

NHPCO Research Agenda May 2004

In April of 2003 NHPCO convened a Research Conclave and invited a group of leading researchers in hospice and palliative care to share their expertise, knowledge, and wisdom. One of the primary aims of the Conclave was to provide a forum for the discussion of the current salient issues in hospice and palliative care, with the objective of using the fruits of the discussion as the starting point for generating a research agenda. From this meeting and other input from NHPCO constituencies we have formulated the following research agenda so that we can focus our efforts to advocate for advancements in the practice of hospice and palliative care.

The agenda is focused on three areas of major concern: 1) improving access to hospice and palliative care 2) improving the quality of hospice and palliative care and 3) improving the conduct of research in hospice and palliative care. The following research topics in each major area are identified, together with research objectives and potential research questions:

Improving Access to Hospice and Palliative Care

Topic: Eligibility and Election

Research Objective:

Identify the factors that influence patients and family decision-making related to election of hospice care.

Research Questions:

1. What are the characteristics of patients who decline hospice care?
2. What components of the patient's illness experience influence the acceptance of hospice care?
3. What are the factors that influence the timing of admission to hospice?
4. What is the effect of a continuity of care model (maintaining initial care structure with added palliative team co-management) on acceptance of hospice care?

Research Objective:

Identify the optimal methods for determining eligibility for hospice.

Research Questions:

1. What is the utility of non-clinical prognostication criteria compared to clinical prognostication criteria?
2. What proportion of deaths could benefit from hospice and palliative care?

3. What factors, in addition to clinical judgment, influence accuracy of determining prognosis?

Research Objective:

Identify optimal models of end-of-life care based on disease and/or functional trajectories.

Research Questions:

1. What are the optimal criteria for initiation of palliative care for patients in the critical care setting?
2. What functional status criteria for patients with non-cancer diagnoses will result in appropriate timely access to hospice care?
3. What are the patient and healthcare system effects of over-treatment and futile care?
4. What model of care best meets the end-of-life care needs of individuals with chronic progressive life-limiting illnesses (e.g., frailty/dementia, advanced CHF, multi-system failure)?

Topic: Regulatory/Reimbursement Barriers

Research Objective:

Identify effective and efficient modifications of the current reimbursement system that will result in increased access to hospice and palliative care.

Research Questions:

1. What is the effect of a system of concurrent curative/palliative care on access to service, quality of care, and cost of care?
2. What is the effect of the existing hospice eligibility structure on timeliness of hospice referral and length of service?
3. What are the characteristics of a model outlier payment system for hospice providers?
4. What is the effect of an outlier payment system for hospice provider on the burden associated with the provision of high cost palliative therapies?

Topic: Needs of Special Populations

Research Objective:

Identify the unmet end-of-life care needs of racial, ethnic and cultural minority populations and the implications for modification and reorganization of delivery of hospice and palliative care services.

Research Questions:

1. What do various ethnic and cultural populations value and want from healthcare when faced with life-limiting illness?
2. What factors explain the variation in minority use of hospice care?
3. What are the racial and cultural differences in the various palliative care domains, including symptom distress, psychological/emotional

distress, social-familial concerns, spiritual distress, access to care, continuity of care, and bereavement?

Research Objective:

Identify the unmet end-of-life care needs of vulnerable populations (children, long-term care residents, prison inmates, rural residents) and the implications for modification and reorganization of delivery of hospice and palliative care services.

Research Questions:

1. How can hospice and palliative care programs work with the healthcare system to increase access to service for children?
2. What modifications to delivery of hospice services will effectively address the identified unmet needs of long-term care residents?

Research Objective:

Identify the unmet end-of-life care needs of individuals with AIDS.

Research Questions:

1. What is the location of death for individuals with AIDS?
2. What is the quality of death for individuals with AIDS?

Topic: Community Engagement and Social Marketing

Research Objective:

Identify the key concepts and social, cultural, and behavioral factors that should inform social marketing and community engagement strategies.

Research Questions:

1. Who should the target audiences/markets be for social marketing
i. interventions?
2. What are the focus and components of the social marketing message for specific audiences?
3. What insights can be gathered from minority community social, political, religious, and service organizations for reframing hospice and palliative care concepts to make them more acceptable and culturally sensitive?
4. What are the optimal methods of message delivery for specific audiences?

Research Objective:

Identify effective approaches for community outreach, education, and engagement strategies that improve access to care.

Research Questions:

1. What is the effect of community caregiver education on provider hospice referral patterns?

Improving the Quality of Hospice and Palliative Care

Topic: Quality Measurement

Research Objective:

Identify methods for evaluation of quality of end-of-life care that have utility for all healthcare settings.

Research Questions:

1. What are the quality indicators at the structure, process, and end-result outcomes levels, for which validated measures exist?
2. What are the areas of end-of-life care for which quality of care measures are needed?
3. What are the outcomes of discontinuity of care for patients and families?
4. What are the structures and processes of care that facilitate continuity across settings?

Research Objective:

Explore the relationship between evidence-based practice and quality end-of-life care.

Research Questions:

1. What are the methods for translating evidence into practice have utility in hospice and palliative care?
2. What is the effect of evidence-based practice on patient outcomes?

Topic: Clinical Practice

Research Objective:

Identify effective and feasible approaches to patient symptom assessment and management.

Research Questions:

1. What is the effect on patient outcomes of the implementation of a standardized set of symptom assessment tools by multiple hospice and palliative care providers?
2. What is the safety, efficacy, and cost-effectiveness of single fraction radiation therapy for hospice and palliative care patients?
3. What are the multi-dimensional factors that affect assessment of a given symptom?
4. What is the effect on patient outcomes of screening for various types of distress (e.g. symptom burden, psychological, spiritual) and early implementation of interventions?
5. What is the relationship of the non-physical dimensions of symptom expression to symptom management?

Research Objective:

Identify effective approaches to ensuring and enhancing caregiver wellbeing.

Research Questions:

1. What are the positive caregiver outcomes (e.g., satisfaction, self-efficacy, personal growth) that are the result of experiencing hospice/palliative care?
2. What is the effect of specific interventions aimed at reducing caregiver distress and burden?
3. What are the consequences for the caregiver of not accessing hospice or palliative care?

Research Objective:

Identify approaches to effective bereavement care.

Research Questions:

1. What is the effect of hospice/palliative care on bereavement outcomes?
2. What are the effects of bereavement interventions in families with uncomplicated bereavement?
3. What bereavement interventions are effective in preventing health problems and promoting well-being in individuals at risk of poor outcomes
4. What are the components of a predictive, reliable bereavement risk assessment tool?

Improving the Conduct of Research in Hospice and Palliative Care

Research Objective:

Identify ways to promote and increase participation in end-of-life care research by hospice and palliative care providers.

Research Questions:

1. What methods will promote, effectively utilize, and expand practice-based research networks in hospice and palliative care?
2. What methods will increase involvement of hospices in clinical trials research?

Research Objective:

Identify methodological approaches and modifications that will facilitate end-of-life care research.

Research Questions:

1. What types of infrastructure and informatics systems are needed to support end-of-life healthcare services research?
2. What data gathering methods will facilitate the inclusion in research of hospice/palliative care patients with communication and cognitive deficits?
3. What modifications to the current data collection/reporting system will facilitate end-of-life healthcare services research?