



Research Opportunities in Palliative Care AACN Doctoral Conference January 30, 2015

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Imperative for palliative care research

- Need for a better quality of care for persons with serious and complex illnesses
- Medical care for patients with serious illness is usually characterized by:
 - inadequately treated physical distress
 - fragmented care systems
 - poor communication between clinicians, patients, and families
 - enormous strains on family caregiver and support systems.



Palliative Care Research – current status



Palliative care research lags behind clinical growth

- Despite growth of hospice & palliative care, palliative care research relatively underdeveloped
- Evidence base guiding clinical practice “woefully inadequate”
- Must focus on:
 - Answering important clinical questions
 - Using appropriate research instruments, designs, and analytic techniques

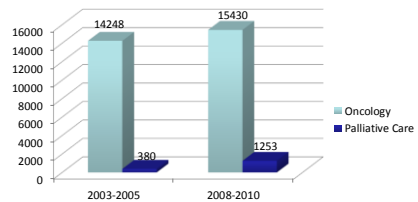


Evidence base - Current status

- Inadequate evidence base to support appropriate care of persons with serious and life-limiting illness
- Lack of junior and mid-career investigators
- Lack of sustainable research centers



Evidence Base: Research Publications in Oncology and Palliative Care



Gelfman LP, Morrison RS. J Palliat Med, 2008.
Gelfman LP, Du Q, Morrison RS J Palliat Med, 2013.



Why the Gaps in Research?

- Symptoms previously seen as unimportant
 - Interesting in so far as they guide the clinician to a diagnosis
 - Will go away when the disease is cured
- Difficult population to study
 - Multiple symptoms and concurrent problems
 - Very sick population with limited tolerance for lengthy protocols and instruments
 - High mortality rate with associated missing data
 - Difficult outcomes to study
 - Often not amenable to traditional research designs



The Result:

- Current palliative care practice guided by:
 - Data from other populations
 - Results form small series of patients from single institutions
 - Anecdote and hearsay
- Is this the type of care that we want for our patients or for ourselves?



Urgent Needs - Palliative Care Research

- Randomized, longitudinal efficacy/effectiveness studies
- Consensus on the most valid and reliable palliative care outcomes measures
- Minimize respondent burden
- Strategies to assure ethical treatment of patients as research subjects
- Combination of qualitative and quantitative methodologies
- Rigorous dissemination and implementation studies
- Career development for junior investigators



Opportunities: Underdeveloped Research Base

- Measuring symptoms and symptom clusters
- Biological bases of complex symptom clusters
- Symptom interventions
- Family and informal caregiving
- The impact of poverty
- Societal beliefs and approaches
- Quality of life within different cultural milieus
- Performance of the health care system
- Understanding and responding to transitions in care goals
- Use of technology to enhance

Collaborative priority setting – HPNA, NHPCO, AAHPM



National Institute of Nursing Research (NINR)

Lead NIH Institute for end of life and palliative care research

www.ninr.nih.gov/eolpc-spotlight

www.ninr.nih.gov/eolpc-theme



PCRC Proprietary

EXECUTIVE SUMMARY

The Science of Compassion:
Future Directions in End-of-Life and Palliative Care

SCIENCE OF COMPASSION

A Summit Sponsored by the
National Institute of Nursing
Research and Partners

Hyllt Regency Bethesda Hotel
Bethesda, MD
August 10-12, 2011

<http://www.ninr.nih.gov/ResearchAndFunding/scienceofcompassion.htm>



Office of End-of-Life and Palliative Care Research (OEPCR) (www.ninr.nih.gov/oepr)

- Established March 2014
- Chief = Dr. Jeri Miller (jmiller@mail.nih.gov)
- Coordinates and supports ongoing NINR and NIH research efforts in end-of-life and palliative care (EOLPC) science, including:
 - Stimulation of end of life and palliative care research initiatives
 - Creation of opportunities for collaborative activities
 - Facilitation of interdisciplinary EOLPC science
 - Identify opportunities for science to inform policy and practice
- Coordinate development, implementation and evaluation of EOLPC research in direct collaboration with other NIH Institutes and Centers, federal research agencies and outside constituencies



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NINR Innovative Questions

- Next step in implementing NINR Strategic Plan
- NINR convened workshop of experts (May 2014):
 - Identify research questions that point the way forward for nursing science in EOLPC research and inform future NINR efforts
- <http://www.ninr.nih.gov/newsandinformation/iq#.V1eo5jHF6I>
[or, Google "NINR innovative questions"]



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Funding Opportunity Announcements (FOA)

- *Building Evidence: Effective Palliative/End of Life Care Interventions* (PAR-13-289)
 - Aims to stimulate research to develop and test palliative and end-of-life care interventions based on measurable outcomes
- *Advancing the Science of Geriatric Palliative Care* (PA-13-354, PA-13-355, PA-13-356)
 - Develop new evidence surrounding places and systems of care to address the unique palliative needs of the aging population
- *Arts-Based Approaches to Palliative Care* (PAR-14-294)
 - An initiative between NINR, NCCAM, OBSSR, and ORWH.



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Conversations Matter™ Easing Symptoms and Enhancing Lives (www.ninr.nih.gov/conversationsmatter)

- NINR national awareness campaign re. pediatric palliative care
- Launched January 2014
- Goals:
 - Increase the number of health care professionals recommending pediatric palliative care
 - Encourage early and ongoing conversations around pediatric palliative care
 - Increase the number of families requesting pediatric palliative care
 - Increase the use of palliative care for children living with serious illnesses or life-limiting conditions



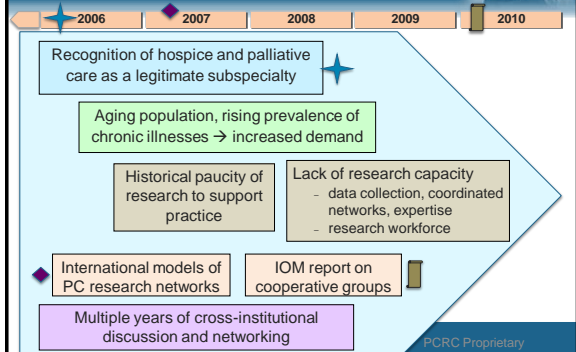
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Palliative Care Research Cooperative Group (PCRC)

Funded by National Institute of Nursing Research
(UC4-NR012584, U24-NR014637)

History: Timing of Events and Milestones that made the Development of the PCRC possible



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PCRC Vision

Excellent palliative care at the bedside is contingent on best evidence and a scientific underpinning for what we do, so that:

- No patient dies alone, in pain, or without dignity.
- Palliative care responds effectively to suffering at all points in the life/illness trajectory.
- Palliative care enhances *living*.



PCRC Mission

To develop **scientifically-based methods** that lead to **meaningful evidence** for **improving quality of life of patients** with advanced and/or potentially life-limiting illnesses, and their **caregivers** including family members and providers of care.



PCRC Overarching Strategy

1. Develop **efficient** palliative care **research capacity** nationally.
 - Infrastructure
 - Data systems and procedures
 - Metrics
2. Support the conduct, analysis, and dissemination of **high-quality research** in palliative care.
3. Train and mentor **new, existing, and future clinician-scientists** committed to advancing palliative care research.



Grant funding through NINR

- UC4 award (ARRA funding) : UC4NR12584
 - **Creation and Demonstration of a Palliative Care Research Cooperative Group**
 - 10/1/2010 - 09/30/2013 [3 year]
- U24 award: 1U24NR014637
 - **Enhancing palliative care research capacity through refinement and expansion of the Palliative Care Research Cooperative Group**
 - 10/1/2013 - 09/30/2018 [5 year]

Co-Principal Investigators: Amy Abernethy, MD PhD (Duke)
Jean Kutner, MD, MSPH (UC)



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Palliative Care Research Cooperative (PCRC)

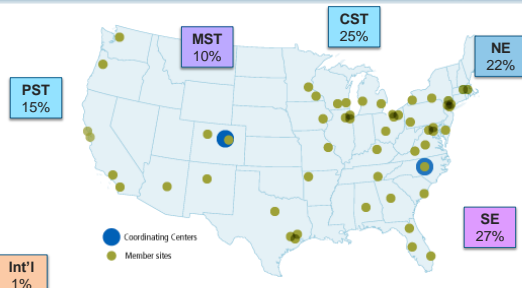
- Founded in January 2010
- First research cooperative in the US that focuses specifically on issues relevant to palliative and end of life care (PCEOL)
- Developed infrastructure to provide centralized services, including informatics and electronic data capture interface

Abernethy AP, Aziz NM, Basch E, Bull J, Cleveland CS, Currow DC, Fairclough D, Hanson L, Hauser J, Ko D, Lloyd L, Morrison RS, Olin-Green S, Parlati S, Portenoy RK, Riche C, Rocker G, Wheeler JL, Zafar SY, Kutner JS. A strategy to advance the evidence base in Palliative Medicine: Formation of a palliative care research cooperative group. *J Palliat Med.* 2010; 13(12): 1-7

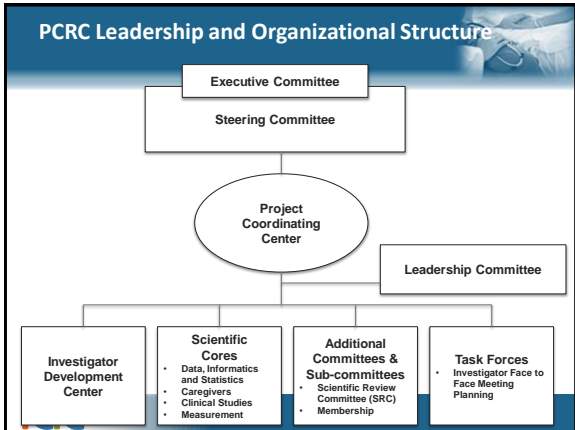


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Membership Metrics: Site locations and % Members by region



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PCRC Leadership: Executive and Steering Committees

Executive Committee:

- Amy Abernethy, Duke Univ
- Jean Kutner, Univ of Colorado
- Christine Ritchie, UCSF

Steering Committee:

- Maria Bakitas, UAB
- Janel Bull, Four Seasons
- Betty Ferrell, City of Hope
- Laura Hanson, UNMC
- Steve Paribhat, UCSF
- Greg Samsa, Duke Univ
- Charles von Gunten, Ohio State
- Susan Marden, NIVR representative

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Project Coordinating Center

Co-Directors: Amy Abernethy & Jean Kutner

- **Study development:** grant development & writing, protocol development, concept review
- **Study conduct:** site development, training, quality assurance, data management
- **Study management:** administration, finance, grant management, performance monitoring, reporting
- **Coordination** within and between studies, participants, investigators, stakeholders, and sites
- **Communication:** website, newsletters, investigator meetings
- **Dissemination:** increase visibility of PCRC and its studies

Investigator Development Center (IDC)

Director: Christine Ritchie

- Multi-faceted approach to workforce development for PCEOL research
 - Leverages PCRC resources and infrastructure
- Provide **resources and expertise** to junior PCEOL investigators
- Facilitates **mentorship** relationships between senior mentors and researchers new to PCEOL research or particular types of research (e.g., industry trials, collaborating with the VA)
- **PCRC Pilot Grant Awards**

Data, Informatics and Statistics Core (DISC)

Director: Greg Samsa, PhD
Lead Statistician: Patrick (Jud) Blatchford, PhD

- Statistical and data-related aspects of trial design, evaluation, quality assurance, data analysis, reporting, and data sharing
- IT and clinical informatics support (e.g., standardized electronic data collection methodologies)
- Create interoperable data elements (variables) and core measures (instruments / questionnaires)
- Align with and incorporate relevant national initiatives
- Integrate information from electronic health records (EHRs)

PCRC Caregiver Research Core

Director: Betty Ferrell, PhD RN
Sub-Investigator: Virginia Sun, PhD RN

Advance caregiver research through:

- Identifying preferred caregiver study designs, measures, and instruments
- Elevating quality and prominence of caregiver research
- Defining priority gaps in caregiver research and providing direction to investigators
- Seeking opportunities to add caregiver component to approved PCRC studies

Clinical Studies Core

Director: Francis (Frank) Keefe, PhD
Sub-Investigator: Tammy Somers, PhD

- Provide guidance in matching study design to research question
 - Methods relevant to PCEOL intervention studies, clinical trials, and bio-behavioral outcomes
- Facilitate prompt responses to funding opportunities
- Connect investigators to consultants (including PCRC experts) who work closely with investigators to develop high-quality PCEOL studies
- Incorporate novel approaches into PCEOL studies, such as bio-behavioral interventions for symptom management



Measurement Core

Director: Ethan Basch, MD MSc
Sub-Investigator: Antonia Bennett, PhD

- Provide advice regarding study measures and study-specific challenges
- Identify measures relevant to EOLPC populations, eg:
 - measurement tools appropriate for populations with changing and declining cognition;
 - tools for measuring quality-of-life among caregivers of PCEOL patients; and
 - instruments appropriate for use in people with multiple co-morbid conditions.
- Provide centrality and standardization of outcomes, measures, and metrics in study conceptualization, design, conduct, and analysis



EXAMPLES OF PCRC PRODUCTS



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Core Measures & Core Data Elements Library

- Standardized formats
 - Commonly used forms such as enrollment, demographics, and baseline clinical data.
- Common forms library
 - Survey instruments to measure concepts such as: symptoms, pain, health related quality of life, depression, coping, well-being, self-efficacy, satisfaction with care, and caregiver burden
- Library of PCRC-preferred common data elements
 - Provide recommendations for elements in use / existence that are relevant and applicable to be cost effective and allow for multi-study data analysis.
 - Common data formats and web-based data forms /electronic data entry system



PCRC Studies: Completed

Study #	Title	PI (Institution)	Type	Status	Funding
PCRC 10-01	Statin Discontinuation	A Abernethy (Duke Univ) Kutner (Univ Colorado)	Randomized Control Trial	Closed; manuscript under review after revision	NINR UC4



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PCRC Studies: SRC Reviewed / Active

Study #	Title	PI (Institution)	Type	Status	Funding
PCRC 13-01	Pharmacovigilance	A Abernethy (Duke Univ)	Quality	Active enrollment	CLHC, UC GIM & UCSF
PCRC 14-01	Best Supportive Care	Yousuf Zafar (Duke Univ)	Implementation	Site training study roll-out	American Cancer Society (ACS)
PCRC 14-02	QDACT Feasibility	Arif Kamal (Duke Univ)	Quality	Site training study roll-out	Agency for Healthcare Research (AHRQ)
PCRC 14-07	Caregiver-guided pain management	Laura Porter (Duke Univ)	Randomized Control Trial	SRC reviewed	NINR RFA-NR-14-003
PCRC 14-08	Legacy intervention in pediatric palliative care	Terrah Foster-Akard (Vanderbilt)	Intervention	SRC reviewed Active site recruitment	NINR RFA-NR-14-003
PCRC 14-09	Lung cancer palliative care intervention	Betty Ferrell (City Of Hope)	Intervention	SRC reviewed	NINR RFA-NR-14-003



PCRC Proprietary Information

PCRC 2014 Pilot Grant Awardees

PI	Institution	Title	Amt	Type	Population
Nrupen Bhavsar PhD	Duke University	Implications of increased statin use among patients w/ limited prognosis	\$15K	survey + decision model	statin registry
JJ Furuno PhD	Oregon State	Anticoagulation Therapy on discharge to hospice care	\$15K	retrospective cohort + in-depth interviews	patients discharged directly to hospice care; patients / discharging physician dyads
Ann Long MD MS	University of Washington	Experiences of family members of patients admitted to the ICU from the acute care floor	\$25K	semi-structured interviews	surrogate decision-makers for patients admitted to the acute care floor
Virginia Sun RN PhD	City of Hope	Feasibility of an interdisciplinary palliative care planning intervention in pancreatic cancer	\$25K	feasibility pilot planning intervention	advanced/metastatic pancreatic cancer



PCRC Proprietary Information

Online Resources & Information

The screenshot displays the PCRC website's 'GUIDELINES FOR INTERESTED INVESTIGATORS' page. It includes sections for 'INVESTIGATOR SUPPORT INFORMATION' and 'CONTACT US'. The website URL palliativecareresearch.org is highlighted in a red box at the bottom.



Multiple Approaches to Communication

The screenshot shows the PCRC Facebook page. The page name is 'Palliative Care Research Cooperative Group - PCRC'. The cover photo features a group of people, and the profile picture is the PCRC logo. The page includes a 'Timeline' and 'About' section.



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Knowledge Products

- Publications
- Abstracts
- Authorship Tables
- Poster and templates

The screenshot shows a research paper titled 'DISCONTINUING CHRONIC MEDICATIONS: PERCEPTIONS OF PATIENTS WITH LIFE LIMITING ILLNESS'. The paper is published in the 'Journal of Clinical Pharmacy and Therapeutics'. The authors listed are Robert J. Wilby, Thomas M. Probst, and David C. Reardon. The paper includes an abstract, a table of contents, and a list of authors.



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PCRC Investigator Support

- Grant / Study Development
 - Letters of Support
 - Guiding research questions from concept to study design
 - Connect investigators with appropriate methodologies, metrics and measures
 - Pilot grant awards
- Investigator and Site Development
 - Training site-based study personnel
 - Investigator training and mentoring
- Efficient Study Conduct
 - Replicable research infrastructure
 - Access to multiple sites and investigators across the country
 - Development of comprehensive protocol & study-specific materials
- Assisting with enrollment initiation
- Ensuring high quality data collection
- Regular tracking of performance metrics
- Streamlining of programming code
- Leverage across studies
 - Consistent variables across data sets and studies
 - Standardize data collection for easy data merging and transfer
 - Enhance data utility for secondary use
- Dissemination
 - Supporting publication in accordance with PCRC Authorship Protocol



The screenshot shows the PCRC website with a large blue oval containing the text 'Apply for PCRC Membership!!'. Below the oval, there is a red box with the website URL palliativecareresearch.org. The website header includes 'ANNOUNCEMENTS' and 'NEWS' sections.



University of Colorado Palliative Care and Aging Research Training (T32)


- Funded by a [Ruth Kirschstein National Research Service Award NRSA T32](#) from the National Institute on Aging (NIA)
- **Training Components:**
 - Mentorship
 - Interdisciplinary Research Training & Experience
 - Professional Development Opportunities
 - Research Seminar and Journal Club
- **Contact:**
 - Jean.Kutner@ucdenver.edu





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Contact / Network

Palliative Care Research Cooperative Group [PCRC]

 palliativecareresearch.org

 @pcrcgroup

 pcrcgroup

 pcrc@duke.edu

