# Improving the Hospice Patient Experience

The following summaries of recent peer-reviewed articles describe the benefits of improving patient experience and reducing suffering in the hospice setting. Citations are linked to full-text articles [*] when available.

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<th>Study</th>
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| Claxton-Oldfield, S., & Bhatt, A. (2017). *Is there a place for humor in hospice palliative care? Volunteers say "yes"!* American Journal of Hospice and Palliative Care, 34(5), 417-422. | To examine the frequency, acceptability, and function of humor between hospice palliative care volunteers and their patients. | ▪ Humor has a place in hospice palliative care, with the patient being the determining factor as to whether and when it is appropriate. Volunteers must take their lead from, and be adept at, reading their patients.  
▪ Humor reduces tension, relaxes the patient, lightens the mood, establishes or builds a relationship/connection with the patient, and serves as a distraction.  
▪ Laughter and social support go hand in hand; humor, if used appropriately, fulfills one of the main goals of hospice palliative care which is to improve patients’ overall quality of life. |
  — Decreased costs in the last ninety days of life ($3,346 and $5,824 per person, respectively)  
  — Fewer hospitalizations in the last thirty days of life (57 and 40 per 1,000 people, respectively)  
▪ The patient navigation model is associated with fewer ED visits in the last 30 days of life and increased hospice enrollment in the last two weeks of life.  
▪ A comprehensive approach to cancer care could include features from all three interventions to improve end-of-life outcomes. |
| [*] Kumar, P., Wright, A. A., Hatfield, L. A., Temel, J. S., & Keating, N. L. (2017). Family perspectives on hospice care experiences of patients with cancer. Journal of Clinical Oncology, 35(4), 432-439. | To determine whether hospice use by patients with cancer is associated with their families’ perceptions of patients’ symptoms, goal attainment, and quality of end-of-life (EOL) care. | ▪ Family members of patients enrolled in hospice are more likely to report that patients received “just the right” level of help with pain and dyspnea—not “too much” or “too little.”  
▪ Hospice use is associated with higher rates of family-reported patient-goal attainment and quality of EOL care.  
▪ Patients who receive more than 30 days of hospice are more likely to receive optimal pain management, care that was congruent with their wishes, and care that family describes as of “excellent” quality—compared with patients enrolled for three days or less.  
▪ Encouraging hospice enrollment, particularly weeks before death, may improve EOL experiences of patients with cancer. |
<p>| [*] The Joint Commission (2017). The Joint Commission enterprise content library index. | To inventory links to current Joint Commission content, organized into typical | ▪ Patients and their families can benefit from the specialized approaches of palliative care, which aim to improve a patient’s quality of life while facing problems associated with life-threatening illnesses. |</p>
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<td>Hudak, C. D., &amp; von Gunten, C. (2016). <em>The Talk</em>: Discussing hospice care. <em>Current Oncology Reports</em>, 18(7), 46.</td>
<td>To frame a communication approach that oncologists can incorporate into their practice to facilitate the timely referral of appropriate patients for hospice care.</td>
<td>▪ Resources listed in the Palliative Care section of the index include webinars, brochures, periodical articles, and podcasts related to meeting the needs of seriously ill patients.</td>
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<td>Cagle, J. G., Pek, J., Clifford, M., Guralnik, J., &amp; Zimmerman, S. (2015). Correlates of a good death and the impact of hospice involvement: Findings from the national survey of households affected by cancer. <em>Supportive Care in Cancer</em>, 23(3), 809-818.</td>
<td>To identify correlates of a good death and provide evidence on the impact of hospice on the quality of death.</td>
<td>▪ The following model can facilitate conversations with patients about hospice: 1. Establish a setting – Schedule a meeting with the patient and family members to discuss overall goals of care 2. Assess patient understanding – Ask open-ended questions to find out what the patient understands about her/his health situation and how much information s/he wants to know 3. Identify patient expectations – Ask the patient what s/he wants the future to look like and reflect back the words the patient uses. Use the opportunity to educate patients who have inaccurate or exaggerated fears 4. Discuss hospice – Review patient’s goals and, if fitting, suggest that hospice is the best way to meet those goals. Offer an informational hospice visit. 5. Respond to emotions – Respectful silence on the part of the physician can be a powerful initial response to the variety of emotions patients may express 6. Establish a plan – If the patient is agreeable, arrange the hospice informational visit and schedule a follow-up call or visit with the patient</td>
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<td>[*] Tabler, J., Utz, R. L., Ellington, L., Reblin, M., Caserta, M., Clayton, M., &amp; Lund, D. (2015). Missed opportunity: Hospice care and the family. <em>Journal of Social Work in End-of-Life and Palliative Care</em>, 11(3-4), 224-243.</td>
<td>To explore the ways that bereavement needs of caregivers, either pre- or post-death of their spouse/partner, can be more effectively addressed.</td>
<td>▪ The perceived knowledge and expertise of providers has a direct effect on quality of death. ▪ Oncology health care providers should strive to stay informed about current best practices for end-of-life care—including ways to improve communication about end-of-life matters, enhance bedside compassion, manage pain and other distressing symptoms, and attend to non-medical factors like coping and social support. ▪ Hospice is strongly associated with quality of death, and high-quality pain management is the leading reason for this. Providers should be vigilant about tailoring treatments to patient wishes and timely referrals to hospice. ▪ There are missed opportunities in how hospice practices address the needs of family caregivers, especially regarding the transition into bereavement. ▪ A pre-death intervention to caregivers can better prepare them for their role as a widow or widower. For example, providing workbooks that encourage the caregiver to engage in anticipatory bereavement (e.g., address feelings of grief, think about daily life tasks s/he will need to address after the spouse dies).</td>
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<td>Jones, B. W. (2013).</td>
<td>To define a balanced approach to quality outcomes in hospice care that involves both quantitative and qualitative research.</td>
<td>▪ Continuity of hospice services from pre-death into bereavement can provide a better transition into bereavement services. For example, rather than a generic letter sent to the caregiver after the death of a spouse, perhaps staff members present with the family during the pre-death phase could deliver the letter to the caregiver during the bereavement phase.</td>
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<td>Motley, M. (2013).</td>
<td>To describe how discussing end-of-life issues can reduce overtreatment and undertreatment and improve patient satisfaction with care.</td>
<td>▪ Applying a purely scientific approach with randomized clinical trials to research on the pain and suffering of hospice patients ignores many elements and components of pain; not all pain is medically-based. ▪ Empathy and compassion are components that come into play in end-of-life care and must be considered in a research paradigm that strives to determine the most effective practices for improving end-of-life care. ▪ The greater medical research field needs to recognize how invaluable qualitative research is to end-of-life care and that qualitative research findings may at times have greater relevancy than quantitative methods.</td>
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<td>Terry, M. (2013).</td>
<td>To outline best practices that produce real and sustained performance improvement for home health care and hospice organizations.</td>
<td>▪ Communication between patients and surrogates before a medical crisis is crucial to in-the-moment decision making. ▪ Advance care planning meetings are a medium through which the clinician can clarify the patient’s questions, fears, and values. ▪ An increased frequency of clinician-guided end-of-life discussions of all levels of care can lead to improved patient-centered care.</td>
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<td>Candy, B., Holman, A., Leurent, B., Davis, S., &amp; Jones, L. (2011).</td>
<td>To identify evidence on the effectiveness of hospice care and the experiences of those who use and provide hospice services.</td>
<td>▪ Patient engagement and patient activation—or putting the patient at the center of care—is at the core of home health care and hospice best practices. ▪ Patient engagement is the “blockbuster drug of the century.” Each clinician, leader, and physician needs to embrace this concept so patients can truly benefit. ▪ Each leader must develop a roadmap to achieve success that includes providing training resources to develop the organization’s capacity to begin performance improvement.</td>
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<td>Candy, Holman, Leurent, Davis, &amp; Jones, L. (2011).</td>
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<td>▪ Hospice services are highly valued by patients and their families. ▪ Hospice care reduces general health service use and costs. ▪ Using hospice care increases the likelihood of effective pain management and of death not occurring in a hospital.</td>
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▪ Using a patient-centered approach that employs end-of-life planning helps achieve the goals of care.  
▪ End-of-life care planning must include questions about control of end-of-life symptoms (e.g., pain, shortness of breath, nausea), allowing time with family, desire to go home, spiritual peace, reflection on life, and mending broken relationships. |
| Furman, C. D., Doukas, D. J., & Reichel, W. (2010). *Unlocking the closed door: Arguments for open access hospice*, *The American Journal of Hospice and Palliative Care*, 27(1), 86-90. | To cite arguments that support open access hospice as a tenable option over standard hospice. | ▪ Open access hospice allows for fuller informed consent of available beneficial treatments that may slow or halt disease (i.e., treatment beyond “comfort care”).  
▪ Open access hospice has demonstrated improvement in patient satisfaction and lower costs of care.  
▪ Open access hospice allows patients to be enrolled earlier in hospice, enhancing the quality of end-of-life care. |
▪ EMK is associated with considerable improvement in patient outcomes related to symptom management.  
▪ Both managers and clinicians in hospice perceive significant improvement in quality of care measures (e.g., time to symptom control) and a trend toward increased satisfaction. |