

Care for the People with Life Limiting Illness: Current Trends

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Received: July 25, 2020; **Published:** September 30, 2020

Abstract

The past twenty years have seen 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 [1]. The advances brought about by palliative and end of life care research has led to a new century of palliative and end of life care analysis and implementation with universal recognition of its accomplishments and achievement. 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 vital 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. Leading scientists in the field were charged with assessing gaps in knowledge and propose future areas of inquiry reflecting key domains of palliative and end of life care research [2].

Keywords: Life Care; Palliative Care; Care-Givers

Overview

Psychosocial, cultural, and spiritual aspects of end of life

Different cultures may have vary beliefs about the meaning of death, how individuals who are dying should be cared for and how grief may be revealed. Some cultures, death is viewed as a social occasion with great explanation for the entire society. Whereas for others, death viewed as a private, hidden occurrence. Some cultures openly celebrate, death, believing the person who has died has gone to a better place, whilst people from other cultures mourn for extended periods of time. Some cultures grieve openly with great expression, whilst others will only express their own feelings and emotions within a private circle. Death brings with it all kinds of emotional such as Sadness, worry, fear, anger, shock, confusion. A person experiencing death or the death of a loved one may also feel cheated, relieved, guilty, exhausted or empty. Spiritual beliefs, religious traditions provide a framework for understanding the experience of death and dying and the meaning of illness and suffering. Their expression of religious beliefs within their spiritual values Social factors could cause them to worry about the impact their death will have on other. This often referred to as a social pain. Loss of relationship; their social placement within the family unit. Worry about how their family will cope emotionally, phycological and socially after their death. Worry

about how their family will manage financially. The meaning and purpose of their life and whether they have fulfilled their ambitions and needs. Environmental perspectives such as their method of burial. Their reflections upon key life events, love and family relationships. Cultural and family traditions which they would refer to be upheld during and of life care. In their paper, present a thoughtful review of health disparities in the context of palliative and end of life care research [3].

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 [4]. 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. 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 [5].

Pain and symptom management in palliative care and end of life

The literature review 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 ethnoculturally 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 [6]. 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) [7].

The authors also find that many barriers interfere with the symptom management process. Patient related barriers include patient misconceptions, anxiety and concerns, unwilling to report symptoms, and complication 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 delayed symptom management include clinicians placing low priority on symptom management, lack of satisfaction and access to care issues, and restrictive regulation for some therapies. Co-occurring multiple symptoms present another challenge. Although a nurse lead 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 [8], 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.

Perinatal and pediatric issues in palliative and end of life care

It 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 necessities 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. 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 [9]. 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 [10].

Palliative care: The caregiver

It provide a comprehensive review of informal caregiving and articulate a vision of future priorities to strengthen the next generation of research. Researcher 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 [11].

Larger research studies with strong 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 care giving 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 care giving [11].

Communication about end of life care

Review the current literature on advance care planning and communication about end of life care. There are crucial challenges encountering clinicians, researchers, and policy-makers as to improving communication about palliative and end-of-life care with patients and families. There is also mounting evidence that the intensity of care at the end-of-life is increasing, despite the fact that most patients report they would prefer not to die in high-intensity medical settings. Recent research suggests that improved communication about palliative and end-of-life care is associated with reduced intensity of care at the end of life, improved quality of life for patients and families, upgrade quality of dying for patients, and lowers psychological symptoms for families. In addition, the most essential and profitable ways to attain improved communication are not clear. One foremost step to improving communication is being able to accurately measure the standard of this communication [12]. 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 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. However, these are often time-consuming and resource-intensive, and we need a larger body of evidence to show effectiveness.

Nursing science is grounded in the principles of protecting, promoting, maintaining and optimizing a patient's health and function; alleviating suffering; and tending to the actual or potential response to illness. The art of nursing lies in compassionate care. The nurse assists the palliative patient as he or she responds to the diagnosis of a serious illness, manages treatment, and begins to psychologically cope. Communication is the fundamental element to all aspects of palliative nursing: development of the nurse-patient-family relationship; review of patient preferences of care; assessment of physical, psychological, and psychosocial symptoms; and implementation of care plans. Since palliative care is by definition interdisciplinary, nurses work within multidimensional teams. Given their constant and therapeutic presence with the patient, nurses have an essential role on the interdisciplinary team and assure quality care through collaboration and consistent communication [13].

The use of technology in advance care planning

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 documen-

tation guides for patients and families, and web-based repositories of advance directives [14]. 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.

Summary

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 ethnoculturally diverse populations must also be conducted utilizing the best methodology possible.

Conclusion

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. 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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Volume 9 Issue 10 October 2020

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