Research Needs and Challenges Regarding Palliation for Individuals in Long-Term Care Settings

Millions of older adults will call a long-term health care center “home” as they age. Residents of long-term care are likely to have multiple chronic illnesses and often have symptoms of dementia. The advances in health technology will continue to allow older adults to live longer with their chronic illnesses. Palliative care has the potential to ease suffering of individuals living with chronic illness through the management of symptoms and provision of care consistent with the individuals’ advance care planning. Palliative care is underutilized in long-term care. There are substantial gaps in evidence available on palliative care needs and interventions for frail older adults with non-cancer chronic illness and multiple comorbid conditions living in long-term care residences.

Interviews with three research experts (Drs. Betty Ferrell, Carol Long, and Patricia Berry) and three Directors of Nursing in long-term care (Elaine Dyer, Linda Struhar, and Lori Verley) were conducted for the current editorial. A theme that was echoed by both groups was the difficulties providing care and conducting research with populations that have cognitive impairments and chronic illnesses, such as dementia, chronic obstructive pulmonary disease (COPD), heart failure (HF), renal failure, stroke, Parkinson’s disease, and head injuries. Not only are these illnesses chronic, many also have uncertain trajectories. One nurse researcher indicated that longitudinal studies are cumbersome to maintain in regard to keeping participants enrolled; however, as these diseases share uncertain prognoses and illness trajectories, longitudinal research designs are a logical choice.

Research is limited on the practice or effects of implementing palliative care early in the disease progression for patients with chronic illnesses such as dementia, COPD, and HF. An area that needs further research is appropriate timing for initiating palliative care. Recommendations from various professional organizations and the definition of palliative care indicate that palliative care can be appropriate at diagnosis; however, timely referrals have not been adopted by many health care providers (Institute of Medicine [IOM], 2014). Oftentimes, palliative care is initiated late in the disease trajectory. Matlock et al.’s (2010) study is one example that found more than one half of the cardiologists surveyed would not initiate palliative care for late stage HF patients, as is recommended in clinical practice guidelines. Further research is needed to identify the time period or qualifying characteristics in an illness trajectory when palliative care would be most effectively initiated.

Medicare restrictions on reimbursement and problems defining early-stage palliation make it difficult to identify individuals receiving palliative care in the early or middle stages of their illness. Yet, longitudinal studies that follow the individual through critical condition and care preference changes as well as transitions in care are needed to more clearly understand temporally unfolding processes.

Symptom presentation and trajectory of decline vary in those needing palliative care, and the target population of older adults in long-term care is heterogeneous. Research methods chosen for palliative care studies must be designed with consideration of the multiple factors that contribute to within-group differences. For example, statistics that are based on group means may obscure and distort results. The use of sampling and analytical techniques to control for possible confounding variables and the need to test for interaction effects based on subgroup characteristics may be used to enhance confidence in causal inferences. Longitudinal designs accommodate better techniques that statistically control for sample heterogeneity.

Ethical issues often require careful consideration when palliative care research is conducted. Potential participants are considered a vulnerable population, have high
rates of dementia, and emotional and symptom distress. The benefit–burden analysis when random assignment to interventions is used for residents who are in distress can make it difficult to obtain approval from institutional review boards and consent from residents or their proxy.

Death is not just an expected outcome being studied, but a source of study attrition that can make findings biased and difficult to interpret. Missing data are another potential problem caused by mortality, and symptom distress or medical care can make data collection impossible at certain time points.

Measurement biases and error may be introduced by the need for surrogate respondents and difficulty determining appropriate outcomes and methods for assessing those outcomes. There are multiple self-report scales that have good validity and reliability for measuring symptoms in the advanced stage of illness. In addition to widely used scales to measure pain, many symptom assessment scales exist. The Memorial Symptom Assessment Scale (MSAS) and Edmonton Symptom Assessment Scales (ESAS) are two examples of measurement tools that assess more than one symptom. The MSAS measures the presence, frequency, severity, and distress level of 24 different symptoms, including pain, nausea, feeling sad, and lack of energy (National Palliative Care Research Center, 2013). The ESAS is similar to the MSAS but measures 10 different symptoms and asks patients to rate their symptom severity on a 0 to 10 scale (National Palliative Care Research Center, 2013). Both scales have been tested for reliability and validity with good results. Chang, Hwang, Feuerman, Kasimis, and Thaler (2000) reported good reliability for the MSAS short form and also established that this form was appropriate for use with different populations. The ESAS has been tested and found to have good reliability and can be used with a variety of different populations (Aktas, Walsh, & Kirkova, 2015; Cheifetz, Packham, & MacDermid, 2014).

In addition to measurement tools that test multiple symptoms on one tool, there are also self-report scales that measure one symptom, such as the Geriatric Depression Scale (GDS) and Lee Fatigue Scale (LFS). The GDS has a long and short form that have been tested and found to have good reliability and validity in practice and research (Hartford Institute for Geriatric Nursing, 2012). Reliability and criterion-related validity scores were acceptable when the long versions of the GDS were administered to individuals with mild to moderate dementia (Lach, Chang, & Edwards, 2010). Meek et al.’s (2000) analysis of the LFS showed the tool had good reliability with an acceptable Cronbach’s alpha score.

Measurement scales can also be disease specific. The Minnesota Living with Heart Failure Questionnaire and Clinical COPD Questionnaire are self-report measurement tools used to evaluate symptoms specific to these diseases (Berkhof, Metzemaekers, Uil, Kerstjens, & van den Berg, 2014). Both of these tools have been tested and found to have Cronbach’s alpha scores >0.7 and good test–retest reliability scores (Berkhof et al., 2014).

As symptoms become worse, self-report scales may not be feasible, and observational scales become more important. Increasingly, observational scales are being developed that have good validity and reliability for measuring symptoms in advanced stages of these illnesses. The Abbey Pain Scale, Pain Assessment in Advanced Dementia, and Non-communicative Patient’s Pain Assessment Instrument are all tools designed to assess non-verbal or cognitively impaired adults for pain (Lukas, Barber, Johnson, & Gibson, 2013). All of these scales are reasonably reliable, with Cronbach’s alpha scores ranging from 0.74 to 0.85 (Lukas et al., 2013). The Palliative Performance Scale (PPS) is a provider-rated scale that includes many different symptoms, similar to the self-report tools, MSAS and ESAS. Ho, Lau, Downing, and Lesperance (2008) analyzed the PPS measurement tool and found good reliability and validity for assessing palliative care patients.

Biobehavioral measures are more complex and costly, but the science around using some of these measures is growing. Kovach, Woods, Devine, Logan, and Raff (2014) discussed the use of biobehavioral measures for health care interventions. These authors outlined guidelines for using these types of measures to avoid risk to research integrity (Kovach et al., 2014). Biobehavioral measures may be meaningful outcome measures and are particularly important to consider for research involving individuals who cannot provide accurate self-report. Biobehavioral measures can also help elucidate important mechanisms of action between behaviors and symptoms or symptoms and outcomes. Understanding these mediating factors can help scientists develop interventions that directly address the processes that contribute to symptoms and poor outcomes.

Many comments by the interviewed experts point to confusion around conceptualizations of aspects of palliative care and the need for theory development. Dr. Berry spoke at length about the problem of the general public and health care providers not understanding the broader view of palliative care. She spoke of the terminology used to describe palliative care as hospice/palliative care and palliative care/end-of-life care when in essence palliative care should be singled out or an “and” should replace the...
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slashes. Dr. Berry also described palliative care as being “all about goals and preferences,” not necessarily end-of-life care alone. Theoretical explanations for organizational factors impacting palliation in long-term care, symptom trajectories for specific long-term care populations, and factors influencing symptom trajectories in specific populations are needed to establish a conceptual foundation for the development and testing of empirically and theoretically derived interventions.

The experts interviewed for this editorial spoke of the need for translational research to understand optimum ways to enhance the adoption of evidence-based palliation by licensed and unlicensed staff in long-term care. Drs. Long and Ferrell noted the low level of training among staff in long-term care facilities, the majority of whom are not RNs. According to Harris-Kojetin, Sengupta, Park-Lee, and Valverde (2013), nursing assistants account for 65.4% of nursing staff in nursing homes, with licensed practical or vocational nurses accounting for 22.9%, and RNs accounting for 11.7%. All three researchers highlighted the need to include educating unlicensed staff to provide adequate palliative care in these settings. Dr. Long emphasized that staff want knowledge to provide better care, but better and more creative ways to disseminate knowledge for practical use are needed.

All of the directors of nursing worked in facilities that used outside hospice agencies to provide palliative or hospice care to residents at different intervals, times of crisis, or to help staff nurses triage in long-term care. These outside agencies also provided educational sessions to the long-term care nursing staff. Although outside agencies are an important resource, they are not a long-term solution if the use of palliative care is expanded to its full potential to meet the needs of the growing populations of chronically ill individuals. The IOM (2014) report discussed the importance of general practitioners having a basic competency in palliative care. There are a limited number of specialists to provide the amount of care for the chronically ill that will be needed as Baby Boomers enter their later years. Dr. Long spoke of the gaps in research including a limited amount of knowledge in the care of adults older than 65.

Palliative care has historically been associated with cancer patients, and much of the research in palliative care reflects this trend. Palliative care can be implemented with any life-threatening illness, and the main goals of palliative care include symptom management and quality of life. Dr. Berry and Elaine Dyer highlighted the importance of defining goals in palliative care. All directors of nursing spoke about the challenge of smooth transitions when residents transferred to and from the nursing home and maintaining resident and family goals with each move. Future research should focus on interventions that may help with these transitions to maintain and enhance the continuity of care based on patient and family goals.

To conclude, nurses working in long-term care should be experts in providing palliative care. Yet, studies have consistently shown inadequate and inconsistent provision of palliation in long-term care. Palliative care has the potential to decrease suffering and aid in decision making before crisis strikes an individual with a chronic or life-threatening illness. But there is much left to learn about the provision of palliative services along the trajectory of chronic illness for those in long-term care. Despite the challenges to performing palliative care research, studies must be conducted with scientific rigor. The gaps in knowledge and methodological challenges also present opportunities for researchers and theorists to make substantial contributions to science in this emerging field.

REFERENCES


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