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Model for the First NIH-funded Center of Excellence in End-of-Life Research

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Abstract

Centers of excellence are widely acknowledged as a mechanism to promote scientific advances in a particular field of science, but until recently there have been no end-of-life or palliative care research centers funded by the National Institutes of Health (NIH). The purpose of this article is to describe aims, framework, and organizational structure of the first NIH-funded Center of Excellence on end-of-life research, the Center for End-of-Life Transition Research (CEoLTR), and the advances in end-of-life research that the CEoLTR will facilitate. The teams of researchers involved in the CEoLTR have grown impressively since it was funded in 2007. Collectively, the teams are on target to accomplish all of the original goals for this five year award.

Introduction

More than a decade ago, the Institute of Medicine (IOM) issued the *Approaching Death*¹ report of dying in America. Shortly thereafter, the National Institute of Nursing Research (NINR) became the lead agency at the National Institutes of Health for end-of-life research. NINR issued a request for applications for centers of excellence in end-of-life research in 1998, but none were funded until 2007. The Center for End-of-Life Transition Research (CEoLTR) (1P30 NR010680) was established at the University of Illinois at Chicago (UIC) College of Nursing (CON) in 2007 to advance the science of care for people facing end-of-life transitions across the life-span (e.g., infants, children, adults, and older adults). The CEoLTR builds on a strong end-of-life and palliative care research base at the CON that is focused on perinatal loss, pain and symptom management in adults, advance care planning in African Americans with dementia, delirium in hospitalized older adults, and informatics.

End-of-life research is sorely needed to improve care to the more than 2.4 million people in the United States (US) who die annually and their families.² The top-ranked causes of death continue to be related to chronic illnesses such as heart disease and cancer, and many who die experience a variety of symptoms that often are not well controlled. Many individuals do not implement plans in advance of crisis events (advance care planning) that would help their health providers and families to assure that the care they receive is consistent with their wishes. Additionally, approximately 10% of family members are at risk for a complicated, prolonged grief response that can pose challenges to their health and functionality and require healthcare interventions.^{3, 4} These problems and unmet needs provide opportunities for improvement of end-of-life care. Research, however, is desperately needed to fully understand all of the issues surrounding the end-of-life experience for individuals and families so that appropriate interventions can be developed and tested. The purpose of this article is to describe the CEoLTR and the advances in end-of-life research that it will facilitate.

CEoLTR Aims

The mission of the CEoLTR is to promote respectful death through advancing the science of care for people at any age who are confronted with the end-of-life transition. To accomplish this mission, the CEoLTR has four aims (Table 1) that are facilitated through an Administrative Core with support from two scientific cores (Mixed Methods Research; Nursing and Health Informatics). The aims enable the conduct of efficient and effective biobehavioral oriented research designed to: (a) elucidate the underlying physiological, experiential, and behavioral mechanisms that prognosticate or influence approaching death or bereavement; and (b) test culturally relevant interventions for death awareness and respectful death.

Methods

Framework

The CEoLTR facilitated research is organized around an ecologic, quality of life framework focused on patient-centered and family-focused respectful death (Figure 1). Together, advance care planning, approaching death experience, and bereavement constitute components of a respectful death. In seeking to understand end-of-life phenomena from a biobehavioral perspective, emphasis is placed on using biologic measures in conjunction with experiential and behavioral measures to enhance explanation and prediction of the end-of-life transition.

This framework evolved from an adaptation of the human response model.^{5, 6} With this focus, it allows incorporation of the essential components of end-of-life care for individuals and families across the life span.^{1, 7-11} This framework also accommodates the eight domains of quality palliative care as designated by the National Quality Forum.⁹

The research facilitated through the CEoLTR contributes to an enhanced understanding of person and environmental variables that influence a respectful death for patients and families or important others across the life span. Through the CEoLTR, we support research to design and test person factors and care system interventions to promote a respectful death, with the ultimate goal of improving awareness about the importance of advance care planning and the quality of the death experience for patients and families across the life span.

According to the framework, *person factors* and *environmental factors* are key to understanding the constellation of factors that contribute to the status of respectful death.

Person factors are characterized as being either fixed characteristics or modifiable dimensions.⁷ For example, age and ethnicity are fixed characteristics, and physical symptoms, such as discomfort in the oral cavity, and a sense of purpose and meaning are modifiable dimensions. Environment factors include home, community and care system factors that exist outside the person to influence outcomes.⁷

A respectful death (also known as a good death) is desired. Salient components of respectful death are advance care planning and the death experience (*approaching death, which includes palliative care, and bereavement*) as person-family-healthcare professional interactive processes. Ideally, advance care planning occurs before the patient and family are approaching death and is depicted as such in the model. For example, an individual's previous experience with the death experience of others can influence subsequent advance care planning. The death experience as a construct includes *approaching death* (the time from awareness of a life-limiting illness until death) and *bereavement*.^{1, 12} *Approaching death* encompasses the individual who manifests the signs and symptoms of dying and also the experiences of family, friends and caregivers around this time.¹ *Bereavement* refers to having experienced the loss of someone significant through death,¹³ including mourning behaviors reflective of personal, social, and cultural expressions.

Within the CEoLTR biobehavioral framework and in the context of approaching death, nursing and healthcare related components considered important to end-of-life care for respectful death (with advance planning and bereavement) include biological function, symptoms, perceived health, quality of life and functional status. These constructs represent realms that can be measured physiologically, experientially (personally reported) or behaviorally (observed).

Research base

The CEoLTR is housed at the UIC, CON with a research base that is supported by interdisciplinary teams. The initial research base for the CEoLTR included five NIH R01 (research award) grants, a NIH R21 grant and an AHQR R01 grant. The CEoLTR has grown to include 30 investigators and affiliates whose intra- and interdisciplinary research directly or indirectly supports advance care planning; approaching death, and bereavement. One investigator's research focuses on reducing the risks of poor management of acute, chronic, and cancer pain in cancer patients.^{14–18} Another investigator studies delirium in older adults.^{19–21} One investigator's interdisciplinary research focuses on palliative and end-of-life care for infants and their families.^{22–26} One investigator's research focuses on advance care planning for African Americans with dementia^{27–30} and another's on quality of life in persons with dementia.^{31–34} Finally, one investigator has extensive research on health care informatics.^{35–42}

The administrative, mixed methods and informatics cores were designed specifically to support the creation and expansion of CEoLTR infrastructure and research to include investigators across campus and at other institutions. CEoLTR personnel developed special programs that promote the interactions across investigator groups such as annual colloquia, research forums, special interest groups, mock reviews for grant applications, and seminars with external researchers presenting their research to faculty and students.

Mixed methods core

The purpose of the mixed methods research core is to strengthen the infrastructure for research methodology at the CON, particularly for research related to end-of-life transitions and other complex, sensitive transitions. End-of-life research is inherently complex and contextually challenging; mixed method designs are crucial to yielding a more complete

understanding of end-of-life transitions while increasing the validity of the findings.⁴³ By combining qualitative and quantitative methods, researchers are able to use a wide variety of sampling, data collection, and analysis techniques to optimize study outcomes. To date, the mixed methods approach has not been utilized extensively to address the complex dynamics at end of life. To date, the mixed methods approach has been used in a limited way to address the complex dynamics at end of life.³¹ One reason identified for lack of utilization of mixed methods is the lack of knowledge about and experience with mixed methods.^{43, 44} The activities of this Core (Table 2) address the need for developing a cadre of researchers prepared in the application of mixed methods that advance end-of-life science.

Informatics core

The Informatics Core addresses the NIH challenge to develop more efficient and productive research systems that facilitate and accelerate the discovery of knowledge to improve people's health.⁴⁵ The specific purpose of the Informatics Core is to advance end-of-life science by strengthening resources available to investigators for incorporating informatics-based solutions into their research. The Informatics Core is comprised of scientific and technical teams that support CEoLTR investigators and affiliates to incorporate informatics-based solutions into all stages of the research process.

In addition, Informatics Core teams regularly collaborate with the Mixed Method Core in sponsorship and coordination of activities that promote the application of informatics to scientific methods. The two Cores also collaborate on the development and maintenance of (a) common data sets, (b) expansion of the instrument library previously developed, and (c) the CEoLTR website.

CEoLTR progress

The CEoLTR infrastructure and core resources are in place with the planned activities for years one through three completed as scheduled. Collectively, the administrative, mixed methods and informatics cores have been instrumental in the successful implementation of the CEoLTR. The main activities that have been executed to date include the technical and human resource components and a wide range of pertinent educational and consultation offerings. Ongoing research studies directed by the research base investigators continue or have recently ended and are supported by CEoLTR resources as new applications are developed and submitted for funding consideration.

Three of the four pilot studies selected by the CEoLTR leadership for support by CEoLTR funding are also underway. For each of the projects, designated co-investigators with content expertise serve as mentors to assist each of the PIs in successfully implementing the research plans. The project PIs meet regularly with their mentors and also with the CEoLTR leadership team for additional advice and counseling on informatics issues and solutions, data collection, and data analysis. These bimonthly meetings are specifically designed to monitor progress of the PIs, troubleshoot issues that arise during the research, and create and implement dissemination strategies. For example, it is during these meetings that recruitment strategies have been adjusted to ensure sufficient data will be captured for future R01 applications. Additionally, the bimonthly meetings have provided the venue to work with PIs on developing related research applications, presentations, and publications. The project PIs are new investigators and represent the perspective of two health disciplines; three are nurses and one is a dentist. Each pilot project addresses an important component of the CEoLTR framework.

The first project is entitled "Prediction of mortality in advanced heart failure patients using symptom clusters." A research assistant professor and clinical expert in critical care is the PI

(awarded in years 1, 2, and 3, total direct costs = \$168,257). The long term goal of this research is to accurately predict the end of the illness trajectory for people with advanced heart failure. Although many researchers have tried to develop a simple method to accurately and reliably predict death in this patient population, to date, none have been successful due to the highly fluctuating pattern of decline. The innovative new model is designed to identify the symptom clusters that predict mortality at various stages in advanced heart failure patients. The model, once fully tested, is expected to help identify earlier in their disease trajectory the patients who can benefit from palliative care and hospice programs.

"Characterization of oral health problems at the end of life," is the second project. The principal investigator is an assistant professor with expertise in diagnosis and management of oral complications of cancer treatment in the UIC College of Dentistry (awarded in years 1, 2, and 3, total direct costs = \$150,000). The goals of this study are to characterize oral health problems in terminally ill cancer patients undergoing palliative or hospice care from the perspectives of the care recipient, primary caregiver, and oral health professional and to determine primary caregiver knowledge about oral health problems and treatment. Oral conditions are common for patients at the end of life. Such problems have largely gone unrecognized and yet are believed to have a significant impact on the symptom burden during the end-of-life transition. Understanding the extent and impact of oral health problems on the terminally ill and their caregivers can provide knowledge to help identify, manage, and decrease symptom burden at the end of life.

"End of life care for people with intellectual and developmental disabilities," is the third study with a research assistant professor and clinical expert in ethics and pediatrics as principal investigator. In a qualitative study, the investigator will examine advance care planning in individuals with intellectual or developmental disabilities (awarded in years 3, 4, and 5, total direct costs = \$147,179). Ultimately, data that are generated in this study will inform intervention studies designed to promote patient-centered and family-focused respectful death that is consistent with the patient's and family's values and priorities and death experiences. Finally, findings from this study have the potential to inform similar investigations of vulnerable groups where participants are often excluded from research.

The fourth study is "Cultural sensitivity in suicide awareness using a video with Asian American audiences." An assistant professor with mental health expertise is the PI and will conduct this cross sectional study to 1) compare suitability ratings (cultural relevance, credibility, and appeal) by Asian American and non-Hispanic White college students for a suicide awareness video; and 2) determine the effects of cultural orientation (individualism-collectivism) and attitudes toward suicide on their suitability ratings and referral of the video to others (awarded in years 4 and 5, total direct costs: \$99,625). Participants will complete computerized questionnaires about their cultural orientation and attitudes about suicide, watch a streaming video, complete the online interactive facilitated session, and then complete a computerized questionnaire about suitability of the video. The study will serve as a pilot for examining the impact of this intervention on suicide awareness in Asians Americans.

Future Directions

The CEoLTR is well poised to meet its primary objectives and to advance the science of end-of-life transition research. The research-base investigations continue with some accruing participants and others progressing to analysis and dissemination phases.^{18, 22–26, 35–42, 46–56}

An important new direction for the CEoLTR is addition of a multidisciplinary research effort directed at automated analysis, mining, and visualization of textual, audio, and visual data that are available from CEoLTR investigators, research-base investigators, and affiliate investigators. We recently received additional support from the American Recovery and Reinvestment Act funds to add affiliates from the UIC College of Engineering. With these affiliates, we are developing intensive computational methods and applying information technology to the analysis of video and electronic data and to improve the user interface for software delivered at the point of care. The intent is to aid expert investigator analysis by processing, summarizing, and displaying information in an automated manner to reduce the labor-intensive tasks in expert analysis. The resulting technology will advance the science of care at end of life and provide technologic resources to investigators in the field. The goal of the new focus of our research is to facilitate the multidisciplinary team to collaborate on discovering new meanings from the data and on enabling technology for data analysis, mining, and visualization, and then on applying the technology to advance the science of care for people facing the end-of-life transition across the life span. The methods will consist of application of a variety of techniques--multimedia signal analysis techniques, statistical inference and data mining methods, and visualization techniques-- to the data with an iterative method of feedback from investigators who seek to advance end-of-life science. The technology developed by this new collaborative effort will provide efficient techniques to support the heart failure project, which will have extensive data. New ways to analyze the data and visualize the results may be very fruitful for the field of end of life in people with heart failure. The outcomes will be computational tools and scientific conclusions to aid the advancement in our understanding of factors and interventions that are most effective in providing care for people facing the end-of-life transition across the life span. An additional outcome will be a multidisciplinary team that knows how to effectively work together to advance science in ways inconceivable to us before our collaboration began. For example, we have made substantial progress during the first five months of our collaboration toward development of an automated system for coding videotaped facial expressions of pain by building on previous research in lung cancer.⁵⁷ These outcomes will position our CEoLTR to apply for additional research grants that build on the innovations and further advance the science of end-of-life and palliative care.

Another new direction for CEoLTR work is to outreach to affiliates with an emphasis on practice-based and education-based research on end-of-life and palliative care. Affiliates have been attracted to the CEoLTR for its capacity to support development of a research-oriented palliative care consulting service with a strong interdisciplinary education focus. Economic constraints have slowed these efforts, but the team is positioned with a strong implementation plan when the economy improves. Affiliates have also been attracted to maximize education-based research with the well-known EPEC (Education on Palliative and End-of-life-care)⁵⁸ and TNEEL (Tool-kit for Nurturing Excellence at End of Life)⁵⁹ resources. This effort involves an inter-institutional collaboration. These new research initiatives facilitate opportunities to translate CEoLTR findings to venues that have potential to improve care of people facing the end-of-life transition.

Summary

The CEoLTR is the first NIH-funded Center of Excellence to be focused on end-of-life research. The teams of researchers involved in the CEoLTR have grown impressively and collectively are on target for accomplishing all of the original goals. By the end of the five year funding period, it is expected that the CEoLTR will be self sustaining and that all four projects funded by the CEoLTR will have received or be positioned to receive R01 awards. Most importantly, we expect that the enormous amount of knowledge and experience gained

through the interdisciplinary experiences facilitated by the Cores will position the CEoLTR for increased research productivity as well as provide for quick translation into practice.

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Framework for End-of-Life Transition Research

Figure 1.

Table 1

Aims of the Center for End-of-Life Transition Research

1. Advance the science through creating an infrastructure that effectively links priority research questions, resources, and investigator expertise (novice to expert).
2. Strengthen the appropriate and ethical use of qualitative and quantitative (mixed methods) methodologies by Center investigators/affiliates in the measurement of biobehavioral variables, management of data, and analysis of data.
3. Expand the use of informatics in the conduct of all phases of end-of-life research to improve the efficiency, effectiveness, and speed of translation into practice.
4. Facilitate the dissemination of end-of-life research findings to the scientific and clinical communities and to the general public.

Table 2**Mixed methods core activities**

1. Provide programs and resources for Center investigators/affiliates and project staff to motivate and support them in using mixed methods in the study of respectful death and address the challenges inherent in studying end-of-life transitions through the use of: special interest groups; research seminars; participation in college wide think tanks; expansion of instrument library; interviewer training; development of narrated power point presentations; and a peer support strategy.
2. Provide mixed methods consultation and services related to: research design and data collection; evaluation and adaptation of instruments to be used with specific age and ethnic groups at various phases of experiencing end of life; data management strategies; and complex and advanced analysis strategies and statistics and data management services.
3. Optimize recruitment and retention strategies for mixed methods end-of-life research by providing consultation on issues related to recruiting and retaining subjects for end-of-life and other sensitive research.
4. Build collaborative community relationships with input from community-based advisory groups, including those aligned with end-of-life services.
5. Mentor investigators to collaborate with professional staff at clinical agencies where patients are recruited for end-of-life research.
6. Collaborate with Institutional Review Boards to reduce barriers to approving end-of-life research.

Table 3

Informatics core activities

1. Provide training sessions to create awareness of how informatics-based solutions can support Center research
2. Provide consultation for the development, testing, and deployment of informatics solutions that optimize subject recruitment, retention, and tracking; instrument design; data collection, monitoring, storage, and analysis, and data mining.
3. Facilitate collaboration across investigators to ensure informatics solutions are readily accessible, efficient, effective, and non-redundant while also speeding research translation.
4. Expand the compendium of biobehavioral measures to support studies of: symptoms, quality of life, quality of dying, environment, co morbidity, functional status, health perception, and function (biological and physiological)