Does Comfort Care Make You Uncomfortable? Use of the CARES Tool for End-of-Life Symptom Assessment and Management

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Does Comfort Care Make You Uncomfortable? Use of the CARES Tool for End-of-Life Symptom Assessment and Management

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Abstract

Acute care nurses caring for end-of-life (EOL) patients often feel unprepared for and undereducated about this high-need population. According to current literature, many nurses lack adequate training in providing EOL care. This project aimed to improve symptom management of dying patients by providing acute care nurses education about EOL symptom assessment and medication use for symptom management. The revised Iowa model, which emphasizes clinician involvement, guided this evidence-based practice project. Sixteen acute care nurses received 30-minute in-person education, consisting of instruction in EOL symptom assessment and management via use of the CARES (comfort, airway, restlessness, emotional, self-care) tool and basic pharmacology review of common medications used for EOL symptom management. The thanatophobia scale was administered before, immediately after, and 1 month following the educational session to evaluate nurses’ uncomfortable feelings and sense of helplessness when caring for EOL patients. A benefit of the intervention appeared to be a decrease (though not a statistically significant decrease) in these negative feelings, which may have improved symptom management. Doses of medications used for symptom management in the last days of life were counted via electronic medical record review before and after education. Statistical analysis was not conducted due to the low number of doses. However, medication doses for symptom management appeared to increase after the educational session. The outcomes of this project support the necessity of EOL symptom management education for nurses.

*Keywords:* comfort care, nurse education, end-of-life, symptom management
Does Comfort Care Make You Uncomfortable? Use of the CARES Tool for End-of-Life Symptom Assessment and Management

Bedside nurses bear the weight of caring for hospitalized patients at the end of life (EOL). In addition to aggressive symptom monitoring and management, nurses are responsible for navigating emotional and spiritual support resources for the patient and family. These demands stretch the boundaries of nursing comfort and education on patient care during this life transition. Ferrell et al. (2016) found the key components of palliative care identified by the National Consensus Project Guidelines for Palliative Care and the End of Life Nursing Education Consortium training curriculum were inconsistently covered during primary nursing education. If a significant percentage of acute care nurses do not feel comfortable or are not adequately educated to care for patients in this stage of life, symptom management quality decreases (Powazki et al., 2014). In 2018, 793,000 hospital deaths occurred among adults aged 25 or older (Centers for Disease Control and Prevention, 2020), emphasizing the importance of addressing this problem. Additionally, lower quality ratings for EOL care are associated with nurses working in a poor practice environment, defined by Lasater et al. (2018) as high workloads, limited clinical authority, and lack of interdisciplinary support. Cheong et al. (2020) viewed death education as a key element for the transition to better quality EOL nursing care.

Understanding the needs of nurses caring for EOL patients, Freeman (2013) developed the CARES (Comfort, Airway, Restlessness and delirium, Emotional and spiritual support and Self-care) tool. This reference, based on the most common symptom management needs of dying patients (Freeman et al., 2015), provides educational reminders about symptom management at EOL. Instruction in the use of the CARES tool assists nurses to act as advocates in providing compassionate, evidence-based care for the dying (Freeman et al., 2015).
Purpose

The unfortunate common problem of poorly managed symptoms in dying patients highlights the challenges acute care nurses face when managing EOL patients and the patients’ unintended suffering. Nurses must address the physical and emotional demands of caring for high-need EOL patients in tandem with focusing on other patients with a curative goal. A literature review demonstrated that foundational nursing education provides minimal training in EOL care. Additionally, acute care nurses do not feel adequately educated about or supported when caring for this population. The author’s experience as a palliative nurse practitioner providing support for EOL patients and witnessing the need for nursing education and support in this area are the driving forces behind this project.

Based on the evaluation of this problem, a PICOT question was developed: In EOL patients admitted to an acute care hospital, how does nursing education on the use of the CARES tool and EOL symptom management compare to current practices of nurses assigned to care for EOL patients without explicit EOL education, and improve nursing comfort in caring for dying patients and managing EOL symptoms over 1 month?

Evidence-Based Practice Model

Reflecting on the multiple models of evidence-based practice (EBP) implementation, the revised Iowa model (Iowa Model Collaborative, 2017) was selected to guide this EBP change project (see Figure 1). First, the model compels users to focus on a precise problem in relation to a patient population (in this instance, poor symptom management of dying patients), then determine if the issue is significant enough to ensure availability of support and resources to implement and sustain an EBP change. A critical factor is engaging individuals
Figure 1

The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care

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who will be affected by the practice change to participate on the EBP change team and embrace the new way of practice (Steelman, 2015). Next, a literature review is completed; if the evidence is deemed sufficient to make a practice change, an implementation plan is designed and piloted. The revised Iowa model explicitly recommends implementing a pilot process to address any needed adjustments and determine if the intervention is feasible before implementing a systemic change (Iowa Model Collaborative, 2017).

Literature Review

A literature review was conducted to support this intervention by searching PubMed, the Cumulative Index to Nursing and Allied Health Literature, and Google Scholar using the following key terms: end of life, end of life care, comfort care, imminently dying, palliative care, symptom assessment, symptom management, nursing knowledge, nursing comfort, nursing education, nursing role, hospitalized patients, acute care setting, and inpatient. The articles were limited to those published in the last 7 years, printed in English, and focused primarily on adult patients. This search led to selection and evaluation of seven manuscripts.

The overarching theme through current literature was that nurses caring for actively dying patients in an acute care setting felt unprepared for and undereducated in giving care to this high-need population (Karbasi et al., 2018; O’Shea & Mager, 2019; Puente-Fernández et al., 2020; Sekse et al., 2018; Stacy et al., 2019). Several studies supported the idea that EOL symptoms are often poorly controlled due to lack of time, preparation, and nursing education (Karbasi et al., 2018; Lai et al., 2018; Puente-Fernández et al., 2020; Sekse et al., 2018).

Through a metasynthesis of 28 articles, Sekse et al. (2018) conceptualized the nurse’s role in caring for dying patients as a spider in a web, holding the components of patient care together. Nurses’ feelings of immense pressure without additional support, combined with their
documented perceptions of lacking knowledge and training on EOL care, contributed to patient suffering at EOL (Sekse et al., 2018). The strengths of this metasynthesis include a focus on nurses’ evaluation of personal needs and abilities, which provides clear direction for practical initiatives and research. Limitations include the possibility of missing important articles in the literature search and a wide geographical and cultural variability of the included studies.

Puente-Fernández et al. (2020) completed a systematic review to determine nursing professionals’ attitudes, strategies, and care practices toward death. Critical evaluation of 17 qualitative studies demonstrated lack of training in EOL care caused nurses to experience feelings of inadequacy and a lack of confidence when caring for dying patients. These studies showed the death and dying process substantially impacted acute care nurses by causing distress and generating emotions that negatively influenced EOL care and nurses’ well-being. Additionally, nurses experienced emotional disconnection with—and avoidance of—patients and their families, leading to painful and undignified patient deaths. Puente-Fernández et al. (2020) determined that to avoid the emotional exhaustion associated with caring for dying people, appropriate nurse education and support are essential. A limitation of this review is the scarcity of available studies focused on nursing attitudes toward death; however, the authors included two metasyntheses, which strengthened findings.

O’Shea and Mager (2019) completed a cross-sectional study of 57 nurses to evaluate the effectiveness of an EOL education program on the knowledge of and attitudes toward caring for patients with advanced illness or at EOL. A thanatophobia scale (TS; Merrill et al., 1998) was given pre and posteducation to measure change in attitudes toward caring for dying patients. The education helped nurses identify areas of needed improvement and elevated nurses’ confidence in their ability to identify patient needs. Inadequate knowledge was a significant barrier to
providing high quality EOL care. Encouragingly, most respondents noted after the education that they intended to change their practice; however, self-reported intent does not indicate actual change (Sheeran et al., 2016) and this study did not allow for evaluation of change in providing EOL care after education. A low response rate and a short time frame of 1 month for survey completion may have affected validity. Additionally, the researchers focused on measuring nurses’ “attitudes toward caring for dying patients” (O’Shea & Mager, 2019, p. 2), but the TS was designed to measure “uncomfortable feelings and sense of helplessness” (Merrill et al., 1998, p. 83).

A qualitative study by Lai et al. (2018) explored 26 healthcare providers’ (including 13 nurses) experiences in providing EOL care in nonpalliative settings. Nurses expressed several difficulties in providing EOL care: lack of support, lack of effective interventions to manage symptoms, and inability to resolve EOL suffering using their skill set. These difficulties led to nurses’ perceptions of poor quality of patient death. Although this study’s strengths include components such as demonstration of gaps in research and education supporting EOL care, the cultural relevance to nurses in the United States may be limited as the nurses in this study lived and worked in China. Moreover, recruitment was conducted via social media, which may have contributed to the lack of diverse inclusion of nurses, including veteran nurses who may not access technology as often.

Powazki et al. (2014) completed a cross-sectional mixed-method study based on a two-part questionnaire to evaluate nurses’ self-described ability and comfort with EOL care to determine if nurses’ comfort or ability was associated with specific demographic characteristics, and assess clinical barriers to implementing best nursing practices. An analysis of 123 surveys determined older nurses with more experience and ongoing specialized education were more
likely to have higher self-described ability and comfort levels when caring for EOL patients. Interestingly, there was no correlation between education level and degree of comfort in caring for EOL patients. The study protocol did not provide for the ability to determine the demographics of nurses who completed the questionnaire and those who did not. Also, the placement of neutral responses to survey questions in the negative category for statistical analysis may have influenced study results. Furthermore, completion of the study in an academic medical center may make generalizability outside that setting unreliable. Development of an EOL toolkit to support nurses caring for EOL patients is a notable outcome of this study.

Karbasi et al. (2018) organized a mixed studies review of 19 manuscripts to determine nurses’ perceptions of personal knowledge, skills, and experiences in caring for EOL patients, and to assess knowledge gaps and educational needs. Themes of nursing self-identity while caring for EOL patients included protector, advocate, and reflective caregiver. The review also identified several obstacles to high-level EOL care, most notably nurses’ lack of education and knowledge related to psychosocial, emotional, and spiritual symptom management at EOL. Time constraints and divided focus were additional barriers to quality EOL care. Supportive measures for quality EOL care included clear communication, having a known plan of care, and education focused on symptom management at EOL. Possible omission of relevant articles and a focus on critical care nurses instead of all inpatient nurses are limitations. However, this review included rigorous analysis and the inclusion of a variety of study types, making the information applicable in multiple settings.

Stacy et al. (2019) evaluated the effectiveness of the CARES tool (Freeman, 2013) in increasing nurse knowledge and comfort in providing EOL care. Using a quasi-experimental study, nine nurses completed a pre and posteducational intervention survey to evaluate their
knowledge and comfort in caring for EOL patients. Five of the nine areas assessed yielded statistically significant improvements, demonstrating EOL education and use of the CARES tool improved nurses’ comfort with EOL care and symptom management in dying patients. A small sample size may affect the validity of results. Additionally, the participants consisted of nurses on units with an increased number of EOL patients, which could lead to bias as these nurses may previously have had an increased level of comfort when caring for EOL patients.

This literature review yielded overwhelming evidence that many nurses caring for EOL patients in acute care settings lack the experience and knowledge to effectively provide this level of care (Karbasi et al., 2018; O’Shea & Mager, 2019; Puente-Fernández et al., 2020; Sekse et al., 2018; Stacy et al., 2019). EOL education may help empower health professionals to change clinical practice. Providing high-quality, evidence-based EOL care can be accomplished by using the CARES tool and providing additional symptom management education (Freeman et al., 2015; see also Karbasi et al., 2018; Lai et al., 2018; Puente-Fernández et al., 2020; Sekse et al., 2018). Attitudes, norms, and self-efficacy show a causal effect on intention and behavior, and interventions that positively influence these thoughts can foster behavior change (Sheeran et al., 2016).

**Method**

This evidence-based project was initiated by informing acute care nurses on a med-surg unit that an advanced practice nurse specializing in palliative care would be providing education sessions focused on symptom management of dying patients. If nurses were interested, they could present to the advanced practice nurse within the specified time frame for education. Sixteen nurses participated.
Before an educational session, nurses completed a TS (Merrill et al., 1998). The validated TS (Mason & Ellershaw, 2004) is designed as a 7-point Likert scale and assesses uncomfortable feelings and sense of helplessness when caring for dying patients (see Figure 2). As demonstrated in the literature review, these feelings are commonly expressed by nurses caring for this patient population.

**Figure 2**

*Thanatophobia Scale*

<table>
<thead>
<tr>
<th>Q1</th>
<th>Dying patients make me feel uneasy</th>
<th>Very strongly disagree</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
<th>Very strongly agree</th>
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</thead>
<tbody>
<tr>
<td>Q2</td>
<td>I feel pretty helpless when I have terminal patients on my ward</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Q3</td>
<td>It is frustrating to have to continue talking with relatives of patients who are not going to get better</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Q4</td>
<td>Managing dying patients traumatizes me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Q5</td>
<td>It makes me uncomfortable when a dying patient wants to say goodbye to me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Q6</td>
<td>I don’t look forward to being the personal nurse of a dying patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Q7</td>
<td>When patients begin to discuss death, I feel uncomfortable</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>


After completing the TS, nurses participated in a 30-minute in-person presentation that included an instructional review of the CARES tool (Freeman, 2013; see Figure 3), and basic pharmacology of medications used for EOL symptom management. Nurses were reevaluated using the TS immediately after education and 4 weeks later to determine if their level of
Figure 3

CARES tool

The following are recommendations for care of the dying based on the Guidelines for End-of-Life Care (GEC) project and the second edition (2013) National Consensus Project for Palliative Care Clinical Practice Guidelines for Quality Palliative Care. These recommendations are aimed at the acronym CARES (Comfort, Airway, Restlessness, Emotional support, and Self-care) to organize the most common needs and education requirements to support the dying patient and their family. The tool is intended to prompt nurses to obtain clear from symptom management, increase awareness of resources and promote communication with the ultimate goal of achieving a peaceful death for the patient and family.

Note. The tool is intended to support nurses in managing symptoms and increase awareness of resources (Freeman et al., 2013).
uncomfortable feelings and sense of helplessness when caring for dying patients changed after
the educational session and over time.

Electronic medical record review provided the number of symptom management
medication doses given to the EOL patients (n=11) on the unit who had a comfort focused care
order set placed within 30 days posteducation. Patients with this order set are expected to die
within hours to days. Medication doses were counted from the onset of comfort care orders, but
no more than 72 hours before death or discharge. The number of medication doses per patient
was compared with that of patients (n=9) on the same unit who had a comfort care order set
during the same 30-day period 1 year prior to determine if there was an increase in the number of
symptom management medication doses provided to EOL patients after the educational session.

**Ethical Considerations**

Hospital administration was informed of the project and provided preliminary
authorization. The project proposal was submitted to the Scripps Mercy Hospital Institutional
Review Board (IRB) and approved. The project was also submitted to the University of San
Diego IRB and approved. Each participant provided verbal consent following an explanation of
the project goals during the face-to-face recruitment process. Nurses had the right to refuse to
participate in the project or withdraw at any time without penalty. Confidentiality and anonymity
of participants were maintained by summarizing and reporting all data in aggregate.

**Results**

One benefit of the project appeared to be a decrease (though not statistically significant)
in the uncomfortable feelings and sense of helplessness nurses experienced when caring for a
dying patient (see Figure 4 and Figure 5). This change in feelings may have led to improved
Note. After education, there appeared to be a decrease (though not statistically significant) in the uncomfortable feelings and sense of helplessness nurses experience when caring for a dying patient.
symptom management. Posteducation, there appeared to be an increase in medication doses for symptom management when compared to the same 30-day period the year prior (see Table 1 and Table 2). Due to the low number of overall doses, statistical analysis could not be conducted.

**Limitations**

A limitation of this project was that eight of the nurses who initially received instruction were lost in the follow-up process and did not complete the 30-day posteducational TS. Due to a low number of comfort care patients, not enough medication doses were given to conduct statistical analysis. Also, this project was implemented on a single unit of an urban hospital during the COVID-19 pandemic, possibly limiting its efficacy and the ability to effectively assess benefits.

**Cost-Benefit Analysis**

The total cost of this educational intervention for 16 nurses is estimated at $902, or $56.38 per nurse. Although some revenue return is presumed due to increased charges related to increased medication doses, there is no immediate overall financial gain. The connection between reimbursement and patient satisfaction must be considered; theoretically, improved symptom management leads to increased satisfaction at a cost that is not prohibitive to the organization.

**Implications for Clinical Practice**

This intervention is clinically relevant and easy to replicate in future efforts. EOL symptom management may be improved by providing acute care nurses a 30-minute educational session about use of the CARES tool and basic pharmacology of EOL symptom management medications. Implementation of an asynchronous online format would increase ease of access.
Table 1

*Use of Medications for Symptom Management (Preintervention)*

<table>
<thead>
<tr>
<th>Age</th>
<th>Gender</th>
<th>Comfort care date</th>
<th>Comfort care time</th>
<th>Discharge or death date</th>
<th>Discharge/death time</th>
<th>Hours of comfort care</th>
<th>Scheduled med or pump with basal?</th>
<th>Morphine doses</th>
<th>Hydromorphone doses</th>
<th>Oxycodeone doses</th>
<th>Fentanyl doses</th>
<th>Lorazepam doses</th>
<th>Midazolam doses</th>
<th>Haloperidol doses</th>
<th>Ondansetron doses</th>
<th>Glycopyrolate doses</th>
<th>Total PRN doses</th>
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Table 2

Use of Medications for Symptom Management (Postintervention)

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<th>Age</th>
<th>Gender</th>
<th>Comfort care date</th>
<th>Comfort care time</th>
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<th>Morphine doses</th>
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Note: There appeared to be an increase in medication doses for symptom management after education compared to the same 30-day period 1 year prior.
and minimize the risk of losing nurses to follow-up, as a reminder can be sent to encourage nurses to complete the final TS. It may be valuable to consider additional nursing support to assist in caring for EOL patients, or debriefing after patient death.

**Conclusion**

This evidence-based intervention influenced nurses’ attitudes toward caring for EOL patients by demonstrating a decrease (though not statistically significant) in nurses’ self-reported uncomfortable feelings and sense of helplessness when caring for EOL patients, which may have led to improved symptom management. There was an apparent increase in medication doses for symptom management after nurse education, although due to the low number of overall doses, statistical analysis could not be conducted.
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 DOES COMFORT CARE MAKE YOU UNCOMFORTABLE

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