

**EXECUTIVE
SUMMARY**

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



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

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OVERVIEW

The National Institute of Nursing Research (NINR), together with partners from across NIH Institutes, Centers and Offices, convened a three-day national Summit on, “The Science of Compassion: Future Directions in End-of-Life and Palliative Care.” The Summit examined the state of research and clinical practice in end-of-life and palliative care (EOL PC) and, with almost 1,000 registrants, provided an opportunity for scientists, health care professionals, and public advocates to come together to catalyze and shape the future research agenda for this critical scientific area. The conference centered on four key objectives:

- Examine the current status of palliative care and end-of-life research and practice
- Propose strategies to overcome barriers and ensure scientific/methodologic rigor
- Delineate action items to galvanize progress in vital EOL PC research
- Envision and map ways to achieve a future rich with scientific endeavor and achievements

National experts dedicated to building the science of EOL PC discussed a range of issues—from studies on the management of pain and other symptoms to the creation of effective models of health service and strengthening of metrics to evaluate improvements to care. Additionally, the Summit hosted a series of opportunities to showcase the advances in the field through a public Town Hall, keynote presentations, plenary panel discussions, break-out reports, and a juried poster viewing and reception. Efforts to strengthen the translation of science to the public and build partnerships with researchers in the field were nurtured through Summit dyads of research-mentor partnerships and multiple opportunities for public discourse throughout the conference.

The Summit served as a significant milestone to not only reflect on past accomplishments, but to address the scientific contributions of one of the most important areas of health care in our Nation today. Recordings of sessions by podcast or videocast are archived on the NINR Summit Web Site at: <http://www.ninr.nih.gov/ResearchAndFunding/scienceofcompassion.htm>

I. AUGUST 10, 2011 OPENING CEREMONIES AND TOWN HALL

COMMENCEMENT REMARKS

Dr. Patricia A. Grady, Director, National Institute of Nursing Research

Dr. Patricia Grady, Director of NINR, introduced the Summit as an opportunity and a forum where science, practice, and the public can meet, converse, and build knowledgeable relationships.

- NINR has remained committed to comprehensive, biobehavioral research to improve health and health outcomes, including the quality of care provided at the end of life (EOL). Since NINR’s 1997 designation to lead the coordination of EOL research at the National Institutes of Health, NINR has endeavored to build integrative research programs to address a constellation of palliative and end-of-life symptoms experienced by individuals and their families and to translate this evidence into meaningful health care practices.
- The positive transformations in the care of those with life-limiting illnesses have been realized by the contribution of scientists and the important role that research makes to ensure that those with serious, advanced illnesses are living well. While the national debate has challenged the understanding of EOL care, the Summit provides an opportunity to ensure that the best of

science is disseminated to raise awareness of the importance of the end of life and ensure creative solutions are enacted to educate and inform the public.

- As we seek to understand what it means to live well while dying, the work of EOL PC science is not yet done. There is much to learn, much to understand, and much to consider in translating what is known into meaningful practice. To help close the gap between research, evidence, and practice, interventions must be based on the best possible evidence, the knowledge base expanded, and the use of best available science-tested programs and policies promoted. Building a solid research base in EOL PC requires open dialogue about the strengths and the challenges of this science and a commitment to seek new ways to implement and disseminate findings into practice. The Summit is a realization of how we might together advance the very best of the science of compassion in EOL PC.
- The success of the Summit is due, in part, to the support and efforts of many partners across the NIH, including the NIH Office of Rare Diseases Research, the NIH Office of Research on Women's Health, the National Center for Complementary and Alternative Medicine, the National Institute on Aging, the NIH Clinical Center Department of Bioethics, and the Foundation for the NIH, with generous support from Pfizer, Inc. NINR is grateful to all partners, the Summit presenters, and the attendees for their participation, enthusiasm, and compassion for the science of EOL and palliative care.

THE ETHICS OF SCIENCE AT THE END-OF-LIFE: A TOWN HALL DISCUSSION

Mistress of Ceremonies: Dr. Marie T. Hilliard, The National Catholic Bioethics Center; Moderator: Ms. Susan Dentzer, Editor-in-Chief, Health Affairs; Panelists: Dr. Nancy Berlinger, Hasting Center; Dr. Joseph J. Fins, Weill Cornell Medical College; Dr. Karla FC Holloway, Duke University

A pre-Summit Town Hall provided an opportunity for expert panelists to discuss current issues related to the bioethics of the design and the implementation of end-of-life research. With close to 600 members in the audience, this first NIH-Institute-led public forum on EOL research ethics included discussion on these topics:

- The term 'vulnerable populations' does not reflect the patient as a particular individual who is vulnerable. Vulnerability is an extrinsic characteristic assigned by others to persons who may wish to direct their own care, even with recognized risks.
- It is important that during consent that a presumption is not made that patients are involved in the design and product of the research. Greater involvement reinforces the presumption that inclusion will make the protocol look better and improve the likelihood of approval, yet, patient representatives do not have the same authority in an IRB as scientific experts. Instead, emphasis should be placed on refining protocols to improve the outcome.
- There often is an enormous disconnect between the way clinical trials are discussed by researchers and the patients' or surrogates' understanding and purpose for enrollment. Many patients perceive trials as a last course of treatment when all else has failed. Powerful beliefs, such as a cure, emerge if the patient survives long enough, and are difficult to meld with an informed consent process.
- Researchers need to address how to balance patients' therapeutic misconceptions of the risk-benefits of a clinical trial and ensure these notions are adequately addressed through informed consent. The portrayal of risk also should be examined, as many investigators consider the risk benefit ratio positive for their studies.
- Surrogate decision makers may be vulnerable in watching their loved one progress through life-altering changes, especially as death draws near. It is imperative that the level of risk be

accurately explained throughout the progression of the illness. More discussions are warranted about the surrogate and the level of risk that must be calculated while respecting patient privacy.

Summary. No clinical trial, regardless of potential scientific benefit or level of risk that a patient is willing to assume, can compromise the humane care that should always be the foundation of EOL PC research. Advanced illness may require renegotiation of informed consent as well as assurance that strict adherence to a research protocol does not interfere with good palliative or end-of-life care. Bioethics scholars must address the implications of cultural, ethnic, and gender perspectives, which intersect with questions of justice.

Future Directions. The ethical aspects of EOL PC research may warrant special guidelines or restrictions, particularly in relation to scientific conduct, findings, and reporting of those findings. Current research has not fully addressed the significant impact of new technologies on decision making or on the ethical, legal, and social issues relating to patient self determination and consent. Guidelines are needed to address the need for unique design and implementation of EOL PC research, including subject recruitment and retention, consent, the minimization of incremental risks, burdens and distress, the use of placebos, and other factors. Connections should be explored between EOL PC and clinical studies to apply appropriate standards for research while protecting patients, including those willing to assume greater risks to benefit future patients.

II. AUGUST 11, 2011 KEY NOTE, PLENARY AND LUNCH HOUR SESSIONS

OPENING KEYNOTE—TAKING THE LONG VIEW: THE RESEARCH AND PRACTICE INTERFACE

Dr. Ira Byock, Professor and Dorothy & John J. Byrne, Jr. Distinguished Chair of Palliative Medicine, Dartmouth Medical School; Director, Palliative Care Service, Dartmouth-Hitchcock Medical Center

The opening Keynote articulated the ideals and imperatives that are the foundation for research in EOL PC. Attention was given to a broad framework for further discussion and future work that safeguards ethical concerns for vulnerable patients, and ensures the integrity of evidence-based research.

- There are numerous challenges in the provision of palliative care faced by patients and their loved ones. "Caring" is embedded in the human genetic makeup, and "compassion" in its meaning "to suffer with" is both a quality of the excellence of care and the impetus for care.
- While family and communal responses to care gradually matured across the generations, and religion played a role, the medical and nursing professions emerged in early antiquity to provide special expertise and knowledge in service to society; playing important roles in providing the best care to seriously ill or otherwise frail patients. Responsibilities, in addition to the provision of care for these professions included, and continue to include, improvement of care through the conduct of research and social and cultural leadership.
- The scientific roots of this field are deep in nursing and research is essential to establish the field as a legitimate discipline. It is necessary to continue to improve on the models of care delivered to individuals facing serious illness and/or end of life; train those who will continue and expand this field; and pay greater attention to communication as an integral area underlying many facets of research in this field.
- Assessing causal linkages among structural attributes in the settings in which care occurs, the processes of care and the outcomes of care continue to be critical needs. This imperative

includes the utilization of shared decision making techniques as the foundation for informed medical decision making.

Future Directions. Research and practice in palliative care needs to expand in new directions. The issue of access versus quality versus cost should become a synergy of access, quality, and lowered costs. Models of palliative care service delivery should be tested that integrate diagnosis, age, social role, geography, ethnicity, and socioeconomic status. Of critical importance, health care and palliative care communities need to reintegrate the end of life within the fullness of living. Success will occur to the extent that medical, nursing, psychology, and social sciences are brought within a true science of compassion with intellectual excellence, ethical integrity and love.

PLENARY SESSION 1: IDENTIFYING OUR STRENGTHS

Plenary One examined the progress made in EOL PC research through the lens of four presentations and discussant comments. Progress made in these critical areas of research is the springboard for future research endeavors.

Presentation 1: Symptom Trajectories, Palliative Care, and Quality of Life

Dr. Christine Miaskowski, Professor, University of California, San Francisco SON

- A key issue in symptom management research is the understanding of multiple symptoms. A patient never presents with a single symptom, and many symptoms in palliative care patients remain unrelieved.
- Another critical challenge is presented by variability in both research and clinical practice. Patients can have similar symptoms, but they differ in their response to treatment. This variability presents *opportunities* in research, such as differentiating patients by phenotype and identifying those with higher risk of poorer outcomes so that greater economies of scale can be yielded for treatment regimens.
- Substantial gaps in the literature include a preponderance of cross-sectional, rather than longitudinal studies. Pain, dyspnea, and nausea are the three most common symptoms examined and a more comprehensive set of symptoms is needed. Studies of patients with single and multiple symptoms based on phenotypic and genotypic perspectives may contribute to improved design of intervention studies.

Presentation 2: Integrating Palliative and Critical Care: Focusing on Communication

Dr. J. Randall Curtis, University of Washington; Harborview Medical Center

- A significant proportion of deaths in the United States occur in the intensive care unit (ICU), with high rates for very young patients. Communication is primarily with the family, as fewer than 5 percent of patients can participate in ICU decisions about withholding treatments. Thus, families suffer from immense burdens of anxiety and even depression, and rank provider communication skills as higher in importance than clinical skill. Shared decision making should balance clinician expertise and family preferences.
- Integrative models are needed among palliative care consultants and ICU clinicians. Needed are communication skills training; improved communication between patients, families, and interdisciplinary care teams; frequent and better patient and family shared decision-making; and, utilization of advance care planning.

- A communication research agenda is needed for continuation of improvements including measures and methods, particularly outcome measures; study designs and implementation tools; the development and testing of interventions that improve communication and shared decision-making; an increased use of Phase 2 trials; and, testing of models of care and greater emphasis on the interdisciplinary clinical and research team.

Presentation 3: The Child’s Voice in Palliative and End-of-Life Research

Dr. Pamela Hinds, Children’s National Medical Center; George Washington University

- The “child’s voice” during EOL PC involves a direct report using qualitative and/or quantitative approaches to convey the child’s experience. Children tend to report in the context of their concern for family and clinicians to whom they have become attached.
- The child’s voice is thus beneficial in research and care as it provides a more accurate symptom and quality of life report that could impact therapy, care, and the patient’s and parent’s trust of clinicians and satisfaction with the care given. In addition, several reports indicate that parent satisfaction with EOL care and trust in the clinical team is higher when parents believe that the child’s voice has been considered.
- The definitions of the “good dying child” and the “good clinician to the dying child” have not been fully explored and the tension that occurs between family, child, and clinicians warrants study. A seven-site study with an established instrument that measures toxicity of treatment (CTCAE) is being conducted with the hypothesis that the child’s voice may contribute to the report regarding adverse events, toxicities, and symptoms.

Presentation 4: Models of Care in Palliative and EOL Care: The Impact of Early Palliative Care

Dr. Jennifer Temel, Harvard Medical School; Mass Gen Hosp Cancer Center

- Early integrated palliative care is a feasible and potentially beneficial model of care for patients with advanced lung cancer. These patients experience high physical and psychological symptom burdens. Many patients with advanced illnesses tend to have a limited view about their illness and prognosis; this is problematic because their perceptions of these elements impact their decisions about their EOL care.
- Recent research has found that patients randomized to early palliative care had a significantly higher quality of life score than those in standard care. Differences in mood also were shown in this study.
- Gaps in current research that need to be addressed include determining the nature of the palliative care intervention; examining the variability between care providers, sites of care, and diseases; assessing whether the effects of early palliative care provided to some cancer patients are generalizable to other advanced disease populations; outcome measures that are better understood; and, the cost-effectiveness of early palliative care.

Summary and Future Directions: Plenary 1: Identifying Strengths

Critical Illness, Ethics, Patients and Families Facing Palliative Care and End of Life

Dr. Robert S. Krouse, Southern Arizona Veterans Affairs Health Care System

- There remain multiple perceived barriers related to palliative care research, including ethical, cultural, and population barriers, as well as resistance in the medical and funding communities. Other obstacles may include endpoints and the difficulty of the randomized trial in palliative care research.

- Perceptions can be overcome and barriers can become strengths in EOL PC research. Advantages in EOL PC research include the interdisciplinary team approach; short timeframe to endpoints; and many outcomes available to study, such as communication, quality of life, surrogate endpoints, economic factors, survival issues, and caregiving and care delivery.
- Fields that do not prove interventions through randomized controlled trials, the standard to judge effectiveness, are at risk of being relegated to a second-class status in the medical hierarchy. Nevertheless, the EOL PC community has been able to initiate prospective trials and use alternative methods and statistical techniques to reach important outcomes.

LUNCH SESSION: PARENTS AND CLINICIANS AS PARTNERS IN RESEARCH

Ms. Dianne Gray, Hospice and Healthcare Communications; Dr. Cynda Hylton Rushton, Johns Hopkins University

A special lunch hour presentation supported by the NIH Office of Rare Diseases Research featured an advocate parent and a leading pediatric researcher. With approximately 260 audience members, the presentation focused on how consumer-researcher partnerships might improve the design and the conduct of science, create educational initiatives, and increase the quality of and family satisfaction with palliative and end-of-life care.

- Families with children who have life-limiting illnesses want to work with clinicians and palliative care teams, but parents will protect their children if they feel anything is threatening the child or the family. Enrollment in research is influenced by a desire to both benefit them and help others. Such participation is a way for parents as a collective group to share what is happening in their suffering.
- Families teach clinicians and researchers things that cannot be learned from interval appointments and share their most intimate stories and possessions, and contribute an important voice to developing research priorities. The synergy between the family and clinician/researcher lies in the shared goal of improving QOL and finding a cure. It is a mutually dependent relationship in which one cannot be fully successful without the other.
- There often is a clash of cultures as patients and families search for meaning and benefit and researchers seek knowledge. Many of the challenges to developing authentic partnerships are based on fear of losing control, but when these different perspectives converge, a relationship is built in a fragile trust. There are potential conflicts of interest that are very much intensified when a clinician is also a researcher. Families may nurture therapeutic misconceptions that participation in a clinical trial offers hope, however remote the possibility, of a cure or benefit for their child; they also may fear abandonment, inferior treatment, or disregard of their concerns if they decline to participate.
- Other challenges to authentic partnerships involve ethical considerations and biases in defining research questions. Family members are oriented toward protecting their children and speaking as a surrogate for that child. Clinicians must do no harm and work to benefit their patients. These ethical imperatives can lead to unjustified paternalism—that is, protecting families in research because of fears and concerns about the fragility of their involvement. In addition, researchers wish to protect autonomy and informed choice; this can narrow the questions asked, result in missed opportunities to improve QOL on a daily basis and to observe the variability and individual experiences of families living with dying, and disregard the goals of families who are no longer seeking cure.

Future Directions. Opportunities for collaboration exist in the design of research, education for researchers and family members, dissemination, and funding partnerships. Community-based participatory research offers a way to achieve authentic partnerships between patients and family members with clinicians and researchers. Ideas to consider in collaborating in research design include equal partnerships in all phases of research, enhanced relevance of research for patients and their families, recruitment of research subjects, and informed consent processes. Notions of informed consent could be expanded beyond the rational aspects of informed consent to incorporate timing and the emotional tenor of the people who are living in a time of great stress. In addition, relationships with funders can be leveraged to create funding streams for the research that families and clinicians care about and that advance EOL PC knowledge and delivery.

PLENARY SESSION 2: MARSHALLING OUR RESOURCES

Plenary Two focused on the need to integrate resources, build capacity, develop connections, and move individual research forward such that the sum of the whole is greater than its parts.

Presentation 1: Integrating Mind and Body - Key Issues in Palliative and End of Life Care

Dr. Jeff Dusek, Abbott Northwestern Hospital, Allina Hospitals and Clinics

- Palliative care is a holistic approach that seeks to provide the best possible quality of life for EOL patients and their families.
- Observational approaches should help researchers understand what has worked and what components need to be studied in a controlled fashion that can then move directly into clinical practice. In addition to the quantitative component of data collection, providers note qualitative observations in narrative form thereby allowing researchers to use mixed-model approaches and identify specific attributes of individuals at the end of life who respond differently to different interventions and pain and anxiety outcomes.
- Integrative therapy can serve as an effective model for palliative care and provide alternatives to typical pharmacologic agents in the reduction of pain.

Presentation 2: Economics of Care - Special Considerations in Palliative Care for Complex Comorbidities and End of Life

Dr. Joan Teno, Brown University

- Recommendations to advance research in palliative care for complex comorbidities and EOL in the current economic downtime are to: (1) invest in junior investigators; (2) understand and intervene on geographic variation, recognize that the issue is multifaceted, and consider how to combine these changes with policy; and, (3) develop the evidence base to determine who can be randomized.
- Tremendous regional variation exists across the United States in ICU use during the last 6 months of life, with the heaviest use in the southeastern half of the country. Various hypotheses try to account for this variation, including diet and diseases, racial compositions, and poverty levels.
- The decision to insert a feeding tube in nursing home residents with advanced dementia depends more on the hospital to which the patient is admitted than a decision-making process that elicits and respects patient choice.

- Strategic consideration of future research must remain patient centered with investment in junior investigator. Use of administrative databases with appropriate accounting methods to control for selection bias can help improve knowledge and monitor the implementation of interventions in the real world without harm.

Presentation 3: POLST - Evaluating a Clinical Innovation

Dr. Susan Hickman, Indiana University Fairbanks Center for Medical Ethics

- The Physician Orders for Life-Sustaining Treatment (POLST) Program began in Oregon in the early 1990s as a way to confront a lack of communication about treatment preferences. Its use has spread methodically across the United States during the past decade, sometimes under modified names (e.g., MOLST, POST, and COLST).
- Lessons learned from the POLST Program include strategies for working with multi-state teams, including the value of in-person meetings. There also are issues of capturing detail versus promoting efficiency.
- Areas for further work include determining whether the POLST orders truly reflect patient preferences; the national POLST Task Force is recommending now that states require a patient of surrogate signature on the form. In addition, there are some limits in generalizability, questions about the continuity of care throughout the health care system, and the need to have a standard definition of comfort. There are significant policy implications to the findings, and the national POLST Task Force has been working individually with states for implementation of the POLST form.

Presentation 4: Marshalling Care – Integrating Palliative Medicine into Oncology Practice Individually and Organizationally

Dr. Jamie H. Von Roenn, Northwestern University Feinberg School of Medicine; Robert H. Lurie Comprehensive Cancer Center Cancer Control Program

- Personalized medicine in oncology care focuses on basing the goals of treatment on the molecular characteristics of the tumor. However, personalized medicine overall is about the person and so should consider the targeted therapy at the tumor in the context of the individual patient and his/her roles, social interactions, and goals of therapy.
- The entire continuum of cancer care, including disease presentation, survivorship, recurrence, chronic disease, increased debility, and last days of life, is appropriate for palliative care. Challenges in palliative care include who will provide the care, particularly for a growing aging population.
- Another challenge is presented by the significant resistance to palliative care that continues within the oncology community; there continues to be a misconception that palliative care is EOL care, especially in the oncology setting.

Summary and Future Directions: Plenary 2: Marshalling Our Resources Palliative Care and End-of-Life Care Research - The Views from 3000 and 3 Feet

Dr. Chris Feudtner, University of Pennsylvania

- There are many different ways to consider how to conduct palliative care research. From this perspective, the palliative care agenda needs more resources, and the existing resources must be used more effectively. To be effective in research or in one's program evaluation, one must study the target audience to determine how best to persuade them through the data or

information brought forward. The value proposition in EOL PC research is articulated through the mission of enhancing the quality of life of persons affected by serious illness.

- There is need for more evaluations of competing theories and fewer specific aim hypotheses, as well as a move beyond the “what” to the “why” and “how”; to revisit basic science and basic assumptions; borrowing and building on ideas from other cohorts and fields, such as the social sciences; and using a mixed-method research agenda that combines quantitative and qualitative methods.
- The research community should continue to train young investigators with the knowledge to challenge existing ideas. The EOL PC community has wonderful strengths, including its patient and family focus, and commitment to advancing research on behalf of patients and their families.

III. AUGUST 12, 2011 BREAK-OUT SESSIONS, PLENARY AND CLOSING KEYNOTE

BREAK-OUT SESSIONS

This session featured reports from ten breakout sessions as key topics in palliative care and end-of-life research and practice.

Aging and Quality of Life

Dr. Christine Ritchie, University of Alabama at Birmingham

- Many of those experiencing serious illness and EOL are more than 65 years old. There is an inadequate understanding of quality of life in this age group, and measurement can be difficult in the older population because of sensory and cognitive issues.
- A number of questions need answers, including: What is quality of life? The term can be amorphous. How does quality of life vary by characteristics? What is old? Should aging be defined biologically or chronologically? What measurement tools are valid and reliable? How should changes in quality of life be accounted for over time? What is the impact of technology in quality of life assessment? The issue of aging and quality of life matters because there are a large proportion of older adults with chronic illnesses who are costing a large amount of dollars.

Communication and Advance Care Planning

Dr. Deborah Waldrop, University at Buffalo School of Social Work

- A confluence of forces has resulted in the increased use of advance care planning, including advances in medical technology, and historical, social, political, and economical contexts. Technology has brought to the forefront the possibility of “medicalized” death and raised expectations about what are possible vs. desired by patients and their families.
- Among the challenges facing advance care planning are significant shortcomings in communications and the frequency of aggressive treatment. Patients desire clear, consistent communication from providers. Work in advance care planning thus far has shown that good communication improves patient outcomes. However, there is wide variability in state and organizational policies regarding advance directives.

Complex Co-Morbidities in EOL PC

Dr. Steven Albert, University of Pittsburgh; Dr. James Tulsky, Duke University

- Approximately 75 percent of dying patients are over 65 years old and many have multiple conditions: serious illnesses often coexist with other morbidities. Complex comorbidities at EOL should be studied.
- A significant issue in researching EOL comorbidities is that patients are categorized into separate disease groups, which makes studying the interrelationship challenging. For patients, however, the most pressing concern often is that which affects function and quality of life; except for cancer, patients do not usually self-define by illness.

EOL PC and the Caregiver

Dr. Deborah McGuire, University of Maryland

- The majority of research about the informal caregiver is descriptive, divided between qualitative and quantitative studies, which are challenged with small samples and single settings, and generally retrospective in nature. In addition, quantitative studies often lack a conceptual foundation. A smaller amount of research addresses pilot or full-scale interventions and measurement tools. The collective body of research offers a solid foundation for the development of interventions to help caregivers.
- Numerous issues face research. Few interventions have been tested or found efficacious. Longitudinal, trajectory-based studies that include the perspectives of both the patient and the caregiver are needed. One topic that has been notably neglected is caregivers dying before the patient does. In terms of the delivery and costs of care, models of care should be tested, and professional caregivers further educated. Transitions for patients and caregivers within and across settings also should be examined.

Methodological Issues in EOLPC

Dr. Amy Abernethy, Duke University

- Methodologies in EOL PC can be considered and advanced in a myriad of ways. Advocacy is needed to ensure that palliative care methodologies are embedded in peer review study sections. Careful thought should be given regarding the mentoring of developing and junior investigators to ensure an appropriate workforce is trained. Moreover, methodologies should be published and knowledge shared to create the literature base to support the work in this field.
- Gaps should be identified through a repository of research questions, and the current state of research should be captured and made available via *clinicaltrials.gov*. Methods related to outcomes, multi-morbidity, recruitment, and attrition could be expanded; missing data and determination of a baseline also should be considered.

Pain and Symptom Management

Dr. Kathleen Puntillo, University of California, San Francisco

- Researchers have made an amazing number of discoveries regarding pain during the past 30 years, and the community now has a basic understanding of pain and symptom management. However, gaps in research remain, such as the insufficient characterization of pain and symptom phenotypes, longitudinal effects, mechanisms, and variable responses to treatment, insufficient characterization of the variable responses to treatment, or factors influencing the effectiveness of pain medication. Other issues warranting further research

- are the limits of self-care interventions in palliative care as well as pediatric responses to therapeutics, such as label analgesics for children.
- Foundational concepts based on biological and behavioral theories are needed. They could be focused on neuropathic pain, for example, or determine how current knowledge might be better applied, such as through thirst interventions.

Pediatrics/Perinatal Issues

Dr. Joanne Youngblut, Florida International University

- Children are not in the forefront of EOL research, but more than 40,000 die in hospitals each year. Study samples have been small and heterogeneous. The age at the time of death can range from fetal to adulthood. A heavy sampling bias exists, as most recruitment for trials occurs through support groups, concerned friends, and the like. Most studies are retrospective, even many years following the child's death; some IRBs withhold approval to talk with parents within the initial 6-month timeframe following death.
- There also is limited research on health and functioning. Mothers are the most often studied as a group, and understudied groups include fathers, grandparents, and siblings. Non-White, non-English speaking persons also are not well studied. Next steps in pediatric and perinatal research include a need for stronger, longitudinal designs, greater cultural diversity, a focus on omitted groups, inclusion of multiple family members to study within-family variance, and triangulation of qualitative and quantitative data from both the child and the parents.

Psychosocial, Cultural, and Spiritual Aspects of EOL Care

Dr. Bronwynne Evans, Arizona State University College of Nursing and Health Innovation

- Research on informal family caregiving has become more prominent since 2006. The research has been driven by “concrete universals” or common ideas drawn from an historical context: the integral relationship of spirituality and religion with culture and ethnicity can assist in trial recruitment, retention, and behavior change.
- These cultural and other elements are both barriers and nuances to care, as evidenced by the Hispanic population's espousal of “marianismo.” By knowing familial culture, researchers and providers can employ culturally based communication to meet needs respectfully. Informal family caregiving is not new. Nursing homes are relatively new, and recent economic factors likely will drive an increase in home care. The more optimal home death experience lies in the preparation of family caregivers in their roles in EOL. Important questions include: When does EOL care begin? What opportunities can help direct individuals toward community assistance and support? Future research should be theory based, prospective, and longitudinal, and it should adopt multi-method data collection strategies.

The Era of “E” – The Use of New Technologies in EOLPC

Dr. Michael Green, Penn State University

- Technology is a tool that can be used to improve EOL PC, and many new technologies are available. Advance care planning can be supported by a number of technologies and can help overcome multiple challenges facing the EOL PCL community. Dependency on technology can be limiting, however, as patients' stories can be lost through system failure.
- Research is needed regarding the use of technology to reduce suffering and pain in patients and caregivers. Studies also could evaluate the impact of technology in the home setting,

determine patient preferences for technology, and harness technology to improve the quality and safety of care.

PLENARY SESSION 3: MOBILIZING FOR THE FUTURE

Plenary Session Three presented ways that we collectively can focus our efforts for the future of EOL PC research and care by utilizing the unique resources developed as a result of ongoing capacity building endeavors.

Presentation 1: The Palliative Care Research Cooperative Group (PCRC) - A National Collaborative Approach to Palliative Care and End of Life Research

Dr. Amy Abernethy, Duke University

- The Palliative Care Research Cooperative (PCRC) is an endeavor initiated in 2010 in recognition of palliative care as a legitimate health subspecialty. It was a response to the rising prevalence of chronic illnesses, the needs of an aging population, and the historical paucity of both research and research capacity to support palliative care practice. The PCRC's vision incorporates best evidence and a scientific underpinning 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; and palliative care enhances living.
- The goals are to develop a cooperative group based on the scientific areas of palliative care and end of life, demonstrate the feasibility of conducting RCTs in palliative care, and develop metrics to facilitate research in the field.
- The PCRC is developing processes and procedures that will serve as a how-to manual for members, using process mapping and metrics to facilitate efficient operations within the group, encouraging cross-linking among sites, and considering the best ways to design and use the emerging data structure. Additional components for PCRC sustainability include the development of a workforce cadre by engaging junior investigators into PCRC activities and making the resource available for external investigators.

Presentation 2: Palliative Care Interventions and Clinical Outcomes

Dr. Marie Bakitas, Dartmouth Institute for Health Policy and Clinical Practice

- The Educate, Nurture, Advise, Before Life Ends (ENABLE) Project is an RWJF-funded study of palliative care for advanced cancer patients in various settings. Because hospice is not accessible to all persons in need and improvements to inpatient EOL care will not avoid hospitalized death, ENABLE focused on interventions to prevent or detect crises before hospitalization.
- ENABLE was feasible, improved communication, decreased rates of hospital death, and increased the rates of advance care planning. ENABLE provided an in-person, psycho-education intervention that worked with patients and families on charting their EOL course along with family bereavement issues. Further study is needed to improve symptom intensity. Concerns that palliative care might shorten survival are unfounded, and estimates of survival suggest an ameliorating effect.
- Areas for future research include assessments of mechanisms and improvements among caregiver outcomes, including adverse caregiver bereavement issues. Key steps include identifying mechanisms and theories, measuring targets, and fostering multi-institutional collaboration.

Presentation 3: Mobilizing for the Future - Biobehavioral Issues in Palliative Care Research

Dr. Jean Kutner, University of Colorado School of Medicine

- Biobehavioral science explores the links between biology, physiology, psychosocial, behavior factors, and health or health outcomes, including quality of life. Understanding the complexity of biological, behavioral, and social risk factors will help researchers, clinicians, providers, and others improve palliative care-related outcomes in a plethora of populations and settings.
- This complex interaction has been examined in various trials that provide models for palliative care, including studies of pain, cortisol, proinflammatory markers, and prognosis of heart failure. Pain varies greatly by individual and over time and encompasses both psychological factors and physiological responses. It is poorly understood, and biological, cognitive, sociocultural, socioeconomic, and environmental components influence a patient's perception of pain. Studies of the cortisol awakening response found that an increase in the hormone following waking is positively associated with stress and negatively associated with fatigue, exhaustion, and posttraumatic stress syndrome.
- Barriers to conducting biobehavioral research include defining the clinical relevance through longitudinal changes, making validated links between biologic markers and outcomes, and understanding individual differences.

Summary and Future Directions: Plenary 3: Mobilizing for the Future

Dr. June Lunney, Hospice and Palliative Nurses Association

- Palliative care practice follows the trajectories of death; it is not a one-size-fits-all process. Some patients and families have advanced warning about EOL; others, such as organ transplant recipients, may experience many misses, which affects how decisions are made and care is managed. Others approach EOL by virtue of their age.
- The three professional groups devoted to EOL—palliative care teams, hospices, and advanced illness teams—should collaborate fully to improve the interface of practice and policy for dying patients and their families.
- Palliative care is a field that encompasses the paradox of living and dying at the same time. Compassion involves understanding the unique and complex aspects of family dynamics during the dying process. The goal of the science of compassion is to ensure that the appropriate support teams are with patients as they journey through life's health stages, including the time as they are approaching EOL.

V. CLOSING KEYNOTE – SCIENCE OF COMPASSION: FUTURE DIRECTIONS IN PALLIATIVE AND END-OF-LIFE CARE

Dr. J. Randall Curtis, University of Washington

The Closing Keynote addressed issues raised during the Summit in terms of the strengths, resources, and future of scientific research in EOL PC using the framework of the plenary session themes to review the Summit sessions.

- The majority of Medicare spending is provided to patients with more than five chronic conditions; multiple conditions or comorbidities influence patients significantly at the end of life, and research is beginning to examine this area.
- Opportunities have been created by the electronic health record, which increases access to administrative data and will allow researchers to better understand what patients and families

are undergoing. Other technologies also can be drawn upon to improve the health of patients and their families, such as the Web, smartphones, electronic social networking, and telehealth. Pertinent innovations from other fields should be adopted and adapted to EOL PC, including methods, statistics, and biomarkers that can identify patients and families at risk for poor outcomes, studies on models of care, as well as advances in genomics, proteomics, and other “omics.”

- Palliative care scientists should focus on the quality of the science. The community should serve on study sections and educate the importance of the public as a voice in palliative care and palliative care research.
- The next generation of scientists should be developed and nurtured. Finally, collaboration with scientists from other disciplines should be promoted to enhance research training.

POSTER SESSION AWARDS

Top Junior Investigator Award

*Cynthia Ellis Keeney, MSN, RN of the University of Louisville School of Medicine
The Impact of a Telehealth Intervention on Symptom Burden and Quality of Life for Head and Neck Cancer Patients.*

Third Place

*Dr. Debra Parker-Oliver of the University of Missouri Department of Family and Community Medicine
Preliminary Results of the ACTIVE Randomized Trial*

Second Place

*Dr. Sharon Hewner of the State University of New York at Buffalo School of Nursing
Improving Care Transitions and Care Coordination in Frail Elders at the End of Life*

First Place Award

*Dr. Karen E. Steinhauer
Burden and Well-Being among Long-Term Caregivers*

This award recognizes the efforts of a team of researchers from Duke University, the Durham VA and Medical Center, MD Anderson, and the University of North Carolina at Chapel Hill, under the direction of Dr. James A. Tulsky.

APPENDIX: PLANNING COMMITTEE

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