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Pain and Symptom Management in Palliative Care and at End of Life

Diana J. Wilkie, PhD, RN, FAAN[+] and
Professor and Harriet H. Werley Endowed Chair for Nursing Research Director, Center of Excellence for End-of-Life Transition Research Voicemail: 312.413.5469; Fax: 312.996.1819

Miriam O. Ezenwa, PhD, RN[+]
Assistant Professor, Sickle Cell Scholar, and Mayday Fellow Voicemail: 312.996.5071; Fax: 312.996.1819;

Diana J. Wilkie: diwilkie@uic.edu; Miriam O. Ezenwa: moezenwa@uic.edu

Abstract

The purpose of this review is to provide a literature update of the research published since 2004 on pain and symptom management in palliative care and at end of life. Findings suggest that pain and symptom are inadequately assessed and managed even at the end of life. Although not pervasive, there is evidence of racial/ethnic disparities in symptom management in palliative care and at end of life. There is a need for a broader conceptualization and measurement of pain and symptom management as multidimensional experiences. There is insufficient evidence about mechanisms underlying pain at end of life. Although there are advances in the knowledge of pain as a multidimensional experience and the many symptoms that occur sometimes with pain, still gaps remain. One approach of addressing the gaps will involve assessment and management of pain and symptoms as multidimensional experiences in people receiving palliative care and at end of life.

Substantial research findings elucidate characteristics of pain and symptoms among individuals with life-limiting illnesses, and a variety of interventions have been tested to reduce pain and symptoms. In December 2004 at the State-of-the-Science Conference on Improving End-of-Life Care (Grady, 2005), interdisciplinary experts evaluated the end-of-life research and concluded that interventions and measures required validation, especially for diverse settings and groups (NIH, 2004). Since then, a number of systematic reviews have been published to report on pain and symptom assessment or interventions among selected groups of patients with life-limiting illnesses (Docherty et al., 2008; Dy, 2010; Gilbertson-White, Aouizerat, Jahan, & Miaskowski, 2011; Kumar, 2011; Lorenz et al., 2008; Mularski et al., 2009; Robinson et al., 2009; von Gunten, 2005). In August 2011, the National Institute for Nursing Research convened a Summit on Palliative Care to take stock of the current state of the science. As an outcome of that meeting, the purpose of this article is to provide a literature update of the research published since 2004 on pain and symptom management in palliative care and at end of life.

Correspondence to: Diana J. Wilkie, `diwilkie@uic.edu`.

[+] College of Nursing, Department of Biobehavioral Health Science and Comprehensive Sickle Cell Center University of Illinois at Chicago 845 S. Damen Ave. (MC 802) Chicago, IL 60612-7350

Adequate pain and symptom management is an essential component of palliative and end-of-life care. Whereas end-of-life care and palliative care both focus on pain and symptom management, palliative care does so along with life-extending disease management (e.g., cancer chemotherapy, dialysis) for people with life-limiting illnesses. Current funding for end-of-life care (e.g., hospice), however, typically does not support life-extending disease management, which means that for individuals seeking life-extension, palliative care would be more consistent with their goals than hospice care.

Unfortunately, many barriers interfere with the pain and symptom management process, despite many basic science findings relevant to clinical pain care and the recognition for the need to control symptoms. Some barriers relate to patients, such as misconceptions about pain and treatments (Schrader, Nelson, & Eidsness, 2009), fears and concerns about pain medications and side effects, reluctance to report pain and symptoms, and complexity of the symptom experience. Other barriers relate to providers, such as lack of knowledge, skills, and time for adequate pain and symptom assessment (Fineberg, Wenger, & Brown-Saltzman, 2006). Providers also lack knowledge about analgesics, symptom interventions, and side effects of therapies. Still other health care system-related barriers impede pain and symptom management, such as low priority given to pain and symptom management, reimbursement and access issues, and restrictive regulation for some therapies (Berry & Dahl, 2007; Imhof & Kaskie, 2008). Some progress has been made in research to reduce some of these barriers, which have been known for nearly three decades, but others remain, especially in palliative care and end-of-life settings. The specific aims of this review are to appraise the critical evidence and issues in pain and symptom management research in palliative care and at the end of life and to present the lessons learned and next steps for research, and the continuing gaps that offer opportunity to advance pain and symptom science in palliative care and at the end of life.

To accomplish these aims, we searched the CINAHL database for publications published 2004 to 2012 using the following search terms (number of publications): pain palliative care (1007); pain end of life (363); symptoms palliative care (629); symptoms end of life (236); and advanced cancer pain (3). We imported the citations into Endnote X (New York, NY), read all abstracts, and obtained full-text articles for the English language, patient-centered research focused on pain or symptom assessment or management in palliative care and at end of life. Citations are exemplars, not exhaustive due to page limits.

Critical Evidence and Issues

Pain is a frequent companion of people receiving palliative care or at the end of life, and symptoms often occur simultaneously with pain in many disease conditions, including heart failure patients (Goebel et al., 2009), cancer and hospice patients (Downey, Engelberg, Curtis, Lafferty, & Patrick, 2009), nursing home residents (Hanson et al., 2008), and community-dwelling elders (McCarthy et al., 2008). These findings are disturbing, given that Americans value pain control (McCarthy et al., 2008) and are concerned about receiving adequate pain management (Valente, 2010). Pain is highly prevalent, especially in the four months prior to death (60% of sample) (Smith et al., 2010), and is linked to nociceptive or neuropathic mechanisms or both pain types. The temporal nature of either type of pain can be acute (present for less than 6 months) or chronic (persistent for longer than 6 months). Experts suggest that therapies are differentially effective for nociceptive and neuropathic pain because the pain mechanisms vary, but at different doses, some therapies show effects for both types of pain (Ripamonti et al., 2009). Few studies of patients receiving palliative care or at the end of life, however, present sufficient evidence about the type of pain experienced by study participants (Epstein, Wilkie, Fischer, Kim, & Villines, 2009). Even fewer studies provide evidence of the effects of different therapies within the context of nociceptive, neuropathic, or both pain types.

Generally, pain is recognized as a multidimensional experience with sensory, affective, cognitive, and behavioral dimensions. As a sensory experience among patients receiving palliative care or at the end of life, pain for many is moderate to severe in intensity (Brechtl, Murshed, Homel, & Bookbinder, 2006; Fadul, El Osta, Dalal, Poulter, & Bruera, 2008; Goebel et al., 2009; Goy, Carter, & Ganzini, 2008; Kutner, Bryant, Beaty, & Fairclough, 2007; Strassels, Blough, Veenstra, Hazlet, & Sullivan, 2008), often in more than one location (Fischer, Villines, Kim, Epstein, & Wilkie, 2010), commonly reported as possessing complex qualities (Fischer et al., 2010), and variable in its pattern (Fischer et al., 2010). Pain is often associated with an affective dimension that includes distress and suffering (Fischer et al., 2010; Goebel et al., 2009; McMillan & Rivera, 2009). The cognitive dimension of pain also contributes to the experience, and it influences coping with the experience (Goebel et al., 2009; Prasertsri, Holden, Keefe, & Wilkie, 2011; Vallerand, Templin, Hasenau, & Riley-Doucet, 2007). The behavioral responses to pain can be misinterpreted by others, especially health providers (Wilkie, Berry et al., 2010). Well-known examples of pain-related behaviors include behaviors to control the pain such as preventing it, reducing it through positions, reporting it, and taking analgesics (Wilkie, Keefe, Dodd, & Copp, 1992), some of which have informed behavioral assessment tools for persons not able to communicate their pain (McGuire, Reifsnyder, Soeken, Kaiser, & Yeager, 2011). Other behavioral responses include interference with activities of daily living (Goebel et al., 2009; Vallerand et al., 2007), can be complex, and involve caregivers. For example, at the end of life, caregivers assume responsibility for administering drug therapy for pain and symptoms and do so with a sense of empowerment and mindful of ethical and safety issues (Anderson & Kralik, 2008). Yet, caregivers also have important educational needs to most effectively perform their roles in management of pain and other symptoms near the end of life (Docherty et al., 2008).

People receiving palliative care or at the end of life commonly experience many symptoms other than pain. In acquired immunodeficiency syndrome, cancer, chronic obstructive pulmonary disease, heart disease or renal disease, more than 50% of patients with all five of the diseases had three symptoms: pain, breathlessness, fatigue (Solano, Gomes, & Higginson, 2006). Four symptoms intensify as death approaches: lack of appetite, drowsiness, dyspnea, and fatigue (Cheung et al., 2009). Although a nurse-led 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), an indication of the challenge but not the impossibility of reducing pain (Pitorak, Beckham Armour, & Sivec, 2003) and other symptoms. The number of symptoms and symptom distress are among the predictors of quality of life reported by home hospice patients (Garrison, Overcash, & McMillan, 2011). In nursing home residents, symptoms other than pain were present for 22% and undertreated for 60% (Rodriguez, Hanlon, Perera, Jaffe, & Sevick, 2010). In the month prior to death, patients with renal disease experienced high symptom burden similar to or higher than patients with cancer (Murtagh et al., 2010). Literature synthesis and clinical practice guidelines address the symptom burden of patients with end-stage renal disease (Douglas, Murtagh, Chambers, Howse, & Ellershaw, 2009) and the evidence for palliative care in multiple populations (Lorenz et al., 2008).

Unfortunately, pain and symptom management is often inadequate, even for people facing the end-of-life transition with palliative and hospice care (Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2008; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007) and can affect survivor health (Jonasson et al., 2009). A variety of medications are typically used for pain yet are not predicted by patient characteristics or care setting (Zerzan, Benton, Linnebur, O'Bryant, & Kutner, 2010). Palliative care consult service is associated with greater attention to pain and symptoms for hospitalized patients than those who do not receive palliative care (Pekmezaris et al., 2010). Hospitalized patients with cancer pain and symptoms drive use of palliative care service (Dhillon et al., 2008). Patients consider unrelieved pain as an important factor eroding dignity at the end of life (Periyakoil, Kraemer, & Noda, 2009). Sedation is one therapeutic option when symptom relief is difficult to achieve (Mercadante et al., 2009). Dyspnea and drowsiness symptoms significantly predicted survival in patients with cancer (Palmer & Fisch, 2005). Continuously infused sedation reduced previously uncontrolled symptoms (e.g., dyspnea, delirium) experienced by inpatients with cancer receiving palliative care (Mercadante et al., 2009). Many hospice programs report providing emergency drug kits for management of symptoms (e.g., pain, dyspnea, nausea and vomiting, seizures) at home and they appear to be used by about 50% of the patients, but prospective study is needed to determine actual use and outcomes (Bishop, Stephens, Goodrich, & Byock, 2009). Despite frequent and moderate to severe symptoms experience by patients receiving palliative care and at end of life, symptom management research is insufficient to predict the specific therapies likely to provide enough relief of all the symptoms. Additional research is needed to provide stronger evidence to guide practice. People from racial and ethnic minority groups are not adequately represented in theses pain and symptom studies.

Research evidence shows racial/ethnic disparities in the use of hospice and palliative care at the end of life (Enguidanos, Yip, & Wilber, 2005; Haas et al., 2007; Yancu, Farmer, & Leahman, 2010). However, evidence on racial/ethnic disparities in pain and symptom assessment and management at the end of life is scarce. Available evidence shows: (1) no racial/ethnic disparities in the use of high-intensity medication (prescribed to treat moderate to severe pain) in women deceased from ovarian cancer (Rolnick et al., 2007); (2) pain treatment did not differ for Caucasian and minorities (African American and Hispanic) veteran patients hospitalized for end-of-life care (Fischer et al., 2007); and (3) no difference in pain location, intensity, quality or pattern or in the use of pain medication between African American and Caucasian cancer patients receiving care from a hospice/palliative care program (Stapleton, 2010). The results are consistent but contrary to reports of pervasive racial and ethnic disparities in pain management of patients who are not facing the end of their lives (Cintron & Morrison, 2006; Ezenwa, Ameringer, Ward, & Serlin, 2006; Meghani, Byun, & Gallagher, 2012). Consequently, evidence of no racial disparity in the pain treatment of dying patients is a positive and noteworthy finding. This finding suggests that hospice/palliative care programs are living up to their goal of providing pain relief and comfort to dying patients. Perhaps, emulating and extending the hospice/palliative care pain management model to patients in pain but who are not yet at the end-of-life could decrease the persistent racial disparities in pain management in the United States.

Evidence is conflicting about racial/ethnic disparities in symptom assessment and management for minorities receiving palliative care at end-of-life care. Some findings show no racial or ethnic disparities in documentation of symptoms of restlessness and delirium in patients who died in intensive care units (Muni, Engelberg, Treece, Dotolo, & Curtis, 2011) or in symptom distress scores or the majority of symptom cluster scores in patients in hospice/palliative care programs at the end of life (Stapleton, 2010). Investigators found no racial differences in acceptability scores for reporting symptoms with the tool (Wilkie et al., 2009). Other findings, however, show that documentation of anxiety was less likely in non-White than in White patients who died in intensive care units (Muni et al., 2011) and that Hispanic/Asians reported statistically higher pain-fatigue symptom cluster scores compared to Caucasians with cancer in hospice/palliative care programs (Stapleton, 2010). Taken together, these studies suggest the existence of racial disparities in some aspects of symptom assessment and documentation, regardless of setting, but clearly more symptom research is needed with adequate numbers of minority patients.

When investigators examined racial or ethnic disparities in pain and symptom management for patients in palliative care or at the end of life, the majority of the findings were positive. Findings suggested that minority patients (African Americans, Hispanics, and Asians) who use hospice and palliative care at the end of life equally benefit from pain and symptom assessment and management as Caucasians. However, minorities are less likely than Caucasians to use hospice and palliative care services at the end of life. Several barriers, such as patient-provider racial discordance (Yancu et al., 2010), residential segregation (Haas et al., 2007), and the combined effect of religious affiliation and having no insurance (Francoeur, Payne, Raveis, & Shim, 2007) are some of the contributing factors. Efforts are needed to address and ameliorate patient-level as well as system-level factors that are deterrents to minority patients benefiting optimally from the palliative care and hospice services.

Advances in the science of pain and symptoms in palliative care and at end of life are progressing, but more slowly than needed to address the ballooning need for care that the baby boomers will require. The studies published since 2004, however, also provide a number of insights about research in this area of science.

Lessons Learned and Next Steps for Research

The knowledge outcomes from the recently published pain and symptom research are important to guide future research. We conclude that the complexity of the pain and symptom experience, especially in people facing life-limiting illnesses warrants broader conceptualization of pain and symptoms than has been typical in previous research. In general, physiological and disease-oriented perspectives have guided the pain and symptom research studies. Although this focus is important, it is narrow, and scientific advances could be speeded by expanding the theoretical bases for future pain and symptom research. To advance this science area requires research that focuses on (1) translation of knowledge from basic science to humans, evaluating the effects, and informing future basic science studies; (2) the cognitive and behavioral dimensions of the pain and symptom experience; (3) specific strategies for effective symptom management; and (4) interventions for effective training of health professionals, patients, and caregivers to implement their respective roles in pain and symptom assessment and management.

Within the recent literature are other lessons for approaches and methods that are appropriate for palliative care and end-of-life research. From a methods perspective, the challenge of sample selection and participant burden require innovations, including multi-site network-based research (Kutner et al., 2010; Kutner et al., 2008), to address the special needs of this population. Measurement challenges of studying those close to death should not compromise the research that can be done with patients earlier in the trajectory of their illness. Patient-reported outcomes using pentablet, tablet, or other mobile devices are possible, especially in patients with a Palliative Performance Scale score of 40 or higher (Wilkie et al., 2009). For example, PAIN*Report*It® (Nursing Consult, LLC, Seattle, WA) is an interactive, touch screen computer program (Wilkie et al., 2003) based on the McGill Pain Questionnaire (Melzack, 1975). PAIN*Report*It® measures pain location, intensity, quality, and pattern, and by doing so, allows investigators to determine the types of pain, (nociceptive, neuropathic, or mixed noceceptive and neuropathic) (Wilkie, Huang, Reilly, & Cain, 2001). We conclude that such characterization of the pain is crucial for effective analgesic trials in people receiving palliative care or at the end of life. In a study of massage for home hospice patients with cancer, investigators also measured symptoms with a computerized version of the Symptom Distress Scale (McCorkle & Young, 1978), which measures 11 common symptoms. As well, the Barriers Questionnaire (Ward et al., 1993) has been computerized and used in patients with cancer (Boyd-Seale et al., 2010) or sickle cell disease (Wilkie, Molokie et al., 2010). The demonstrated capacity for technology to enhance pain and symptom measurement in people receiving palliative care or at the end of life, including those from racial/ethnic minority groups, is an important lesson for the research community.

Finally, intervention studies are needed with research designs that maximize detection of effects at the individual rather than the group level to move the science forward more rapidly. Data analysis techniques are needed to describe phenomena that now lack sufficient description and for greater focus on inferential procedures that can accommodate missing data without undue bias.

Continuing Gaps in Research

This review highlights the areas where evidence is growing and where it is thin. As Kumar (2011) documented, the palliative care literature includes a small proportion of pages devoted to pain research, despite high prevalence of pain and inadequate pain control for many patients in palliative care and at end of life (Yao et al., 2012). Clearly there is insufficient characterization of pain and symptom phenotypes, longitudinal changes in pain and symptoms, mechanisms underpinning the pain and symptoms, and variable responses to treatments. It is not clear from the current evidence how much pain of neuropathic origin contributes to symptom outcomes in the palliative care and end-of-life settings.

There is insufficient evidence about the death-hastening effect of opioids and sedatives when used for control of pain and other symptoms (Portenoy et al., 2006), but some clinicians believe that the opioids and sedatives rather than the disease result in death (Sprung et al., 2008). Additional prospective, well-designed research is needed to resolve this debate and help clinicians control pain and other symptoms during the dying process (Claessens, Menten, Schotsmans, & Broeckaert, 2008).

As electronic health records are implemented across the United States, large observational studies with structured electronic data can be used to generate knowledge about interventions from real clinical practice that are associated with improved patient outcomes. Documentation of the intellectual work of nurses, not just the tasks that they complete, in the electronic health record using standardized terminologies will provide rich sources for data mining and generating practice-based knowledge to complement knowledge generated from other research approaches (Al-Masalha et al., In press; Keenan et al., 2012).

Conclusions

There are advances in the knowledge of pain as a multidimensional experience and the many symptoms that occur sometimes with pain and as clusters. Insufficient research addresses the pain and symptom experiences in palliative care and at the end of life, particularly in people from minority groups. From the few studies, health disparities in palliative care and at the end of life appear not as pervasive as in other pain patient populations not dying. However, additional research needs to confirm these findings since minority patients often are under-represented hospice enrollees. If additional research confirms the findings of reduced health disparities, then it is critical to systematically identify the active ingredients in the interventions that reduced those disparities. If new research identifies health disparities, then it is pertinent to critically identify and systematically examine mediating factors that could be amenable targets for interventions for reducing racial and ethnic disparities. Finally, technologies can be used effectively to conduct research related to pain and symptoms in people in need of palliative and end-of-life care. Technologies improve data collection, data entry efficiency, and the rigor of the science. New technologies could be available to nurses at the point of care that would capitalize on electronic health record information and feedback benchmarks to generate practice-based evidence and improve patient outcomes.

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