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Palliative and End of Life Care Research: Embracing New Opportunities

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I. Introduction

The past two decades have witnessed dramatic advances in palliative and end of life care research. Not only have these advances increased our understanding of the burden of life-limiting diseases on patients, families, clinicians, and our healthcare system, they have also documented that palliative care interventions can improve patient and family outcomes and reduce the costs of care (Detering, Hancock, Reade, and Silvester, 2010). The advances brought about by palliative and end of life care research...has led to a new era of palliative and end of life care research and practice with widespread recognition of its accomplishments and successes. Consequently, we now have an important opportunity to reassess our recent successes and challenges and to identify the goals and benchmarks that will ensure ongoing robust advances in this now recognized and critical scientific area. We must identify and disseminate standards for research, critically examine methods to effectively advance research and practice, and develop and adopt strategies, tools and models that allow timely translation of research evidence into practice. It will be through such efforts that we will be able to respond to the opportunity to create a science that transcends disciplines and effects improvements in the quality or length of survival for patients with life-limiting diseases, and their care-givers, families, and formal care providers.

High quality palliative and end of life care will be best informed by methodologically strong research efforts that generate a strong and robust body of evidence. Developing such an evidence base is a necessity not only due to its capacity to support and direct care, but also to effect changes in practice. As a corollary, when translating evidence into practice, it is critical that research findings from studies in palliative and end of life care be reliable, valid, and generalizable. Such research should incorporate rigorous study designs that address potential limitations, develop and examine meaningful research questions and research domains, mitigate bias or error, ensure quality control, and support the formation and catalyze the efforts of teams of transdisciplinary researchers.

It is in this context that the National Institute of Nursing Research (NINR) conceptualized and led a Summit entitled “The Science of Compassion: Future Directions in End of Life and Palliative Care Research,” in August, 2011, in collaboration with several partner Institutes and Offices across the NIH. Leading scientists in the field were charged with assessing gaps in knowledge and propose future areas of inquiry reflecting key domains of

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palliative and end of life care research. In addition to plenary sessions, breakout sessions on specific topics examined the state of the science relating to each area and identified avenues for future research. Six of these were selected as articles for this Special Issue of Nursing Outlook. In this summary article, we present brief overviews of these articles, examine their key conclusions, articulate gaps and needs, and discuss next steps in palliative and end of life care research through the lens of these six topics.

II. Overview of Breakout Session Topics

A. Psychosocial, Cultural, and Spiritual Aspects of End of Life [Health Disparities]

In their paper, Drs. Evans and Ume (ref Sp Issue) present a thoughtful review of health disparities in the context of palliative and end of life care research. They note that while health disparities are quite well-documented, the extent to which they affect end of life care is unknown. This is a key limitation that future work must address. They observe that the limited existing research consists of sparse, often contradictory findings (Evans, Coon, & Ume, 2011), and that there are few studies on causal mechanisms (Carr, 2011). Evans and Ume's paper presents an important exploration of the psychosocial, cultural and spiritual disparities existing in palliative and end of life care research that is based on reviews of the recent literature from multiple databases. An important conclusion is that minorities appear to make less use of hospice, often because of lack of knowledge, family-centered cultures, and preferences for more aggressive end of life care than hospice allows, in addition, culturally mediated beliefs appear to impact uptake of palliative and hospice care, and openness to research participation. These represent important issues that future interventions need to incorporate and address.

Areas for future research include the need to search for theoretical and causal mechanisms that underlie outcomes; and to develop and implement prospective longitudinal investigations designed and powered to meaningfully include diverse patients, conditions, contexts, and settings (Evans et al., 2011). Methodological rigor and the interface with and impact on concepts such as diversity are key questions for researchers to incorporate in order to develop culturally appropriate study designs and interventions. An integral relationship between spirituality and religion with culture and ethnicity is another important finding (ref. this article). Understanding this relationship may facilitate subject recruitment, retention, and behavior change. Since cultural elements are both barriers and nuances to care, understanding these may facilitate respectful communication (Johnson, Kuchibhatla, Tulskey, 2009).

B. Pain and Symptom Management in Palliative care and End of life

Drs. Wilkie and Ezenwa (ref Sp Issue) have reviewed the literature on pain and symptom management in palliative and end of life care since 2004. They have found many symptoms to be inadequately assessed or managed especially among ethno culturally diverse groups. The need for broader conceptualization and measurement of pain and other symptoms as multidimensional experiences is noted. In addition, authors note, based on their review, that insufficient evidence exists regarding mechanisms underlying pain and other symptoms at the end of life. Advances have occurred regarding the knowledge of pain as a multidimensional experience, and the authors note that many symptoms co-occur with pain. However, gaps remain (Wilkie, Berry, Cain et al. 2010). The authors articulate that many studies elucidate characteristics of symptoms in those with life-limiting diseases and a variety of interventions that can reduce them. While adequate symptom management is an essential component of palliative and end of life care, this is usually being done at the same time as aggressive disease management (e.g., cancer chemotherapy) (Garrison, Overcash, & McMillan, 2011).

The authors also find that many barriers interfere with the symptom management process. Patient related barriers include patient misconceptions, fears and concerns, reluctance to report symptoms, and complexity of the symptom experience. Other barriers relate to providers' lack of knowledge, skills and time for adequate symptom assessment interventions. Health system-related barriers that impede symptom management include clinicians placing low priority on symptom management, lack of reimbursement and access to care issues, and restrictive regulation for some therapies. Co-occurring multiple symptoms present another challenge (Dy, 2010). Although a nurseled palliative care intervention compared to usual oncology care improved quality of life and depressed mood for patients with cancer, other symptom outcomes were not significantly improved (Bakitas et al., 2009), indicating the challenges in pain and symptom management. The science of symptom management and clusters in palliative and end of life care is progressing, but slowly, and improvements that address ongoing gaps in knowledge and the barriers articulated in this overview are needed.

C. Perinatal and Pediatric Issues in Palliative and End of Life Care

Drs. Youngblut and Brooten (ref. Sp Issue) provide an informative review of the state of perinatal and pediatric palliative and end of life care science and practice. They highlight many unique and important aspects of research in this field and draw attention to new and emerging areas of study, including: prenatal and antenatal demise, the complexities of holistic pediatric symptom management, incorporating family systems approaches as part of comprehensive palliative and end of life care, and early integrated palliative and critical care for infants and children. The child and family unit necessitates thoughtful recognition of the emotional and psychosocial experiences of living with a child facing a life-threatening illness and careful attention to compassionate support for a myriad of stressors occurring within the family (IOM, 2003; Escibano & Aremi, 2012). This review provides a framework for future research in pediatric palliative and end of life care research. Additional data are needed in areas such as progressive decline, non-progressive frailty, or adolescence/young adulthood) (Randall, Cervenka, Arday, Hooper, & Hanson, 2011; Knapp & Madden, 2010). Future efforts must strengthen provider communication and listening skills incorporating the parents', families' and children's beliefs, problems, resources, and culture into the context of shared care decisions (Hexem et al, 2011; Knapp, Madden, Wang, Curtis, Sloyer & Shenkman, 2011). Priorities include developing demonstrable indicators of quality improvement across diverse pediatric illnesses, and assessing the impact of ethnicity, and also culture and provider settings (ref IOM report).

D. Palliative Care and End of life: The Caregiver

McGuire, Grand and Park (Ref Sp Issue) provide a comprehensive review of informal caregiving and articulate a vision of future priorities to strengthen the next generation of research. Authors describe an evolving area of study, predominantly descriptive, that focuses on informational, educational, and support needs of caregivers, and highlight the paucity of tested interventions and validated measures of caregiver burden. Health care planning for individuals with serious illness must attend to the needs of the informal caregiver since different individuals require a different, perhaps varying range of social, emotional, and spiritual supports that reflect personal values, beliefs and needs (Reinhard, Danso-Brooks, & Kelly, 2008; IOM, 2008).

Larger research studies with robust designs must reflect these needs and look beyond evaluation of the spouse to an extended network of caregivers, including communities, friends, and neighbors. The individual, sometimes conflicting, values, needs, and skill sets these 'caregivers' bring must be understood, including how the caregiving process (throughout the entire illness experience) influences the care provided. Such work can shift

research beyond preliminary to more advanced foci such as evidence-based, quality standards of practice; integrated preventative screenings; self-management training; measures that evaluate individual-caregiver centered health risks and consequences; and, interventions that improve the quality of caregiving (Reinhard, Danso-Brooks, & Kelly, 2008; IOM, 2008).

E. Advance Care Planning and Communication About End of life Care

Waldrop and Early (ref Sp Issue) review the current literature on advance care planning and communication about end of life care. Many studies document that the quality of clinician communication about end of life care remains poor, including discussions about prognosis, (Fried, Bradley, & O'Leary, 2003; Christakis & Lamont, 2000) advance care planning, (Tulsky, Chesney, Low, 1996; Tulsky, Fisher, Rose, & Arnold, 1998; Fisher, Tulsky, Rose, Siminoff, & Arnold, 1998) and shared decision-making (White, Braddock, & Bereknyei, & Curtis, 2007). These findings hold true for physicians and nurses (Bradley, Cherlin, McCorkle, et al., 2001). Early studies of interventions to implement advance directives – the precursor to advance care planning – were not successful at changing the care patients received (Schniederman, Kronick, Kaplan, Anderson, & Langer, 1992; Danis, Southerland, Garrett et al., 1991) and the landmark SUPPORT study did not show benefit of an intervention designed to improve communication about end of life care (SUPPORT, 1995). These negative studies raised concerns that interventions to improve advance care planning and communication about end of life care were unlikely to be successful. However, more recent studies have shown that communication about end of life care among patients with cancer is associated with increased quality of life as well as reduction in the use of intensive life-sustaining treatments and reduced healthcare costs at the end of life (Wright, Zhang, Ray, et al., 2008; Zhang, Wright, Huskamp et al., 2009; Hammes, Rooney, & Gundrum, 2010). A recent randomized trial of hospitalized patients over age 80 showed that advance care planning was associated with improved quality of life and reduced ICU use at the end of life, as well as reduced psychological symptoms among family members (Detering, Hancock, Reade, Silvester, 2010). However, this intervention required that a trained advance care planning facilitator spend a median of an hour with each patient. Translating these recent successes into clinical practice remains challenging. A number of studies also suggest that interventions to improve clinicians' skills at communication about end of life care can be successful, as demonstrated by improved patient and provider satisfaction with the communication and other outcomes. (Au, Udriș, Engelberg et al., 2012, In Press; Fallowfield, Jenkins, Farewell, Saul, Duffy, & Eves, 2002; Back, Arnold, Raile, et al., 2007; Tulsky, Arnold, Alexander et al., 2011). However, these are often time-consuming and resource-intensive, and we need a larger body of evidence to show effectiveness. (It seems as if the two highlighted statements immediately above contradict each other or am I missing something?)

Next steps needed for research concerning advance care planning and communication about end of life care are broad. We need ongoing studies of the basic mechanisms for improving communication and decision-making about palliative and end of life care in order to improve patient and family understanding and involvement. These studies should include diverse patient populations including diversity in race/ethnicity, education and socioeconomic status, health literacy and numeracy, and disease characteristics. Importantly, we also need studies that test the effectiveness of these interventions at improving patient and family outcomes and studies of models for implementing advance care planning and communication about end of life care in routine clinical practice in a cost-effective way.

F. The Use of Technology in Advance Care Planning

Green and Levi (ref Sp Issue) review the state of the science for applying technology to help patients and family members engage in advance care planning. There have been a number of efforts to use technology that include computer-based reminders for physicians, interactive decision and documentation guides for patients and families, and web-based repositories of advance directives (Dexter, Wolinsky, Gramelspacher et al., 1998; Heiman, Bates, Fairchild, Shaykevich & Lehmann, 2004; Tung, Vickers, Lackore, Cabanela, Hathaway, & Chaudhry, 2011; Green & Frost, 1997; Green & Levi, 2009). While these technological systems present great opportunity, and many of them have been evaluated for their ability to enhance completion of advance directives, few of them have been evaluated for their effectiveness at improving patient and family outcomes and none have been evaluated for cost-effectiveness. Authors identify a significant risk of these technologies – they may be developed but then not updated and maintained in a way to ensure they achieve their intended effect – making advance care planning information available when it is needed for clinical decision-making.

The next steps for the science of using technology for advance care planning is similar to the next steps for the broader field of advance care planning. We need ongoing studies to identify the best ways to develop, validate, and use these technologies to ensure diverse patients and families are able to fully understand and participate in advance care planning. We also need studies to identify the effectiveness of these technologies for improving patient and family outcomes and studies that identify the most cost-effective models for implementing and maintaining these technologies in routine clinical practice. Ongoing advances in the electronic health record create both opportunities and challenges for integrating advance care planning technologies and this represents an important area for future study and evaluation.

III. Discussion

Important advances have been made in palliative and end of life care research relating to the six research areas included in this special issue. The NINR remains committed to comprehensive research strategies that build the capacity to affect improved health and health outcomes among those diagnosed and living with serious or advanced life limiting diseases and their caregivers. Many studies have documented the adverse outcomes associated with life-limiting diseases and others have tested intervention strategies to enhance the quality or length of life of those living with and dying from serious, advanced illness. Designated in 1997 as the lead NIH Institute for end of life care research, NINR supports an integrative program of research in palliative and end of life care issues including a new Palliative Care Research Cooperative, and has sponsored numerous research initiatives on a wide range of topics in these areas.

Much needs to be done in a number of key prioritized research areas in palliative and end of life care. This is especially true in the realms of health disparities research, communication and decision making, and the development and testing of, or the assessment of barriers to, models of optimal palliative and end of life care. The impact of bio-behavioral factors on palliative and end of life care outcomes remains an emerging area that must be examined, along with interventions that mitigate adverse outcomes of Life Limiting Diseases and ways to disseminate research into practice settings. Achieving success in these domains of research will ultimately enhance the quality and length of survival of those facing such life-limiting diseases, and their caregivers or formal care providers. It is also a basic need to manage symptoms adequately for all, including those who are medically underserved. Differences in palliative and end of life care across ethno culturally diverse groups must be explored, along with similarities and differences by gender, geography, and age, with results used to design effective interventions and increase recruitment and retention.

Definitions, methods, and measurement strategies vary across studies limiting our ability to address sources of error. We must therefore address methodologic weaknesses and develop a foundation of rigorous research that adds to the evidence base and helps improve patient and family outcomes during the receipt of palliative and end of life care. Longitudinal, prospective, theoretically driven designs offer opportunities to assess causal mechanisms, and explore mediators, confounders, and interaction effects. We also must avoid unclear definitions, better assess health disparities, and use theoretical frameworks. Comparative effectiveness and cost effectiveness studies, and those that address topics such as advanced care planning, pediatric issues, and ethno culturally diverse populations must also be conducted utilizing the best methodology possible. Randomized controlled interventions, quasi-experimental studies, and rigorous qualitative research are necessary to achieve significant improvement in patient and family outcomes. Triangulation with archival or administrative data, qualitative observation, and the use of mixed method studies, guided by a sound theoretical framework, can provide a richer picture of the patient and caregiver experience.

IV. Conclusions

Many positive changes have occurred in research and care strategies available to those with life-limiting diseases due to significant contributions of scientists leading research endeavors in palliative and end of life care. Collaborations built through years of leadership by the NINR, culminating with this Summit, and the dissemination of recommendations stemming from it, must be reinforced at future events. Visionary efforts that build a solid research base will require collaborative research, commitment, and dialogue to develop and sustain value-added science that continually nurtures the next generation of research and researchers. At the crossroads of a new phase, what we do next will greatly influence the reduction and elimination of the limitations in our science. To achieve our ambitious goals, we must achieve interdisciplinary work; build robust, theoretical models; understand causal mechanisms; conduct prospective longitudinal investigations of diverse patient populations, conditions, contexts, and settings; implement methodological rigor and diversity of study designs and approaches; and develop and test interdisciplinary, culturally-sensitive care models and interventions.

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