institute of Medicine (IOM) report triggered a series of philanthropic and public research activities to improve the quality of care and the quality of life for those nearing the end of life and public and private sector concern to ensure a strong scientific evidence base for this care. But despite multiple recommendations calling for investment in EOL PC research, there remains a lack of congruence in identifying the many stakeholders of the science, what have been and what will be—the sources of research funding, and how partnerships between public government agencies and private philanthropic organizations will be fostered to collaboratively build next generations of research. It is both timely and important as the field approaches a decade of research since the 2004 *State-of-the-Science Consensus Report* that attention is given to systematically assess whether directed funding streams for EOL PC research by federal and major philanthropic sources are fully addressing the breadth and depth of EOL PC scientific issues that now encompass the field and the vitality of research funding to continue its momentum.

The Private Philanthropic Sector

The major proportion of early U.S. research in EOL PC was supported through private foundations. Philanthropic, nonprofit organizations and foundations historically invested in EOL PC research well before the 1997 IOM *Approaching Death* report (IOM, 1997). Hundreds of millions of research dollars invested by private organizations created new areas of EOL PC research, and became the impetus for policy initiatives, consortiums, education, and mass media projects. Most notably, the initiation of the 1989 research investigation, *Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments* (SUPPORT, 1995) was realized by a $28 million award from the Robert Wood Johnson Foundation (RWJF) (RWJF, 2003). Since 1996, RWJF had invested more than $148 million in funds to improve care at the end of life and to collaborate through numerous initiatives such as the 1994 George Soros Open Society Institute's initial investment of $15 million in the Project on Death in America (PDIA) (Open Society Institute, 2004) or the 1999 Midwest Bioethics Center-RWJF $11.25 million collaboration of Community-State Partnerships to improve end-of-life care (Center for Practical Bioethics, 2012). These germinal efforts created momentum across the private sector to support research, including creation of the National Palliative Care Research Center established by a grant from the Emily Davie and Joseph S. Kornfeld Foundation in 2005 in recognition of the importance of research for developing the evidence base required to improve palliative care. Gelfman and Morrison's review of published research articles from 2003-2008 underscored the contributions of private funding support (Gelfman and Morrison, 2008); while 72% of the principle investigators acknowledged receipt of extramural funding in their publications, 51% of these investigators *also* reported support from private philanthropic sources. In 2009, more than 100 philanthropic organizations that fund and conduct EOL PC research were identified (Collaborative to Advance Funding for Palliative Care, 2009).

> *PHILANTHROPIC FUNDING SUPPORT FOR EOL PC RESEARCH IS REACHING A PRECIPICE WITH EVIDENCE TO SUGGEST A WIDENING GAP IN FUNDING RESOURCES AND AN EROSION OF INTEREST IN FUTURE RESEARCH.*

But despite the enormous contributions of RWJF, the Open Society Institute, and other private entities, the face of EOL PC research philanthropy is changing amidst evolving missions, fewer dollars, and new donor interests. From 2003 to 2006, data derived from published foundation reports of the Collaborative to Advance Funding for Palliative Care reported that of the almost $4.4 billion in privately funded health care grants in 2006, only $43.5 million (less than 1%) focused on palliative care, end-of-life, or hospice research (Collaborative to Advance Funding for Palliative Care, 2009). In these data, approximately 110 funders provided 67% of all palliative care grant awards ranging in dollar value from $7,000 to $6.7 million in research funds (Collaborative to Advance Funding for Palliative Care, 2009). Large research grants, on par with the National Institutes of Health (NIH) Research Project Grant Program (R01)-funded projects, were the exception, rather than the rule, for many of these foundations. While health science is being funded by a widening range of foundations in terms of endowment size, geographic focus, and number and size of grants awarded, there appears to be an overarching trend for funding themes associated with developing health practices and assisting service delivery rather than support for fundamental EOL PC research. It is clear that concerted programmatic focus to improve care at the end of life must be threaded with efforts for strategic social change and awareness of how grantmakers might influence future research initiatives and incentivize new interest in funding EOL PC research (Weisfeld, Miller, Gibson, and Schroeder, 2000).

There is also a clear trend that the historical sources of philanthropic funding of EOL PC research are reaching a precipice with evidence to suggest a widening gap in funding resources and an erosion of private foundation missions to fund EOL PC research. A cursory review of requests for proposals via philanthropic websites of the *Foundation Directory* (2010) and *GuideStar* (2010) indicated that those foundations currently providing funding in EOL PC are trending toward decreased prioritization of this area.[3] In the past, more than $200 million in grant funding awarded through RWJF and the Open Society Institute have been targeted toward developing and expanding palliative care research (Collaborative to Advance Funding for Palliative Care, 2009). However, many of these grants are reaching maturity with no public information to suggest future plans for new EOL PC initiatives. As examples, the 1994 inception of the Open Society Institute's $45 million Project on Death in America initiative completed all grantmaking at

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[3] The *Foundation Directory Online* and *GuideStar*. The *Foundation Directory Online* provides information on nonprofit organizations and their funding activities. *GuideStar* provides information on nonprofit organizations only; information on funding is not provided.

the end of 2003. Since 2006, the Archstone Foundation's End-of-Life Initiative had committed $8 million in funds to address improved quality of care in EOL PC and to support training and education in palliative care for health care providers; however, the initiative was completed in 2010 (Archstone Foundation, 2009). The American Cancer Society reports spending approximately 1% of its budget on targeted EOL PC cancer-related topics with $1.5 million in research grants awarded to 10 institutions aimed specifically for palliative care (American Cancer Society). Clearly, these and other efforts like the Collaborative to Advance Funding for Palliative Care program 'Fund PalCare' have actively sought to address this trend, and encourage funders already engaged in palliative care grantmaking to build the number of new philanthropists needed to advance funding, improve education and services, inform policy, and engage the public (FUND PALCARE).

The Public Federal Sector

The National Institute of Nursing Research (NINR), as part of the National Institutes of Health (NIH), began a series of research solicitations that focused on issues related to the end of life and together with the then NIH Office of Alternative Medicine (now the National Center for Complementary and Alternative Medicine, or NCCAM), the division of AIDS Research of the National Institute of Allergy and Infectious Diseases, the National Cancer Institute (NCI), and the National Institute of Dental and Craniofacial Research convened Symptoms in Terminal Illness. This 1997 workshop was a seminal effort by trans-NIH Institutes and Centers (IC) to bring together leading researchers in the field to evaluate the breadth of current research and to define future steps and fields of inquiry in end-of-life care. In addition, it laid the foundation for a standing program in end-of-life science.

From these efforts, focused support of research grew not only throughout the NIH, but also across federal agencies. NINR was designated the lead NIH Institute on research in end-of-life care and facilitated a co-sponsored Program Announcement released the following year that solicited research on Management of Symptoms at the End of Life. In early 1999, another request for applications was announced targeting developing the scientific field, Research on Care at the End of Life. Led by NINR, this initiative was cosponsored by seven NIH ICs as well as the Agency for Health Research and Quality (AHRQ) and resulted in the co-sponsored, collaborative funding of 19 research projects. These efforts became the basis for targeted funding by NIH and other federal agencies to support EOL PC research.

> *NIH RECOGNIZED THE NEED FOR STEWARDSHIP IN END-OF-LIFE SCIENCE. SINCE 1997, NINR HAS BEEN DESIGNATED BY NIH TO LEAD RESEARCH IN END-OF-LIFE CARE.*

Further collaborative federal initiatives helped to define the science and identify areas for future research investment. A 2001 workshop on End-of-Life Issues in Genetic Illnesses in collaboration with various NIH Offices and Institutes and another 2001 trans-U.S. Department of Health and Human Services (DHSS) agency and private foundation supported *Integrative Workshop on End-of-Life Research: Focus on Older Populations,* helped to define the science and future directions for early NIH research initiatives (End-of-Life Research Focus on Older Populations, 2002). In December of 2004, the NINR and the NIH Office of Medical Applications of Research sought to build consensus through an interdisciplinary *State-of-the-Science Conference on Improving End-of-Life Care* (NIH, 2004). Co-sponsors included the Centers for Disease Control and Prevention (CDC), the Centers for Medicare and Medicaid Services, NCI, NCCAM, the National Institute of Mental Health (NIMH), and the National Institute on Aging (NIA). The conference also demonstrated the collaborative nature of this field across federal agencies and between the public and private sectors. AHRQ, through its Evidence-based Practice Center program and using funds from NINR, contracted with the RAND Corporation and its partner, the Veterans Administration Greater Los Angeles Healthcare System, to conduct the first systematic review and analysis of end-of-life research (Lorenz K, Lynn J, Morton SC, et al., 2004). This review served as important background for discussion at the 2004 Consensus Conference.

The results from the 2004 Consensus Panel identified that end-of-life research since the 1997 IOM report was, in many ways, still in its infancy in terms of rigorous testing and evaluation of models of care, in terms of patients and family outcomes, and in terms of resource utilization. There were numerous knowledge gaps and future research needs that provided, in 2004, a new template of next steps to continue building the science of EOL PC. The NIH and other federal government agencies responded to the need to develop the field by creating numerous funding opportunities, projects, and initiatives to advance the science. The NINR, NCI, NIA, NCCAM, NIMH, and other NIH ICs continued to develop funding solicitations within new areas of science and opportunities to train new investigators in the conduct of EOL PC research. For example, NCI is the main source for EOL PC science related to cancer. In addition to its scientific mission, NCI actively focuses on the translation of research information to its constituents and in creating liaisons with the practice community. In 2008, NCI disseminated an evidence-based training program, Education in Palliative and End-of-Life Care for Oncology (National Cancer Institute, 2008) to serve as a multimedia, train-the-trainer professional curriculum. It was developed by Northwestern University, with funding from NCI and the Lance Armstrong Foundation. Numerous other awards, clinical trials, working groups, and training and educational initiatives by NCI have built the evidence base for EOL PC support for those experiencing advanced cancer. NCCAM has championed efforts to address complementary and alternative medicine approaches for use in hospice and for those in pain. NIA has also been a primary supporter of EOL PC science with numerous research grant solicitations and public education initiatives, including *End of Life: Helping with Comfort and Care* (National Institute on Aging, 2010). The critical role of NIA continues to grow as emphasis on aging and the impact of Alzheimer's disease threads with EOL PC care issues surrounding chronic and advanced illness issues.

Other DHHS agencies responded to the 2004 State-of-the-Science with focused efforts to increase research translation and inform the public about EOL PC issues. AHRQ developed several evidence-based reports on advance care planning and palliative wound care at the end of life as well as supported numerous research initiatives. Through federal-state-industry partnerships sponsored by AHRQ, the Healthcare Cost and Utilization Project focused on exploring the costs of end-of-life hospitalizations. AHRQ also requested a systematic review on end-of-life and hospice care as part of the 2011 Closing the Quality Gap: Revisiting the State-of-the-Science series (AHRQ, 2011). This initiative provided critical analysis of the existing literature on quality improvement strategies for a selection of disease and practice priority areas for transforming health care quality and recently issued the 2012 report, *Improving Health Care and Palliative Care for Advanced and Serious Illness* (AHRQ, 2012). CDC and its National Center for Vital Health Statistics, in turn, have actively engaged in the development of critical data briefs on topics such as end-of-life care in nursing homes, use of advance care directives in long-term care, and hospice and complementary and alternative medicine (National Committee on Vital Health Statistics, 2012). Included in the 2006 appropriation bill for the Departments of Labor, Health and Human Services, and Education was language that directed the Secretary of DHHS to consider how best to promote advance directives. Congress requested that DHHS conduct a study on how best to promote advance directives. The DHSS Office of the Assistant Secretary for Planning and Evaluation (ASPE) followed with a 2008 *Report to Congress on Advance Directives and Advance Care Planning* that emphasized the national need for continued attention to these issues (ASPE, 2008). This DHHS report was a product of research by RAND Health, several commissioned papers, “Roundtable Discussions” with experts, and ASPE.

The U.S. Department of Veterans Affairs (DVA) has also contributed to significant initiatives to provide evidence-based hospice and palliative care services to a growing number of veterans at each of its medical centers. The Health Services Research and Development Service supports numerous research studies and implementation projects in end-of-life, hospice, and palliative care (Health Services Research & Development Service, 2013). Other programs have been cultivated through the Geriatric Research Education and Clinical Centers (GRECCs), initiated in the 1970s with the goal to increase the basic knowledge about the aging process and how diseases of the elderly are best managed, transmit this knowledge to health care providers, and improve the quality of care delivered to elders. Each GRECC has a research component, an education component, and a clinical component. In addition, the Comprehensive End-of-Life Care Initiative was initiated as a large-scale effort to increase access to high-quality hospice and palliative care services among veterans. Performance Reporting and Outcomes Measurement to Improve the Standard of Care at End-of-life is an integral part of this initiative and an example of the many contributions by DVA to the field of EOL PC (Promise Center, 2013).

Within NIH, NINR has continued to foster opportunities for trans-NIH support for the field of EOL PC science and create public sector stewardship for EOL PC research. In 2009, NINR created a central coordinating Office of Research on End-of-Life Science and Palliative Care, Investigator Training, and Education to realize new initiatives to expand the capacity and capability of EOL PC science across NIH. More recently, NINR, with partners from various NIH ICs and Offices, hosted a 2011 National Summit on The Science of Compassion: Future Directions in End-of-Life and Palliative Care and a Town Hall on The Ethics of Research in End-of-Life Care (NINR, 2011).

Challenges for Continued Momentum in End-of-Life and Palliative Care Science

IDENTIFYING CURRENT KNOWLEDGE GAPS AND FUTURE RESEARCH PRIORITIES PROVIDES A TEMPLATE FOR BUILDING MOMENTUM TO STRENGTHEN THE EVIDENCE BASE SUPPORTING END-OF-LIFE AND PALLIATIVE CARE.

The previous sections describing many of the factors that have influenced the growth of end-of-life and palliative care (EOL PC) science are important considerations in creating a template for building new momentum in this important area of research and clinical practice. The challenges of creating a contemporary, meaningful, and unified definition of the field are a challenge for both science and clinical care—conceptually and operationally. Building the evidence base from an accepted definition is fundamental, but translating such knowledge into practice is essential. Building momentum to strengthen support across public and private sectors cannot be overlooked. Despite the multiple recommendations from the Institute of Medicine (IOM) calling for investment in EOL PC science, many organizational interests in research are evolving; some are specific, while other missions are broad. Many of the early stakeholders in funded EOL PC research have changed and investments in research initiatives have reached maturity. Amidst the clear momentum across the public sector to build the scientific foundation for EOL PC, the level of federal support for this science remains limited. Comparatively, the U.S. commitment to investment in EOL PC science has paralleled under-resourced and underdeveloped funding trends for similar research across Europe (World Health Organization, 2004). Funding support from 388 research articles published from 2003 to 2005 indicated only 31% of the studies reviewed specified funding received from the National Institutes of Health (NIH), with 85% of the NIH funding coming from only three NIH Institutes—National Cancer Institute, National Institute of Nursing Research, and National Institute on Aging (Gelfman and Morrison, 2008). Of the $31.2 billion in funds allocated to the NIH budget for fiscal year 2010, only a fraction of total federal research dollars are dedicated to EOL PC science, suggesting that the trends noted by Gelfman and Morrison may be more pervasive (NIH Office of Budget).

As well, the evidence base, while demonstrating enormous development, is—in many aspects of clinical practice, standards of care, and outcomes—still evolving. While there is a growing body of high-quality research covering a wide range of issues, EOL PC research is still in its infancy in terms of rigorous testing and evaluation of interventions and models of care, establishing quality outcomes, and assessing needs and resource utilization. Research must continue to expand to new areas of science to understand patient, caregiver, and health care system influences on quality outcomes. Cross-integration between disciplines and targeted interventions is still emerging with a need to find new ways to foster interdisciplinary team science and create new approaches that will de-fragment care "systems" as a whole. Much more is needed in terms of building support for various clinical standards, training, and translation of research findings into meaningful patient care across multiple health services, patient populations, and health conditions. It is also important to continue to build momentum in the translation of research findings that facilitate the public's understanding of the services that are available and the factors that point to the need to transition into end-of-life care.

Building momentum to foster EOL PC science (now and in the future) will require data that clearly point to strategies needed to address knowledge gaps while also specifying opportunities to translate this information into meaningful evidence-based practices. As various NIH Institutes and Centers, federal agencies, and private organizations look to prioritize future scientific agendas, a clear understanding as to whether the scope of national EOL PC research funding has significantly increased since the 1997 IOM report and across what agencies and research sectors and whether there are trends that elucidate opportunities for continued commitments toward dedicated support will help address barriers to research development and identify strategies to build the science of EOL PC in the future. This review provides data to support the above needs and to provide the scientific community, providers, and policymakers with an appraisal of both the progress made since the 1997 IOM report and the successes in building this research since the 2004 State-of-the-Science. Such information is important to identify the scope of the research literature, determine its scientific leaders and stakeholders, and build momentum to strengthen the breadth and depth of future research in terms of trends, gaps, and priorities.

The purpose of this current review is to provide a map of the nature and extent of themes related to end-of-life and palliative care (EOL PC) science within published research studies from 1997 through 2010. This information was evaluated to identify current trends and future research needs. Systematic reviews of the scientific literature are commonly used as a reflection of how much the field has advanced and in what areas the field still needs to expand. The research summarized in many previous literature reviews since the 1997 Institute of Medicine (IOM) report has analyzed data on a wide range of EOL PC conditions, populations, settings, and topics. These reviews have been specific and many have provided evaluations of research quality that has provided the scientific community, practitioners, and policymakers with detailed information on the body of knowledge and research needs. This current report reviewed data on several areas including the public and private sources of funded EOL PC research, the topics and trends in research publication themes, and a consideration of existing gaps and priorities for future support of EOL PC science. As an additional component, this review provided data accrued from federal databases that address the trends since 1997 in federal funding and grantmaking in EOL PC research. Methods and results were developed to address the questions:

- *What are the trends in EOL PC published research themes and topics?*
- *What are the federal, philanthropic, and other nonprofit funding sources cited in this published research and overall trends for EOL PC science support?*
- *Are EOL PC research interests and research priorities changing over time?*
- *Who are the stakeholders in EOL PC science?*
- *What opportunities exist for future partnerships to harmonize and strengthen research in EOL PC across U.S. funding bodies?*

IV. METHODS

The National Institute of Nursing Research contracted with NOVA Research Company to accrue data on research publications. Specific and detailed procedures of the methods used in this report are provided in Appendices A through E. Methods were designed to produce data from which to tabulate the themes and topics presented in published research abstracts and titles. A comprehensive search of the published research was then conducted using standard methods to identify those studies addressing the key questions of this report. Staff reviewed relevant articles, compiled tables of targeted study characteristics, appraised the evaluation factors, and summarized results. Methods did not include an evaluation of the quality of the research published or a review of research in the grey literature.

Sources of Data

Four databases (Appendix A) were used to search published end-of-life and palliative care (EOL PC) research articles: *PubMed®,* the *Web of Science*, the Cumulative *Index to Nursing and Allied Health Literature* (CINAHL), and the *Cochrane Database of Systematic Reviews* (CDSR). They are described as:

- **PubMed®**. This is a database of biomedical journal articles and abstracts created by the U.S. National Library of Medicine. *Medline*, the largest component of *PubMed®,* includes 5,400 journals published in the United States. Medline records are indexed with NLM's controlled vocabulary, *Medical Subject Headings*, which are also used by other research databases.
- **Web of Science.** This multidisciplinary database contains literature from 11,400 journals in the sciences, social sciences, and arts and humanities fields. It includes three citation databases and two conference proceedings databases.
- **Cumulative Index to Nursing and Allied Health Literature (CINAHL)**. CINAHL provides indexing for nearly 3,000 journals from the fields of nursing and allied health. The database contains more than 2.2 million records dating back to 1981.
- **The Cochrane Database of Systematic Reviews (CDSR)**. CDSR is a database designed for researchers, government, and the public to search for evidence-based health care research.[4]

Figure 1 describes the main steps and numbers of citations identified at each step. A total of 7,085 published research article citations were pulled from the various databases (PubMed®, Web of Science, CINAHL, and CDSR). Citations that were duplicated (*n*=1,329) and citations that lacked inclusion criteria (*n*=1,846) or did not meet second-level review (*n*=755) were further excluded from the search. The resulting 3,155 research publications were used to code the EOL PC research topic and evaluation themes per identified variables (Appendices A-E). Funding source information was contained within 1,258 of these articles. Additional follow-up of sources of the research funding support was obtained for an additional 216 publications for a total of 1,474 manuscripts with research funding information.

Data Analysis

All data analysis used various software and analysis programs. Data were exported from *FileMaker* to an *MS Excel 2007* spreadsheet and, from there, to *SPSS 17*. Total count tabulations and percentile scores were used to describe available data on funding of end-of-life and palliative care (EOL PC) research, including whether research that served as the basis for published studies was supported by funding, funding source(s) of research, type of funding received (e.g., federal, nonfederal, both), and associations between funding sources and published research in the field. Data analysis also addressed the numbers and types of EOL PC research studies funded, topics most commonly researched, health conditions of focused research, and other variables of interest.

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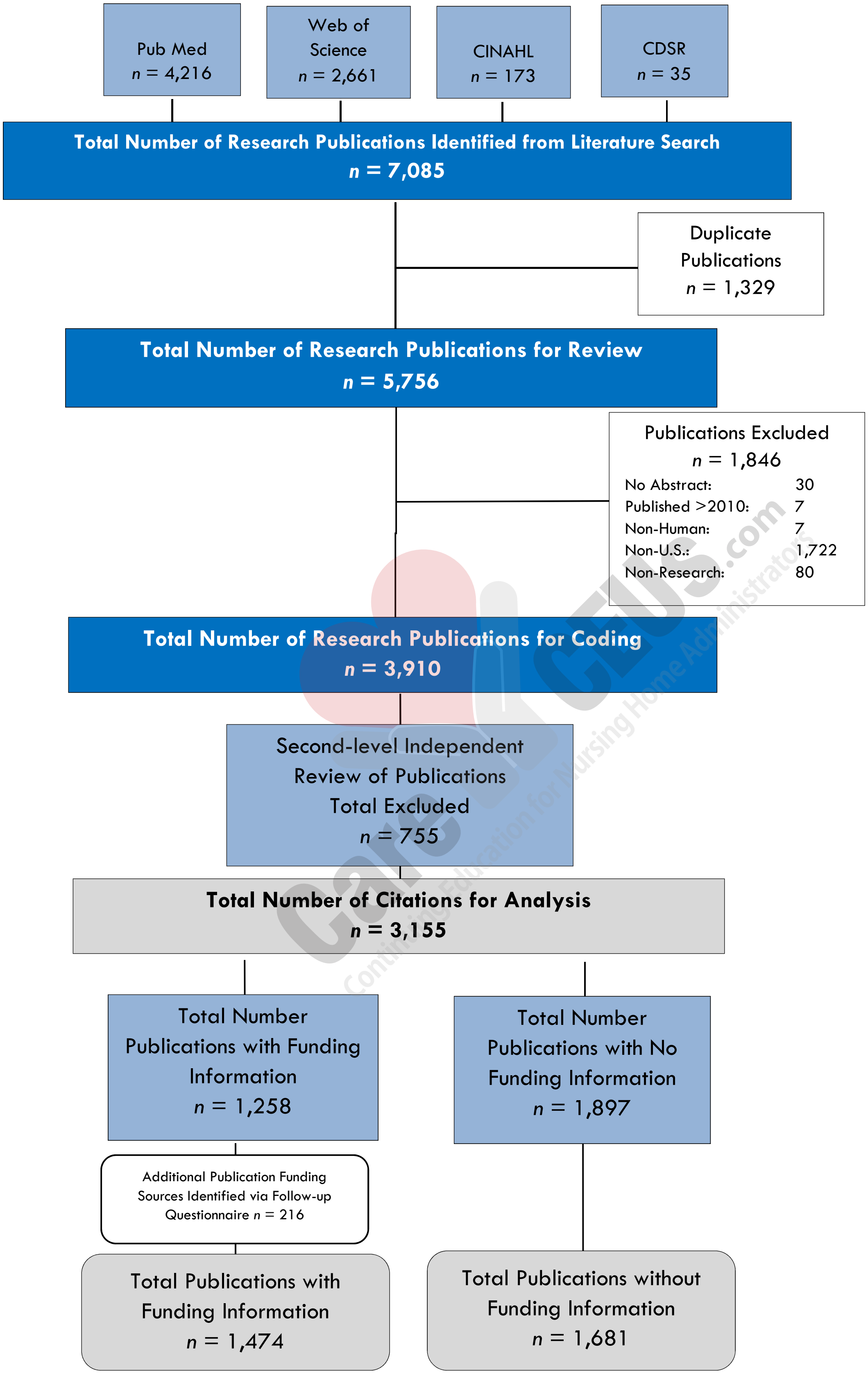
[4] *CDSR* consists of other databases that are not included in this review of the literature.

Figure 1. Process of Research Publication Identification.



Data Reporting

Within the report, studies that satisfied the inclusion criteria were summarized in data tables and figures. These tables provide information about the study targets and data outcomes. Narrative text summarized in the results provided qualitative analysis of the key questions for each topic area. The study sample size offers a measure of the weight of the evidence.

V. RESULTS

A. End-of-Life and/or Palliative Care: Research Publications, 1997-2010

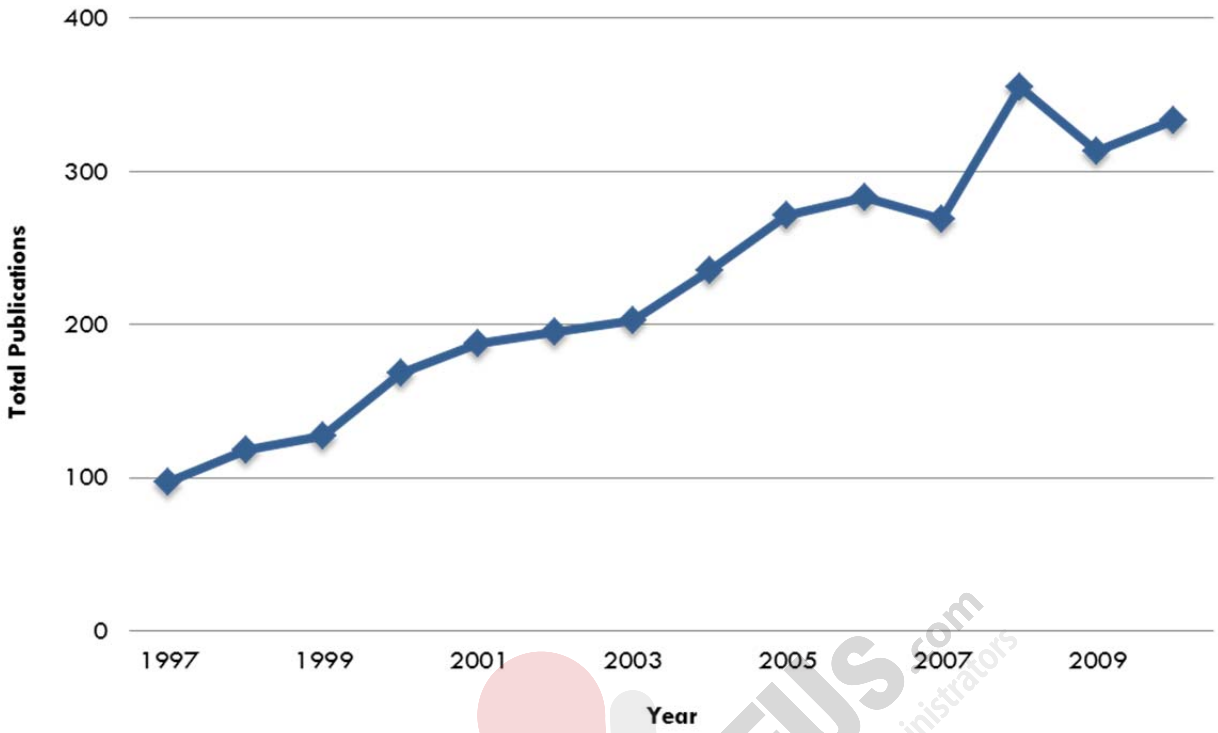
A total of 3,155 identified research manuscripts in end-of-life and palliative care (EOL PC) were published between 1997 and 2010. The number of publications consistently increased over the years, despite minor annual fluctuations (Table 1, Figure 2). Publications in the field more than tripled between 1997 (97 studies, 3.1% of total) and 2010 (333, 10.6% of total). A substantial increase in the numbers of publications across years was particularly evident in 2008, where 355 (11.3% of total) studies were published. This total represented the largest number of published EOL PC research studies in any given year.

Table 1. Total End-of-Life and/or Palliative Care Research Publications, 1997-2010.

Year	Number of Publications	Percent of Total
1997	97	**3.1**
1998	118	**3.7**
1999	127	**4.0**
2000	168	**5.3**
2001	188	**6.0**
2002	195	**6.2**
2003	203	**6.4**
2004	235	**7.4**
2005	271	**8.6**
2006	283	**9.0**
2007	269	**8.5**
2008	355	**11.3**
2009	313	**9.9**
2010	333	**10.6**
TOTAL	**3,155**	**100**

SOURCE: Literature Review

Figure 2. Total End-of-Life and/or Palliative Care Research Publications, 1997-2010.



Source: Literature Review

B. End-of-Life and/or Palliative Care Research Publications: Demographics

Publications Focused on a Specific Age Group. These data are explicit to end-of-life and palliative care (EOL PC) research publications that focused research specifically on a target age group of the subject population as described within the key fields searched (title, abstract, or key words). The scope of the ages per each category is defined in Appendix D. The data may not reflect information on subject demographics that may have been contained within the entire manuscript.

Information on the age of the populations studied within the published EOL PC research literature between 1997 and 2010 was available in approximately two-thirds (65%) of all abstract, title, and key word fields reviewed. Unspecified data on age of the studied population as extracted from the abstract, title, or other search fields ranged from 23% (27 studies) in 1998 to 44% (148 studies) in 2010 (Table 2).[5]

Across all years, abstracts reviewed showed that published research on EOL PC was conducted primarily in adult populations. More than half of published EOL PC studies (1,765 studies, 56%) were focused on adults; however, data specific to age subgroups such as geriatric populations (> 65 years) were not extrapolated. EOL PC research publications with pediatric populations were tabulated for age groups from newborns to 17-year-olds and did not parse out publications

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[5] "Unspecified data" regarding age implies that reviewed abstracts did not include information (see Data Dictionary in Appendix D) to code study participants into a given age group category.

unique to subgroups such as adolescents or young adults. A total of 125 (4%) research publications from the dataset indicated research conducted with children, while 172 (6%) publications involved combined groups of both adults and children.[6] Despite growing scientific literature, research with children represented only 10% of all annual EOL PC publications.[7]

Table 2. Total (Percent Row Total) Research Publications Focusing on a Subject Age Group, 1997-2010.

Year	Total (Percent Row Total) Publications Focusing on a Subject Age Group[a]				Total (Percent Row Total)
	Children	Adult	Combined	Unspecified[b]	
1997	-	60	4	33	**97**
	-	(61.9%)	(4.1%)	(34.0%)	**(100%)**
1998	-	81	10	27	**118**
	-	(68.6%)	(8.5%)	(22.9%)	**(100%)**
1999	6	76	6	39	**127**
	(4.7%)	(59.8%)	(4.7%)	(30.7%)	**(100%)**
2000	8	105	7	48	**168**
	(4.8%)	(62.5%)	(4.2%)	(28.5%)	**(100%)**
2001	3	110	11	64	**188**
	(1.6%)	(58.5%)	(5.9%)	(34.0%)	**(100%)**
2002	6	113	9	67	**195**
	(3.1%)	(57.9%)	(4.6%)	(34.4%)	**(100%)**
2003	5	114	7	77	**203**
	(2.5%)	(56.2%)	(3.4%)	(37.9%)	**(100%)**
2004	4	138	13	80	**235**
	(1.7%)	(58.7%)	(5.5%)	(34.0%)	**(100%)**
2005	5	171	18	77	**271**
	(1.8%)	(63.1%)	(6.6%)	(28.4%)	**(100%)**
2006	14	163	15	91	**283**
	(4.9%)	(57.5%)	(5.3%)	(32.2%)	**(100%)**
2007	14	158	15	82	**269**
	(5.2%)	(58.7%)	(5.6%)	(30.5%)	**(100%)**
2008	18	177	21	139	**355**
	(5.0%)	(49.9%)	(5.9%)	(39.2%)	**(100%)**
2009	21	153	18	121	**313**
	(6.7%)	(48.8%)	(5.8%)	(38.7%)	**(100%)**
2010	21	146	18	148	**333**
	(6.3%)	(43.8%)	(5.4%)	(44.4%)	**(100%)**
TOTAL (Percent Row Total)	**125 (4.0%)**	**1,765 (55.9%)**	**172 (5.5%)**	**1,093 (34.6%)**	**3,155 (100%)**

[a]Children = Newborn to 17 years; Adult = > 18 years; Both = Children and Adult Populations

[b]Age of study population was not included in the publication's title, key words, or abstract.

SOURCE: Literature Review

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[6] Studies with both "children" and "adults" could focus on families or children and adults (e.g., parents, health care professionals).

[7] Emerging research interests on subgroups of very young children (e.g., neonates, premature infants) could not be assessed because the category "children and adolescents" used in the study included newborns through 17-year-olds.

Publications Focused on a Specific Male and/or Female Subject Group. These data are specific to EOL PC research publications that focused specifically on male and/or female population subject groups as described within the key fields searched (title, abstract, or key words). This tabulation sought to address health conditions that may have been exclusive to males (e.g., prostate cancer) or females (e.g., ovarian cancer) or related to issues in EOL PC that may address specific needs (e.g., female wives as caregivers). The key fields from which these data were accrued may not reflect information on the subject population studied that may have been contained within the full manuscript.

EOL PC studies published between 1997 and 2010 describing research for a specific male and/or female population were found for more than half (52%) of all studies reviewed (Table 3). More than two out of five studies (43%, 1,345 studies) were conducted with mixed groups. Studies that targeted a specific male or female subject group were found for 9% of publications (4% males, 129 studies; 5% females, 155 studies). Further analysis indicated that most of these published studies focused on gender-specific cancer populations (63% of gender-specific studies related to cancer in male populations and 53% of gender-specific studies related to cancer in female populations). Other topics included studies related to spouses, parenting (mothers and fathers), and caregiving. Unspecified data in the studies regarding targeted male and/or female population ranged from 37% (101 studies) in 2005 to 64% (212 studies) in 2010.[8]

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[8] It is possible that many studies not specifying this information were population-based studies or studies conducted with groups of patients at a given place (e.g., hospital, hospice); however, these assumptions were not examined during analysis.

Table 3. Total (Percent Row Total) Research Publications Focusing on a Specific Male and/or Female Subject Population, 1997-2010.

Year	Subject Groups				Total (Percent Row Total)
	Male	Female	Both Groups	Unspecified[a]	
1997	3	6	43	45	**97**
	(3.1%)	(6.2%)	(44.3%)	(46.4%)	**(100%)**
1998	7	7	59	45	**118**
	(5.9%)	(5.9%)	(50.0%)	(38.1%)	**(100%)**
1999	6	7	57	57	**127**
	(4.7%)	(5.5%)	(44.9%)	(44.9%)	**(100%)**
2000	7	5	84	72	**168**
	(4.1%)	(3.0%)	(50.0%)	(42.9%)	**(100%)**
2001	7	9	87	85	**188**
	(3.7%)	(4.8%)	(46.3%)	(45.2%)	**(100%)**
2002	8	12	79	96	**195**
	(4.1%)	(6.2%)	(40.5%)	(49.2%)	**(100%)**
2003	9	8	101	85	**203**
	(4.4%)	(3.9%)	(49.8%)	(41.9%)	**(100%)**
2004	17	4	107	107	**235**
	(7.2%)	(1.7%)	(45.5%)	(45.5%)	**(100%)**
2005	8	12	150	101	**271**
	(2.9%)	(4.4%)	(55.4%)	(37.3%)	**(100%)**
2006	13	16	135	119	**283**
	(4.6%)	(5.7%)	(47.7%)	(42.0%)	**(100%)**
2007	10	14	119	126	**269**
	(3.7%)	(5.2%)	(44.2%)	(46.8%)	**(100%)**
2008	10	19	145	181	**355**
	(2.8%)	(5.4%)	(40.8%)	(51.0%)	**(100%)**
2009	14	16	88	195	**313**
	(4.5%)	(5.1%)	(28.1%)	(62.3%)	**(100%)**
2010	10	20	91	212	**333**
	(3.0%)	(6.0%)	(27.3%)	(63.7%)	**(100%)**
TOTAL (Percent Row Total)	**129 (4.1%)**	**155 (4.9%)**	**1,345 (42.6%)**	**1,526 (48.4%)**	**3,155 (100%)**

[a] Sex (male, female) of study population was not included in the publication's title, key words, or abstract.

SOURCE: Literature Review

Publications Focused on a Specific Race/Ethnicity. The published literature was reviewed to ascertain EOL PC research foci within a specific racial or ethnic group. These data are specific to EOL PC research publications that focused research specifically on a target ethnic or racial population as described within the key fields searched (title, abstract, or key words). The data do not reflect details that could have been described within the full manuscript.

Definitions

For the purposes of this review, the coding categories for this section followed the National Institutes of Health procedures of ethnic and racial definitions of minimum standard categories (Office of Management and Budget, 1997).

Ethnic Categories:

- ***Hispanic or Latino***: A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term "Spanish origin" can also be used in addition to "Hispanic or Latino."
- ***Not Hispanic or Latino****:* This category is not used in this review.

Racial Categories:

- ***Asian:*** A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam. (Note: Individuals from the Philippine Islands have been recorded as Pacific Islanders in previous data collection strategies.)
- ***Native Hawaiian (NH) or Other Pacific Islander (PI):*** A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- ***Black (B) or African American (AA):*** A person having origins in any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American."
- ***American Indian (AI) or Alaska Native (AN):*** A person having origins in any of the original peoples of North, Central, or South America, and who maintains tribal affiliations or community attachment.
- ***White****:* A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Table 4 shows that the review of abstract, key words, and title fields from 1997 to 2010 indicated a total of 317 EOL PC research publications (10% of the total 3,155 publication data set) with an emphasis on topics related to a specific racial/ethnic population (Table 4). When publications with more than one Race/Ethnicity or White categories are removed, this number decreases further to 119 published studies. Combined categories for *B or AA, Asian, NH or PI, AI or AN, and Hispanic/Latino* represented 3.8% of the total EOL PC research publications. The "Unspecified" data on race/ethnicity (2,838 publications, 90% of total) as derived from coding of the abstracts, key words, and titles reviewed should be interpreted with caution. “Unspecified” indicates that the publication, in its abstract or title fields, did not specify a particular racial/ethnic study population. The data should not be interpreted as an indication that publications did not specify the ethnic/racial composition of subject samples; in fact, the inclusion of race/ethnicity information for a study sample is commonly described in manuscripts.

Table 4. Total (Percent) Research Publications Focusing on a Specific Race/Ethnicity, 1997-2010.

Year	Racial/Ethnic Category						Total
	More than One Race/ Ethnicity	White	B or AA	Asian, NH or PI, AI or AN	Hispanic or Latino	Un-Specified[a]	
1997	3	3	4	-	-	86	**96**
1998	3	3	2	-	-	110	**118**
1999	4	5	-	1	1	115	**126**
2000	5	6	2	1	-	154	**168**
2001	5	5	4	3	-	171	**188**
2002	5	2	3	-	1	183	**194**
2003	4	5	3	2	1	188	**203**
2004	7	4	5	2	1	216	**235**
2005	11	5	7	4	1	244	**272**
2006	11	5	5	1	-	261	**283**
2007	9	9	3	3	1	244	**269**
2008	12	15	10	6	2	311	**356**
2009	15	11	15	2	4	267	**314**
2010	15	11	12	3	4	288	**333**
TOTAL	**109**	**89**	**75**	**28**	**16**	**2,838**	**3,155**
(Percent)	**(3.5%)**	**(2.8%)**	**(2.4%)**	**(0.9%)**	**(0.5%)**	**(90.0%)**	**(100.0%)**

[a] Racial or ethnic information as a study target was not included in the publication’s title, key words, or abstract.

SOURCE: Literature Review

C. End-of-Life and/or Palliative Care Research Publications: Study Design

The key search fields of the published end-of-life and palliative care (EOL PC) literature were reviewed to obtain information on the research design of these studies. Study type was the only variable that was mutually exclusive, meaning that a publication was only coded for one study type category (i.e., one code for analytic review, qualitative, experimental, psychometric, other quantitative/non-experimental, mixed methods, or action research). Evaluation of the quality of the study was not within the scope of this review.

Definitions

Tabulations of EOL PC publication research designs were based on seven categories: 1) quantitative, 2) experimental, 3) qualitative, 4) mixed-methods, 5) analytic reviews, 6) psychometric, and 7) action research (Yin, 1999; Creswell, 2002; National Resource Council, 2002; Flyvbjerg, 2006; Explorable, 2008; Data Dictionary in Appendix D):

- ***Quantitative*** studies are based on numeric data. For this review, "quantitative studies" referred to non-experimental studies such as *descriptive, case-control, case series, cross-sectional, cohort, secondary analysis, longitudinal,* or *correlational* studies.
- ***Experimental*** studies often seek to determine cause and effect or the effectiveness of programs, systems, or interventions. These studies often have a control, comparison, or placebo group. They may or may not have random assignment. Some examples and key words included: *randomized control trials, protocol studies, clinical trials, experimental research, quasi-experimental studies (e.g., nonrandom assignment), comparison group studies (e.g., studies that compare drugs and have no control group), field experiments,* and *twin studies.*
- ***Qualitative*** studies are based on the collection of non-numeric data (e.g., text, narratives, group discussions) and can include *focus groups, interviews, phenomenology, ethnographic research, case study research, grounded theory research,* and *historical research*. In the present review, case studies were also included. Case studies are a type of research often used as instances of a class of phenomena that provide an analytical frame, like a proposition or a situation. They are also exploratory in nature as they lend themselves to both generating and testing hypotheses.
- ***Mixed-Methods*** studies use both qualitative and quantitative methods of data collection.
- ***Analytic Reviews*** use methods to combine the results of independent studies, including *meta-analyses, systematic reviews,* and *syntheses of summaries*. Analytic reviews do not include reviews of literature or narrative reviews.
- ***Psychometric*** studies seek to develop, pilot, or replicate instruments, scales, or measures.
- ***Action Research*** is that in which the community or population is involved in the approach, method, or design of the study. Associated terms *included participatory research, community-based research*, and *community-based participatory research.*

Information on the research design of all published studies between 1997 and 2010 was reviewed (Table 5). In that time period, more than half of all EOL PC research publications focused on quantitative, nonexperimental research designs (1,653 studies, 52%) followed by qualitative designs (741 studies, 24%) and experimental designs (420 studies, 13%). Less than 10% of EOL PC research studies published focused on psychometric, analytic reviews, mixed-methods, or action research. An examination of study types in terms of proportion (percentage) of total annual publications indicates that, in any given year, about half of all studies were quantitative, ranging from 48% in 2006 to 59% in 1997; the proportion of experimental studies ranged from 10% in 2000 and 2008 to 18% in 1998.

Overall, the total number of publications focusing on quantitative and experimental study designs increased since 1997 (Figure 3). Quantitative studies nearly tripled from 1997 to 2010 with 57 studies (59% of total) conducted in 1997 to 171 studies (52% of total) in 2010. The number of experimental studies more than doubled in the period between 1997 to 2010, increasing from 15 studies (16%) in 1997 to 37 (11%) in 2010. The largest number of publications occurred in 2006 with 48 experimental studies representing 17% of all publications. Publications using qualitative research designs increased from 1997 to 2010. The number of publications that were qualitative ranged from 14% of all publications in 1997 (14 studies) to 26% of all publications in the years 2003 (52 studies), 2007 (70 studies), and 2010 (88 studies).

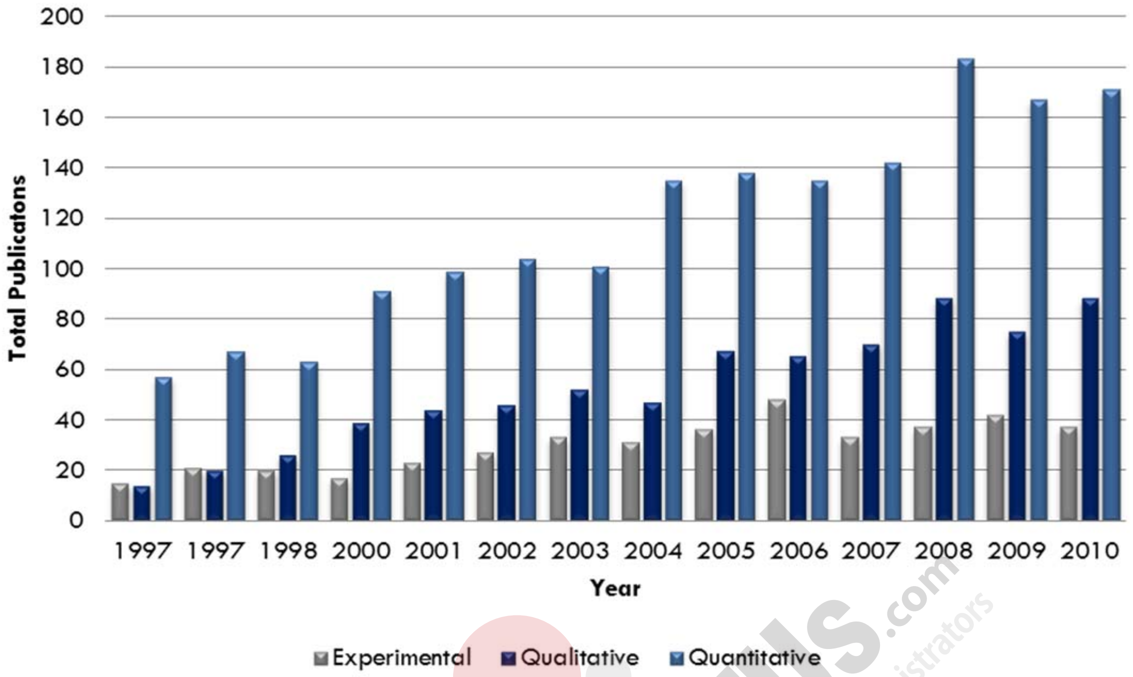
EOL PC research describing psychometric studies, analytic reviews, mixed-methods studies, or action research was limited in the publications reviewed. The proportion of analytic reviews ranged from 3% (three studies) of all publications in 1997 and 1998 to 7% of all publications (26 studies) in 2008 (Figure 4). Psychometric studies accounted for less than 5% of all publications with the highest rate of such studies occurring in 2006 (12 studies, 4%). Participatory action research studies were limited in the EOL PC literature.

Table 5. Total (Percent Row Total) Research Publications per Study Design, 1997-2010.

	Study Design							
Year	**Quantitative**	**Qualitative**	**Experimental**	**Mixed-Methods**	**Psycho-metric**	**Analytic Reviews**	**Action Research**	**Total (Percent Row Total)**
1997	57	14	15	6	2	3	-	**97**
	(58.7%)	(14.4%)	(15.5%)	(6.2%)	(2.1%)	(3.1%)	-	**(100%)**
1998	67	20	21	4	3	3	-	**118**
	(56.8%)	(16.9%)	(17.8%)	(3.4%)	(2.5%)	(2.5%)	-	**(100%)**
1999	63	26	20	9	3	5	1	**127**
	(49.6%)	(20.5%)	(15.7%)	(7.1%)	(2.4%)	(3.9%)	(0.8%)	**(100%)**
2000	91	39	17	8	4	9	-	**168**
	(54.1%)	(23.2%)	(10.1%)	(4.8%)	(2.4%)	(5.4%)	-	**(100%)**
2001	99	44	23	4	7	11	-	**188**
	(52.7%)	(23.4%)	(12.2%)	(2.1%)	(3.7%)	(5.9%)	-	**(100%)**
2002	104	46	27	5	6	7	-	**195**
	(53.3%)	(23.6%)	(13.8%)	(2.6%)	(3.1%)	(3.6%)	-	**(100%)**
2003	101	52	33	3	6	8	-	**203**
	(49.7%)	(25.6%)	(16.3%)	(1.5%)	(3.0%)	(3.9%)	-	**(100%)**
2004	135	47	31	5	6	11	-	**235**
	(57.4%)	(20.0%)	(13.2%)	(2.1%)	(2.6%)	(4.7%)	-	**(100%)**
2005	138	67	36	15	4	11	-	**271**
	(50.9%)	(24.7%)	(13.3%)	(5.5%)	(1.5%)	(4.1%)	-	**(100%)**
2006	135	65	48	11	12	12	-	**283**
	(47.7%)	(23.0%)	(17.0%)	(3.9%)	(4.2%)	(4.2%)	-	**(100%)**
2007	142	70	33	7	4	13	-	**269**
	(52.8%)	(26.0%)	(12.3%)	(2.6%)	(1.5%)	(4.8%)	-	**(100%)**
2008	183	88	37	13	7	26	1	**355**
	(51.5%)	(24.8%)	(10.4%)	(3.7%)	(2.0%)	(7.3%)	(0.3%)	**(100%)**
2009	167	75	42	6	9	13	1	**313**
	(53.4%)	(24.0%)	(13.4%)	(1.9%)	(2.9%)	(4.2%)	(0.3%)	**(100%)**
2010	171	88	37	9	10	18	-	**333**
	(51.4%)	(26.4%)	(11.1%)	(2.7%)	(3.0%)	(5.4%)	-	**(100%)**
TOTAL (Percent Row Total)	**1,653** **(52.4%)**	**741** **(23.5%)**	**420** **(13.3%)**	**105** **(3.3%)**	**83** **(2.6%)**	**150** **(4.8%)**	**3** **(0.1%)**	**3,155** **(100.0%)**

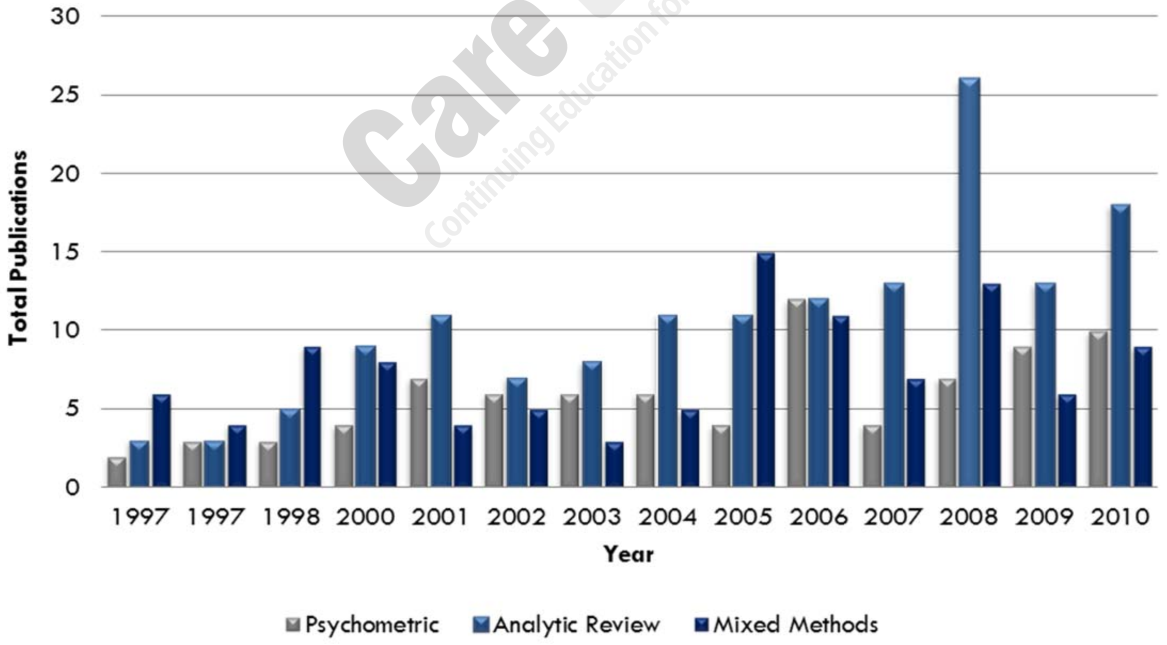
Source: Literature Review

Figure 3. Total Research Publications per Study Design, 1997-2010. Quantitative, Qualitative, Experimental.



SOURCE: Literature Review

Figure 4. Total Research Publications per Study Design, 1997-2010. Psychometric, Analytic Review, Mixed-Methods.



SOURCE: Literature Review

D. End-of-Life and/or Palliative Care Research Publications: Health Conditions/Diseases

End-of-life and palliative care (EOL PC) published research topic categories were developed as a method to ascertain key themes and subject matter trends in the research literature since 1997. Of particular interest was determining trends in the health conditions/disease topics within the published research literature, what health conditions/diseases represented new or emerging areas of interest, and trends for publication of EOL PC research in these areas.

Definitions

To vet publication themes into a discreet number of health condition/disease topic categories for coding, a series of methods were followed that included expert consultations on health condition/disease topic themes and reviews of health conditions/disease topics in previous reports or assessments within the EOL PC research literature. The vetted category topic selections were also reviewed during the coding process to ensure topic themes were identified. Detailed information on the categories and coding procedures are provided in the Appendices. For the purposes of this review, health condition/disease categories were defined as the following:

- ***Cancer*** referred to all conditions related to cancer.
- ***Neurologic*** referred to conditions related to the nervous system (e.g., Huntington's disease, Parkinson's disease) including Alzheimer's disease and other forms of dementia.
- ***Cardiac*** referred to conditions related to the heart and the circulatory system (e.g., congestive heart failure).
- ***Respiratory*** **(*Resp)*** referred to conditions related to the respiratory system, including chronic obstructive pulmonary disease (COPD). Lung cancer was not included in this category.
- ***Renal*** referred to conditions related to the kidney as well as the urologic system (e.g., renal failure, uremia).
- ***HIV/AIDS*** referred to conditions related to human immunodeficiency virus infection/acquired immunodeficiency syndrome.
- ***Musculoskeletal (MSK)*** referred to conditions related to the musculoskeletal system (e.g., muscular dystrophy, arthritis).
- ***Other*** referred to a varied number of additional conditions not specified by a target category (e.g., diabetes, colitis, cystic fibrosis, ulcers).
- ***Hepatic*** referred to conditions related to the liver (e.g., liver failure, chronic hepatitis B).

In this review, when an abstract or title did not contain a reference to a specific health condition/disease, the assumption was made that the research was not focused on a specific topic.

The review of EOL PC research publications between 1997 and 2010 indicated that nearly half (49%, 1,543 of the total 3,155 publications) of the reviewed research literature focused on one or more specific health conditions/diseases (Table 6). The number of publications focused on specific health conditions/diseases in EOL PC has increased.

Table 6. Total Research Publications Focused on One or More Health Conditions/Diseases as Topic, 1997-2010.

Year	Total Publications with One or More Health Conditions/Diseases As Topic
1997	49
1998	51
1999	64
2000	91
2001	92
2002	90
2003	104
2004	122
2005	119
2006	126
2007	127
2008	172
2009	154
2010	182
TOTAL	**1,543**

Source: Literature Review

Some publications emphasized more than one health condition/disease topic. Thus, 1,978 citations of a specific health condition/disease were described in the 1,543 publications identified with this topic category. Table 7 further delineates the number of publications emphasizing each specific health condition/disease category from 1997 to 2010. Figure 5 illustrates the percentage of health condition/disease topics cited in the published research literature from 1997 to 2010.

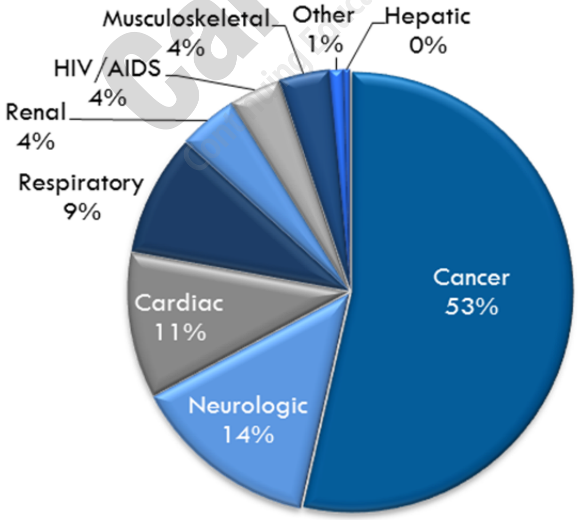
The majority of publications with a health condition/disease focus concentrated on cancer-related themes. Of the 1,978 descriptions of a health condition/disease topic in EOL PC research publications, 1,059 (53% of total described topics) emphasized cancer. Following cancer were neurologic conditions/diseases (271 publications, 13.7% of total), cardiac conditions/diseases (210 publications, 10.6% of total), and respiratory conditions/diseases (176 publications, 8.8% of total). The remaining health conditions/diseases categories encompassed less than 5% of all publications.

Table 7. Total Research Publications with a Health Condition/Disease Topic, 1997-2010.

Year	Specific Health Condition/Disease Topic									Total Publications Health Condition/ Disease Focus
	Cancer	Neurologic	Cardiac	Resp	Renal	HIV/ AIDS	MSK	Other	Hepatic	
1997	32	7	4	3	5	6	-	1	-	**58**
1998	33	10	2	5	4	10	5	1	-	**70**
1999	41	15	9	5	5	5	1	2	2	**85**
2000	64	14	12	17	3	5	1	2	3	**121**
2001	56	18	8	7	7	8	6	2	-	**112**
2002	71	13	15	8	4	5	4	1	-	**121**
2003	82	17	11	10	4	4	4	4	-	**136**
2004	88	22	17	11	6	3	9	-	-	**156**
2005	73	17	21	16	8	9	8	1	1	**154**
2006	84	24	20	18	7	4	8	2	1	**168**
2007	91	24	21	11	9	2	7	1	-	**166**
2008	116	32	25	24	6	4	7	2	1	**217**
2009	107	28	15	20	6	4	7	-	-	**187**
2010	121	30	30	21	12	5	6	1	1	**227**
TOTAL **(Percent)**	**1,059** (53.5%)	**271** (13.7%)	**210** (10.6%)	**176** (8.8%)	**86** (4.3%)	**74** (3.7%)	**73** (3.7%)	**20** (1.1%)	**9** (0.5%)	**1,978** (100%)

Source: Literature Review; Abbreviations: Resp = Respiratory, MSK = Musculoskeletal

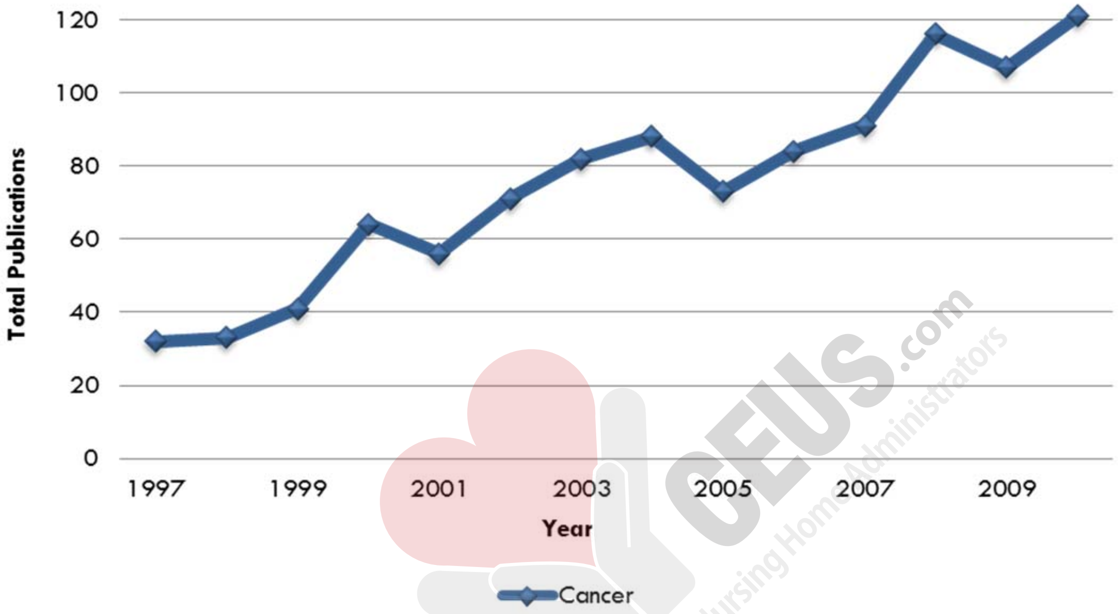
Figure 5. Total Percent Health Conditions/Disease Category Topic per Research Publications, 1997-2010.



SOURCE: Literature Review

Figures 6 through 8 illustrate trends in publications with specific topics of health conditions/diseases for each year. Figure 6 illustrates an overall increase in the number of EOL PC research publications with emphasis on the topic of cancer, from 32 publications in 1997 to 121 publications in 2010.

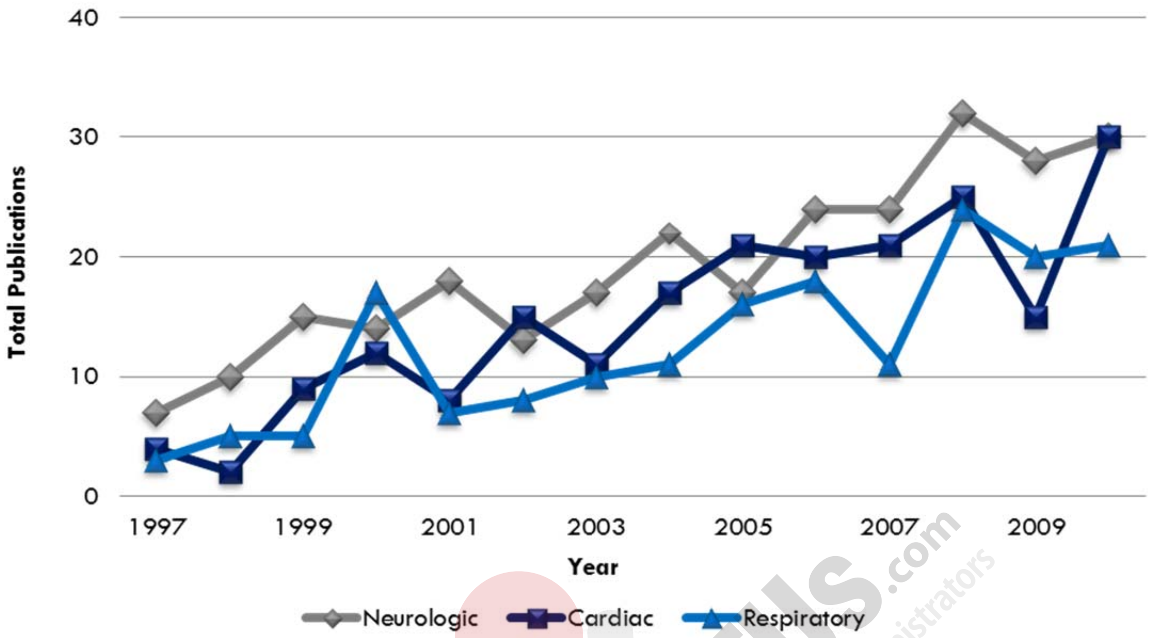
Figure 6. Total Research Publications with Cancer as a Health Condition/Disease Topic, 1997-2010.



SOURCE: Literature Review

Figure 7 illustrates an overall increase in the number of EOL PC research publications related to neurologic, cardiac, or respiratory health conditions/diseases. These three categories represent approximately one-third (33%) of all EOL PC publications focused on health conditions/diseases. Research publications focused on EOL PC-related neurologic health conditions/disease increased from seven publications in 1997 to 30 publications in 2010. Research publications focused on EOL PC-related cardiac health conditions/diseases increased from four publications in 1997 to 30 publications in 2010. Research publications focused on EOL PC-related respiratory health conditions/disease increased from three publications in 1997 to 21 publications in 2010.

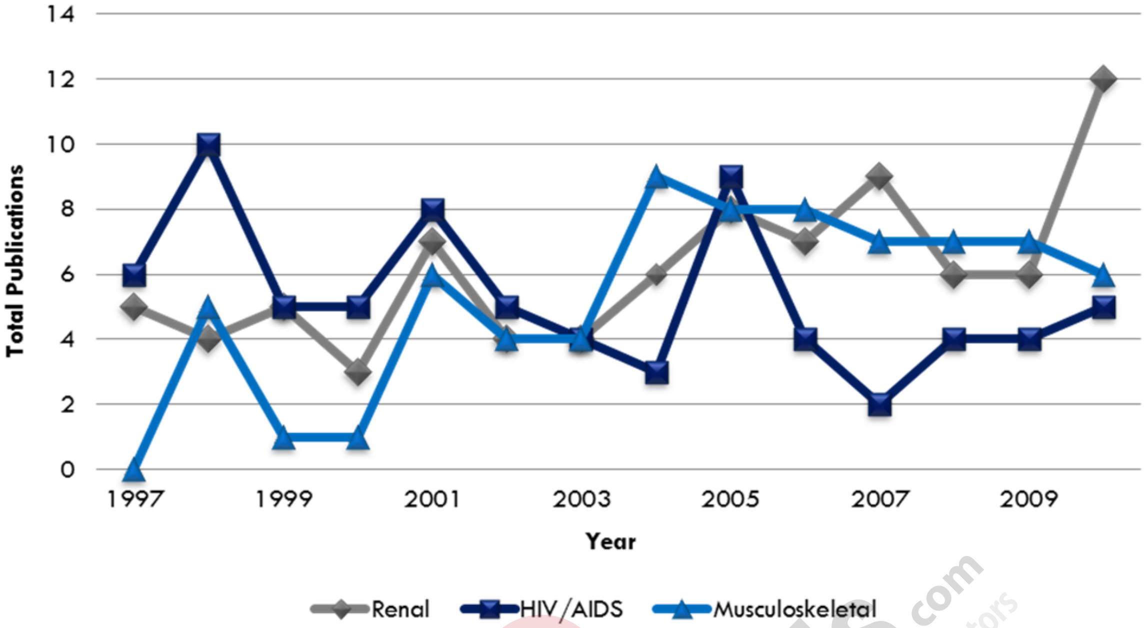
Figure 7. Total Research Publications with Advanced Neurologic, Cardiac, or Respiratory Health Conditions/Disease Topics, 1997-2010.



SOURCE: Literature Review

Figure 8 illustrates the trends in publication topic themes for EOL PC-related advanced renal, HIV/AIDS, and musculoskeletal health conditions/diseases from1997 to 2010. These three categories represent approximately12% of all EOL PC publications focused on health conditions/disease. Publications in the area of EOL PC-related advanced renal health conditions/diseases have increased slightly from five publications in 1997 to 12 publications in 2010. EOL PC-related HIV/AIDS publications have been variable with a small decrease from six publications in 1997 to five publications in 2010. EOL PC-related musculoskeletal health conditions/diseases as a topic focus increased to nine publications in 2004, but decreased to six publications in 2010.

Figure 8. Total Research Publications with Advanced Renal, HIV/AIDS, or Musculoskeletal Health Conditions/Diseases Topics, 1997-2010.



SOURCE: Literature Review

E. End-of-Life and/or Palliative Care Research Publications: Topics Studied

End-of-life and palliative care (EOL PC) published research literature topic categories were developed to ascertain key themes and subject matter trends in the research literature since 1997. Of particular interest was ascertaining what topics in the literature represented new or emerging areas of interest in EOL PC research and the growth of research in areas recommended at the 2004 State-of-the-Science.

To vet publication themes into a discreet number of topic categories for coding, a series of methods was followed to include reviews of published and grey literature on EOL PC research, use of expert consultations on topic themes, and reviews of topics in previous reports or assessments of the EOL PC research (Appendices A-E). In addition, the vetted category topic selections were reviewed to ensure project goals and scope were captured during the coding process. A Data Dictionary (Appendix D) provided additional guidance for the coding of topic categories for all dataset publications extracted from the literature review.

A limited number of topic categories with thematic similarity were merged into the final reported dataset. The topic “Bereavement and Grief” (*n*=40) was merged with the category topic “Social, Emotional, and Mental Health” (*n*=211) under a general inclusive category heading of “Mental Health.” The topic categories “Medical” (*n*=267) and “Alternative Medicine” (*n*=40) were merged into the heading “Medical and Alternative Medicine” and the category topics of “Culture” (*n*=164) and “Religion/Spirituality” (*n*=86) were merged into the heading of “Culture, Religion, and Spirituality.”[9] Research publications coded as “Other” did not meet the definitional criteria for coding a specific topic theme (Data Dictionary in Appendix D).

Of the 3,155 research publications reviews, a total of 4,299 topic themes were identified. The total number of coded topics indicates that approximately one-third (1,144) of the research publications addressed multiple themes. Table 8 lists the total number of research publication category themes identified from the dataset reviewed. The topic categories are listed for each year from 1997 to 2010. Results are presented as the total number of publications per year for each topic category as well as the overall total number of topic themes identified each year.

The total percentage of each topic category in the EOL PC publications is illustrated in the pie chart of Figure 9. The categories of “Advance Care Planning” (*n*=539 occurrences of this theme in all publications, 12.5% of total categories identified), “Care Settings” (*n*=495, 12% total category themes), and “Pain and Other Symptom Management” (*n*=481, 11.1% total category themes identified) were the three most frequently identified EOL PC topic categories representing more than one-third (35.6%) of the themes presented in the 1997 to 2010 research literature. Topic categories that occurred in 5% to 10% of all publications included “Hospice” (*n*=364, 8.5% of total publications), “Medical and Alternative Medicine” (*n*=307, 7.1%), “Mental Health” (*n*=251, 5.8%), “Culture, Religion, and Spirituality” (*n*=250, 5.8%), “Education and Training” (*n*=222, 5.2%), and “Other” (*n*=221, 5.1%). Additional topics such as “Caregivers,” “Ethics,” “Communication,” “Care Services and Standards,” “Economics,” “Quality of Life,” “Quality of Care,” “Service Delivery Models,” or “Prognosis” individually comprised less than 5% of the total percent of all 4,299 topic themes identified. Trends in topic themes across the years reviewed are discussed on the following pages.

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[9] Findings on each topic are largely influenced by categorization and definition of the topic. Some topics such as “care settings and care” involve the provision of EOL PC services in a variety of settings (e.g., nursing homes, assisted living facilities, intensive care units, home care) and, therefore, tend to include a larger number of studies.

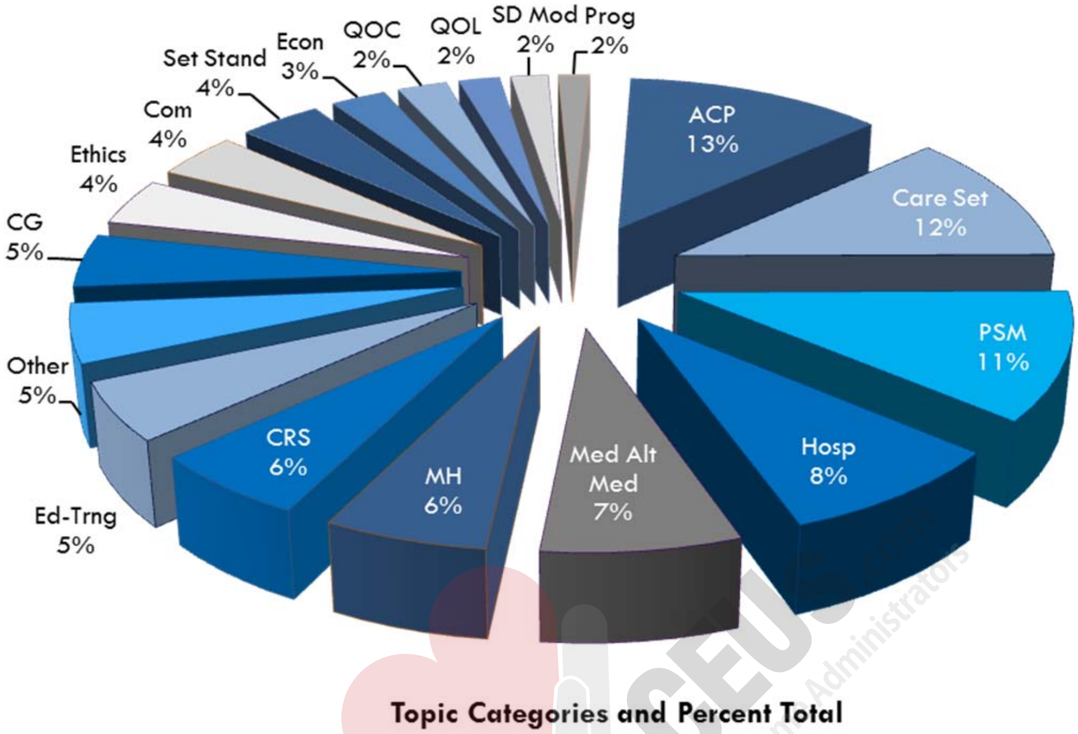
Table 8. Number of Topic Categories Identified in Research Publications, 1997-2010.

Year	Topic Categories																	Total
	ACP	Care Set	PSM	Hosp	Med Alt Med	MH	CRS	Edu-Trng	Other	CG	Ethics	Com	Set Stand	Econ	QOC	QOL	SD Mod	Prog	
1997	26	17	10	14	12	6	5	5	5	5	8	5	2	5	0	0	0	1	**126**
1998	37	22	16	9	12	6	8	6	4	1	7	2	4	4	4	6	4	2	**154**
1999	29	17	18	13	16	3	6	9	6	6	18	1	8	3	3	4	2	2	**164**
2000	25	23	28	19	16	17	12	7	10	9	12	11	14	8	5	5	1	6	**228**
2001	31	26	42	25	20	17	14	10	13	11	13	8	10	2	5	4	3	3	**257**
2002	25	26	27	24	21	15	9	19	16	9	10	4	15	7	7	7	5	4	**250**
2003	23	25	27	27	31	16	11	19	12	15	13	9	9	10	4	7	9	3	**270**
2004	42	43	40	33	27	23	14	13	16	18	11	11	16	12	6	6	5	3	**339**
2005	40	48	28	30	21	25	26	31	21	26	18	20	11	8	6	2	8	4	**373**
2006	40	51	42	29	30	20	31	16	24	16	19	21	14	9	8	10	9	8	**397**
2007	54	41	47	30	21	19	27	16	18	17	8	16	13	13	11	10	4	5	**370**
2008	64	50	63	31	31	31	35	25	21	22	15	24	14	15	21	10	11	10	**493**
2009	58	52	35	37	27	33	25	22	24	21	15	16	20	7	6	4	9	9	**420**
2010	45	54	58	43	22	20	27	24	31	24	10	26	21	12	17	10	8	6	**458**
Total	**539**	**495**	**481**	**364**	**307**	**251**	**250**	**222**	**221**	**200**	**177**	**174**	**171**	**115**	**103**	**85**	**78**	**66**	**4,299**
(Percent)	(12.5%)	(12.0%)	(11.1%)	(8.5%)	(7.1%)	(5.8%)	(5.8%)	(5.2%)	(5.1%)	(4.7%)	(4.1%)	(4.0%)	(3.9%)	(2.6%)	(2.3%)	(2.0%)	(1.8%)	(1.5%)	**(100%)**

Abbreviations: ACP = Advance Care Planning, Care Set = Care Settings and Types of Care, PSM = Pain and Other Symptom Management, Hosp = Hospice, Med Alt Med = Medicine and Alternative Medicine, MH = Mental Health, CRS = Culture, Religion, and Spirituality, Edu-Trng = Education and Training, Other = General Topics (e.g., Technology, Research Issues, Personal Experiences), CG = Caregivers, Com = Communication, Set Stand = Care Services and Standards, Econ = Economics, QOC = Quality of and Satisfaction with Care, QOL = Quality of Life, SD Mod = Service Delivery Models, Prog = Prognosis

SOURCE: Literature Review

Figure 9. Total Percent Research Publication Topic Categories, 1997-2010.



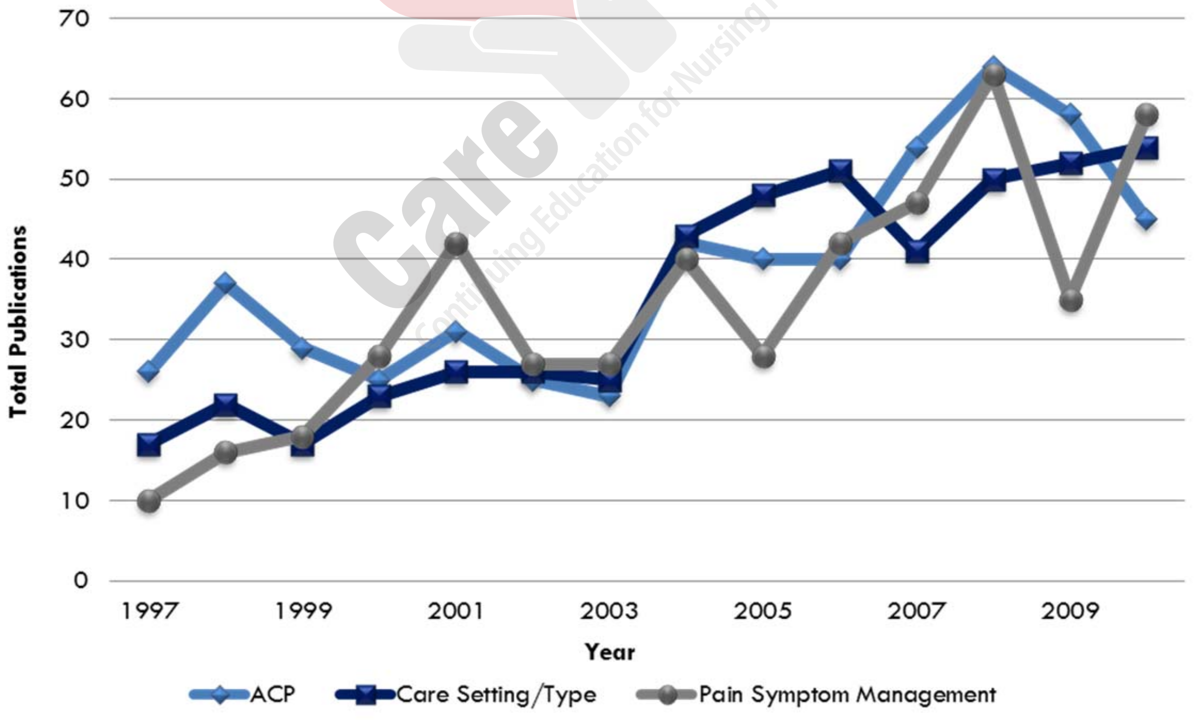
SOURCE: Literature Review. See Table 8 for key to abbreviations.

Advance Care Planning. “Advance Care Planning” (ACP) category themes involved studies on agreements between patients and their families, surrogates, and health care professionals regarding the patients’ treatment, care, or advance directives. These agreements could be formal, informal, verbal, or written and could involve discussions or legal documents conveying EOL PC preferences (e.g., living wills, power of attorney, do-not-resuscitate orders). ACP was the most frequent theme within the literature (*n*=539 of 4,299 topic themes identified, 12.5% of total). While ACP as a topic theme in the published literature increased from 26 occurrences in 1997 (20.6% of 1997 publications) to 45 to 64 occurrences from 2007 onward, the percent total of this theme across all topics has decreased (2007=14.5% of annual publications, 2009=3.8%, 2010=9.6%). The percent total may reflect an increasing number of other emerging topic themes in the literature such as “Standards,” “Ethics,” or “Economics.” Trends for publications with ACP as a topic are illustrated in Figure 10.

Care Settings and Types of Care. Publications that included the research topic theme of “Care Settings and Types of Care” (Care Set, *n*=495 of total 4,299 coded themes, 12% of total) focused on the locations in which EOL PC was provided and the type of care offered, such as: a nursing home/nursing facility, emergency care, intensive care, home health care, primary care, acute care, long-term care, assisted living, and managed care settings. The occurrence of this topic in research publications has steadily increased, tripling in occurrence from 1997 (*n*=17, 13.5% of total number of 1997 topic themes) to 2010 (*n*=54, 11.79% of total 2010 topic themes). The increased number of these themes suggests a shifting trend in newer emerging areas in EOL PC such as services within nursing homes, assisted living facilities, home health care, and other settings. Figure 10 illustrates the trends in publications in this category from 1997 to 2010.

Pain and Other Symptom Management. EOL PC publications that included research themes on "Pain, Other Symptoms, or the Management of Symptoms" (PSM) focused on approaches to alleviate dyspnea, fatigue, dysphagia, nausea, weight loss, bleeding, cachexia, anemia, or other conditions. The dataset included publications that focused on clinical or pharmacological management of pain such as the use of analgesics, opioids, morphine, or methadone. PSM category themes were found in 481 of the 4,299 total coded papers representing 11.1% of the research publication themes from 1997 to 2010. An overall increase in publications with PSM themes was evident from 1997 to 2010; in 1997, 10 articles (7.9% of all 1997 publication topic themes) were coded to include this topic while in 2010, 58 publications were identified with this theme (12.7% of all 2010 publication topic themes). Figure 10 illustrates the trends in publications with this category from 1997 to 2010.

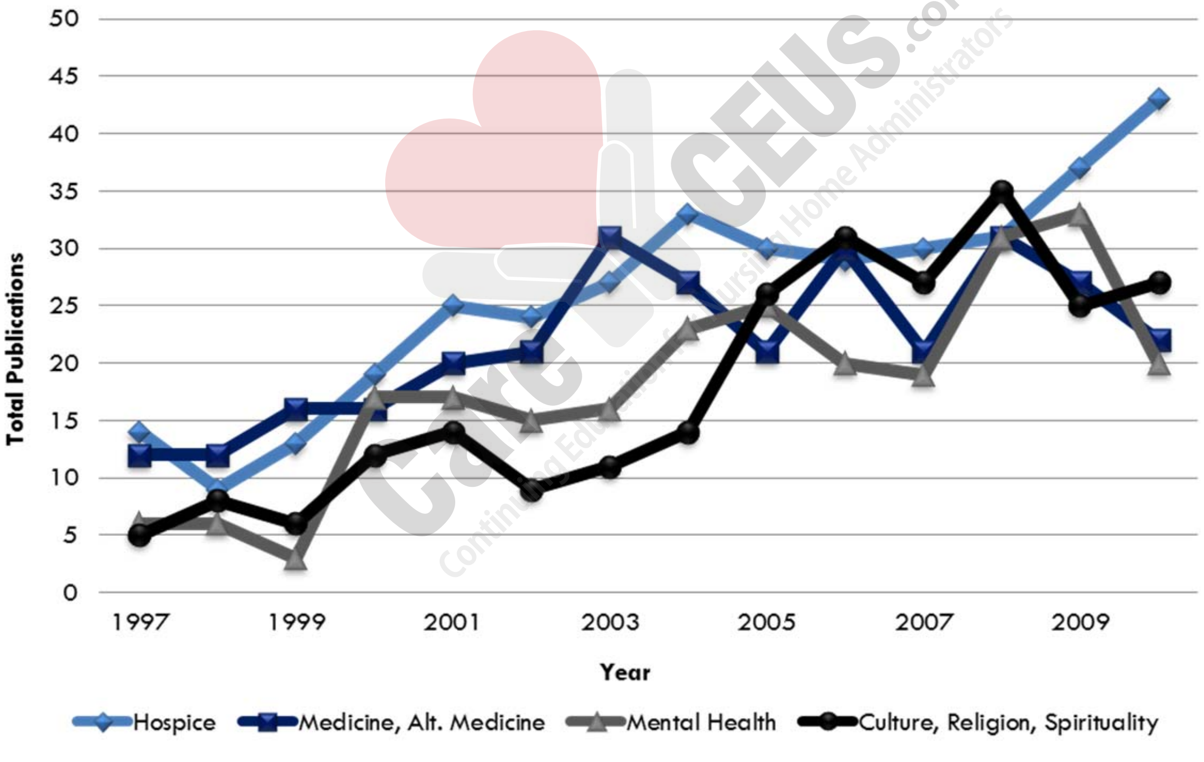
Figure 10. Total Research Publication Topic Categories, 1997-2010. Advance Care Planning, Care Setting and Type, Pain and Other Symptom Management.



Source: Literature Review

Hospice. Hospice is a specific model and philosophy of care for individuals at the end of life and, as a clinical practice, involves a team-oriented approach to medical care, pain management, and emotional and spiritual support across various settings. Because of the contribution of hospice in end-of-life care, it was included as a distinct category. Coded published research themes related to hospice included publications focused on hospice as a setting, a care type, or a care model. Hospice as a topic category within the published EOL PC research literature was the fourth most common theme identified in 364 (8.5%) of all research publications from 1997 to 2010 (Table 8). In parallel with the trend for an overall increase in the number of research publications in EOL PC, hospice as a topic theme of research publications demonstrated a steady increase in the literature, tripling from 14 (11.1%) publications in 1997 to 43 (9.4%) publications in 2010. Figure 11 illustrates the trends in publications with this category from 1997 to 2010.

Figure 11. Total Research Publication Topic Categories, 1997-2010. Hospice; Medicine-Alternative Medicine; Mental Health; Culture, Religion, Spirituality.



SOURCE: Literature Review

Medicine-Alternative Medicine. "Alternative Medicine" (Alt Med) themes in the published research literature were those that focused on alternative or complementary medicine in EOL PC. "Medical" topic themes included publications that addressed the effectiveness of pharmaceutical agents, medical treatments, procedures, therapies, or surgical methods within the contexts of EOL PC.

As the fifth most identified category of published research topics, Alt Med represented 307 (7.1%) of the total publication themes within all reviewed EOL PC research. The category demonstrated a doubling of identified themes in this area from 12 (9.5%) publications in 1997 to 22 (4.8%) of the total publications in 2010. Figure 11 illustrates the trends in publications with this category from 1997 to 2010.

Mental Health. “Mental Health” (MH) as a topic category included research publications with themes that included social, emotional, and psychological concerns or needs of EOL PC patients, families, caregivers, or health care providers who work in EOL PC settings. These included areas such as grief, bereavement, loss, depression, and anxiety.

These topics were represented in 251 (5.8%) of the total 4,299 themes in the published research literature from 1997 to 2010. Research publications that addressed MH categories increased from six publications (4.8% of total 1997 publications) to 20 publications (4.4%) in 2010. Figure 11 illustrates the trends in publications with this category from 1997 to 2010.

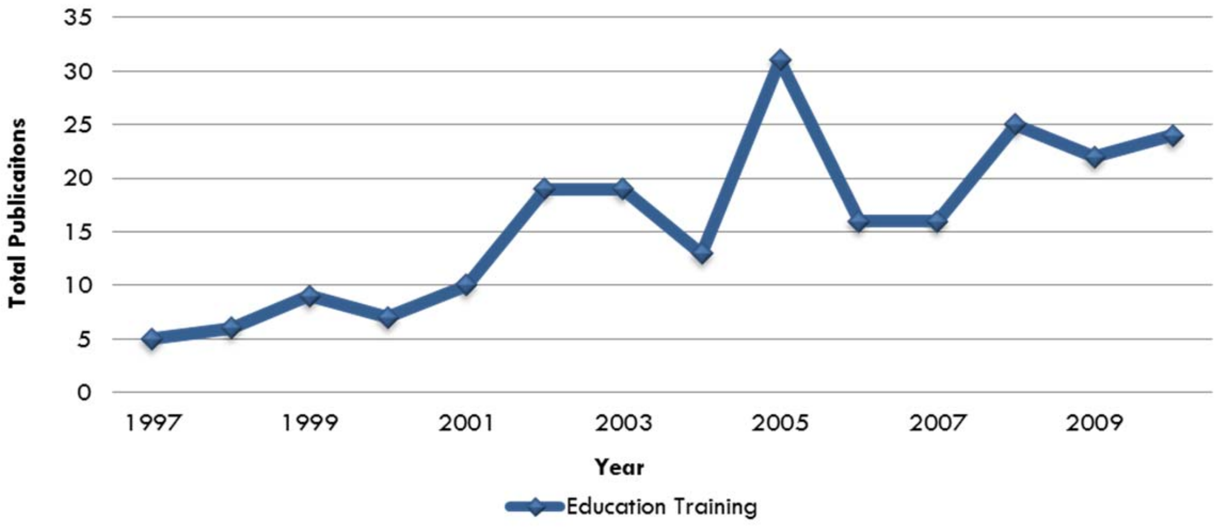
Culture, Religion, and Spirituality. The category of “Culture, Religion, and Spirituality” (CRS) focused on research publications that addressed topics related to culture, religion, and spirituality in EOL PC. Topics in this category were identified across religious denominations and spiritual or existential themes. CRS topics also included themes of research papers focused on race, culture, ethnicity, disparities, or geographic region (urban vs. rural) including multi- and cross-cultural themes, traditions, beliefs, customs, or linguistic differences.

Research publications with CRS themes occurred in 250 articles (5.8%) of the total publications from 1997 to 2010. Over the years reviewed, this occurrence ranged from 3.6% to 7.8% of the total annual publications. As depicted in Figure 11, CRS totals increased from five (4.0%) publications identified with this topic in 1997 to 27 articles with this theme in 2010 (5.9%).

Education and Training. “Education and Training” (Ed-Trng) as a category included publications with topics related to the curriculums, teaching, and training of students, residents, nurses, physicians, and health care professionals specific to EOL PC areas. It did not include education of family, relatives, and other caregivers.

Overall, from 1997 to 2010, 222 research publications (5.2% of total) included this theme. Despite a fivefold increase in the number of publications with this theme—from five (4%) publications in 1997 to 24 (5.2%) publications in 2010 (Figure 12)—Ed-Trng publications represented a small percentage of the total number of research publication themes.

Figure 12. Total Research Publication Topic Categories, 1997-2010. Education and Training.



SOURCE: Literature Review

Other. "Other" as a category represented general and varied topics with small numbers of identified themes within the published literature. These themes addressed important topics that ranged from publications focused on use or development of technology, research issues (e.g., challenges of recruitment or conduct of research), special populations (e.g., the homeless or prison populations), policy and legislation (e.g., implications for state legislative and regulatory policy on public perspectives of advance care planning), or personal experiences (e.g., personal reflections on 'good/bad' death or 'dignified dying').

In total, 221 studies (5.1% of all publications) from 1997 to 2010 contained these themes (Table 8). As an example of "Other" topics, there were 47 publications that specifically included themes on decision-making processes related to EOL PC but not coded under the criteria of ACP. For example, 40 studies focused on issues and challenges in conducting research in the field of EOL PC while 37 publications focused on topics related to the experiences of living while dying from a serious, advanced illness.

Caregivers. Published research was coded for "Caregivers" (CG) when the topic related to the stress/burdens, barriers, physical demands, skills, or cost of expenses experienced by CGs while providing EOL PC to another. CGs were family and friends of individuals/patients, including spouses or parents. Health professionals, health care volunteers, or those in caring roles (e.g., a member of the clergy) were included in this topic category.

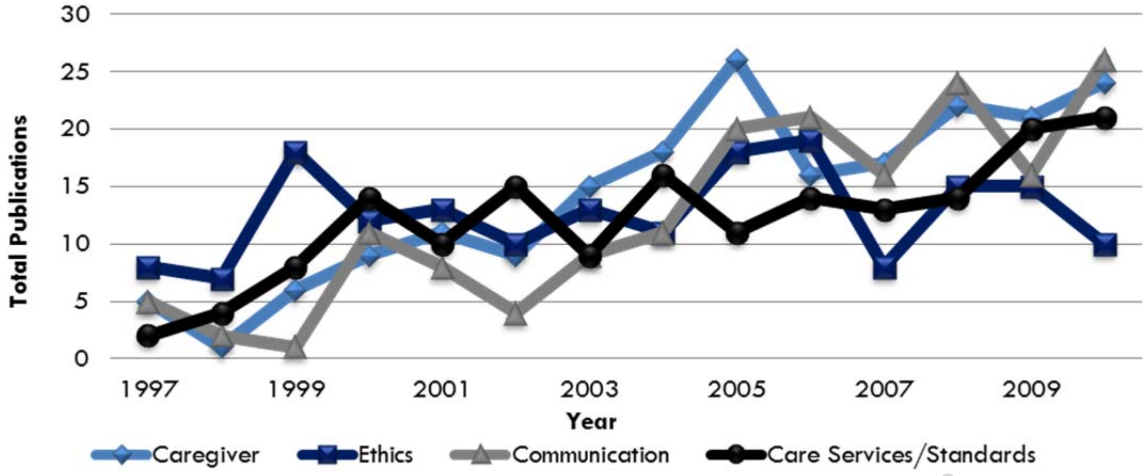
Of the 4,299 topics identified, 200 (4.7%) of the topics focused on caregiving (Table 8). Figure13 demonstrates a small trend for increased publications within this topic theme (five publications or 4.0% of the topics identified in 1997 to 24 published research papers or 5.2% of total topic themes in 2010).

Ethics. Published research literature that focused on topics related to ethics and moral issues (e.g., principles, moral correctness) surrounding EOL PC research, care, treatment, or preferences. Table 8 demonstrates the trends in publications in the area of “Ethics.” This areas was identified in 177 (4.1%) of the 4,299 topic themes with a trend for decreasing numbers of published research in this area (1997=eight published articles or 6.3% of 1997 total publications, 2006=19 articles or 4.7% of that year’s publications, 2010=10 publications or 2.2% of annual publications). Figure13 illustrates this trend.

Communication. Articles coded for “Communication” (Com) focused on communication surrounding the needs of the EOL PC individual/patient and could include topics that focused on strategies and best practices for communication. Published studies also included themes related to communication between patients and health providers, individuals and their family, or communications between health care providers. This category did not include ACP and/or Advance Directive topics. Com as a topic theme was identified in 174 (4.0%) of all research publications from 1997 to 2010. There was an increase (Table 8) in the number of publications during this time period. In 1997, five (4.0% of 1997 total) research publications were related to this theme. In 2010, this increased to 26 (5.7% of 2010 total) of all publications. Figure 13 illustrates the trends in publications with this category from 1997 to 2010.

Care Services and Standards. Published literature coded in this category (Set Stand) focused on topics related to the provision of care services and standards and/or guidelines in providing those services. The category included research on health systems, coordination of care, and service usage. Table 8 demonstrates that the coded research publications for this topic category represented 171 (3.9%) of all published research articles from 1997 to 2010. While the overall percentile is small, this area continues to show increasing numbers of publications from two articles with this theme in 1997 (or 1.6% of all 1997 publications) to 21 (4.6%) articles in 2010. Figure 13 illustrates the trends in publications with this category from 1997 to 2010.

Figure 13. Total Research Publication Topic Categories, 1997-2010. Caregivers, Ethics, Communications, and Care Services and Standards.



SOURCE: Literature Review

Economics. Research literature coded in this category involved topics related to the cost, expenses, or payment of EOL PC care and services. Table 8 demonstrates the number of research articles in this topic category coded from 1997 to 2010. A total of 115 articles contained this theme, accounting for 2.6% of all publications reviewed. Figure 14 illustrates a general trend of publications in this area from five publications in 1997 (4.0% of 1997 literature) to 12 articles (2.6%) of the literature topics identified in 2010.

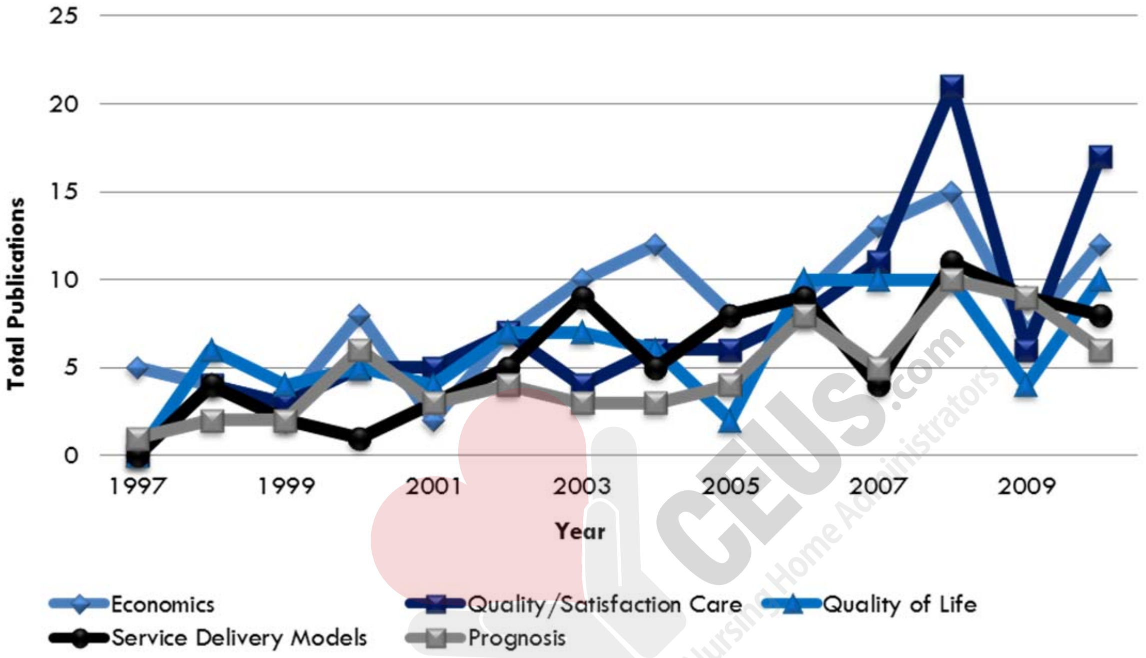
Quality of Life and Quality of and Satisfaction with Care. These two categories focused on specific topic themes. “Quality of Life” (QOL) publications related to quality of life as a health-related construct and outcome. It included physical symptoms, physical functioning, and psychological and social well-being of patients. “Quality of and Satisfaction with Care” (QOC) related to publications that focused on the quality of EOL PC services provided and satisfaction with services received. Patient satisfaction or indicators of quality care received were primary themes in this coding category. Table 8 indicates that QOC represented 103 (2.3%) and QOL represented 85 (2.0%) of the total number of coded publications from 1997 to 2010. Both categories demonstrated variable trends in the number of research publications coded for these two topics (Figure 14).

Service Delivery Models. Studies were coded for “Service Delivery Models” (SD Mod) if themes were related to EOL PC service delivery models other than hospice. Overall, 78 publications (1.8%) of all topics coded focused on this theme, increasing (Table 8, Figure 14) from no publications with this theme in 1997 to eight topics (1.8 % of all topics) in 2010.

Prognosis. This category refers to topics related to time until death, estimates of time until death, or mortality (i.e., survival or life expectancy). The theme “Prognosis” (Prog) was coded in 66

(1.5%) of all publication themes in the literature reviewed. A small but identifiable increase in the number of publications from 1997 to 2010 is demonstrated in Table 8 and Figure 14. In 1997, one article (0.8% of total 1997 publications) contained this theme, while, by 2010, six (1.3%) research publications with this theme were identified.

Figure 14. Total Research Publication Topic Categories, 1997-2010. Economics, Quality/Satisfaction with Care, Quality of Life, Service Delivery Models, Prognosis.



SOURCE: Literature Review

F. End-of-Life and/or Palliative Care Research Publications: Funding Source Information

Table 9 is specific to the 1997 to 2010 published research from the literature review dataset. The 3,155 publications were reviewed for citation of a funding source of the work conducted.[10] Of the 3,155 published research articles identified, 1,258 (39.9%) contained information on sources of research support. This percentile remained relatively constant from 1997 to 2010, ranging from 33 (34%) of studies with identified funding in 1997 to 105 (31.5%) of studies specifying funding in 2010. Of note is the consistent lack of identified sources of funding acknowledged in the published research articles from 1997 to 2010 (Figure 15). A total of 1,897 (60.1%) publications lacked funding information. Since 2007, the percentage of end-of-life and palliative care (EOL PC) research publications identified in this review without acknowledgement of funding source information has been more than 50%: 64.5 % (2008), 70.9% (2009), and

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[10] It is possible that many citations with "unspecified" funding information were based on funded research (Appendices A–C detail steps involved in identifying and coding citations for funding). When funding information was incomplete, the full-text article was accessed to abstract funding information.

68.5% (2010). It is not known if this reflects that researchers conducted unfunded work, private funding, or that funding information was not required in specific publications. The federal government has required acknowledgement of federal sources of support in the full text of articles since 2002.

Table 9. Total (Percent) Research Publications with Specified Sources of Funding, 1997-2010.

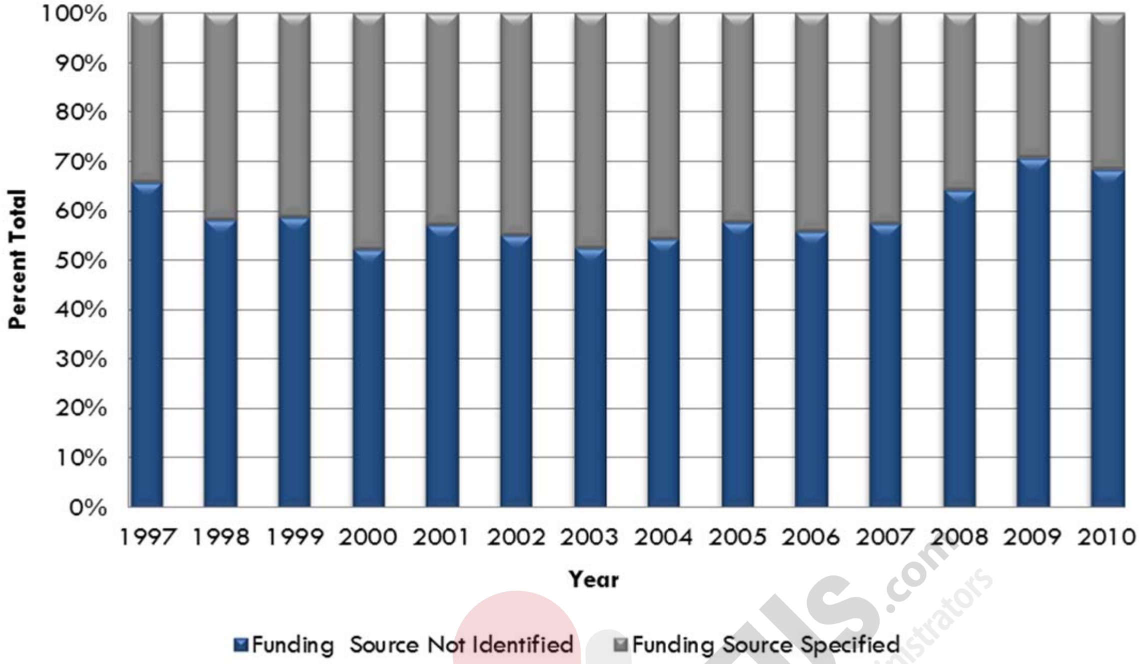
Year	Funding Information [a]		Total
	Specified	Unspecified [b]	
1997	33	64	**97**
	(34.0%)	(66.0%)	**(100%)**
1998	49	69	**118**
	(41.5%)	(58.5%)	**(100%)**
1999	52	75	**127**
	(40.9%)	(59.1%)	**(100%)**
2000	80	88	**168**
	(47.6%)	(52.4%)	**(100%)**
2001	80	108	**188**
	(42.6%)	(57.4%)	**(100%)**
2002	87	108	**195**
	(44.6%)	(55.4%)	**(100%)**
2003	96	107	**203**
	(47.3%)	(52.7%)	**(100%)**
2004	107	128	**235**
	(45.5%)	(54.5%)	**(100%)**
2005	114	157	**271**
	(42.1%)	(57.9%)	**(100%)**
2006	124	159	**283**
	(43.8%)	(56.2%)	**(100%)**
2007	114	155	**269**
	(42.4%)	(57.6%)	**(100%)**
2008	126	229	**355**
	(35.5%)	(64.5%)	**(100%)**
2009	91	222	**313**
	(29.1%)	(70.9%)	**(100%)**
2010	105	228	**333**
	(31.5%)	(68.5%)	**(100%)**
TOTAL	**1,258**	**1,897**	**3,155**
(Percent)	**(39.9%)**	**(60.1%)**	**(100%)**

[a] The federal government required federal grant recipients to acknowledge sources of funding for published federally sponsored research beginning in 2002.

[b] "Unspecified" is based on publications from which no information on funding status was available within the full manuscript.

SOURCE: Literature Review

Figure 15. Percent of Total Research Publications with Funding Source Information, 1997-2010.



SOURCE: Literature Review

G. End-of-Life and/or Palliative Care Research Publications: Funding Sources

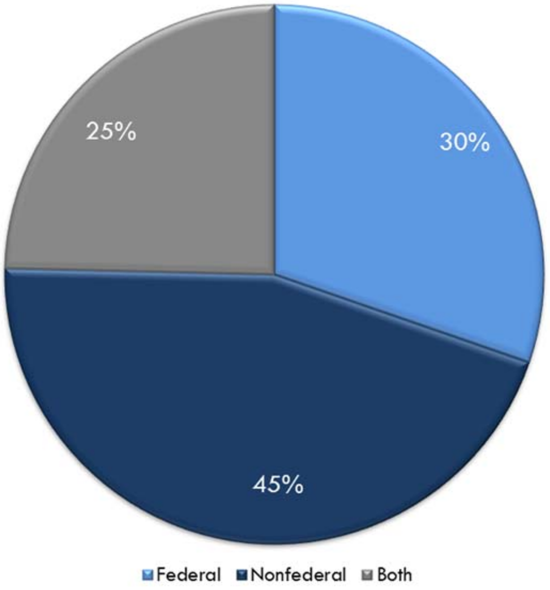
Table 10 displays information on the number of publications reviewed that identified federal and nonfederal sources of funding for end-of-life and palliative care (EOL PC) research publications from 1997 to 2010. Of the 1,258 publications reviewed, 45% (567 studies) identified a nonfederal (private) organization as a source of research funding while 30% (381 studies) of the reviewed publications reported funding support through federal agencies and 25% (310 studies) reported sources of research support from both nonfederal and federal organizations (Figure 16). Over the years, acknowledged nonfederal (private) sources of funding have shown substantial increases including several peaks in 1999 (69%, 36 studies), 2003 (55%, 53 studies), and 2006 (47%, 58 studies). After 2006, a decrease in nonfederal funding acknowledged in EOL PC research publications is evident, particularly recently in 2009 (36%, 33 studies) and 2010 (25%, 26 studies—the lowest percentage recorded).

Table 10. Total (Percent Row Total) Funding Source by Year of Research Publication, 1997-2010.

Year	Funding Source Identified			Total (Percent Row Total)
	Federal	Nonfederal	Both	
1997	8	16	9	**33**
	(24.2%)	(48.5%)	(27.3%)	(100%)
1998	17	24	8	**49**
	(34.7%)	(49.0%)	(16.3%)	(100%)
1999	11	36	5	**52**
	(21.2%)	(69.2%)	(9.6%)	(100%)
2000	5	53	22	**80**
	(6.3%)	(66.2%)	(27.5%)	(100%)
2001	16	41	23	**80**
	(20.0%)	(51.3%)	(28.7%)	(100%)
2002	24	47	16	**87**
	(27.6%)	(54.0%)	(18.4%)	(100%)
2003	25	53	18	**96**
	(26.0%)	(55.2%)	(18.8%)	(100%)
2004	22	47	38	**107**
	(20.6%)	(43.9%)	(35.5%)	(100%)
2005	31	45	38	**114**
	(27.2%)	(39.5%)	(33.3%)	(100%)
2006	40	58	26	**124**
	(32.2%)	(46.8%)	(21.0%)	(100%)
2007	43	44	27	**114**
	(37.7%)	(38.6%)	(23.7%)	(100%)
2008	48	44	34	**126**
	(38.1%)	(34.9%)	(27.0%)	(100%)
2009	41	33	17	**91**
	(45.0%)	(36.3%)	(18.7%)	(100%)
2010	50	26	29	**105**
	(47.6%)	(24.8%)	(27.6%)	(100%)
TOTAL (Percent Row Total)	**381** **(30.3%)**	**567** **(45.1%)**	**310** **(24.6%)**	**1,258** **(100%)**

SOURCE: Literature Review

Figure 16. Percent Total Research Publication Funding Sources, 1997-2010. Federal, Nonfederal, or Both.



SOURCE: Literature Review

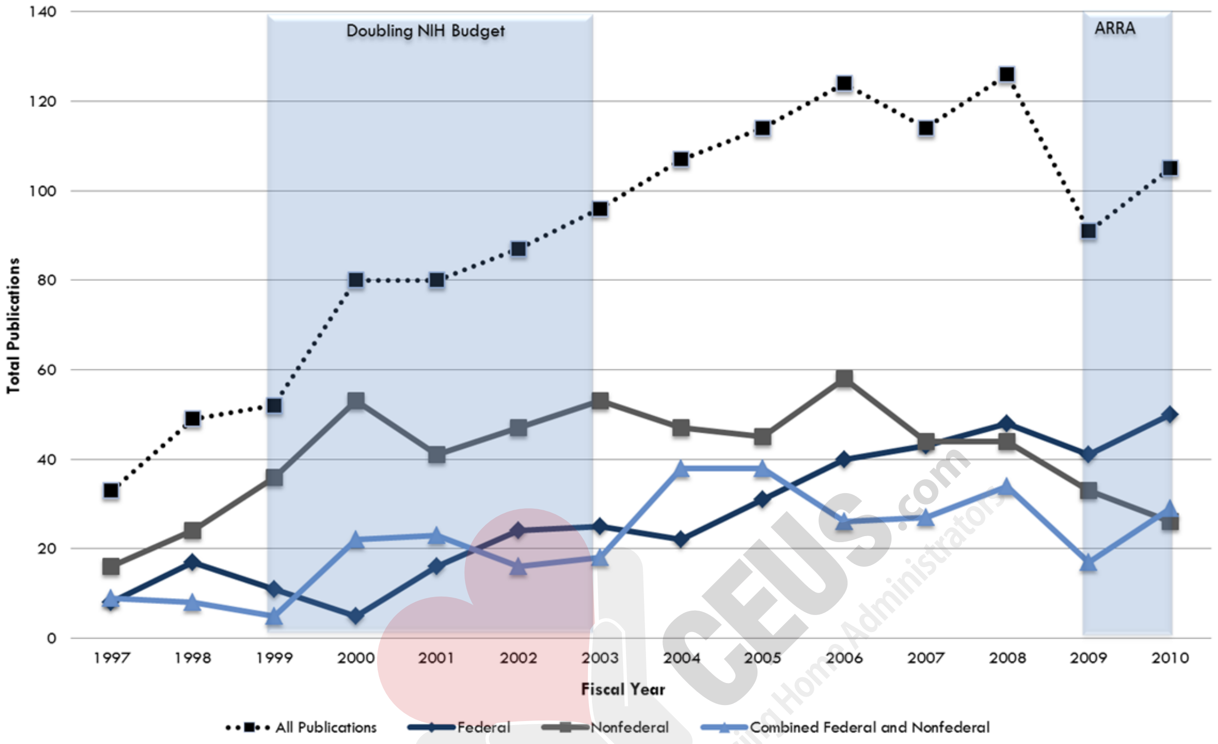
From 1997 to 2003, nearly half or more of all funded EOL PC research publications reported receiving funding from nonfederal organizations. Until 2008, EOL PC research publications with funding source information indicated a higher percentage of funding support solely from nonfederal organizations (ranging from 39% or 44 studies in 2007 to 69% or 36 studies in 1999, Figure 23). Beginning in 2008, this pattern switched. The majority of funded EOL PC research publications reported a higher percentage of funding sources solely from federal organizations (38% in 2008, 45% in 2009, 48% in 2010).

Prior to 2008, the patterns of cited federal funding of EOL PC research fluctuated. The proportion of research studies reporting federal funding decreased sharply from 35% (17 studies) in 1998 to 6% (only five studies) in 2000. However, the level of funding of EOL PC research publications from federal sources was greater than that from nonfederal sources after 2008; 2008 (38%, 48 studies), 2009 (45%, 41 studies), and 2010 (48%, 50 studies).

The proportion of EOL PC research publications based on research funded by both nonfederal (private) and federal (public) sources appears to have increased despite fluctuations over the years (Figure 17). The proportion of publications supported by both funding sources in 2000 has more than doubled since 1997 (22 studies in 2000 compared with nine in 1997). The level of published EOL PC research reporting funding from both sources was highest in 2004 and 2005 (36% and 33%, respectively, each with 38 publications). Figure 17 depicts these trends with highlighting on the period of National Institutes of Health (NIH) budget doubling (1995 to

2005)[11] and the period of additional funds provided through the American Recovery and Reinvestment Act of 2009 (ARRA).[12]

Figure 17. Research Publication Trends, 1997-2010. Funding Sources and Combined Totals.



SOURCE: Literature Review

H. End-of-Life and/or Palliative Care Research Publications: Federal Funding Sources

This section includes information pertaining to identification of specific organizations within the federal sector that were cited as sources of funding in the end-of-life and palliative care (EOL PC) published literature. The data were accrued from the literature review and a follow-up questionnaire to authors who did not specify a funding source. A single publication could list more than one funding source and a single grant award from an organization could be listed in multiple publications. A total of 37 federal agencies or programs were cited 973 times in the literature as a source of research publication support. These organizations and the number of times these organizations were cited in the literature are listed in Table 11. Federal agencies that were identified as a source of support in more than 50 EOL PC research publications included the National Institute on Aging (NIA, 23.6% of total publication funding source acknowledgments), the National Cancer Institute (NCI, 15.1%), the National Institute of Nursing Research (NINR, 14.3% of total), the U.S. Department of Veteran's Affairs, the Agency for Healthcare Research & Quality,

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[11] SOURCE: *grants.nih.gov/archive/grants/financial/QA_Doubling_Period.doc*

[12] SOURCE: grants.nih.gov/recovery/

and the National Institute of Mental Health. Five federal agencies that were identified as sources of funding support in 10 to 49 EOL PC research publications included the U.S. Public Health Service; the National Center for Research Resources; the Health Resources and Services Administration; the National Heart, Lung and Blood Institute; and the U.S. Department of Health and Human Services.

Table 11. Total Research Citations in Publications with a Federal Organization Identified as Funding Source, 1997-2010.

Federal Organization[a]	Number of Citations in Publications[b]
National Institute on Aging (NIA)	230
National Cancer Institute (NCI)	147
National Institute of Nursing Research (NINR)	140
U.S. Department of Veteran's Administration (DVA)	99
Agency for Healthcare Research & Quality (AHRQ)	89
National Institute of Mental Health (NIMH)	60
U.S. Public Health Service (PHS)	36
National Center for Research Resources (NCRR)	26
Health Resources and Services Administration (HRSA)	25
National Heart, Lung and Blood Institute (NHLBI)	19
National Institutes of Health (NIH)[c]	15
U.S. Department of Health and Human Services (DHHS)	12
National Center for Complementary & Alternative Medicine (NCCAM)	11
The Eunice Kennedy Shriver National Institute of Child Health & Human Development (NICHD)	9
Substance Abuse and Mental Health Services Administration (SAMHSA)	6
U.S. Department of Defense (DoD)	6
Centers for Disease Control and Prevention (CDC)	6
National Institute of Neurological Disorders and Stroke (NINDS)	5
National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)	4
National Science Foundation (NSF)	4
National Institute on Drug Abuse (NIDA)	3
National Center on Minority and Health Disparities (NCMHD, National Institute on Minority Health and Health Disparities (NIMHD)	3
Administration on Aging (AoA, Administration for Community Living ACL)	2
Centers for Medicare and Medicaid Services (CMS)	2
U.S. Department of Energy (DoE)	2
National Institute of Allergy and Infectious Diseases (NIAID)	2
U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR)	2
U.S. Food and Drug Administration (FDA)	1
John E. Fogarty International Center (FIC)	1
National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)	1
National Institute of Dental and Craniofacial Research (NIDCR)	1
National Institute of General Medical Sciences (NIGMS)	1
National Human Genome Research Institute (NHGRI)	1
National Library of Medicine (NLM)	1
New Investigator Research Grant (NIH)[c]	1
TOTAL PUBLICATION CITATION OF FEDERAL ORGANIZATION SUPPORT	**973**

[a] The agency name for one publication was unavailable.

[b] One publication can list more than one funding source.

[c] The NIH Institute or Center was unspecified.

SOURCE: Literature Review, Follow-up Funding Source Questionnaire

I. End-of-Life and/or Palliative Care Research Publications: Nonfederal Funding Sources

This section includes information pertaining to identification of specific organizations within the nonfederal sector that were cited as sources of funding in the end-of-life and palliative care (EOL PC) published literature. The data were accrued from the literature review and a follow-up questionnaire to authors who did not specify a funding source. A single publication could list more than one funding source and a single grant award from an organization could be listed in multiple publications.

In total, 533 nonfederal private organizations were cited as funding sources in the reviewed EOL PC research publications between 1997 and 2010. Table 12 indicates that the most common types of nonfederal philanthropic organization support reported in these publications were private foundations (26% of total, 139 foundations, 620 citations of funding support), followed by academic institutions (15% of total, 79 organizations, 198 citations of funding support), professional associations (10% of total, 54 organizations, 164 citations of funding support), and businesses (mostly pharmaceutical, 12% of total, 63 organizations, 109 citations of funding support). Together, these four sources of philanthropy comprised 64% of reported nonfederal EOL PC research funding.

Nonfederal (private, philanthropic, nonprofit) organizations identified as a funding source in more than five publications are listed in Table 13. Organizations with more than 20 EOL PC research publications included the Robert Wood Johnson Foundation (RWJF), the Open Society Institute/Project on Death in America, the Hartford Foundation, the Greenwall Foundation, the American Cancer Society, the Paul Beeson Faculty Scholars Award, the Oncology Nursing Foundation, and the Nathan Cummings Foundation. RWJF (10.5% of all foundations cited) and the Open Society Institute (7% of all foundations cited) were the most frequently cited nonfederal private funding sources supporting EOL PC research (Figure 18).

Table 12. Total (Percent) Research Publications with Nonfederal Organizations Identified as Funding Source, 1997-2010.

Organization Type	Total (Percent Total) Number of Organization Types[a] Cited	Total Publication Citations of Nonfederal Organization as Funding Source
Foundation	139	**620**
	(26.0%)	
Academic Institution[b]	79	**198**
	(14.8%)	
Association[c]	54	**164**
	(10.1%)	
Business[d]	63	**109**
	(11.8%)	
Initiative/Consortium[e]	10	**103**
	(1.8%)	
Fund/Trust	32	**55**
	(6.0%)	
Research Institution[f]	38	**53**
	(7.1%)	
International Organization	43	**45**
	(8.0%)	
Hospital/Medical Center	36	**35**
	(6.7%)	
Fellowship/Award[g]	6	**35**
	(1.2%)	
Local/State Government Agency	21	**28**
	(3.9%)	
Other	6	**9**
	(1.2%)	
Private Donor	7	**7**
	(1.3%)	
TOTAL	**533**	**1,461**

[a] Names of funding organizations for 58 publications that reported receiving nonfederal funds are unknown. Numbers for types of organizations may be higher than reported.

[b] Organizations classified as academic institutions such as colleges, universities, schools, and institutions associated with a university.

[c] Organizations classified as associations include societies or membership groups.

[d] Organizations classified as companies include mainly pharmaceutical corporations.

[e] Organizations classified as initiatives/consortiums include research initiatives, committees, and work groups.

[f] These are independent research institutions that are not part of academic organizations/universities.

[g] These fellowships and awards are often sponsored by multiple institutions.

SOURCE: Literature Review and Funding Source Questionnaire Follow-up Data

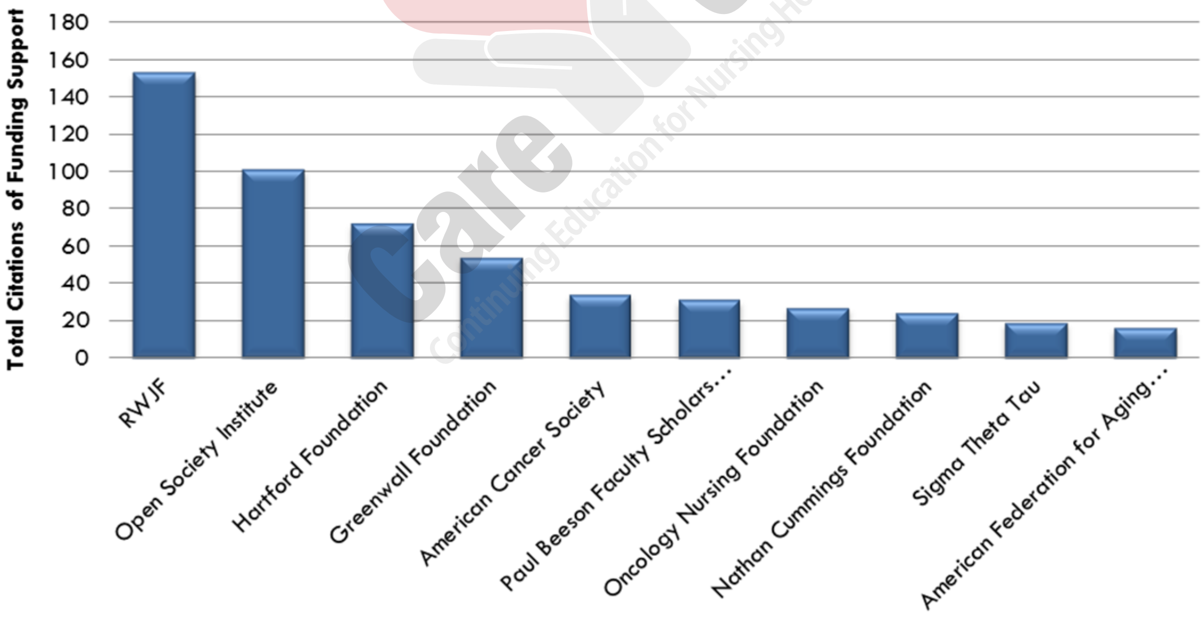
Table 13. Nonfederal Funding Sources Cited in Over Five Research Publications, 1997-2010.

Nonfederal Organization	Total Number Research Publications Citing Foundation Support
Robert Wood Johnson Foundation	153
The Open Society Institute/Project on Death in America	101
Hartford Foundation	72
Greenwall Foundation	54
American Cancer Society	34
Paul Beeson Faculty Scholars Award	31
Oncology Nursing Foundation	27
Nathan Cummings Foundation	24
Sigma Theta Tau	19
American Federation for Aging Research	16
Yale University	14
Pfizer Foundation	13
Alzheimer's Association	12
Donaghue Medical Research Foundation	12
Fan Fox and Leslie R. Samuels Foundation, Inc.	11
Kornfeld Foundation	10
MacArthur Foundation	9
University of California San Francisco	9
American Association of Retired Persons	8
Commonwealth Fund	8
Fetzer Institute	8
University of Colorado	8
University of Pittsburgh	8
Brookdale Foundation	7
Aetna Foundation	6
American Geriatrics Society	6
Amgen, Inc.	6
Brigham Young University	6
GlaxoSmithKline	6
International Union for Cancer Control	6
Janssen Pharmaceuticals, Inc.	6
Kaiser Permanente	6
Ladies Hospital Aid Society of Western Pennsylvania	6
LAS Trust Foundation	6
National Palliative Care Research Center	6
RAND Corporation	6
Retirement Research Foundation	6

Continued Nonfederal Organization	Total Number Research Publications Citing Foundation Support
University of California Los Angeles	6
University of Texas	6
American Nurses Foundation	5
Center to Advance Palliative Care	5
Duke University	5
Hebrew Rehabilitation Center for Aged	5
John D. Thompson Hospice Institute	5
Johns Hopkins	5
Kent State University	5
Meyer Memorial Trust	5
National Hospice and Palliative Care Organization	5
Novartis Pharmaceuticals	5
Pine Tree Apple Tennis Classic Oncology Research Fund	5
University of Wisconsin	5

SOURCE: Literature Review and Follow-up Questionnaire

Figure 18. Top 10 Total Number of Cited Private Sources of Funding in Published Research Literature, 1997-2010.



Source: Literature Review and Follow-up Questionnaire

J. Federal Support of End-of-Life and/or Palliative Care Research: Grants and Funding Trends, FY1997-FY2010

This portion of the review of end-of-life and palliative care (EOL PC) science was to ascertain trends in federal agency support of EOL PC grant awards and funding totals as reported in a specific National Institutes of Health (NIH) database from fiscal years (FYs) 1997 to 2010.

Terminology for Dataset

Various terminologies are used that impact the interpretation of numbers of awards and funding dollars. A detailed glossary of these terms can be found at: www.niaid.nih.gov/researchfunding/glossary. For the purposes of this report, the following concepts and definitions were used:

- ***Competing and Noncompeting Awards*** – In general, a grant application competes for funding against other grants being reviewed in a given fiscal year. A competing application encompasses new, renewal, resubmission, or revision grant applications that must undergo peer review before NIH may fund it. Many grant mechanisms are awarded funds for multiple years of support. At the time of the initial award (in year one) the funding agency (here, NIH Institutes and Centers [IC]) makes a commitment to fund the grant for the full years of the award mechanism. The grant does not compete for funding in the remaining years of the award; therefore, the grant is considered noncompeting. When determining the dollar totals reported to research in a given fiscal year, all awards, both competing and noncompeting, are factored into the total. Reporting of the number of applications that have received funding in any fiscal year is specific to only competing applications.
- ***Direct and Indirect Costs*** – In general, direct costs are the funds that go to the actual research project. Indirect costs are the costs associated with facilities and administration of the grant.
- ***Fiscal Year*** – Unlike a calendar year January 1 to December 31, the federal government fiscal year operates from October 1 to September 30.

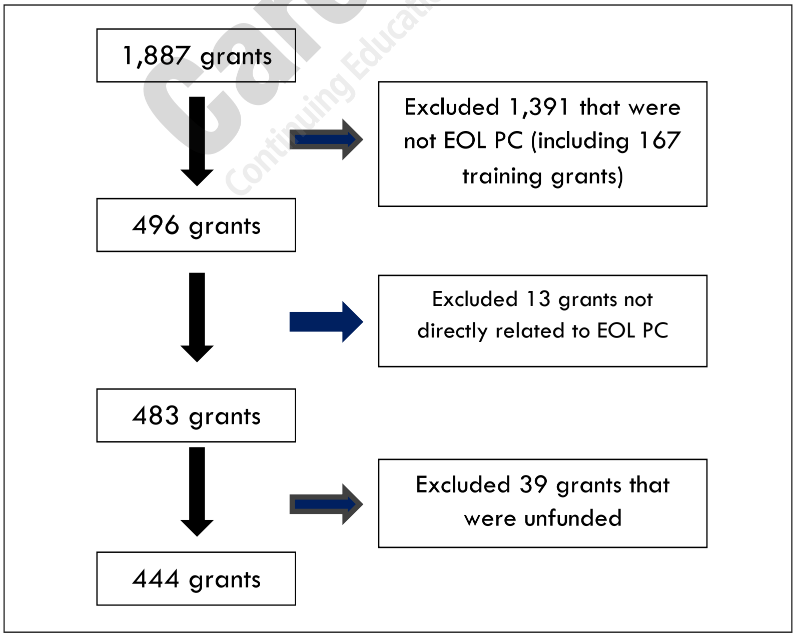
Acronyms Used in This Section: The following abbreviations are used in the text:

Acronym	Federal Agency or National Institutes of Health Institute or Center
AHRQ	Agency for Healthcare Research and Quality
CDC	Centers for Disease Control and Prevention
DHHS	U.S. Department of Health and Human Services
NCCAM	National Center for Complementary and Alternative Medicine
NCI	National Cancer Institute
NCMHD	National Center for Minority Health and Health Disparities (now NIMHD)
NCRR	National Center for Research Resources
NHBLI	National Heart, Lung and Blood Institute
NIA	National Institute on Aging
NIAID	National Institute of Allergy and Infectious Diseases
NIAMS	National Institute of Arthritis and Musculoskeletal and Skin Diseases
NICHD	Eunice Kennedy Shriver National Institute of Child Health and Human Development
NIDCR	National Institute of Dental and Craniofacial Research
NIDDK	National Institute of Diabetes and Digestive and Kidney Diseases
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
NINDS	National Institute of Neurological Disorders and Stroke
NINR	National Institute of Nursing Research
NLM	National Library of Medicine

End-of-Life- and/or Palliative Care-Related Federal Research Awards. This section focuses specifically on federal EOL PC-related research awards (grants and funding dollars) received and the trends in the funds to support this research over the course of the grant. The database used, *NIH Query/View/Report* (QVR), is a tool that integrates information from *IMPAC II*, the NIH Data Warehouse. This database primarily contains NIH grant award data; however, some data from other federal agencies (e.g., AHRQ, CDC) are available. In addition, the identification of IC or Agency awards in EOL PC are defined by the search strategy used. QVR was used to search and view detailed information about NIH and related federal agency grant applications and awards. Data were extracted using the history module in QVR to search for EOL PC grant awards between FYs 1997 to 2010 (October 1 to September 30). Grant titles and abstracts using specified terms (Appendix E) were reviewed by two evaluators. For the purposes of this report and in alignment with federal funding, an award (grant) may receive initial funding followed by a set number of years of additional funding support. In terms of awarded grants per fiscal year, the total number of monetary awards (or obligated funds) provided to grants that year includes both competing and noncompeting awards.

Figure 19 depicts the search strategy for EOL PC research using the *QVR IMPAC II* database. A total of 1,887 grants were identified; 496 focused on or included a primary aim related to EOL PC. The remaining 1,391 grants, including 167 training grants, were excluded because they were not related to EOL PC. Thirteen grants on second-tier review were further excluded; although the grant fields mentioned terms related to the EOL PC search terms, the grants themselves were not directly related to EOL PC science. After excluding additional grants (*n*=39) that were obligated but never funded, 444 unique grants were identified. The total 444 awarded grants encompassed 1,274 competing and noncompeting awards from FY1997 to FY2010.

Figure 19: Search of *QVR IMPAC II* Database. Research Grants, FY1997-FY2010.



Federal Agencies

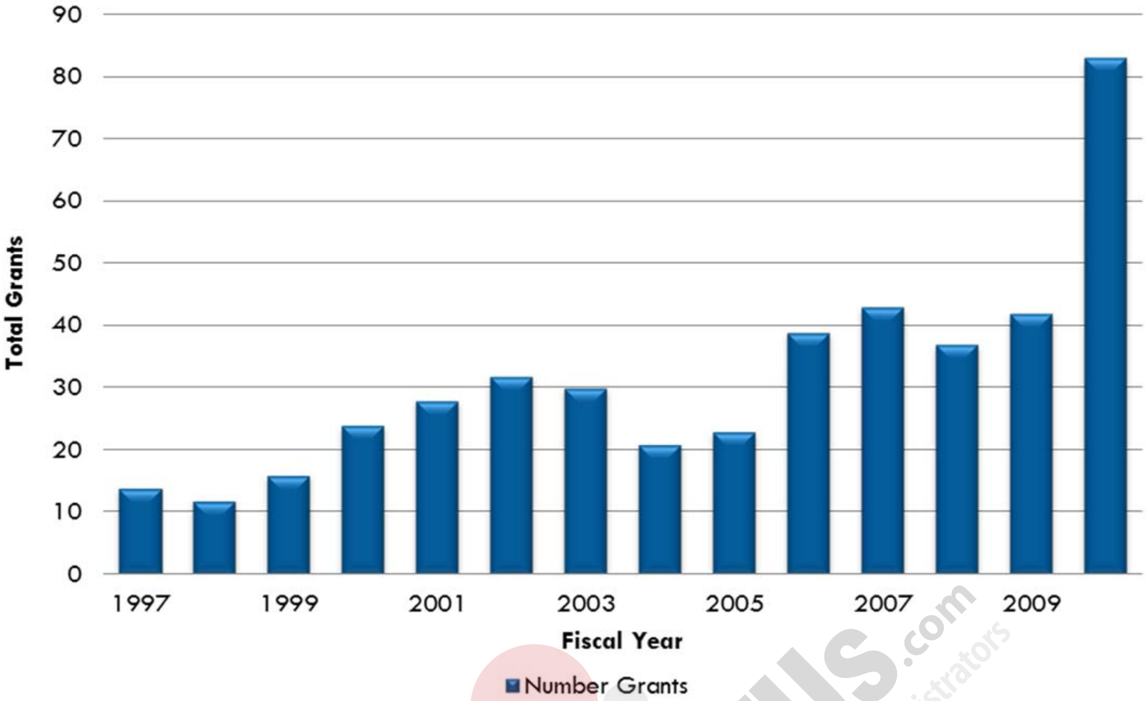
Grant Awards. A total of 444 new federal agency grants were awarded to areas of EOL PC research from FYs 1997 to 2010. Table 14 shows these grants per FY based on the *QVR IMPAC II* database. Figure 20 graphically depicts the number of these grants per fiscal year. A sixfold increase (14 total awards in FY1997 to 83 total awards in FY2010) in the number of EOL PC research grants awarded by federal agencies occurred from FY1997 to FY2009 with a near doubling of the number of grants between FY2009 and FY2010. This increase may reflect the additional grants supported through the American Recovery and Reinvestment Act of 2009 (ARRA).

Table 14. Total New Federal Grants, FY1997-FY2010.

Fiscal Year	Total New Grants
1997	14
1998	12
1999	16
2000	24
2001	28
2002	32
2003	30
2004	21
2005	23
2006	39
2007	43
2008	37
2009	42
2010	83
TOTAL	**444**

NOTE: 2009-2010 values may reflect additional funds awarded to grants through ARRA
SOURCE: *QVR* Database

Figure 20. *QVR* Database. Total New Federal Grants per Fiscal Year, FY1997-FY2010.



Source: *QVR* Database; Data represent 444 grant awards.

Funding. Many grant mechanisms are awarded for multiple years of support. Table 15 depicts funds per fiscal year, along with the cumulative total and the +/- change in annual total funds spent. The *QVR IMPAC II* dataset indicated that from FY1997 to FY2010, EOL PC research awards totaling $432.93 million in awarded funds were provided by federal agencies within the database. The data demonstrate a steady increase in the total federal dollars awarded in EOL PC research from $4.23 million in FY1997 to $61.55 million in FY2010. This represents nearly a 15-fold increase in federal funding since FY1997.[13]

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[13] The noted increase may reflect additional funding support through ARRA funds. As a global comparator of percent NIH budget dollars, the NIH Office of Budget reports the NIH actual obligations for FY2000 as $17.813 billion; FY2004 as $28.099 billion; and FY2010 as $31.036 billion.

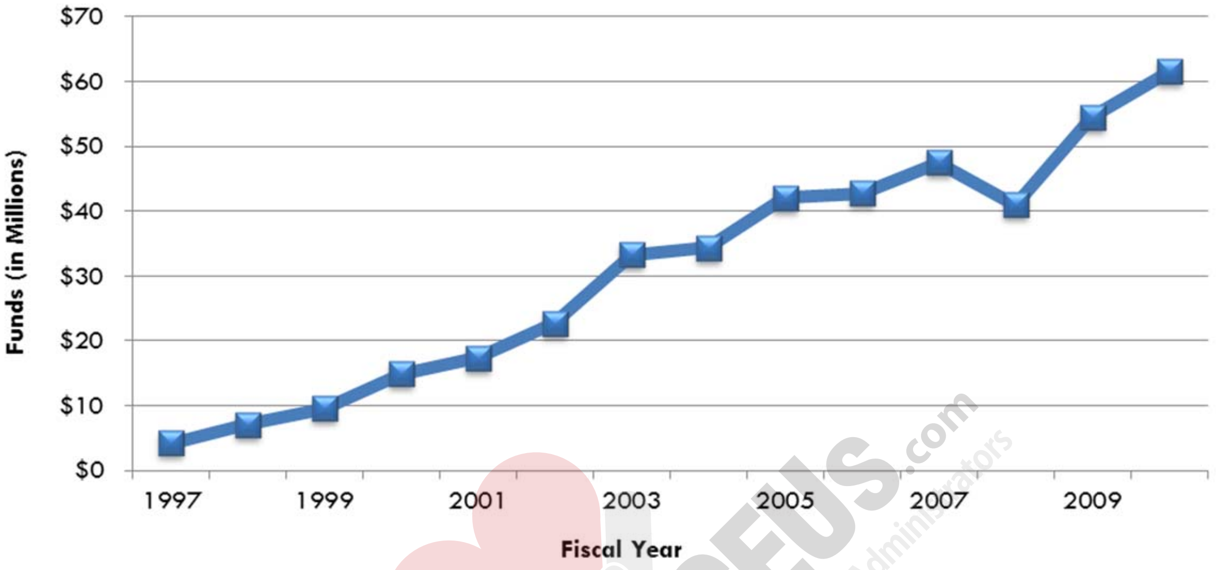
Table 15. Total and Cumulative Federal Funds EOL PC Research per Fiscal Year, FY1997-FY2010.

Fiscal Year	Total Funds	Cumulative Total	Change +/- From Previous FY
1997	$4,233,000	$4,233,000	-
1998	$7,090,000	$11,323,000	+$2,857,000
1999	$9,537,000	$20,860,000	+$2,447,000
2000	$14,882,000	$35,742,000	+$5,345,000
2001	$17,397,000	$53,139,000	+$2,515,000
2002	$22,668,000	$75,807,000	+$5,271,000
2003	$33,332,000	$109,138,000	+$10,664,000
2004	$34,329,000	$143,468,000	+$997,000
2005	$42,087,000	$185,554,000	+$7,758,000
2006	$42,786,000	$228,340,000	+$699,000
2007	$47,472,000	$275,812,000	+$4,686,000
2008	$41,024,000	$316,836,000	-$6,448,000
2009	$54,548,000	$371,384,000	+$13,524,000
2010	$61,547,000	$432,931,000	+$6,999,000

NOTE: FY2009-FY2010 values may reflect additional funds awarded to grants through ARRA
SOURCE: *QVR* Database

Figure 21 illustrates the total *QVR IMPAC II* dataset federal dollars (in millions) per fiscal year for all competing and noncompeting grant awards in EOL PC research from FY1997 to FY2010.

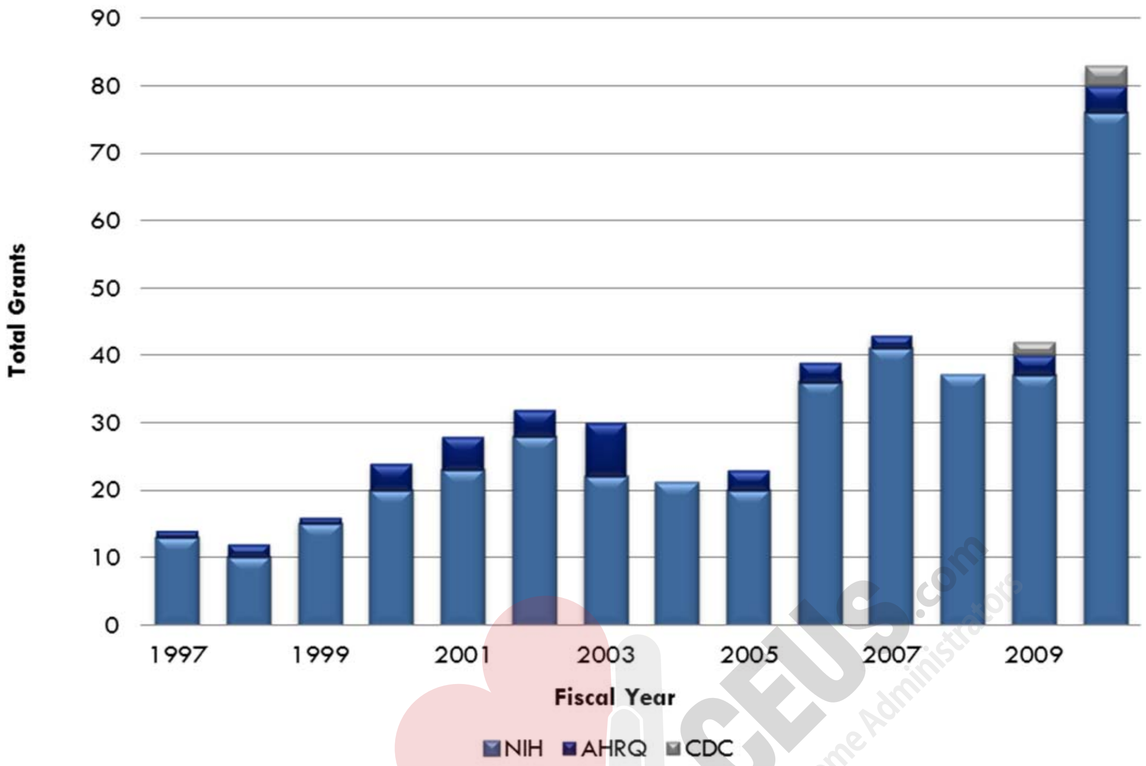
Figure 21. *QVR* Database. Total Federal Funds (in Millions) EOL PC Research per Fiscal Year, FY1997-FY2010.



Source: *QVR* Database. Data represent competing and non-competing, direct and indirect costs. Many grant mechanisms are awarded for multiple years of support.

Most EOL PC grant awards funded by a DHHS agency as based on data within the *QVR IMPAC II* dataset were supported by the NIH (*n*=399, 90% of total number of grant awards FY1997 to FY2010) followed by 9% (*n*=40) by AHRQ and 1% (*n*=5) by CDC. Figure 22 indicates the total number of federal grants per fiscal year awarded by these three agencies based on available database information (Table 15). *It is important to note that the* QVR *system may not capture all EOL PC research grants funded by AHRQ or CDC because of how agency research grants are coded. Further, CDC did not have any listed EOL PC grants in the* QVR IMPAC II *systems until FY2005.*

Figure 22. *QVR* Database. Total New Federal Grants EOL PC Research per Fiscal Year and Agency, FY1997-FY2010.



Source: *QVR* Database. Data represent 444 grant awards.

NIH Insitutes and Centers

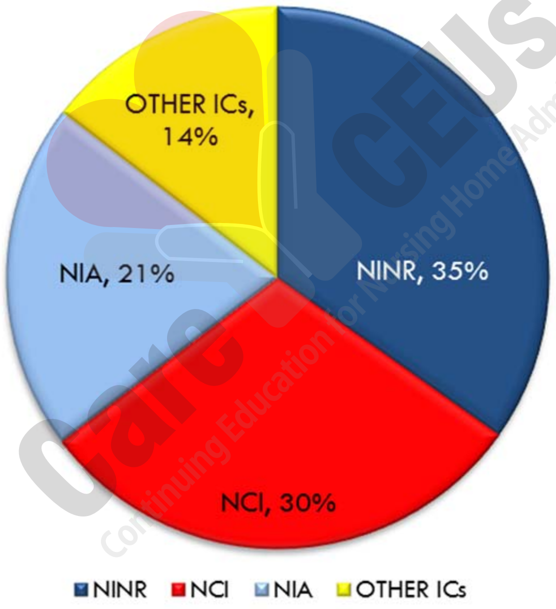
Grant Awards. Within the 399 NIH grants awarded from FY1997 to FY2010, the NINR awarded the largest number of unique EOL PC grants (*n*=139, 35% of total), followed by the NCI (*n*=119, 30%) and NIA (*n*=84, 21%). Together, NINR, NCI, and NIA accounted for 86% of the grants awarded by NIH for EOL PC research (Table 16). The remaining ICs in the dataset (NIMH, NIAID, NIDCR, NIMHD, NINDS, NCRR, NIDDK, NHLBI, NCCAM, NLM, and NICHD) accounted for 57 (14% of total) of all NIH-funded EOL PC grant awards (Figure 23). *It should be reiterated that the* QVR IMPAC II *database identification of NIH IC awards in EOL PC research were defined by a specified search strategy (see Appendices). Totals may not reflect individual internal IC coding of grants or awards.*

Table 16. Total New EOL PC Research Grant Awards by NIH Institute or Center, FY1997-FY2010.

NIH Institute or Center	Total Grant Awards
NINR	139
NCI	119
NIA	84
OTHER IC	57
TOTAL	**399**

Source: *QVR* Database

Figure 23. *QVR* Database. Percent Total New EOL PC Grant Awards by NIH IC, FY1997-FY2010. NCI, NINR, NIA, and OTHER ICs.



Source: *QVR* Database. Data represent 399 new NIH grant awards.

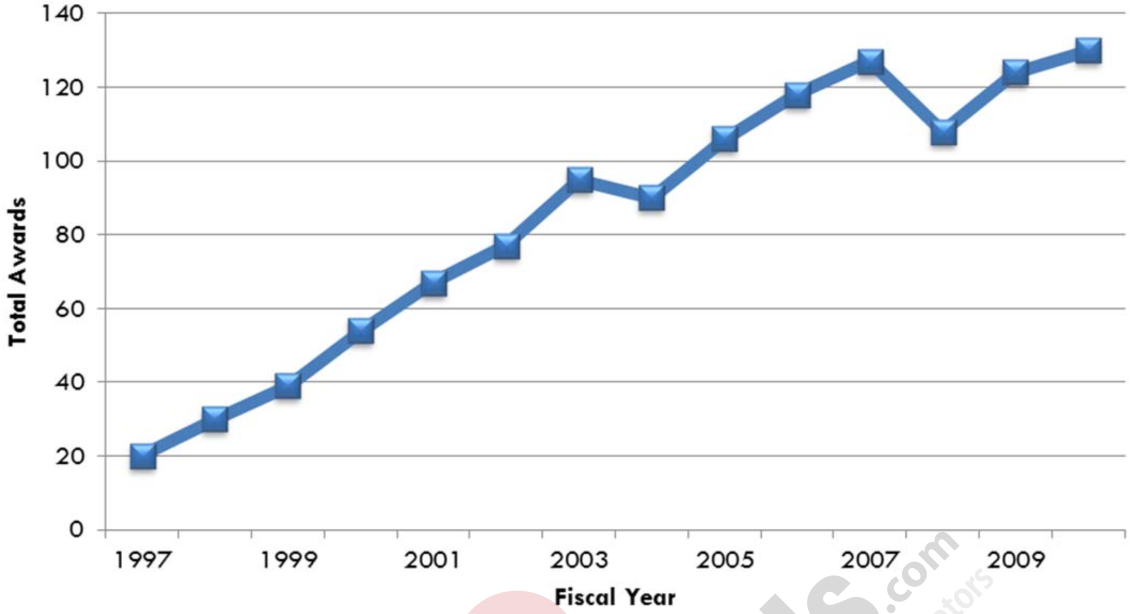
Awards All Grants per Fiscal Year. Many grants are awarded for multiple years of support. When the total number of awards was tabulated across each fiscal year of grant support, a total of 1,185 competing and noncompeting awards were provided within the last 14 years. NCI (*n*=422 awards), NINR (*n*=335 awards), and NIA (*n*=269 awards) comprised the majority of all NIH annual awards (Table 17). The remaining 159 awards were funded through other ICs (NIAID, NIDCR, NINDS, NIDDK, NCRR, NHLBI, NLM, NCCAM, NICHD, NIMHD, and NIMH). Figure 24 illustrates the total number of awards per fiscal year.

Table 17. Total EOL PC Research Awards Across Years of Grant Support, FY1997-FY2010. NCI, NINR, NIA, and OTHER ICs.

FY	NCI	NINR	NIA	OTHER IC	TOTAL AWARDS
1997	8	2	2	8	**20**
1998	14	2	6	8	**30**
1999	15	10	9	5	**39**
2000	16	17	14	7	**54**
2001	20	19	16	12	**67**
2002	24	21	19	13	**77**
2003	35	26	21	13	**95**
2004	38	22	20	10	**90**
2005	47	26	21	12	**106**
2006	53	26	27	12	**118**
2007	52	37	25	13	**127**
2008	31	41	26	10	**108**
2009	36	42	30	16	**124**
2010	33	44	33	20	**130**
TOTAL **(Percent)**	**422** **(36%)**	**335** **(28%)**	**269** **(23%)**	**159** **(13%)**	**1,185** **(100%)**

Source: QVR Database

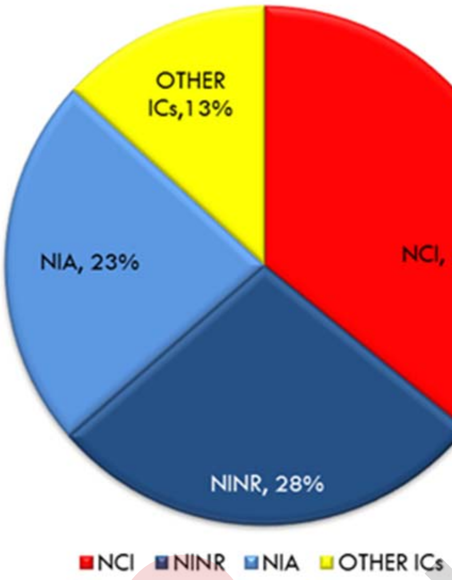
Figure 24. *QVR* Database. Total NIH EOL PC Research Awards Across Years of Grant Support, FY1997-FY2010. NCI, NINR, NIA, and OTHER ICs.



Source: *QVR* Database. Many grants are awarded for multiple years of support. Data include competing and noncompeting awards and direct and indirect costs.

Of the total number of awards (competing and noncompeting, *n*=1,185) provided each fiscal year in EOL PC research by individual NIH ICs, NCI awarded 36% of these awards, followed by NINR (28%) and NIA (23%) (Table 17). Together, these three ICs accounted for 87% of all awards (Figure 25). The remaining ICs accounted for 13% of awards. *It should be reiterated that the* QVR IMPAC II *database identification of IC awards in EOL PC research were defined by a specified search strategy (see* Appendices*). Totals may not reflect values of individual internal IC coding of grants or awards.*

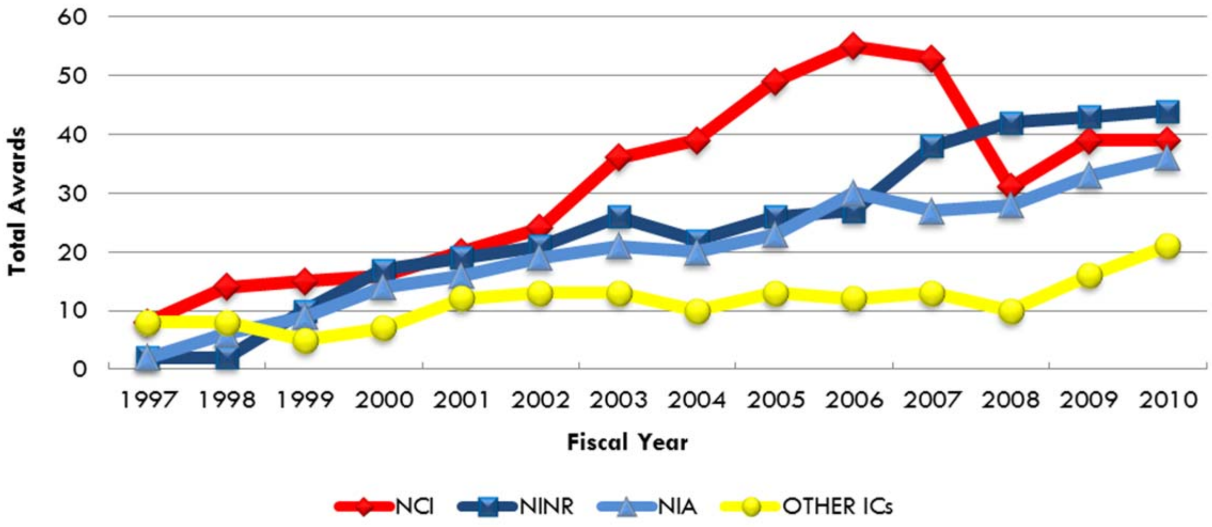
Figure 25. *QVR* Database. Percent Total NIH IC EOL PC Research Awards, FY1997-FY2010. NCI, NINR, NIA, and OTHER ICs



Source: *QVR* Database

From the *QVR IMPAC II* dataset, NIH ICs demonstrated an overall increase in the total number of EOL PC research awards (Table 17). Figure 26 illustrates that NCI, NINR, NIA, and other ICs all contributed to increased EOL PC awards between FY1997 and FY2010.

Figure 26. *QVR* Database. Total EOL PC Research Awards by NIH Institutes and Centers per Fiscal Year, FY1997-FY2010. NCI, NINR, NIA, and OTHER ICs.



Source: *QVR* Database

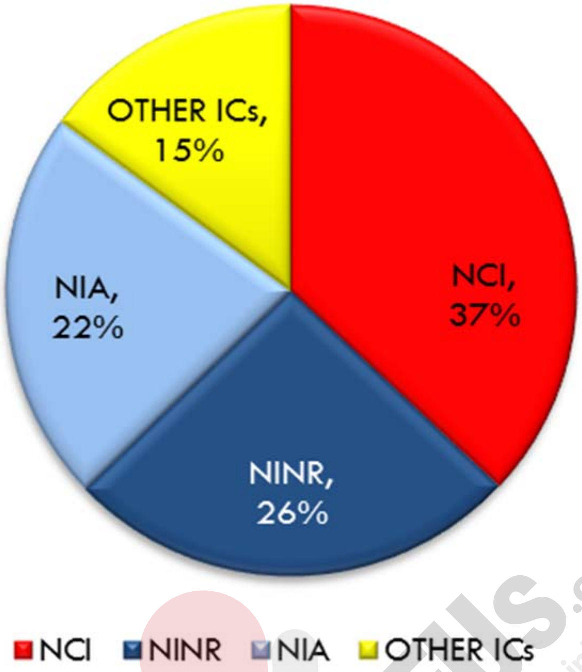
Funding. A total of $389.59 million in EOL PC research funds were spent from FY1997 to FY2010. Of this total, NCI ($143.66 million, 37% of total funds), NINR ($102.03 million, 26% of total funds), and NIA ($84.40 million, 22% of total funds) accounted for 85% of all EOL PC research funding. Table 18 provides fiscal year data on funding totals (in thousands) per NIH IC based on the *QVR IMPAC* II dataset. Figure 27 shows the percent total funding in EOL PC research by these lead NIH ICs. *It should be reiterated that the* QVR IMPAC II *database identification of IC awards in EOL PC research were defined by a specified search strategy (see Appendices). Totals may not reflect values of individual internal IC coding of grants or awards.*

Table 18. Total EOL PC Research Funds by Fiscal Year and NIH Institutes and Centers, FY1997-FY2010.

IC	Fiscal Year														Total
	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	
NCI	779	1,532	2,357	2,963	3,695	4,513	11,882	13,266	16,927	19,566	20,469	12,972	16,763	15,974	**143,658**
NINR	181	198	1,696	3,865	4,127	5,106	6,864	6,429	8,137	8,104	11,133	10,725	13,781	21,681	**102,026**
NIA	214	1,454	1,581	2,489	3,195	5,239	5,284	5,973	8,904	9,452	8,187	9,075	10,963	12,393	**84,403**
OTHER IC	2,651	3,458	2,635	2,872	4,139	4,816	4,451	3,846	5,494	5,069	4,945	2,501	5,731	6,894	**59,503**
TOTAL	**3,825**	**6,642**	**8,269**	**12,189**	**15,156**	**19,673**	**28,481**	**29,514**	**39,461**	**42,191**	**44,734**	**35,274**	**47,238**	**56,943**	**389,590**

Amounts in Thousands
SOURCE: QVR Database

Figure 27. *QVR* Database. Percent Total EOL PC Research Funds per NIH Institutes and Centers, FY1997-FY2010. NCI, NINR, NIA, and OTHER ICs.



Source: *QVR* Database

Federal Grants

Types and Mechanisms. Table 19 lists data on the grant mechanisms of new federal awards in EOL PC research since FY1997.[14] Almost three-fourths (71%) of the 444 EOL PC grants awarded were for specific research projects using R grant mechanisms (R01=30%, 134 awards; Other[15] Rs=41%, 180 awards). The next most frequently awarded EOL PC grant mechanisms were training and career development grants (F/T/ K mechanisms=17%, 76 awards). Remaining grant mechanisms were awarded less frequently including, Small Business awards (6%, 27 awards) and Cooperative Agreement awards (U, 3%, 12 awards) and G or Resource awards (<1%, 4 awards).

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[14] For descriptions of grant mechanisms and types,

[15] Other R grant mechanisms include: R03, R13, R15, R21, R24, R25, R29, R34, R36, R37, R55, R56, and RC1.

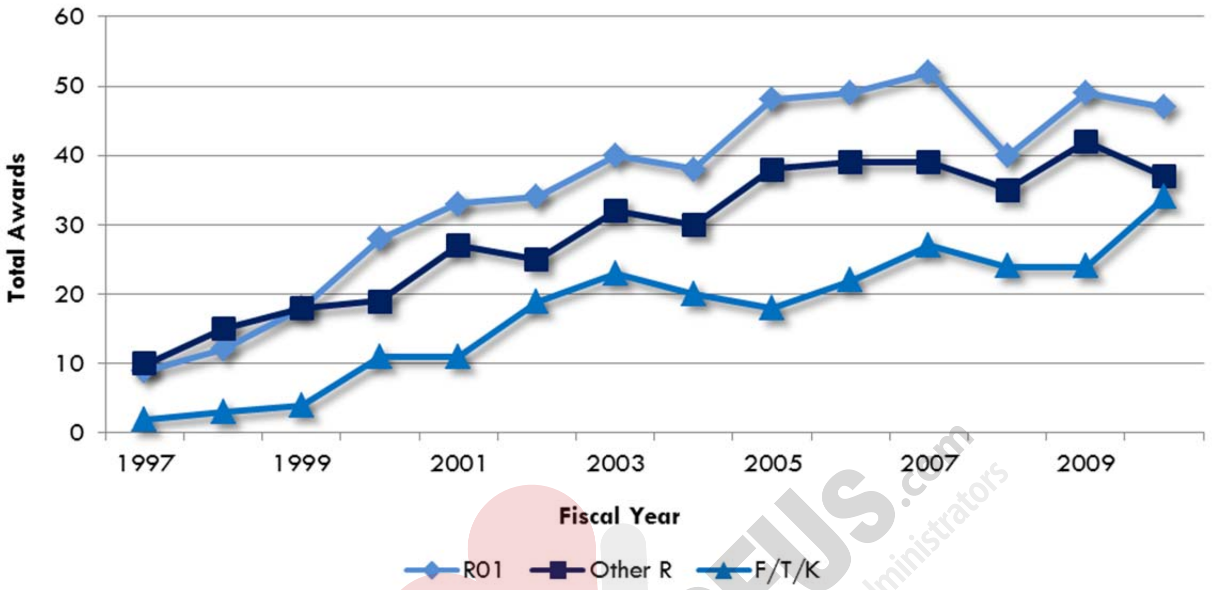
Table 19. Federal EOL PC Research Awards by Grant Type and Mechanisms per Fiscal Year, FY1997-FY2010.

	Grant Mechanism						
Initial FY	**Other R**	**R01**	**F/T/K**	**Small Business**	**U**	**P**	**G**
1997	8	3	1	1	-	-	1
1998	8	1	2	1	-	-	-
1999	6	7	1	2	-	-	-
2000	9	7	7	-	-	1	-
2001	15	9	3	-	-	1	-
2002	13	9	7	2	1	-	-
2003	11	8	7	3	-	1	-
2004	6	8	2	4	-	-	1
2005	11	8	1	-	2	1	-
2006	17	11	6	4	1	-	-
2007	16	15	7	3	1	-	1
2008	16	11	7	2	1	-	-
2009	16	13	6	3	1	3	-
2010	28	24	19	2	5	4	1
TOTAL	**180**	**134**	**76**	**27**	**12**	**11**	**4**

Based on 444 federal grant awards.
SOURCE: QVR Database

Figure 28 shows increasing numbers of awards for R01, Other R, and F/T/K training and education grants.

Figure 28. *QVR* Database. Total Number of Federal EOL PC Research Awards per Fiscal Year and Grant Mechanism, R01, Other R's, and F/T/K Awards.

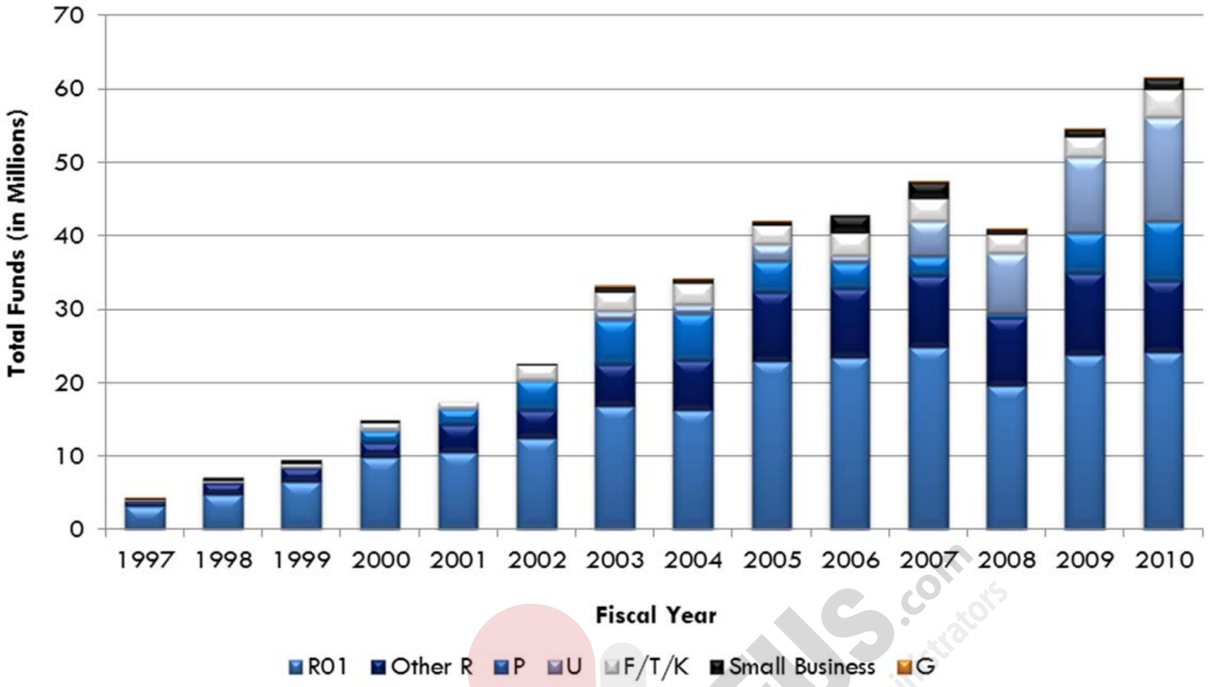


Source: *QVR* Database

Total Funds per Grant Mechanism. As noted in Table 20, R01 awards accounted for more than half of all funded research dollars ($219.21 million, 51% of total). Although the number of "Other R" research awards, such as R03 or R21 awards, were greater than R01 awards, these awards tend to receive fewer total funding dollars, in part, because non-R01 R awards are often exploratory or pilot projects and have fewer years of funding, resulting in lower overall funding levels ($85.43 million, 20% of funding).

F/T/K training-related awards (6.6% of total funding) increased from $129,000 in FY1997 to $3.83 million in FY2010. P mechanism awards (Center grant mechanisms, 10.2% of total funding) began in FY2000 with approximately $1.6 million in funds. By FY2010, P mechanism awards increased to $8.1 million in funding. Cooperative Agreements (U grant mechanism, 9.9% of total funding) were not awarded for EOL PC research until FY2002. Since then, the funding for U grant mechanisms has increased from $84,000 in FY2002 to more than $14 million in FY2010. Small Business award mechanisms have varied and represented 2.65% of funding. The total funds increased from $116,000 in FY1997 to $2.4 million in FY2006; however, since then funding has decreased to a FY2010 total of $1.5 million. A similar trend is noted for G award mechanisms with minimal and variable funding for this mechanism from FY1997 to FY2010 (Table 20). Figure 29 displays the total federal funds per award mechanism and fiscal year.

Figure 29. *QVR* Database. Total Federal Funds (in Millions) EOL PC Research per Grant Mechanism and Fiscal Year, FY1997-FY2010.



Source: *QVR* Database

Table 20. Total Federal Funds (in Thousands) EOL PC Research per Grant Mechanisms, FY1997-FY2010.

Grant Mechanism	Fiscal Year														Total Funds
	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	
R01	3,206	4,743	6,487	9,886	10,500	12,461	16,918	16,248	22,906	23,478	24,840	19,595	23,801	24,138	**219,208**
Other R	755	1,644	1,939	1,980	3,867	3,871	5,596	6,919	9,412	9,497	9,784	9,306	11,131	9,729	**85,430**
P	-	-	-	1,605	2,110	3,957	6,058	6,300	4,205	3,466	2,565	468	5,492	8,112	**44,338**
U	-	-	-	-	-	84	1,145	1,168	2,343	854	4,723	8,213	10,187	14,155	**42,873**
F/T/K	129	233	591	1,031	920	2,095	2,634	2,912	2,606	3,116	3,174	2,612	2,836	3,833	**28,721**
Small Business	116	470	521	380	-	200	792	644	474	2,375	2,253	695	1,037	1,522	**11,479**
G	27	-	-	-	-	-	188	138	140	-	133	134	65	57	**882**
TOTAL FUNDS	**4,233**	**7,090**	**9,537**	**14,882**	**17,397**	**22,668**	**33,332**	**34,329**	**42,087**	**42,786**	**47,472**	**41,024**	**54,548**	**61,547**	**432,931**

Amounts in Thousands. All federal agencies: NIH, AHRQ, CDC

SOURCE: QVR Database

VI. DISCUSSION

This review of the themes and topics within the end-of-life and palliative care (EOL PC) research literature and an evaluation of federal research support was conducted to determine the progress and the trends the field has made since the Institute of Medicine's (IOM) 1997 report, *Approaching Death: Improving Care at the End of Life*. The data from this current review indicate significant progress in the science of EOL PC. The results provide a template from which to address several key recommendations from the IOM report and the efforts made to support numerous research priorities as outlined by the 2004 State-of-the Science Consensus Panel findings. Although this current review was limited to research published in the United States from 1997 to 2010, the results provide perspectives on the broader field of EOL PC in regard to the health conditions examined, the populations studied, and the topics researched. Together, these data facilitate discussion of research gaps, priorities, and future actions to strengthen the evidence base.

As a component of reviewing the published EOL PC research over the past 14 years, this report also reviewed data that provided information on the sources of funded EOL PC research in association with specific topics and trends in the scientific field. Overall findings from this review indicated that directed funding streams for EOL PC research by federal and major philanthropic sources have increased; there are more funding dollars being invested in EOL PC science and there are trends for an increasing breadth and depth in the level of EOL PC issues encompassing the field of research. These key findings are discussed in the following sections within the contexts of the evaluation questions posed for this review.

> *ANY FOUNDATION CONCERNED WITH ALLEVIATING HUMAN SUFFERING CAN HELP IMPROVE END-OF-LIFE CARE FOR PATIENTS AND THEIR FAMILIES—REGARDLESS OF GEOGRAPHIC FOCUS, GRANT SIZE, OR FUNDING PRIORITY. IN THE END, EVERY FUNDER HAS A PERSONAL STAKE IN THE QUALITY OF THE END-OF-LIFE CARE SYSTEM WE CREATE.*

What Are the Trends in EOL PC Published Research Topics?

The data indicate that the number of research publications has tripled since 1997, a finding that substantiates the presence of a growing and diverse body of research and a strengthening of EOL PC science. Three topic categories, "Advance Care Planning," "Care Settings and Standards," and "Pain and Other Symptom Management" comprised more than one-third (35.6%) of the total number of published studies. That there remains a strong emphasis on these topics for over a decade suggests an ongoing need and an interest to further evidence-based knowledge and outcomes within these areas; however, while the data indicate that new research themes are emerging, less than 5% of all dataset publications reflected manuscripts on EOL PC topics such as ethics, economics, service delivery models, spirituality or religion, standards of care, and other areas that are of timely and critical importance in today's society. Specifically, the field has not demonstrated equally strong trends to publish work in the following topic and condition-disease category areas:

Topic Categories: Several trends were noted in the topic themes of the published literature.

- "*Hospice,*" "*Medicine and Alternative Medicine,*" *and* "*Mental Health*" accounted for 21.4% of research publication topics.
- "*Hospice*" as a topic of research tripled from 14 publications in 1997 to 43 publications in 2010. A steady increase in hospice as a topic category identified in publications may represent an evolving trend in attention to an evidence base for hospice care; a maturation of funded research in the area; and increasing research interests in hospice care across new settings, populations, and services. Still, the category represents 8.5% of all publications.
- "*Medicine and Alternative Medicine*" topics within the research literature, while demonstrating overall growth in numbers of publications, have trended toward decreasing overall total percentage of annual publications. In 1997, 9.5% of all publications identified contained these themes while in 2010, only 4.8% of publications with these themes were identified. This trend may reflect evolving or new research emphasis in the topic, or perhaps, fewer grantee publications.
- "*Mental Health*" as a topic has fluctuated as a focus, representing 5.8% of the themes in all publications reviewed. In 2010, this percentile of publications decreased to 4.4%. The area of mental health for EOL PC patients and caregivers is a critical component of high-quality and evidence-based care, yet the percent of total publications identified suggests this area must be developed.
- "*Culture, Religion, and Spirituality*" as research topics varied in the total number of EOL PC research manuscripts, ranging from 3.6% to 7.8% of total annual publications. This area is of critical importance for development in alignment with contemporary interdisciplinary practices in care settings such as hospices, nursing homes, or hospitals; integration with community-based services; sensitivity to values and beliefs of diverse population demographics; and evolving health care trends.

Disease Categories: Nearly half (49%) of all published research focused on a specific advanced health condition, but 53% of these studies were related to topics in cancer research. It is imperative that an EOL PC research emphasis on cancer remains; the field of cancer is not monolithic and many issues related to cancer in EOL PC are understudied (e.g., leukemia, lymphoma). However, the small number or the lack of publications in other health condition/disease areas highlights the need for active discussions as to how to best achieve expansion of the research field to reflect additional complex, multiple conditions in advanced illness.

- While the number of EOL PC publications focused on advanced neurologic, cardiac, and respiratory conditions increased from 1997 to 2010 (14 studies, 28%, to 81 studies, 35%, respectively), the proportion of these individual topics within all publications remained less than 20% of the total for any given year (for cancer, that proportion was more than 60%). This finding is important given that the most common causes of death in the United States (in addition to cancer, which is the second leading cause) are heart disease, stroke, chronic respiratory disease, and Alzheimer's disease.

- The number of EOL PC research publications focused on advanced HIV/AIDS, musculoskeletal, renal, or liver conditions have remained limited, with few increases in the number of publications since 1997 (less than 12 studies on any of these conditions were published in any year after 1999). Particularly, there was a negative trend for EOL PC research publications on health conditions related to HIV/AIDS.

What Are the Funding Sources Cited in the Published Research?

Knowing who supports the science of EOL PC is invaluable for identifying the sources of research funding, the fostering of new collaborations, and the building of future initiatives to address EOL PC needs. Information on the funding sources of EOL PC research publications from 1997 to 2010 was available for 39.9 % (1,258 studies) of the dataset. Of publications with a known source of funding support, 45% (567 studies) of the research was supported solely by the private sector, and 18% of this total received funding through two main philanthropic organizations (the Robert Wood Johnson Foundation [RWJF] and the Open Society Institute) whose projects in EOL PC have reached maturity and/or have closed. Approximately 30% (381 studies) of acknowledged research support was cited as through various federal entities, while 25% (310 studies) of published research studies indicated funding from both the private and public sectors. These findings point to the need to consider both the benefits of collaborative efforts to fund research and the mechanisms needed to build future opportunities and incentives to foster public-private partnerships.

In publications where funding sources were not acknowledged, a second verification procedure using a follow-up author questionnaire was conducted to complete the missing data. This added procedure yielded only minimal additional information, suggesting the possibility that a large percent of published research is unfunded—or that those missing this information were in journals whose publishers did not require such acknowledgements. Since 2007, the number of published EOL PC research publications without a specified acknowledgement of funding sources has increased to 64.5% (2008), 70.9% (2009), and 68.5% (2010), according to the dataset. While some scientific journals may not have required funding source acknowledgment, the National Institutes of Health (NIH) began requiring this information be included for NIH-funded grants in 2002. On the other hand, the potential conclusion that a large percentage of investigators are conducting and publishing unfunded work should be considered.

The Federal Sector: While there was a definite trend for increased federal funding for EOL PC research between 1997 and 2010, actual reporting of federal funding (based on citations in the literature) fluctuated and lagged behind citations of private, philanthropic support.

- Overall, 30% of all publications cited sole support for the research by a federal agency. These results are similar to Gelfman and Morrison's review of U.S. publications from 2003 to 2005, which noted 31% NIH funding support (Gelfman and Morrison, 2008).
- Until 2004, the level of federal funding was often less than half that from nonfederal sources. In 1997, 24% of all publications cited sole support through federal sources; in 2010, this percentage increased to 48%.
- Thirty-seven federal organizations were cited in the dataset as funding EOL PC research from 1997 to 2010. Federal agencies that were acknowledged as a source of funding in more than 50 EOL PC research publications between 1997 and 2010 included the NIH, the Agency for Healthcare Research and Quality, and the U.S. Department of Veteran's Affairs.
- More than 15 NIH Institutes and Centers were cited in the published literature as supporting the EOL PC research; however, three NIH Institutes accounted for 53% of all citations: the National Institute on Aging (NIA, 24%), the National Cancer Institute (NCI, 15%); and the National Institute of Nursing Research (NINR, 14%). While grant awards are not synonymous with consequential publication, other NIH Institutes frequently mentioned as sources of funding included the National Institute of Mental Health; the National Heart, Lung and Blood Institute; the Eunice Kennedy Shriver National Institute of Child Health and Human Development; and the National Center for Complementary and Alternative Medicine.

The Private Sector: Citations of nonfederal funding of EOL PC research were notable. For the period of this review, 45% of all published research in the dataset was supported by the private sector. For a decade (1997 to 2007), the level of acknowledged funding from nonfederal organizations alone was substantially greater than that of federal funding. From 1997 to 2003, nearly half of all funded EOL PC research publications reported receiving sole funding from nonfederal organizations; however, in 2010, this support decreased to 24.8%. Between 1997 and 2010, 533 private organizations supported published EOL PC research.

- The most common type of nonfederal organization reported in research publications were foundations (139 different foundations acknowledged in 26% of all citations), followed by academic institutions (79, 15%), private industry (63, 12%), and professional associations (54, 10%). Nonfederal organizations that funded 20 or more EOL PC research publications included RWJF, the Open Society Institute/Project on Death in America, the Hartford Foundation, the Greenwall Foundation, the American Cancer Society, the Paul Beeson Faculty Scholars Award, the Oncology Nursing Foundation, and the Nathan Cummings Foundation. RWJF was the most frequently acknowledged nonfederal funding source within the EOL PC research literature; 153 publications listed RWJF as a source of funding.

Approximately one-fourth (25%) of all research publications reported support for the work from both the public and the private sectors.

- The proportion of EOL PC research publications based on research funded by both public and private sources increased between 1997 and 2010 despite some changes over the years. The number of publications funded by both sources was highest in 2004 and 2005—36% and 33%, respectively, with 38 publications each, but declined in 2009 to 19% (17 studies), perhaps reflecting the possibility of fewer research projects and solicitations for research emanating from some philanthropic sectors. These data, however, suggest that many investigators have multiple sources of support for their research—a trend that may reflect changing availability of funds for this science. Efforts to build public-private collaborations are critical considerations in discussions of strategies to sustain research infrastructure and maintain momentum.

The results from this current review parallel those from the *Palliative Care Grantmaking Snapshot Report* (2009), which alluded to the changing face of philanthropy noting in their survey data that 44% of philanthropic funders felt that palliative care was a 'low' or a 'very low' priority for their foundations and thus the report's recommendations for leadership in building support. Given the current constraints across both private and public sectors, advancing knowledge in the field of EOL PC may require strategic collaborations within such organizations. Public-private partnerships, collaborative networks that could invest in research, supporting new and innovative topic priorities, and creating better mechanisms to connect the clinical and public sectors might assist the continued viability of private funding in EOL PC and foster new momentum in an area of health care that is so critically needed.

What Are the Federal Mechanisms of EOL PC Research Support?

Across federal agencies, there has been a sixfold increase in the number of new grants for EOL PC research (from 14 grants in FY1997 to 83 in FY2010, 444 total new grant awards). NIH ICs supported 399 of these new EOL PC grants since FY1997. NINR supported 139 grants (35% of total new grants) followed by NCI (119, 30%) and NIA (84, 21%).

- The R01 mechanism accounted for 30% of all federal awards and 51% of all funds for research in this area by federal agencies. The R01 is used to support a discreet, specified, circumscribed research project. These awards are generally from three to five years and have varying dollar amounts awarded based on topic and study requirements. The second most common award was for a variety of other R-award mechanisms.
- Other mechanisms of support are emerging in the form of Small Business awards (6%), Cooperative Agreements (U, 3%), and Center (P's, 2.5%) mechanisms.
- Despite a five-fold increase since 1997 in the number of publications with a focus on "Education and Training," 5.2% of all research publications included education and training issues as a topic of research. In relation to federal funding of awards in this area,

17% of the 444 federal awards were F/T/K type mechanism awards, which focus on training and career development. These accounted for 6.6% of the total funding dollars in federally supported research. Much more needs to be done to foster new strategies in this area and ensure translation of meritorious findings into the literature by emerging scientists. Increased emphasis on evidence-based research in interprofessional education and training is also a critical area for fostering a skilled and knowledgeable workforce in advanced illness care.

How Is This Reflected in Terms of Federal Funding?

The trends associated with federal support for EOL PC research based on information accrued from the Query/View/Report database indicated nearly a 15-fold increase in funding of EOL PC science since FY1997. A total of $432.93 million in funds has been spent by federal agencies for EOL PC research since FY1997. In FY1997, $4.23 million in funding support was identified; in FY2010, this amount increased to $61.55 million.

- The NIH has steadily increased the level of funding for EOL PC research since FY1997. From FY1997 to FY2010, a total of $389.59 million in NIH EOL PC research support has been provided. In FY1997, $3.83 million in annual funds was spent on EOL PC research. In FY2010, these annual funds increased to $56.94 million.
- Total awards (competing and noncompeting) throughout the grant cycle period have demonstrated a sixfold annual increase since FY1997. NCI supported 36% of these awards followed by NINR (28%) and NIA (23%). Together, these three NIH Institutes represented 87% of the number of all awards through the funding cycle of awarded grants and 85% of the total NIH grant funding from FY1997 to FY2010. This pattern of IC funding distribution has not changed since FY1997. In percent total of NIH funding dollars:
    - From FY1997 to FY2010, NCI supported 37% of total funds ($143.7 million).
    - From FY1997 to FY2010, NINR supported 26% of total funds ($102.0 million).
    - From FY1997 to FY2010, NIA supported 22% of total funds ($84.4 million).

Are EOL PC Research Interests and Priorities Changing Over Time? What New Knowledge Gaps Need To Be Addressed?

Despite a growing body of literature that supports the importance and value of EOL PC research in the past 14 years, the foci of much published research remain relatively unchanged. Rigorous research needs to expand beyond cancer, advance care planning, and pain or symptom management to areas that reflect the changing demographics of today's society, including building research momentum to strengthen evidence in ethnic, racial, and pediatric populations and to foster studies of complex and multiple advanced illnesses. These include:

- **Research Design.** More than half (52%) of all published research in the dataset was based on quantitative, non-experimental research designs. Experimental studies represented only 13% of the published literature. Less than 10% of publications involved psychometric studies, analytic reviews, mixed-methods studies, or action research studies. While analytic reviews fared slightly better (increasing from three studies, or 3%, in 1997 to 26 studies, or 7%, in 2008), neither psychometric studies or mixed-methods studies accounted for even 4% of all studies conducted from 1997 to 2010. A *National Research Council* report (Feuer, Towne, and Shavelson, 2002) outlined that stimulating effective research should have primary emphasis on nurturing and reinforcing a scientific culture of educational research to create a stronger sense of research community supported by leadership in professional associations and a federal educational research agency. Newer studies using a variety of designs are needed to broaden such a scope. As advanced care becomes more engrained across a continuum of illness, community-based participatory research, for example, could realize authentic partnerships between patients, families, clinicians, and scientists and allow the community to help define priorities and improve research at all levels, including care planning before serious frailty, disability, or loss of independence. Health service research paradigms could ascertain how organizational structures and processes, as well as personal behaviors, influence equitable access to care. Both evaluative and epidemiological studies are needed to help truly transform the field. The expansion of EOL PC to other research methods offers enormous opportunities to address the critical areas in the social sciences, economics, workforce, and public health sectors and leverage support to advance EOL PC knowledge and care delivery. Recent reports focusing on evidence-based data support the need to address this issue, including studies that address quality improvement research using quality improvement measures (Dy, Asalakson, Wilson, et al., 2012).

- **Measurement.** The field of EOL PC is growing, and so, too, should measures that adequately assess constructs relevant to the field. This review found only 83 publications of studies on EOL PC-related measurements. Measures with strong psychometric properties that can be used with different conditions (e.g., non-cancer), with groups of patients (e.g., children, racial/ethnic minorities, subpopulations), and in different settings (e.g., hospice, home care, nursing homes) and that assess other critical EOL PC constructs (e.g., symptoms other than pain, processes to improve outcomes, continuity of care) are likely to help provide a solid research foundation to the field. Recent reports focusing on evidence-based data support the need to address this issue (Dy, Asalakson, Wilson, et al., 2012).

- **Bioethics**. No clinical trial, regardless of potential scientific benefit, should compromise the humane care that is the foundation of end-of-life research. Bioethicists must collaborate with investigators to address culture-, ethnicity-, and gender-related questions of justice within the milieu of new initiatives in EOL PC science. Ethical standards must be created for protocol design and implementation, including guidance on subject recruitment and retention, consent, minimization of incremental risk, and health information use.

- **Differences and Needs.** The dataset did not parse out the degree of topics that focused on geriatric populations. Chronic, often multiple illnesses associated with an aging population (e.g., diabetes, obesity, stroke, hypertension, osteoporosis, depression) can be long lasting. Those approaching the end of life now present complex conditions and multiple co-morbidities beyond primary symptoms of a single disease. Thus, a next generation of research must evaluate these integrated sets of symptom clusters that vary throughout the continuum of chronic illness. Attention to variability provides prospective opportunities to identify high-risk patients, distinguish deleterious variables, and target individuals for earlier management. It is urgent to validate methods of symptom self-management and reporting, build programs of evolving care planning, develop monitoring and reporting standards, and reinforce case-management interfaces among palliative specialists, general providers, and service sectors. In addition, large-scale, multiple site studies are needed to help look at variation by disease, culture, setting, etc.

  Family caregivers are essential in end-of-life care because they perform activities of daily living, administer health care, provide support, manage schedules and finances, communicate with health care professionals, and take care of a host of other responsibilities. More research needs to be done to elucidate the impact of advanced illness on caregivers, including the interplay of numerous psycho/social, physical, and economic stressors and the creation of caring communities to inform and prepare caregivers throughout the continuum of advanced illness. There are little data regarding which caregivers are at greatest risk for distress and which interventions are likely to relieve that distress. An aspect of caregiving is attention to the unique needs of women, who often serve as primary caregivers for those with advanced illnesses. Studies highlighting the challenges of women as well as all caregivers, in respect to psychosocial needs and health concerns; stressors; and workplace, ethnic, racial and, caregiving characteristics as reflected in their EOL PC experiences (e.g., care needs, preferences for services), are limited. Research must develop and test preventive screening and adult-learning or training tools, create innovative measures to evaluate and monitor health risks, and find new data-driven interventions to improve the caregiving experience.

- **Innovative Models of Care**. Early, integrated palliative care throughout the advanced illness trajectory is a health service model with enormous potential; however, more data are needed to define the integrated team, identification and referral criteria, outcomes, and fiscal benefits across a broad spectrum of services, including acute critical care and nursing home facilities. Research on the timeliness and appropriateness of hospice referral is critical as well as strategies for providers and the public to facilitate early and appropriate referrals. New care models should address quality improvement indicators, especially in areas of individual- and family-centered decision making, communication, and continuity of care. EOL PC research must address issues of patient safety, comparative effectiveness, and quality improvement. Integrative therapies involving complementary and alternative approaches to symptom management must be expanded, use of virtual networks to disseminate simple and standardized care protocols should be created, and support for large, longitudinal data repositories are needed. The use of new technologies may ascertain better ways to assess, monitor, or prevent health crises while new methodological designs may verify effective strategies and move discoveries into the frontline of clinical practice.

- **Substantiating the Value of Advance Care Planning.** Research must identify an acceptable and sustainable process that ensures that the documented values and beliefs of individual preferences for care are realized throughout the progression of advanced illness. The next generation of research must focus on the specific behavioral mechanisms that drive use and adherence to advance care plans and ensure that care reflects a person's values, preferences, and goals. In addition, the next generation of advance care planning research needs to address diversity, health literacy, education, and training issues for the public and all providers, including generalists.

- **Broadening the Scope of Pediatric Research.** Pediatric palliative and hospice care has expanded its scope to include medically fragile neonates, adolescent health, and children with rare diseases. Future research efforts must strengthen the skill sets of pediatric providers and build interventions that incorporate the beliefs, resources, and cultures of families into the context of shared health care decisions. Careful attention must be given to the unique stressors experienced in this field, while inclusion of the child’s voice and parent or guardian as partners in research must be addressed.

- **Diversity.** Culturally mediated beliefs, ethnicity, spiritual values, access to resources, and geographic and socioeconomic variables inherently affect EOL PC research questions, experimental designs, recruitment, the impact of findings, and the translation of meaningful results. Issues of diversity are multifaceted and future research must incorporate into every study those variables sensitive to the changing demographics of advanced illness, including attention to diversity in advance care planning, communication, training, and intervention in our changing society. Consideration also needs to be given to people with physical and intellectual disabilities as well as the lesbian/gay/bisexual and transgender communities (Stein and Bonuck, 2001; Stein, 2008).

Limitations

This review has several limitations that should be considered when interpreting results, including the following:

- This report tabulated the number and categories of themes within the EOL PC literature of several public databases from 1997 to 2010. It was not conducted as an evaluation of the quality of the research, and the methods did not include analysis of each full study. In addition, the review excluded information that may have been contained in the grey literature. To this point, the data do not reflect analyses of the rigor of the science since 1997 and research productivity is considered only in terms of publications in venues accessible to the various database search engines available.
- Methods to identify and code the primary topic of research were problematic. While 3,155 publications were reviewed, 4,299 actual topic themes within the manuscripts were identified. Despite training on coding of the dataset, expert consultations, and reviews to extract specific category identification methodologies, the coders were unable to parse single themes of manuscripts in approximately one-third of the studies accrued, resulting in multiple coding of many topic areas.
- Some areas may have been underreported and may have precluded a deeper understanding of important research trends. For example, age was categorized into two discrete groups: children and adolescents=newborns to 17 years, and adults=18 years of age and older. Emerging research interests on subgroups of very young children (e.g., neonates and premature infants) could not be addressed because the category "children and adolescents" used in the study included newborns through 17-year-olds. The same holds true for parsing differences in adolescents, young adults, and geriatric populations.
- The present review excluded review of other sources of information commonly known as "grey literature" (e.g., letters, commentaries, reports, conference notes, meeting abstracts) within EOL PC research publications that could have expanded information in this report.
- It is possible that many EOL PC research publications labeled "unspecified" with regard to funding were in fact funded, but the sources of support were not required and, thus, funding information was underreported. Unlike the federal government, there is no requirement across all nonfederal organizations to acknowledge the source of funding received for published research. Given that more than 39% of all publications lacked funding source information, and direct follow-up with investigators to complete missing information was made, this information is incomplete. Alternately, the potential of unfunded research as measured by the lack of funding source citations—even with follow-up funding verification by the authors—suggests that investigators are publishing unfunded research.
- Information on federal awards and funding trends is subjective based on the coding and data pull criteria within the *QVR IMPACC II* database. NIH databases such as the *Research Portfolio Online Reporting Tool (RePORT,* formerly *CRISP*) or the *Research, Condition, and Disease Categorization* (*RCDC*) dataset for *RePORT* do not contain award coding fingerprints that can be used to capture the breadth of research in categories such as EOL PC science. The search terms used for this review were based on a draft *RCDC*

palliative care fingerprint that was created by a trans-NIH IC group of advisers. The fingerprint terms, peer-reviewed algorithms, and methods to extract and classify EOL PC research are thus limited to the information within the *QVR IMPAC II* database. Individual ICs may code their own portfolios using IC-specific procedures that are therefore not reflected in this report's dataset.

- Funding trends in 2009 and 2010 may reflect investments in EOL PC research supplemented by *The American Recovery and Reinvestment Act of 2009* (ARRA). This legislation provided an unprecedented level of funding ($8.2 billion in extramural funding) to the NIH to help stimulate the U.S. economy through the support and advancement of scientific research. NIH reported a total of $10.4 billion in ARRA funding; however, the individual percentage for EOL PC research that may be reflected within this amount is not known.
- Similarly, not all private, philanthropic sources of published research support, as defined in this literature review, may have been identified. The philanthropic databases used are dependent on agency participation. Undoubtedly, many other private organizations have contributed to EOL PC research initiatives that were not captured in this report.
- It is important to acknowledge the lack of a one-to-one association between a funded grant and subsequent publication of research. One grant can result in citations within multiple publications, or none.

OPPORTUNITIES | BUILDING MOMENTUM FOR THE FUTURE

The findings from this systematic review of the published literature and federal funding information point toward several opportunities to foster new science in EOL PC research and create momentum to broaden the scope of this field. Despite a clear indication of growth in terms of research awards, funding, and publications, the future of EOL PC science must parallel the evolving nature of the field and the changing demographics of what it means to live with and die from serious advanced illnesses in today's society. Attention to the entire spectrum of diverse needs throughout the entire life-stage spectrum and disease trajectory, from the youngest to the eldest individual, must reflect the changing foci of multiple and complex chronic conditions. The science must widen its reach to ensure equitable access to quality EOL PC as well as to reduce the gaps in services provided to all populations and within all service sectors. Attention to culture, ethnicity, and minorities must demonstrate a measurable shift in the number of grants, funding dollars, and dissemination of meaningful research findings to the public.

CARE AT THE END OF LIFE . . . IS INFORMED BY SCIENTIFIC EVIDENCE, VALUES, AND PERSONAL AND PROFESSIONAL EXPERIENCE.

EOL PC science emanated from the significant support of research from the private sector; as such, the value of such philanthropy to foster research must not be overlooked. Scientific investments in the future should be fostered both within the public and the private sectors. Embracing such opportunities to create public-private partnerships, developing collaborations with these new funding partners, supporting opportunities to measurably fill evidence-gaps, and shifting focus to vulnerable populations and under-researched topics will ensure that future EOL PC science will continue to meet the challenges and needs of a changing and diverse society. Several areas to build momentum in EOL PC science include:

- **Create Opportunities for Public-Private Partnerships**. As the nation prepares for an aging and increasingly diverse population, the demand for high-quality EOL PC services will grow. No one sector alone can fund the scope of this need for evidenced-based research. Now, more than ever, public-private funding partnerships are needed to expand research into emerging areas. Opportunities to connect health funders in other fields are essential to effecting new research endeavors. Considerations of a public-private initiative could bring together stakeholders, including consumer-based organizations, in EOL PC science and create mechanisms to increase investments in research grants, support education and training, and foster new areas of research. Networks of researchers collaborating together should be supported.

- **Consolidate Stakeholders.** It will be important to establish an integrated, trans-federal strategy to increase attention to funding and the conduct of research that incorporates clinical treatments and organizational approaches to delivering EOL PC across disease types and treatment settings. Both within NIH and across federal agencies, a scoping exercise may bring all stakeholders together to review needs and identify new resource strategies to increase funding in EOL PC science.

- **Shift to New Areas of Research Emphasis**. While it is imperative to continue to support research in areas such as cancer, advance care planning, pain, or symptom management, the breadth of this science must also expand substantially and in measurable ways to areas of emphasis that align with changing demographics of serious advanced illness in the United States, including acknowledging the shifts in leading causes of death and the impact of chronic, complex conditions on illness and the dying process. Analysis of the data points to areas of underfunding. Much more needs to be done regarding investing in research due to variations in populations and geographic locations. Barriers to access—particularly in vulnerable populations, better standardized practices, education and training, quality outcomes, and evaluations of meaningful implementation across service sectors are important research areas that still need development.

- **Build Consensus in the Future Direction of EOL PC Science.** In recognition of the evolving nature of the field and the shift in population, a new Consensus Panel may guide focus on next steps in strengthening the direction of EOL PC science such as: identifying and harmonizing definitions, creating templates for training, supporting education and career development, considering ways to foster public-private initiatives, enlisting the support of collaborative partnerships, exploring application review processes, and creating a research agenda that will ensure the continued momentum needed to further evidence-based EOL PC. Part of this effort is to revisit conceptual models and frameworks to guide future research and to continue the progress that has already been recommended by the State-of-Science Consensus Panel to further develop agreement about common definitions and constructs as they relate to EOL PC research.

The findings from this review also point to a need to extend the scope of this research to other advanced and serious health conditions and diseases affecting Americans (e.g., advanced stroke, cardiac and respiratory diseases, dementias) and to expand the focus of EOL PC research to pediatric and geriatric populations. More attention must be given to research on topics that are increasingly relevant to this and future generations who will carry the burden of living longer lives, including new studies on the economics of EOL PC, addressing what it means to have better quality of life and satisfaction with this care, and expansion of quality care to other service delivery models and health care sectors. As the baby boom generation ages and struggles to address end-of-life-care needs, attention to care options, costs, and the personal impact of these decisions will continue to grow.

The information gathered through this review can serve to steer action and inform future funding and planning of EOL PC-related research and help strengthen collaborations among federal, private, and academic research agencies focused on advancing research on EOL PC. The *2004 State-of-the-Science Conference on Improving End-of-Life Care* was an opportunity for the research community to produce a thoughtful and coherent appraisal of the status of our research and, drawing upon leading experts, create a template for change. Since that time, the progress of research has been unquestionable and the significance of the scientific evidence compelling. Remarkable growth has occurred in the number of palliative and hospice programs throughout the United States; there are more and more individuals conversing about advance care planning; and there are new treatments and new programs of care in hospitals, communities, and homes. Hospice and palliative care improves quality of life and reduces health costs during the end of life. And, through research, important information has been aimed that dispels the myth that end-of-life care hastens death. Instead, the enormous significance of compassionate palliative care and the extra opportunities provided by hospice are recognized as an important time for families and patients to find solace and reach closure.

VII. CONCLUSION

The present review of the research literature on end-of-life and palliative care (EOL PC) adopted a comprehensive approach to determine how much progress was made in the field following the 1997 Institute of Medicine (IOM) *Approaching Death* report through 2010. Despite limitations, this review provides data to address the scope of topics within the EOL PC research literature and the relevance of collaborations between federal and nonfederal entities to ensure the advancement of the field, including its funding support. The results verify the unprecedented support of both the public and the private sectors to build and to strengthen EOL PC science. The research establishment has demonstrated leadership in bringing stakeholders together for workshops, symposia, and conferences that have created consensus on current knowledge and future research needs. Agencies and organizations have focused efforts on defining new areas of research to address the physiological mechanisms and treatment of symptoms, evaluate measures, and create new interventions. New clinical guidelines and standards of practice have emanated from this evidence base and have supported the growth of the field of palliative care and hospice, while the dissemination of this science has exponentially increased to provide the public with meaningful information on quality of care that is available to those who live with and die from advanced illnesses. Clearly, the state of the science has grown over the last 14 years, but much more needs to be done.

Almost a decade since the 2004 *State-of-the-Science* conference and more than 14 years since the 1997 IOM report on *Approaching Death*, there is great opportunity to create a new mandate to transform the next decade of the science of EOL PC. As the nation seeks to understand what it means to live well while approaching death, the imperative for research has not changed. There is much to learn, much to understand, and much to consider as we translate evidence into meaningful practice. Now, more than ever, science must align with the needs of the public and incorporate important aspects of the experience of serious, advanced illness into our research. The research agenda must connect to the individual and emphasize the inherent value in recognizing that persons and practice can, in many ways, inform research and substantiate the value of interventions. New initiatives must interlink public concerns with evidence-based solutions to realize that increased research requires a sufficient number of well-trained investigators, stronger infrastructures, organizational support, and public advocacy. Advance care planning, framed in public policy, must be appropriate across the range of cultures and populations within the nation and address unanswered questions regarding the capability of health technologies to improve advance care planning and communication.

Across all sectors, both public and private, momentum must be created by pooling knowledge and resources and by seeking creative solutions to educate and inform the public to raise awareness of this important area of science. New and creative programs must clearly articulate the value of such science and translate its importance to public health in terms of outcomes and resource utilization. Assessment tools must help health care professionals accurately evaluate pain and other co-morbid symptoms. The shift from a focus on cure to that of care redirects emphasis on the patient's needs in terms of compassion, comfort, healing, and respect for preferences of care.

Caregivers' needs also must be addressed so that they are confident in determining the changing needs of an ailing loved one and can be responsive to their care. Shifting family structures are changing the face of caregiving; disparities still exist; and the full potential of new pharmaceuticals, pain management strategies, or complementary and alternative medicines have not been fully realized to meet the needs for care in the context of limited resources. Chronic disease is changing the picture of mortality in America and creating an increased need for earlier and more comprehensive EOL PC programs for the aging population. Additionally, there is a clear need for continued attention to vulnerable populations, minorities, high-risk neonates, and children.

At a time in which there is enormous opportunity to improve the health of the American people through the merits and innovations of science, the findings of this report speak to a new and collaborative call-to-action to continue building EOL PC research. The science of EOL PC with its capacity to inform, educate, build better health services, and empower choices must not be overlooked. There is a national mandate to support this science and its high-quality and evidence-based outcomes that serve to engage the public in meaningful dialogue about what it means to live with and die from advanced illness. Shifting priorities, new practice standards, and evolving perceptions of the meaning of dying and its processes will continue to compel the need for continued research. As public and private organizations look to prioritize new initiatives, allocate resources, and seek new partnerships, it is important to recognize the significance of research and to create new momentum to support EOL PC science.

Appendix A: Steps to Identify and Review EOL PC Research Publications

STEP 1: Identification of search terms and development of strategies for each database to select relevant citations

NOVA Research Company (NOVA) worked with the National Institute of Nursing Research (NINR) to identify the main search terms for all databases. Consultants from an ad hoc evaluation ddvisory committee (EAC) provided input on search terms. In addition, existing reviews on end-of-life and palliative care (EOL PC) were reviewed to identify appropriate terms. These terms were expected to retrieve research articles with topics most relevant to EOL PC.

Step 1a. Identify main terms

Main terms used to retrieve relevant research publications related to EOL PC were:

- *palliative care*
- *end of life*
- *hospice*
- *advance directives*
- *advance care planning*

These terms were searched in the title and abstract fields of citations in all databases and, where applicable, specific fields (e.g., Medical Subject Headings [*MeSH]* terms, major *MeSH* terms).

Step 1b. Identify research publications

Publications considered "research"[16] were identified in all databases as follows:

- **Cochrane Database of Systematic Reviews (CDSR):** Only reviews were selected as a limiter for the search (protocols were excluded).
- **Cumulative *Index to Nursing and Allied Health Literature* (CINAHL):** Research articles were selected as a limiter[17] for the search.
- **PubMed®** and **Web of Science:** Additional search terms were used. The main search terms were combined with terms indicative of research (e.g., *qualitative, quantitative, clinical trials, evaluation*). These research terms were searched in titles and abstracts of citations.

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[16] A research study is one that uses any of the following methods or designs, or is referred to as: randomized controlled trials (RCTs), protocol studies, clinical trials, experimental research, non-experimental research, quasi-experimental studies, case-control studies, comparison group studies, descriptive studies, quantitative research, trend or time studies, qualitative research, focus groups, interviews, phenomenology, ethnographic research, case study research, grounded theory research, historical research, mixed or mixed-method research, participatory research, community-based research, and community-based participatory research.

[17] Most research databases allow the user to limit or filter the search to narrow the results. The search can be limited to specific dates, type of articles, ages, etc.

Step 1c. Set limiters

In addition to the main terms listed previously, all searches were limited to:

- *Journal articles*
- *Articles from 1997 through 2010*
- *Articles with abstracts*
- *Articles with human populations*
- *Articles printed in English*
- *Journal articles published in the United States*[18]

Step 1d. Develop search strategies

Search strategies differed among databases as follows:

- **PubMed®:** Separate searches were done for main terms, research terms, and limiters. These searches were then combined.
- **CINAHL:** Limiters had to be specified before the search.
- **CDSR** and **Web of Science:** Once the search was conducted, results were narrowed by the limiters.

A total of 7,085 citations were identified:

- 4,216 from PubMed®
- 2,661 from Web of Science
- 173 from CINAHL
- 35 from CDSR

All citations were downloaded into an *EndNote*[19] database. Duplicates were identified using an *EndNote* automatic feature that sorts the citations by year, author, and title. In total, 1,329 duplicate citations were identified and deleted from the sample; 5,756 citations remained after duplicates were deleted.

Results from searches and strategies used for each database, along with the number of citations from each search, are included in Appendix B.

A preliminary review of search results showed that the sample (*n*=5,756) still contained citations that needed to be excluded. Results included citations of studies that:

- Were published in 2011
- Had missing abstracts
- Included animal populations
- Were not conducted in the United States
- Were not research

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[18] This does not exclude U.S. journals published by non-U.S. companies.

[19] EndNote X4 version was used.

STEP 2: Identification and exclusion of citations from 2011 and those with missing abstracts

The E*ndNote* fields were sorted to identify citations from 2011 and those with missing abstracts. Seven citations from 2011 and 30 citations with no abstracts were identified and deleted from the sample.

Citation Year/Abstract (*n* = 5,756)	
2011/No abstract	*1997-2010*
37	5,719 (included in further analysis)

STEP 3: Identification and exclusion of citations with nonhuman populations

Several steps were taken to identify and exclude citations with nonhuman populations.

Step 3a. Search main fields using terms related to animals in research studies

A search of the title, abstract, and key word fields was conducted to identify citations with nonhuman populations. The terms used were *rat, rats, mouse, mice, animal, animals*.

Step 3b. Search main fields using the terms *human* or *humans*

Another search of the title, abstract, and key word fields was conducted to identify citations with human populations using the terms *human* or *humans*.

Step 3c. Combine previous searches

The two previous searches (Steps 3a and 3b) were then combined to identify those citations that included nonhuman terms, but not human terms. Using this process, seven citations were identified and deleted.

Human Populations (*n* = 5,719)	
No	*Yes*
7	5,712 (included in further analysis)

STEP 4: Identification and exclusion of studies not conducted in the U.S.[20]

Several steps were taken to identify studies that were not conducted in the United States.

Step 4a. Identify citations using terms indicative of U.S. locality

A search of the title, abstract, and key word fields was conducted to identify citations with terms that indicated U.S. locality. The terms used were:

US, USA, America, American, United States
Not: Latin America, Latin American, North America, North American, South America, South American[21]

Step 4b. Identify non-U.S. countries/regions

Two researchers independently reviewed the titles and key words of all citations to identify non-U.S. countries. Fifty-one countries/regions were identified. A search of the title, abstract, and key word fields that included the 51 countries/regions identified was then conducted.

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[20] Studies conducted in the United States could involve research with U.S.-born populations, immigrants, or foreigners in the United States.

[21] Although the U.S. is part of North America, "Not North America," was used to identify studies conducted in Canada or Mexico. If a study conducted in "North America" included populations living in the U.S., this study would have been identified and included in further review because the terms for U.S. locality: *"US," "USA," "America," "American,"* or *"United States*' would have selected it.

The countries identified were:

- *Africa*
- *Argentina*
- *Australia*
- *Austria*
- *Barbados*
- *Belgium*
- *Bosnia*
- *Brazil*
- *Canada*
- *China*
- *Colombia*
- *Costa Rica*
- *Cuba*
- *Czech Rep*
- *Denmark*
- *England*
- *Eritrea*
- *Europe*
- *France*
- *Germany*
- *Greece*
- *Hong Kong*
- *Hungary*
- *India*
- *Israel*
- *Italy*
- *Jamaica*
- *Japan*
- *Kenya*
- *Korea*
- *Mexico*
- *Netherlands*
- *New Zealand*
- *Norway*
- *Nova Scotia*
- *Peru*
- *Saudi Arabia*
- *Scotland*
- *Singapore*
- *South Africa*
- *Spain*
- *Sweden*
- *Taiwan*
- *Tanzania*
- *Thailand*
- *Trinidad*
- *Turkey*
- *Uganda*
- *United Kingdom*
- *Vietnam*
- *Zimbabwe*

Step 4c. Combine previous searches

The two previous searches (Steps 4a and 4b) were then combined, and 1,722 citations that were included in the non-U.S. countries/regions search and not included in the U.S. locality search were identified and excluded. To verify that the excluded citations were studies conducted outside of the United States, a set of 20 citations was randomly selected and reviewed. All of the citations were studies conducted in non-U.S. countries/regions.

Studies Conducted in the U.S. (*n* = 5,712)	
No	*Yes*
1,722	3,990 (included for next step of analysis)

STEP 5: Identification of research studies

A set of research-related terms was used to identify research studies. Research-related terms used are listed below.[22]

- *analyses*
- *analysis*
- *database*
- *evaluate*
- *method*
- *predictor*
- *research*
- *study*
- *case*
- *focus group*
- *interview*
- *observation*
- *questionnaire*
- *secondary analyses*
- *secondary analysis*
- *results*
- *cross-sectional*
- *dyad*
- *literature review*
- *longitudinal*
- *meta analyses*
- *meta analysis*
- *psychometric*
- *retrospective*
- *clinical trial*
- *cohort*
- *control group*
- *randomization*
- *randomize*
- *survey*
- *efficacy*
- *scale*

Citations that had none of these research-related terms in the title, abstract, or key word fields were excluded. Eighty citations did not meet the criteria to be considered research and were excluded. Ten of these citations were randomly selected and verified to make sure they were correctly classified as nonresearch; all were correctly classified as nonresearch-related citations.

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[22] Plural spellings of these terms were also included because they resulted in additional citations.

Research (*n* = 3,990)	
No	*Yes*
80	3,910 (included for further next level of analysis)

STEP 6: Identification of terms to code nonbibliographic variables using *EndNote*

NOVA and NINR, with input from the EAC, had previously identified the study variables of interest and related categories within variables (e.g., Variable: sex; Categories: male, female). These variables can be found in the Data Abstraction Tables in Appendix C and include both bibliographic variables—which were part of the reference citations—and nonbibliographic variables. Nonbibliographic variables of interest for the study were:

- *Study type*
- *Age*
- *Sex/gender*
- *Race/ethnicity*
- *EOL PC study topic*
- *EOL PC condition or disease*
- *Funding received*

NOVA researchers identified and piloted terms to code the data into the nonbibliographic variables and corresponding categories of interest. The following steps outline the process by which these terms were determined.[23] This process was done independently by two researchers, using *EndNote*.

1. A preliminary list of potential search terms was created for each variable and related category.
2. All terms from the list were searched in the title, abstract, and key word fields of all citations. Terms were searched one by one and in a consecutive manner. If other relevant terms were identified during the search, these were added to the list.
3. A term was kept if two conditions were satisfied: (a) it identified a minimum of 20 citations related to the variable, and (b) it was still able to independently identify a minimum of 20 relevant citations when other terms were added to the search.

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[23] This process only involved the identification and selection of terms that were later used to code data into the nonbibliographic variables of interest (Step 7). No coding of the data was performed during this step.

An example to illustrate the steps followed is included below.

Example: The variable “EOL PC Condition” includes a category for HIV/AIDS.

1. A preliminary list of potential search terms relevant to HIV/AIDS was created and included the following terms:
    - *HIV*
    - *AIDS*
    - *HIV/AIDS*
    - *Acquired Immunodeficiency Syndrome*
    - *Human Immunodeficiency Disease*
2. Each term from the list above was used to search the title, key word, and abstract fields for all citations. The first term searched was *HIV*.
    a. Results from the search with *HIV* were reviewed to ensure that the identified citations were indeed related to HIV/AIDS and that at least 20 relevant citations were identified.

    The second term searched was *AIDS*. The process was repeated for each term in the list.

    A term that failed to identify at least 20 relevant citations was dropped from the list (not included in step b). The terms that made the list from this step included:
    - *HIV*
    - *AIDS*
    - *HIV/AIDS*
    - *Acquired Immunodeficiency Syndrome*

    b. The searches performed in step a were then combined to select those terms that when added to the others were able to additionally identify at least 20 relevant citations.

    When the term *AIDS* was added to the search with the term *HIV*, a substantial increase in relevant citations occurred (more than 20). Both terms were kept.

    Next, a search with the third term, *HIV/AIDS*, was added to the other two searches (*HIV* and *AIDS*) and results were reviewed. The same process was repeated with the term *Acquired Immunodeficiency Syndrome*. The terms selected for the condition HIV/AIDS were:
    - *HIV*
    - *AIDS*
    - *Acquired Immunodeficiency Syndrome*

1) Two researchers implemented these steps independently to ensure that main terms describing a given variable/topic category were considered. Once the researchers completed their independent searches, the results were compared for accuracy and a final decision made about acceptance for term use. A term for a given variable was retained when both researchers independently identified the same term. For terms identified by only one researcher, each term was added to the search (with the previous terms) and retained as a term only if it identified an additional set of 20 relevant publications.

This process was completed for all nonbibliographic variables and related categories. Multiple consultations, revisions, and refinements of terms in the Data Dictionary in Appendix D occurred to verify the terms and definitions that most accurately reflected the variables of interest and related categories. All terms tested and selected are listed in the Data Dictionary in Appendix D.

The next step involved coding of the dataset for the non-bibliographic variables using the terms identified in this step.

STEP 7: Exportation of database into FileMaker to code publication variables

All publications in the *EndNote* database were exported into an *Excel* file and imported into a *FileMaker*[24] database to organize the publications based on the selected variable terms (Appendix B) and permit automatic coding of all additional non-bibliographic variables. Fields were created in the *FileMaker* database for each variable term and the corresponding topic categories. The data on the publication bibliographic variable terms were automatically uploaded into the *FileMaker* database.

Step 7a. Code non-bibliographic variables

Variable terms identified in Step 6 were used to code the research publications. Nonbibliographic variable terms were searched in the publication title, abstract, and when available, key word fields. If a given variable term was present in any of these fields, that publication was automatically assigned the corresponding code. For example, if a search found 300 publications containing key words related to *experimental study*, a value of "1" was automatically and simultaneously entered into the appropriate variable field for all 300 publications.

Step 7b. Verify accuracy of coding

Thirty-five research publications were randomly selected and manually reviewed to examine the extent to which the publications were appropriately coded for topic terms and category variables.

Coding for the category variables "*age*," "*sex*," "*race/ethnicity*," and "*EOL PC condition*" was relatively accurate, followed in accuracy for variables within the category "*study type*."

However, miscoding was identified for the category variable "*EOL PC topic*." Errors resulted because the automatic coding for *EOL PC topic* was determined by all topic terms found in the fields (title, abstract, or key word) without discrimination regarding the main focus of the study. For example, a research publication with the main focus on patients' advance directives for treatment based on interview data of families of recently deceased patients was automatically coded as several category topics: *advance care planning, caregivers, bereavement*, and *communication*. Despite the accuracy of automatic coding for other category variables, the main EOL PC topic theme of this research publication as described in the publications' abstract should have been coded for the theme of *advance care planning*.

The potential for miscoding errors was therefore reduced by instituting an additional procedure into the review process. Individual reviews of the published literature publications for the topic categories "*study type*" and "*EOL PC topic*" were added with set procedures established to minimize coding errors in these two areas. These procedures are described in Steps 8 and 9.

STEP 8: Coding for the category variable "*study type*"

Study type was the only variable that was mutually exclusive, meaning that a publication must have only one coded category (i.e., one code for analytic review, qualitative, experimental, psychometric, other quantitative/non-experimental, mixed methods, or action research).

STEP 9: Coding for variable "*EOL PC topic*"

To reduce coding errors of variables for the category "*EOL PC topic*," a manual review of the title, abstract, and key word fields was conducted for the entire dataset of research publications. Four coders were trained on EOL PC topic category definitions prior to individual coding using the following methods:

Step 9a. *EOL PC Topic* coding training

- All coders had experience with coding methods and had professional research expertise in health science fields (e.g., public health, research in health topics, health care system); two researchers had doctorates; two had Master's degrees.

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[24] FileMaker Pro version 9.0v3, FileMaker, Inc., copyright 1984-2007.

- Four hours of training related to coding topic areas in EOL PC was conducted by the Project Coordinator and Project Manager. The training objectives were to ensure understanding of the purpose of the EOL PC needs assessment, review and discuss the list of EOL PC topics and identification of main study topic(s), review procedures to monitor and document changes made in the database, and establish adequate inter-rater reliability.
- Coders engaged in reviews of EOL PC topic coding of randomly selected publications. This “hands-on” approach was useful in ensuring understanding of EOL PC topic content and boundaries of EOL PC topic definitions and served as practice in identifying the main focus of the research publication. The training also provided an opportunity to clarify identification of the topic of the publication, resolve misunderstandings, and provide guidance when topic content overlapped. In addition, procedures to monitor and document changes were also revised and refined with the group. Further refinements in the Data Dictionary were done as a result.

Step 9b. Inter-rater reliability

Inter-rater reliability was assessed at several points during and after the training. The average reliability coefficient achieved by coders working in groups of two was R=0.75 (75%). All coders were trained until this reliability level was individually achieved. This low correlation among coders occurred when multiple topics were identified, undecided, or could not be coded for the topic variables listed. A further procedure was introduced to circumvent these errors and retain quality assurance of coding data.

STEP 10: Quality assurance

Additional procedures were established to ensure the accuracy of EOL PC *topic* category coding.

Step 10a. Decision-Matrix Coding of “Other” and “Undecided” EOL PC Topics

The low inter-rater reliability in coding the variable of *EOL PC topic* presented a number of issues (e.g., potential for multiple topics, agreement of topic category variable). Consultations among coders and NINR expert staff were conducted to further assist with coding clarification. A decision-matrix was then determined for review and coding of these areas that included:

Coding of the *EOL PC topic* was based on information derived from the publication title and the abstract description of publication purpose and objectives.

When the *EOL PC topic* of a publication was not included in the list of *EOL PC topics*, the publication was coded as “other” and then re-reviewed by the Program Manager for final coding assignment.

When the *EOL PC topic* of the publication was unclear, the publication was coded initially as “undecided” and reviewed further for coding determination.

- The Project Manager was responsible for reviewing, refining when required, and determining the final coding of *EOL PC topics* for all *“other”* and *“undecided”* publications.

Step 10b. Coding of “*other*” or “*undecided*” *EOL PC Topic*

All publications coded as “*other*” and “*undecided* “for EOLPC *topic* were reviewed by the Project Manager to determine the final code. In some circumstances, the topic theme did not match category variables in the initial Data Dictionary. In these circumstances, the addition of a new category was discussed with NINR expert staff and, when appropriate, added to the original list (see full list of “Other” topic descriptions in Appendix D: Data Dictionary, *EOL PC Topic*).

Step 10d. Verify final exclusion of “excluded” publications

Publication exclusion was based on *a priori* criteria, for instance., that the publications on review were non-research, were not conducted in the United States, or did not involve EOL PC research. A total of 755 publications of the 3,910 publications did not meet the second-tier independent review of the inclusion criterion for EOL PC research publications. These publications were thus excluded from the final publication dataset (*n*=3, 155).

Research (*n* = 3,910)	
No	*Yes*
755	3,155

STEP 11: Identification and abstraction of funding information

The review of the literature also sought to obtain information on funding sources for research publications. Funding-related study variables collected from the literature review dataset included whether funding was reported, funding source(s), grant number(s), and grant title(s). Funding information accrued from the review of research publications was abstracted from the *EndNote* "notes" field.

Step 11a. Use search terms to identify funded publications

The following terms were used to search in the notes field to identify publications that reported funding for the published study:[25]

- *research support*
- *fund*
- *award*
- *fellowship*
- *scholarship*

In total, 1,287 citations were identified as having been funded. These citations were further reviewed to abstract funding information.

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[25] PubMed® and Web of Science are the only databases used in this study that provide funding information. Funding information is exported into the *EndNotes* notes field. PubMed® provides funding information on the grant number, grant code, and name of the federal agency providing the funds. Web of Science includes the text of the article acknowledging the funding source. CINAHL and CDSR do not provide any funding-related information.

Funded Citations (*n* = 3,155)	
*No**	*Yes*
1,868	1,287 (included in further analysis to abstract funding information)

*Citations that received funding may still have been included in this group because classification of funding receipt was based on searches in the notes field only. For example, funding information for citations that were identified only in the CINAHL and CDSR databases is unknown because these databases do not provide this information. In addition, funding information is sometimes included in other sections of a citation (e.g., in acknowledgements, below abstract, at end of text).

Step 11b. Abstract funding information from notes field

Funding information was then abstracted from the notes field. The information abstracted included funding source (name of funder), grant number (available for federal grants only), and grant title (if available). Funding information on these variables was available for 295 citations. The remaining 992 citations did not have all of the required funding information in the notes field; therefore, NOVA accessed the full text online to obtain the necessary information.

Step 11c. Abstract funding information from full-text versions available online

Each citation with incomplete funding information (*n*=992) was accessed online to abstract the information from the full-text version of the article. Often, funding-related information was found in the acknowledgements section of the article, below the abstract, or at the end of the article text. Additional funding information was found for 963 citations.

Funded Studies (*n* = 1,287)	
Funding information NOT found	*Funding information found*
29	1,258

Of the entire sample of 3,155, funding information was not found for 60% (1,897) of the citations.

Appendix B: Search Terms and Strategies Used

Table a: PUBMED® SEARCH STRATEGY

1. EOL PC Terms: advance care planning, advance directives, palliative care, palliative, hospice care, hospices, end of life, end-of-life

Search String: ("advance care planning"[MeSH Terms] OR "advance care planning"[Title/Abstract]) OR ("advance directives"[MeSH Terms] OR "advance directive*"[Title/Abstract]) OR ("palliative care"[MeSH Terms] OR "palliative care"[Title/Abstract]) OR palliative[Title/Abstract] OR ("hospice care"[MeSH Terms] OR "hospice care"[Title/Abstract]) OR ("hospices"[MeSH Terms] OR "hospice*"[Title/Abstract]) OR ("end of life"[Title/Abstract] OR "end-of-life"[Title/Abstract])

HITS: 64,102

2. Research-Related Terms: qualitative, quantitative, mixed method, ethnographic, case control, case series, case study, comparison group, control group, systematic review, literature review, meta-analysis, cohort, focus group, interview, psychometric, randomized, randomization, secondary analysis, participatory research, scale, survey, questionnaire, experiment*, cross-sectional, longitudinal, correlational, protocol study, descriptive study, trend study, trend analysis, time study, time analysis, phenomenolog*, grounded theory, community-based research

Search String: qualitative[Title/Abstract] OR quantitative[Title/Abstract] OR "mixed method*"[Title/Abstract] OR "ethnographic research"[Title/Abstract] OR "ethnographic study"[Title/Abstract] OR "ethnographic studies"[Title/Abstract] OR "case control"[Title/Abstract] OR "case series" [Title/Abstract] OR "case study"[Title/Abstract] OR "case studies"[Title/Abstract] OR "comparison group*"[Title/Abstract] OR "control group*" [Title/Abstract] OR "systematic review*"[Title/Abstract] OR "literature review*" [Title/Abstract] OR meta-analysis[Title/Abstract] OR meta-analyses[Title/Abstract] OR cohort*[Title/Abstract] OR "focus group*"[Title/Abstract] OR interview*[Title/Abstract] OR psychometric*[Title/Abstract] OR randomized[Title/Abstract] OR "randomization"[Title/Abstract] OR "secondary analysis"[Title/Abstract] OR "secondary analyses"[Title/Abstract] OR "participatory research"[Title/Abstract] OR scale*[Title/Abstract] OR "survey*" [Title/Abstract] OR questionnaire*[Title/Abstract] OR experiment*[Title/Abstract] OR cross-sectional[Title/Abstract] OR longitudinal[Title/Abstract] OR correlational [Title/Abstract] OR "protocol study"[Title/Abstract] OR "protocol studies"[Title/Abstract] OR "descriptive study"[Title/Abstract] OR "descriptive studies"[Title/Abstract] OR "trend study"[Title/Abstract] OR "trend studies"[Title/Abstract] OR "trend analysis"[Title/Abstract] OR "trend analyses"[Title/Abstract] OR "time study"[Title/Abstract] OR "time studies"[Title/Abstract] OR "time analysis"[Title/Abstract] OR "time analyses"[Title/Abstract] OR phenomenolog*[Title/Abstract] OR "grounded theory"[Title/Abstract] OR "community-based research"[Title/Abstract]

HITS: 3,017,737

3. Limits: only items with abstracts, Humans, Clinical Trial, Meta-Analysis, Randomized Controlled Trial, Clinical Trial, Phase I, Clinical Trial, Phase II, Clinical Trial, Phase III, Clinical Trial, Phase IV, Comparative Study, Controlled Clinical Trial, Evaluation Studies, Journal Article, Multicenter Study, English, Publication Date from 1997 to 2010

Search String: has abstract[text] AND "humans"[MeSH Terms] AND "United States" [PL] AND (Clinical Trial[ptyp] OR Meta-Analysis[ptyp] OR Randomized Controlled Trial[ptyp] OR Clinical Trial, Phase I[ptyp] OR Clinical Trial, Phase II[ptyp] OR Clinical Trial, Phase III[ptyp] OR Clinical Trial, Phase IV[ptyp] OR Comparative Study[ptyp] OR Controlled Clinical Trial[ptyp] OR Evaluation Studies[ptyp] OR Journal Article[ptyp] OR Multicenter Study[ptyp]) AND English[lang] AND ("1997"[PDAT] : "2010"[PDAT])

HITS: 1,904,060

4. #1 AND #2 AND #3
TOTAL: 4,216

Table b: CINAHL SEARCH STRATEGY

EOL PC Terms: advance directive, advance care planning, palliative care, end of life, end-of-life, hospice

Search String[26]**:** "advance directive*"[TI] OR "advance directive*"[AB] OR "advance care planning"[TI] OR "advance care planning"[AB] OR "palliative care"[TI] OR "palliative care"[AB] OR "end of life"[TI] OR "end of life"[AB] OR "end-of-life"[TI] OR "end-of-life"[AB] OR hospice*[TI] OR hospice*[AB]

Limits: Abstract Available, 1997-2010, English Language Research Article, Exclude Medline Records, Human, Publication Type: Journal Article, Peer Reviewed, Journal Subset: USA

TOTAL: 173

Table c: COCHRANE DATABASE OF SYSTEMATIC REVIEWS SEARCH STRATEGY

EOL PC Terms: advance directive, advance care planning, palliative care, end of life, end-of-life, hospice

Search String: "advance directive*"[Title/Abstract/Keyword] OR "advance care planning"[Title/Abstract/Keyword] OR "palliative care"[Title/Abstract/Keyword] OR "end of life"[Title/Abstract/Keyword] OR "end-of-life" [Title/Abstract/Keyword] OR hospice*[Title/Abstract/Keyword]

Limiters: 1997-2010

TOTAL: 35

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[26] TI = Title, AB = Abstract

Table d: WEB OF SCIENCE SEARCH STRATEGY

1. EOL PC Terms: advance directive, advance care planning, palliative care, end of life, end-of-life, hospice
Search String[27]: TS=("advance directive*" OR "advance care planning" OR "palliative care" OR "end of life" OR "end-of-life" OR hospice*) AND Language=(English) AND Document Type=(Article)
HITS: 9,602

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2. Research-Related Terms[28]**:** qualitative, quantitative, mixed method, ethnographic, case control, case series, case study, comparison group, control group, systematic review, literature review, meta-analysis, cohort, focus group, interview, psychometric, randomized, secondary analysis, participatory research, scale, survey, questionnaire, experiment*, cross-sectional, longitudinal, correlational, protocol study, descriptive study, trend study, trend analysis, time study, time analysis, phenomenolog*, grounded theory, community based research
Search String: TS=(qualitative OR quantitative OR "mixed method*" OR "ethnographic research" OR "ethnographic study" OR "ethnographic studies" OR "case control" OR "case series" OR "case study" OR "case studies" OR "comparison group*" OR "control group*" OR "systematic review*" OR "literature review*" OR meta-analysis OR meta-analyses OR cohort* OR "focus group*" OR interview* OR psychometric* OR randomized OR randomization OR "secondary analysis" OR "secondary analyses" OR "participatory research" OR scale* OR survey* OR questionnaire* OR "experiment*" OR "cross sectional" OR longitudinal OR correlational OR "protocol study" OR "protocol studies" OR "descriptive study" OR "descriptive studies" OR "trend study" OR "trend studies" OR "trend analysis" OR "trend analyses" OR "time study" OR "time studies" OR "time analysis" OR "time analyses" OR phenomenolog* OR "grounded theory" OR "community based research") AND Language=(English) AND Document Type=(Article)
HITS: >100,000

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3. #1 AND #2
HITS: 6,380

Refined By: English, Publication Type: Article, 1997-2010, Place of Publication: US, Subject Areas Excluded: Engineering, Physics, Computer Science, Law, Astronomy, Mathematics, Genetics, Microbiology, Business, History, Environment, Food Science, Sports Science, Meteorology, Dentistry
Search String: Refined by: Countries/Territories=(USA) AND Document Type=(ARTICLE) AND Publication Years=(2010 OR 2007 OR 2001 OR 1998 OR 2008 OR 2005 OR 2002 OR 1997 OR 2009 OR 2004 OR 2000 OR 2006 OR 2003 OR 1999) AND [excluding] Subject Areas=(STATISTICS & PROBABILITY OR ENGINEERING, MECHANICAL OR PHYSICS, APPLIED OR COMPUTER SCIENCE, INTERDISCIPLINARY APPLICATIONS OR AUTOMATION & CONTROL SYSTEMS OR BUSINESS OR OPERATIONS RESEARCH & MANAGEMENT SCIENCE OR TRANSPLANTATION OR ENGINEERING, INDUSTRIAL OR MATHEMATICAL & COMPUTATIONAL BIOLOGY OR MEDICAL LABORATORY TECHNOLOGY OR COMPUTER SCIENCE, INFORMATION SYSTEMS OR ELECTROCHEMISTRY OR ENGINEERING, AEROSPACE OR ENGINEERING, ELECTRICAL & ELECTRONIC OR ENGINEERING, CIVIL OR GENETICS & HEREDITY OR MINING & MINERAL PROCESSING OR HISTORY & PHILOSOPHY OF SCIENCE OR NUCLEAR SCIENCE & TECHNOLOGY OR ENERGY & FUELS OR OTORHINOLARYNGOLOGY OR ROBOTICS OR VETERINARY SCIENCES OR ASTRONOMY & ASTROPHYSICS OR COMPUTER SCIENCE, HARDWARE & ARCHITECTURE OR MANAGEMENT OR MATERIALS SCIENCE, MULTIDISCIPLINARY OR ERGONOMICS) AND [excluding] Subject Areas=(METEOROLOGY & ATMOSPHERIC SCIENCES OR MICROBIOLOGY OR REPRODUCTIVE BIOLOGY OR BIOLOGY OR CELL BIOLOGY OR CHEMISTRY, ANALYTICAL OR CRIMINOLOGY & PENOLOGY OR ECOLOGY OR ENGINEERING, BIOMEDICAL OR ENGINEERING, CHEMICAL OR ENGINEERING, MULTIDISCIPLINARY OR FOOD SCIENCE & TECHNOLOGY OR INTERNATIONAL RELATIONS OR MATHEMATICS, INTERDISCIPLINARY APPLICATIONS OR PHYSICS, FLUIDS & PLASMAS OR PHYSICS, NUCLEAR OR POLYMER SCIENCE OR SOCIAL SCIENCES, MATHEMATICAL METHODS OR VIROLOGY) AND [excluding] Subject Areas=(ENGINEERING, MANUFACTURING OR SPORT SCIENCES) AND [excluding] Subject Areas=(ENVIRONMENTAL STUDIES OR DENTISTRY, ORAL SURGERY & MEDICINE)

TOTAL: 2,661

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[27] TS= Topic Search. A topic search in Web of Science includes the title, abstract, and keyword fields.

[28] These are the same research-related text terms that were used in the PubMed® search.

Appendix C: Data Abstraction Tables

General description of citation

Year	Title	Abstract	Authors	Author Affiliation	Journal	Volume	Issue	Pages	Key words

Funding Information

Research Notes	Funding received	Funding source	Grant number	Grant title
This field contains information on funding for published article	Yes No			

Characteristics of Study Population, Type of Study, and Focus of Study

Age	Sex	Race/ Ethnicity	Study Type (mutually exclusive)	EOL PC Topic	EOL PC Condition
• Children • Adult Non-elderly • Adult Elderly	• Male • Female	• White/Non-Hispanic • African American/ Non-Hispanic • Hispanic/Latino • Other	• Analytic Review • Qualitative • Experimental • Psychometric • Other Quantitative/ Non-Experimental • Mixed Methods • Action Research	• Bereavement & Grief • Caregivers • Communication • Education & Training • Social, Emotional, Mental Health • Advance Care Planning • Ethics • Care • Hospice • Service Delivery Models • Economics • Pain, Symptoms, Symptom Management • Alternative Medicine • Religion & Spirituality • Culture • Quality of Care • Other:________	• Alzheimer's • Cancer • COPD • Heart Conditions • HIV/AIDS • Kidney Conditions • Liver Conditions • Musculoskeletal Conditions • Respiratory Conditions • Neurodegenerative Conditions • Other:__________

Appendix D: Data Dictionary

VARIABLES	CATEGORIES[29]	DESCRIPTIONS	SEARCH TERMS
Year	--------------	--------------	--------------
Title	--------------	--------------	--------------
Abstract	--------------	--------------	--------------
All Authors	--------------	--------------	--------------
1st Author Affiliation	--------------	This is the first affiliation that is provided by the specific databases from which the citations were downloaded	--------------
Journal	--------------	--------------	--------------
Volume	--------------	--------------	--------------
Issue	--------------	--------------	--------------
Pages	--------------	--------------	--------------
Key words	--------------	--------------	--------------
Notes	--------------	This field contains information related to funding and may include: type of organization (federal, nonfederal), name of funding organization, and grant numbers associated with the study and/or the authors of the study, and grant, award, and fellowship titles associated with the study and/or the authors of the study	• research support • fund • award • fellowship • scholarship
Funding Source(s)	--------------	Names of all organizations, awards, fellowships, and scholarships listed as sources of funding for the study and/or the authors of the study	
Grant Number	--------------	Federal grant numbers associated with the study and/or the authors of the study	
Grant Title	--------------	Title of the grant (may not always be available)	

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[29] Unless otherwise noted, these categories are not mutually exclusive. Each citation may be coded for more than one category.

VARIABLES	CATEGORIES[29]	DESCRIPTIONS	SEARCH TERMS
Study Type[30,31]	Analytic Review	Studies that use methods to combine the results of independent studies, including: • meta-analyses • systematic reviews • syntheses of summaries • does not include reviews of literature, narrative reviews	● literature review ● systematic review ● meta-analysis *Also tested*[32]: analytic review, syntheses of summaries
	Qualitative Study ONLY	Studies that use only qualitative approaches, methods, or design such as: • qualitative research • focus groups • interviews • phenomenology • ethnographic research • case study research • grounded theory research • historical research	● qualitative ● interview ● focus group ● phenomenon ● historical ● case study *Also tested*: ethnographic, grounded theory, content analysis
	Experimental Study (Quantitative)	Studies that often determine cause and effect or the effectiveness of programs, systems, or interventions; often have a control, comparison, or placebo group; and may or may not have random assignment Some keywords: ● randomized control trials (RCTs) ● protocol studies ● clinical trials	● random ● clinical trials ● experiment ● control group *Also tested*: pre post, protocol studies, quasi, trial, quasi-experimental, comparison group, field experiment, twin studies

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[30] Categories for Study Type are mutually exclusive, which means each citation can only be classified under one category.

[31] Selection and definitions of these EOL PC topics are based on the following references:
Creswell JW (2002). Research design: Qualitative, quantitative, and mixed method approaches. Thousand Oaks: Sage Publications.
Explorable (2008).
Feuer MJ, Towne L, and Shavelson RJ (2002). National Research Council Committee on Scientific Principles for Education Research. Scientific Culture and Educational Research. Washington, DC: National Academies Press. *Educational Researcher*, 31(8):4-14.
Myers M (2000). Qualitative research and the generalizability question: Standing firm with Proteus. *The Qualitative Report, 4*(3/4).
McLean JE (1995). Improving education through action research: A guide for administrators and teachers. Thousand Oaks, CA: Corwin Press, Inc.
McMillan JH (1999). Educational research: Fundamentals for the consumer (3rd Ed.). Reading, MA: Addison-Wesley.
O'Brien K (n. d.). Research paradigms. Latrobe University.

[32] The terms under *Also Tested* were excluded because they either did not identify additional citations already captured by the selected terms or they resulted in irrelevant citations.

VARIABLES	CATEGORIES[29]	DESCRIPTIONS	SEARCH TERMS
		• experimental research • quasi-experimental study (e.g., non-random assignment) • comparison group studies (e.g., studies that compare drugs and do not have a control group) • field experiment • twin studies • control group	
	Other Quantitative/Non-experimental	Quantitative studies that are not qualitative studies AND are not experimental studies Examples include: • descriptive studies • non-experimental research • case-control studies • quantitative research • trend or time studies • case series • cross-sectional • cohort • secondary analysis • longitudinal • correlational	• quantitative • cohort • case-control • cross-sectional • secondary analysis • case series • longitudinal • correlational • survey • questionnaire • p= , p = • p<, p < • prospective • retrospective NOT • randomized • clinical trials • experiment • control group *<u>Also tested</u>*: descriptive study, non-experimental, trend or time studies, case control, survey
	Mixed-methods Study	A study that uses BOTH qualitative and quantitative methods of data collection	
	Psychometric Study	Studies to develop, pilot, or replicate instruments, scales, or measures related to EOL PC	• psychometric • factor analysis *<u>Also tested</u>*: scale development, test a measure, scale, measure, index, instrument
	Action Research	Research in which the community or population is involved in the approach, method, or design of the study: • participatory research • community-based research • community-based participatory research	• action research • participatory research *<u>Also tested:</u>* community based research, community research
Age	Children	Newborns to 17	• child • infant • pediatric

VARIABLES	CATEGORIES[29]	DESCRIPTIONS	SEARCH TERMS
			• adolescent *Also tested*: newborn, pregnant, teen, tween, teenager, baby, neonatal, kid
	Adult Non-elderly	Persons 18 to 64	• middle age
	Adult Elderly	Persons 65 or older	• elder • 80 and over • 65 or older
	Adult Unspecified	Adult persons for which the specific age range for the adult period is unknown/not specified in the title, abstract, or key words	• adult • senior citizen • aged • geriatric • NOT Elderly • NOT Non-elderly
Sex	Male	----------------	• male (Matched)[33] • men (Matched) • man (Matched) *Also tested*: boy
	Female	----------------	• female • woman • women *Also tested*: girl
Race/Ethnicity[34]	White/Non-Hispanic	A person having origins in any of the original peoples of Europe, the Middle East, or North Africa	• White • Caucasian • European American *Also tested*: Middle Eastern, North African
	African American/ Non-Hispanic	A person having origins in any of the black racial groups of Africa	• African • Black *Also tested*: African American

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[33] Matched terms are searched as whole words with no variation in spelling, prefixes, or suffixes.

[34] Definitions were taken from the 1997 Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity, referenced in the 2010 US Census Bureau Report.

VARIABLES	CATEGORIES[29]	DESCRIPTIONS	SEARCH TERMS
	Hispanic/Latino	A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race	• Latino • Hispanic • Mexican • Puerto • Spanish *Also tested*: Chican, Latina, Cuban, Latin
	Asian American	A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent	• Asian (Matched) • Chinese • Japanese • Korean • Filipino *Also tested*: Vietnamese, Hmong
	American Indian/Alaskan Native	A person having origins in any of the original peoples of North and South America (including Central America) and who maintain tribal affiliation	• American Indian • tribe *Also tested*: Alaskan, Native American, native
	Pacific Islander/Native Hawaiian	A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands	• Pacific Islander • Caribbean • Hawaii *Also tested*: Samoa, Guam
EOL PC Topic[35,36,37]	Bereavement & Grief	Topics related to the bereavement and grief process of EOL PC patients, families, and caregivers (including health care professionals) (Bereavement or grief must be related to the dying or death of an EOL PC patient.) Example: Bereavement services for family caregivers: How often used, why, and why not?	• bereave • grief *Also tested*: mourn, loss

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[35] Topic must be the main focus of the study, primarily determined from a review of the title and purpose/objective of the study (per agreement with NINR, 04/20).

[36] Selection and definitions of these EOL PC topics are based on the following references:

Hui D, Parsons HA, Damani S, et al. (2011). Quantity, design, and scope of the palliative oncology literature. *The Oncologist*, 16, 694-703.

Lorenz K, Lynn J, Morton SC, et al. (2004). End-of-Life Care and Outcomes. Evidence Report/Technology Assessment No. 110. (Prepared by the Southern California Evidence-based Practice Center, under Contract No. 290-02-0003.) AHRQ Publication No. 05-E004-2. Rockville, MD: Agency for Healthcare Research and Quality. http://www.ncbi.nlm.nih.gov/books/NBK37517/

Lorenz KA, Lynn J, Morton SC, et al. (2005). Methodological approaches for a systematic review of end-of-life care. *Journal of Palliat Med, 8*(1), S4-S11.

Institute of Medicine (1997). Approaching Death: Improving Care at the End of Life. Committee on Care at the End of Life, Field MJ and Cassel CK (Eds.). Division of Health Care Services, Washington, DC: The National Academies Press.

Schaub N., and Hagen P. (2009). Palliative Care Grantmaking Toolkit.

[37] The examples provided in the Descriptions section are actual titles of publications from the EOL PC literature search.

VARIABLES	CATEGORIES[29]	DESCRIPTIONS	SEARCH TERMS
	Social, Emotional, & Mental Health	Topics related to social, emotional, and psychological concerns or needs of EOL PC patients, families of EOL PC patients, or health professionals who work in EOL PC settings Example: Depression among surviving caregivers: Does length of hospice enrollment matters? Impact of treatment for depression on desire for hastened death in patients with advanced HIV/AIDS. Impact of protocol on nurses' role stress: A longitudinal perspective.	• emotion • coping • social support • stress • well-being • mental health • psychiatric • anxiety • depression • counseling • adaptation, psychological • burden *<u>Also tested</u>:* family support, transition, adaptation, support group, mental illness, caregiver support, therapy
	Caregivers	Topics related to stress/burdens, barriers, physical demands, skills, or cost of expenses experienced by caregivers as they provide end-of-life care to patients Caregivers include: • family and friends of EOL PC patients (including spouses and parents) • health professionals and health care volunteers • clergy Example: Strain experienced by caregivers of dementia patients receiving palliative care: Findings from the Palliative Excellence in Alzheimer Care Efforts (PEACE) Program.	• caregiving • family • friend • parent • physician • social worker • nurse • doctor • health professional • health personnel *<u>Also tested</u>:* CNA, home aide
	Communication	Topics related to communication about the health of the EOL PC patient; can include strategies to communicate and best practices for communication (Communication can be between the patient and health professionals, between the patient and the family, OR between health care professionals about the patient.) Example: Best practices in communication among physicians, patients, and family caregivers?	• communicate • conversation *<u>Also tested</u>:* relationship, interaction, dyad, information
	Education & Training	Topics related to the education and training of *health care professionals only* about EOL PC; does not include education of family, relatives, other caregivers Example: Interdisciplinary education: Evaluation of a palliative care training intervention for pre-professionals.	• curricula • student • medical education • training • nursing education *<u>Also tested</u>:* medical school, residents, education, teach

VARIABLES	CATEGORIES[29]	DESCRIPTIONS	SEARCH TERMS
	Advance Care Planning	Topics related to formal OR informal, verbal OR written agreements regarding treatment, care, or advance directives between patients and their families, surrogates, and health care professionals Advance Care Planning includes: a) Advance directives: legal documents that convey EOL PC preferences ahead of time prior to incapacitation (e.g., living wills, power of attorney for health, do-not-resuscitate orders) Example: Advance care planning in nursing homes: Correlates of capacity and possession of advance directives. b) Formal OR informal discussions about a patient's preferences or wishes about end-of-life or EOL PC care with health care providers, family, or clergy Example: A randomized, controlled trial of advanced care planning discussions during preoperative evaluations. c) Discussions/communications about decisions, preferences, wishes, desires, consideration of options available, or how patients or families go about making decisions about their care Example: Improving advance care planning by accommodating family preferences. d) Knowledge, attitudes, and beliefs about advance care planning; studies on "completion rates" or "barriers to completion" Example: Cross-cultural similarities and differences in attitudes about advance care planning.	• advance care plan • directive • living will • proxy • surrogate *__Also tested__:* power of attorney, wills, advance decision
	Ethics	Topics related to ethics and moral issues (e.g., principles, moral correctness) surrounding end-of-life research, care, treatment, or preferences Example: Ethnographic analysis of everyday ethics in the care of nursing home residents with dementia: A taxonomy.	• ethic • moral • suicide • resuscitation • right to die

VARIABLES	CATEGORIES[29]	DESCRIPTIONS	SEARCH TERMS
	Care Settings & Types of Care	Topics related to the types of care and settings of care in which EOL PC is provided Example: Intensive care unit cultures and end-of-life decision making; challenges facing families at the end of life in three settings.	• home care • nursing home • intensive care • primary care • care setting *<u>Also tested</u>:* home health care, home based care, respite care, primary care, acute care, long term care, assisted living, managed care
	Quality of & Satisfaction with Care	Topics related to the quality of EOL PC health services provided and the individual's or population's satisfaction with health services received Example: Identifying potential indicators of the quality of end-of-life cancer care from administrative data. Satisfaction with end-of-life care for nursing home residents with advanced dementia.	• quality of care • quality-of-care • quality of health care • quality care • satisfaction with care
	Hospice	Topics related to Hospice as setting, care type, or care model (Hospice is a specific EOL PC model of care that can be delivered to patients in their homes and involves a team-oriented approach to medical care, pain management, and emotional and spiritual support.) Example: Hospice care in a cohort of elders with dementia and mild cognitive impairment. Barriers to hospice care and referrals: Survey of physicians' knowledge, attitudes, and perceptions in a health maintenance organization.	• Hospice care *<u>Also tested</u>*: hospice
	Service Delivery Models	Topics related to EOL PC service delivery models other than hospice; models may or may not have specific name or acronym associated with program Example: The TLC model of palliative care in the elderly: Preliminary application in the assisted living setting. A place called LIFE: Exploring the advance care planning of African-American PACE enrollees.[38]	• care program • PACE (Matched) *<u>Also tested</u>:* navigation, managed care model, healthcare model, model, service model, health services model, health care model, model, service delivery, ACE, care model

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[38] The Program of All-inclusive Care for the Elderly (PACE) model is centered on the belief that it is better for the well-being of seniors with chronic care needs and their families to be served in the community whenever possible.

VARIABLES	CATEGORIES[29]	DESCRIPTIONS	SEARCH TERMS
	Economics	Topics related to the cost, expenses, or payment for EOL PC care and services Example: The cost-effectiveness and cost-utility of high-dose palliative radiotherapy for advanced non-small-cell lung cancer. What families know about funeral-related costs: Implications for social work practice.	• Medicare • Medicaid • cost • economics • finance *<u>Also tested</u>:* economic, reimbursement, cost of illness, health care cost, cost-benefit, finance, financial, insurance, coverage, benefits, fees, expenditure, reimbursement, payment, care costs
	Pain, Symptoms, & Symptom Management	Topics related to pain, symptoms, or management of symptoms related to EOL PC conditions and EOL PC patients Example: Pain reports by older hospice cancer patients and family caregivers: The role of cognitive functioning.	• pain • symptom • analgesic • opioid • fatigue • cognition • dyspnea • nausea • dysphagia • gastro • weight loss *<u>Also tested</u>:* anorexia, bleed, cachexia, anemia, morphine, delirium, methadone
	Alternative Medicine	Topics related to the use of alternative or complementary medicine in EOL PC care Example: Massage therapy as a supportive care intervention for children with cancer.	• alternative medicine • massage • acupuncture • music therapy • meditate *<u>Also tested</u>:* yoga, mindfulness, alternative health, alternative therapy, complementary therapy, complementary medicine, herb, aromatherapy
	Religion & Spirituality	Topics related to religion and spirituality in EOL PC Example: Identifying barriers to psychosocial spiritual care at the end of life: A physician group study.	• spirit • religion *<u>Also tested</u>:* spiritual, religious, clergy, Zen, Catholic, Jewish, God, Christian, Buddhism, Muslim, Islam, Hinduism, Christ, denomination, church
	Culture	Topics related to race, culture, ethnicity, disparities, or geographic region (urban vs. rural)	• racial • culture • ethnic

VARIABLES	CATEGORIES[29]	DESCRIPTIONS	SEARCH TERMS
		Example: Racial and ethnic differences in the treatment of seriously ill patients: A comparison of African-American, Caucasian and Hispanic veterans. Rural-urban differences in medical care for nursing home residents with severe dementia at the end of life.	• international *<u>Also tested</u>:* multicultural, cross-cultural, acculturation, custom, tradition, belief, language, rural-urban
	Medical	Studies examining the effectiveness of drugs, medical treatments, procedures, therapies, or surgical methods Example: Arterial chemotherapy as adjuvant and palliative treatment of hepatic colorectal metastases: An update.	----------------------------
	Other:_________	Other EOL PC topics that do not fit into any of the above categories	----------------------------
	***Note**: During analysis, the "other" category was reviewed again and new topics were identified. New topics are described below.*		
	Other: Prognosis	Topics related to time until death, estimates of time until death, or mortality (i.e., survival, life expectancy) Example: Predicting 6-month mortality for patients who are on maintenance hemodialysis. Survival in end-stage dementia following acute illness.	----------------------------
	Other: Care Services & Standards	Topics related to the provision of care services and standards/guidelines in providing those services; includes research on health systems, coordination of care, and service usage Example: Cancer Quality Alliance: Blueprint for a better cancer care system. Standards for palliative care delivery in oncology settings. Hospice, opiates, and acute care service use among the elderly before death from heart failure or cancer.	----------------------------
	Other: Quality of Dying	Topics related to a person's experiences of living while dying (Institute of Medicine, 2009); includes "good/bad death," dignified dying Example: The experience of dying: An ethnographic nursing home study. Providing a "good death": Critical care nurses' suggestions for improving end-of-life care.	----------------------------

VARIABLES	CATEGORIES[29]	DESCRIPTIONS	SEARCH TERMS
	Other: Quality of Life	Topics related to quality of life as a health-related construct and outcome; includes physical symptoms, physical functioning, and psychological and social well-being of the patient (Kaasa S and Loge JH, 2003) Example: Noninvasive ventilation in ALS: Indications and effect on quality of life.	----------------------------
	Other: EOL PC Experiences	Topics related to general experiences with EOL PC Example: I'm sitting here by myself ... ": Experiences of patients with serious illness at an urban public hospital. End-of-life experiences of nurses and physicians in the newborn intensive care unit.	----------------------------
	Other: Decision-Making	Topics related to the process of decisionmaking as related to EOL PC and others Example: Decision making by elderly patients with cancer and their caregivers. To hospitalize or not to hospitalize? That is the question: An analysis of decisionmaking in the nursing home.	----------------------------
	Other: Research	Topics related to EOL PC research, including issues and challenges related to conducting research on EOL PC (e.g., recruitment of chronically ill patients) Example: Palliative care program effectiveness research: Developing rigor in sampling design, conduct, and reporting. Are hospices ready to participate in palliative care research? Results of a national survey.	----------------------------
	Other: Special Population	Topics related to populations that have unique circumstances or are not often researched in the EOL PC literature Example: Cancer pain management in prisons: A survey of primary care practitioners and inmates. Dying on the streets: Homeless persons' concerns and desires about end of life care.	----------------------------
	Other: Policy and Legislation	Topics related to legislation or policies that directly or indirectly influence EOL PC care or the field of EOL PC Example: The public's perspectives on advance directives: Implications for	----------------------------

VARIABLES	CATEGORIES[29]	DESCRIPTIONS	SEARCH TERMS
		state legislative and regulatory policy.	
	Other: Technology	Topics related to the use of technology or media in EOL PC care Example: Technology available in nursing programs: Implications for developing virtual end-of-life educational tools.	----------------------------
	Other:________	Other EOL PC topics that do not fit into any of the above categories	----------------------------
EOL PC Condition[39]	Alzheimer's	Alzheimer's disease	Alzheimer *Also tested*: Alzheimer's, dementia
	Cancer	All types of cancer Example: lung cancer, pancreatic cancer	• cancer • carcinoma • chemo • radia • radio • malignant • lymphoma • leukemia *Also tested*: cancer, chemotherapy, carcinoma, lymphoma, malignant, tumor, leukemia, radiation therapy, cancer surgery, radiation, radiology
	COPD	Chronic obstructive pulmonary disease Example: emphysema	• COPD • obstructive pulmonary *Also tested*: chronic obstructive pulmonary disease; chronic bronchitis, emphysema
	Heart Conditions	Chronic conditions related to the heart and circulatory system Example: congestive heart failure	• heart • cardiac • NOT cardiopulmonary *Also tested*: heart, cardiac, cardiovascular
	HIV/AIDS	HIV or AIDS	• HIV • AIDS

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[39] Chronic conditions are those that involve "suffering," "functional impairment," or "persistent care."

VARIABLES	CATEGORIES[29]	DESCRIPTIONS	SEARCH TERMS
			• acquired immunodeficiency syndrome *Also tested*: human immunodeficiency disease, HIV/AIDS
	Kidney Conditions	Chronic conditions related to the kidney and urologic system Example: renal failure	• kidney • dialysis • renal *Also tested:* urology, uremia
	Liver Conditions	Chronic conditions related to the liver Example: liver failure, chronic hepatitis B	• liver (matched) *Also tested*: hepatitis
	Musculoskeletal Conditions	Chronic conditions related to the musculoskeletal system Example: muscular dystrophy	• musculoskeletal • sclerosis • ALS *Also tested*: dystrophy, amyotrophic
	Respiratory Conditions	Chronic conditions related to the respiratory system Example: pneumonia	• lung • pulmonary • pneumonia • NOT lung cancer *Also tested*: bronchi, respiratory
	Neurodegenerative Conditions	Chronic conditions related to the nervous system other than Alzheimer's Example: Huntington's	• neuro • Huntington • Parkinson • dementia *Also tested*: neurodegenerative
	Other:___________	Other chronic conditions that do not fit into any of the above categories	Examples: diabetes, sickle cell, cystic fibrosis, Down syndrome

Appendix E. NIH *Query/View/Report (QVR) IMPAC II* Database Extraction Methods and Procedures

Single Terms:

End of life	
Palliative care	Palliative treatment
Hospice	Advanced care planning
Advanced directives	POLST
MOLST	Five Wishes
Quality of death	Quality of dying
Living will(s)	

Combination Terms:

Each term from the Left box is combined with each term from Right box to create additional search terms (Table 1).

Table 1: Combination Terms Used for Searching EOL PC Research *in QVR IMPAC II*

- Decision-making
- Decision Making
- Durable Power of Attorney
- Health Proxy
- Surrogate Decision Maker
- Grief
- Bereavement
- Loss

AND

- Life-limiting
- Life-threatening
- Illness
- Serious Illness
- Advanced Illness
- Fatal Condition
- Terminal Illness
- Terminal
- Condition
- Advanced
- Condition
- Incurable
- Critically Ill
- Death
- Dying

- Organ Donation
- Brain Death/Persistent
- Vegetative State
- Euthanasia
- End Stage Renal Disease
- End-Stage Kidney Disease
- Advanced Heart Failure
- Terminal Cancer
- Advanced Cancer
- Advanced Dementia
- Organ Donation

Using the above search terms, 1,887 grants were identified. Grant titles and abstracts were reviewed by two evaluators. Of the 1,887 grants, 483 focused on or included a primary aim related to EOL PC. Thirteen which mentioned EOL PC terms but were not directly related to EOL PC were not included in this analysis. For example, the grant *Pain Assessment via Role-play Internet Simulation* was excluded. The remaining 1,391 grants were excluded because these were not related to EOL PC. These ranged from lab based grants such as *Kidney pericytes in vascular regeneration after injury* to a variety of clinical studies such as *Shared Decision Making: Prostate Cancer Screening*. Also, there were a number of training grants using the T mechanism (*n*=167) that were excluded because the aims did not mention EOL PC. An example of an excluded T grant is *STD/AIDS Research Training Grant*. After excluding additional grants (*n*=39) that were obligated but never funded, 444 unique grants were identified.

Care CEU's
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"This course was developed from the public domain document: Building Momentum: The Science of End-of-Life and Palliative Care. A Review of Research Trends and Funding – The National Institutes of Health, the National Institute of Nursing Research, (2013)."