A Holistic perspective on comfort care as an advance directive

Critical care nurses are frequently involved with patients and families who must choose among the various advance directives. Although “comfort care” is a familiar option, there is a lack of clarity about specific components of comfort as well as the nurse’s role as a member of the interdisciplinary team. This lack of clarity can result in disruption of the patient or family decision-making process surrounding impending death. This article defines comfort care as a holistic and positive choice for patients and families among advance directive options. A two-dimensional grid is applied to assist with discussion and decision making regarding the dying process. Methods for applying the framework and developing a care plan are presented in case study format. Practicing these methods will enable critical care nurses and other team members to empower patients and families to work through the dying process with optimal comfort. Key words: advance directive, comfort care

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In acute and critical care settings, an available choice among various advance directives is comfort care. Comfort care has been discussed in reference to terminally ill patients with cancer or acquired immune deficiency syndrome who often have had time to review and summarize their lives, come to terms with their prognosis, and discuss and select treatment options. A difference exists, however, for the critically ill patient. Despite the age of the individual, many patients and families have not discussed their wishes regarding life-sustaining measures or have done so with limited knowledge of what such a choice entails. The variable trajectory of critical illnesses is associated with a greater degree of uncertainty of outcome, hence creating gray areas for decision making. Thus, families of critically ill patients often choose comfort care reluctantly and without full knowledge of the impact of their decisions or lack of decisions on the comfort of their loved ones.

Critical care nurses play a pivotal role in working with patients, families, and the interdisciplinary comfort care team. The process is initiated by the recognition that comfort care measures can be simultaneously used to increase quality of life. The comfort care process may include ventilator removal, discontinuation of artificial nutrition, discontinuation of intravenous hydration, discontinuation of dialysis, and discontinuation of specific medical interventions. Each measure exists, however, to initiate or continue medical or interventional treatments. Medical interventions, despite their existence, would be helpful to team members in helping families through the dying process.

The problem with the lack of a formal conversation about comfort care and the choice entails the discomfort entailed by the decision itself. Comfort care, a potential solution, is not always relevant or can be a source of discomfort. This article presents a process for guiding the interdisciplinary team in the process of implementing comfort care measures when indicated.
A Holistic Perspective on Comfort Care

Theoretical Background

A theory of holistic comfort provides the theoretical framework for an expanded and positive conceptualization of comfort care. Briefly, the theory states that interventions should be designed and implemented to meet actual comfort needs of patients. Patients and families judge the effectiveness of these interventions in light of existing intervening variables. Intervening variables are defined as factors that each patient brings to the situation and that nurses cannot change, such as poverty, lack of social support, or a strong will to live. The recipients of nursing care judge the effectiveness of interventions. If their comfort is enhanced, the interventions qualify as comfort measures. Such comfort measures strengthen the patient and the family during the dying process, and they facilitate a peaceful death.

The theory of comfort entails three important elements that are relevant for the care of dying patients. First, the term comfort is derived from the Latin word, confortare, meaning to strengthen greatly. The strengthening component of comfort care provides the rationale for health care providers to try to enhance comfort. Second, the process of comforting involves active participation by the patient and family to enhance the patient’s comfort. Thus, for recipients, comfort care implies a continued active involvement that may be facilitated with coaching from the critical care nurse and health team. Third, comfort care consists of the process of comfort and the product (outcome) of enhanced comfort. The process exists only if the product is brought into being. These three elements from the theory of comfort indicate that an expanded sense of comfort care constitutes a positive, active, moral, and humane framework for discussion and action. The expanded definition of comfort care is an active process that strengthens patients and families by enhancing their holistic comfort during the experience of death.
Although the definition of comfort care was not developed with advance directives in mind, its principles are applicable to the care of critically ill or dying patients. According to Schlofenfelt, nurses can and should discover factors related to health-seeking behaviors or a peaceful death. Theoretically, enhanced comfort is one factor. To understand the derivation of the framework for comfort care, the definition of holistic comfort will be reviewed.

DEFINITION OF HOLISTIC COMFORT

Comfort has been defined for nursing as the immediate experience of being strengthened through having the needs for relief, ease, or transcendence met in four contexts of experience. The three types of comfort, relief, ease, and transcendence were derived from the literature in an earlier concept analysis of comfort, using the literatures from psychology, ergonomics, nursing, medicine, and theology. From the literature about holism, the four contexts in which comfort is experienced, physical, psychospiritual, environmental, and social, were derived. These four contexts were identical to the sources of suffering named and described by Spross, affirming the relevance and inclusivity of the contexts for human experience. When the three types and four contexts of comfort are juxtaposed, a 12-cell grid diagramming the many nuances of comfort emerges. The types of comfort and contexts in which comfort is experienced are defined in Fig 1.

Each component of comfort is represented by one cell of the grid that interacts with other components holistically. That is, interventions directed toward one component affect other components of comfort simultaneously. Moreover, total comfort is enhanced beyond what would be expected when single components are enhanced (at separate times or jointly) and their effects added together. For example, if undesired noise in the patient’s room (environmental comfort) is attended to, physical, psychospiritual, and social comfort are likely to be enhanced. Thus, if one comfort need is addressed, then total comfort is enhanced. The idea is intuitively correct because of nurses own experiences with comfort. Because of their familiarity with personal comfort, nurses can readily integrate the concept of comfort into practice.

APPLICATION OF COMFORT CARE IN CAREGIVING OF DYING PATIENTS

The comfort grid is a framework for holistic care, providing an organizing structure for thorough and efficient care to dying patients and their families. The steps, demonstrated in the case studies that follow, are taken when applying the framework. Numbers have not been assigned to these steps to be consistent with the nonlinear nature of the comforting process.

- Comfort needs are assessed subjectively (what patients and families say) and objectively (what the nurse observes). In addition, supporting data are collected from charts and from opinions of other health care providers. Sometimes these assessments are contradictory and other evidence must be gathered for an accurate comfort assessment to result.
- Comfort measures, sometimes several at one time, are designed to meet the needs of each unique situation, taking into account all intervening variables. In each of the four contexts of comfort,
A Holistic Perspective on Comfort Care

Type of comfort

<table>
<thead>
<tr>
<th>Relief</th>
<th>Ease</th>
<th>Transcendence</th>
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<tbody>
<tr>
<td>Physical</td>
<td>Psychospiritual</td>
<td>Environmental</td>
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<td>Social</td>
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Type of comfort:

Relief: The state of a patient who has had a specific need met.
Ease: The state of calm or contentment.
Transcendence: The state in which one rises above one's problems or pain.

Context in which comfort occurs:

Physical: Pertaining to bodily sensations.
Psychospiritual: Pertaining to internal awareness of self, including esteem, concept, sexuality, and meaning in one's life; one's relationship to a higher order or being.
Environmental: Pertaining to external surroundings, conditions, and influences.
Social: Pertaining to interpersonal, family, and societal relationships.

Fig 1. Diagram of comfort.
the needs for relief, ease, or transcendence are addressed. Needs, comfort measures, and desired outcomes designed for the patient and family are unique, interactive, and complex. That is, when one comfort need is met, other needs are positively affected and total comfort is enhanced.

- Comfort measures are implemented after active decision making or consideration of all contexts by the patient and family throughout the comfort care process.

- Comfort is reassessed to determine the effectiveness of comfort measures and to determine whether other actions could further enhance total comfort. The nurse’s reassessment of enhanced patient and family comfort is evaluated in reference to the identified and emerging intervening variables. Subjective, objective, and supporting data are likewise reevaluated during this phase. Follow-up comfort measures are implemented when the nurse determines that comfort has not been enhanced by earlier measures or when comfort can be enhanced further with the addition of new measures or by repeating former comfort measures. In this way, a holistic plan of care is built using the comfort grid as a framework to meet current and evolving comfort needs in each unique situation. Note that in most health care situations, it is rare for patients to experience total comfort. Rather, interventions (comfort measures) are designed to enhance comfort compared with a previous baseline assessment.

- Finally, verbal and written interdisciplinary communication, using the comfort grid as a framework for discussion, ensures that consistent and effective care is administered. Although the framework of comfort care is a flexible guide for caregiving and decision making for patients and families, it also facilitates communication among other health care providers as they discuss, weigh, and manage emerging comfort needs.

Some interventions, such as keeping the patient clean and providing a peaceful environment, are not controversial issues in terminal care and occur automatically, without using the framework of comfort care. However, other interventions, such as hydration, tube feeding, and the discontinuing of current biotechnological therapies, are more controversial. The framework for comfort care is a guide for nurses in leading discussions about the decision to choose this option and those controversial interventions that may not promote the patient’s comfort. The framework generates such questions as: “Is intervention X a comfort measure?” “To whom does intervention X provide comfort?” “Whose comfort (patient, family, physician, nurse, administrator) is of primary concern?” “How can this family best be comforted so that the patient is more comfortable?” “Is there anyone I can call on to help with this decision(s)?” “Have I communicated everything about the comfort needs and comfort measures that work to the next shift or the next visitors or the interdisciplinary team?” These questions can serve as important points of consideration in creating a patient-centered and integrated plan of comfort.

CASE STUDIES

The following case studies illustrate the utility of the comfort framework with patients and families who chose or came to choose comfort. The use of all the first case

Case 1

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choose comfort care as an advance directive. The use of a comfort care plan is included in the first case model as a learning device.

Case 1

JA was a bright, assertive 43-year-old marketing consultant diagnosed 6 months earlier with metastatic melanoma. Respiratory complications resulting from massive pulmonary emboli precipitated JA’s transfer to the intensive care unit for continuous mechanical ventilation. Over the next few days, JA’s condition stabilized and he was weaned from the ventilator to a 50% Venturi mask. Greenfield filters were inserted in both femoral veins.

Before this admission, JA was hopeful that he would go into remission and he wanted full medical management. The current episode, however, caused him to reevaluate the deadliness of his disease, and he verbalized that he did not want the “breathing machine” in the future.

As JA’s wishes for a natural death became more defined and articulated, his wife expressed disapproval that he was “giving up.” She believed that his feelings were precipitated unjustifiably by a negative staff. Nurses observed that family interactions appeared to deny the possibility of impending death. However, based on evaluation of the intervening variables, namely the patient’s strong desire to be allowed to die without further technical interventions and his incurable condition, JA’s advance directive was changed legally to comfort care. His wife continued to be angry with her husband and the staff, but a plan for holistic comfort care was initiated by the interdisciplinary team.

Comfort measures were directed toward the four contexts in which comfort is experienced. Physical comfort was addressed because JA was clean, warm, and dry, but he could no longer swallow adequate food or oral fluids. His wife asked that intravenous hydration be implemented. Because JA’s veins were in poor condition as a result of chemotherapy, a central venous line was ordered. Before insertion of the central line, JA again stated that he did not want further invasive procedures. His family urged him to reconsider because they did not want him to “die of thirst.” The nurse explained that dehydration could enhance JA’s comfort because he would have less coughing, shortness of breath, swelling, pain, vomiting, and diarrhea, all discomforts that he was experiencing. Likewise, dehydration would provide a natural anesthesia to pain centers in the brain and to peripheral pain receptors.

Allowing JA to refuse the central line provided physical comfort by decreasing pain and secretions and psychospiritual comfort by acknowledging JA’s control over his dying process. The family was encouraged to support him in the decision by not arguing with him (further enhancing his psychospiritual comfort) and by providing physical comfort measures such as mouth care and ice chips to counteract the mild oral discomforts of dehydration.

JA consented to pain medications because of severe headaches he experienced from metastases. Because of poor IV access, the intramuscular route was chosen initially. The family noted, however, that JA experienced increased pain with turning for injections and asked if another route was available for analgesia administration. JA consented to the insertion of an epidural catheter for administration of analgesics. This intervention enhanced his physical comfort by relieving his pain and providing ease by not having to be turned. Psychospiritual comfort again was
enhanced by giving him control over important decisions.

A further need was identified for JA when he requested to be taken outdoors. His nurses, along with family members, took him in his bed (with oxygen and an epidural pump) to an outdoor patio. They provided environmental comfort for JA, as well as psychospiritual comfort by facilitating his participation in his own care and his breathing of fresh air. JA verbalized a sense of transcendence or rising above pain and fear during this comfort measure and exhibited a state of calm while interacting with his family.

Social comfort needs were met by facilitating the family’s open access to JA and teaching them how to provide loving physical and emotional care to him, even during their feelings of impending loss. A cot was provided in his room for overnight stays, and privacy signs were posted. JA did not wish to talk with the hospital chaplain, but he did want to talk about his life’s work, relationships, funeral wishes, and insurance procedures. The family was encouraged to participate openly in these poignant, but necessary, conversations.

Staff members also spent extra time facilitating JA’s search for meaning through active, uninterrupted listening and by continuing to laugh at his humor. Attention was given to the comfort needs of the family as they learned how to follow the nurses’ lead, carrying out JA’s requests. The comfort model at this point became three dimensional in that family comfort further enhanced comfort experienced by JA.

Continuity of care was ensured by detailed verbal and written communication to all caregivers regarding the predominant comfort needs of JA and his family. (See Fig 2 for a care plan that condenses and organizes the above comfort measures.) Patient and family needs were continuously reevaluated and discussed in conferences that included them as well as nurses, physicians, and others associated with JA’s care. Comfort measures were modified as JA’s case evolved. Total comfort for JA and the family was enhanced, and his death was peaceful, as he wished.

Case 2

AV was a 58-year-old woman 1 week post-coronary artery bypass graft surgery. She was readmitted to the intensive care unit with respiratory failure and massive gastrointestinal bleeding. She was placed on a ventilator, and a pulmonary artery catheter and nasogastric tube were inserted. Multiple transfusions were administered, along with vasoconstrictors to maintain her systolic blood pressure above 90 mm Hg. Two days later, AV developed severe abdominal pain, and a laparotomy revealed necrosis of the bowel with peritonitis. A colostomy was performed, and the wound was left open to permit granulation.

After surgery, AV remained alert on the ventilator. Over the next 2 months, AV developed liver failure, sepsis, and renal failure necessitating placement of a vascath and daily hemodialysis. Her primary physician communicated to the family that he was not ready to “give up hope.” The family struggled with the physician’s beliefs, plus the fact that before her original surgery, AV was healthy and vitally active. However, AV wrote on a magic slate, “I am dying—no more.”

Although comfort care was not selected legally as an advance directive, the framework of comfort care was implemented because of the acute comfort needs of AV and her family. The issue of physical comfort was
Patient and family comfort care plan. To facilitate reading, only comfort needs (first two columns) are categorized. Because interventions are holistic, they are not categorized.

<table>
<thead>
<tr>
<th>Comfort needs of patient</th>
<th>Comfort needs of family</th>
<th>Interventions</th>
<th>Intervening variables</th>
<th>Patient's perception of comfort</th>
<th>Family's perception of comfort</th>
<th>What next?</th>
<th>Health-seeking behavior</th>
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<tbody>
<tr>
<td>Alpha press</td>
<td>Beta press</td>
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<td>Physical</td>
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<td>The nurse</td>
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<td>Objective...</td>
<td>What next?</td>
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<td>Hygiene</td>
<td>Place for rest or sleep in hospital</td>
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<td>No peripheral venous access</td>
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<td>Health-seeking behavior</td>
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<tr>
<td>Thirst</td>
<td>Take JA outside</td>
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<td>JA loves to be outside</td>
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<td>through dying experience</td>
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<tr>
<td>Rest</td>
<td>Provide ice chips and good oral care</td>
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<td>JA an advertising executive</td>
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<td></td>
<td></td>
<td>Understand positive aspects of a “good death”</td>
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<td>Headaches</td>
<td>Explain to family effects of dehydration in dying process</td>
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<td>JA has three young children and a wife who does not work outside the home</td>
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<td>Communicate openly</td>
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<td>Pain with turning</td>
<td>Listen to JA’s instructions and needs to plan for family’s future</td>
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<td>JA laughing occasionally</td>
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<td></td>
<td>Feel like they can cope in this situation</td>
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<td></td>
<td>Encourage JA to reminisce</td>
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<td>Feel they can let go</td>
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<td>Psychospiritual</td>
<td>Suggest JA make a tape for his children</td>
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<tr>
<td>Wants a peaceful death</td>
<td>Encourage children to touch JA and spend as much time as possible with him</td>
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<td>Need for control</td>
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<td>Fresh air</td>
<td>Clutter-free room</td>
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<td>Sunshine</td>
<td>Privacy</td>
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<td>Privacy for family time</td>
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<tr>
<td>Family disapproval of wishes</td>
<td>Need to help JA with physical care</td>
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Fig 2. Patient and family comfort care plan. To facilitate reading, only comfort needs (first two columns) are categorized. Because interventions are holistic, they are not categorized.
complex because medication sufficient to bring relief from pain caused drowsiness, a state that AV resented especially during family visits. She asked that medication be withheld at those times so she could fully experience her family’s presence and her own existence. However, AV’s pain was so generalized and severe that the family requested that she be medicated frequently and allowed to sleep. In her effort to talk with her family around the ventilator, AV frequently coughed so forcefully that her eyes filled with tears. At this point, the family demanded that AV be totally sedated, and they reduced their visits, believing their presence caused her further upset.

Because the family’s wishes contradicted AV’s psychospiritual comfort, education was directed toward increasing the family’s understanding of her need to remain alert for their visits and that her tearing was related to coughing and not pain or sorrow. The issue of pain was discussed with AV in the presence of the family. The family agreed that pain medication could be lightened during visits; psychospiritual comfort was enhanced for both AV and her family despite her apparent physical discomfort during their visits.

Another physical comfort need was for body warmth. Because she was septic and constantly feverish, antipyretic medications were administered and she was placed on a cooling blanket. The cooling blanket made her feel very cold, causing her more discomfort. Nurses covered her with blankets to warm her, circumventing the effects of the cooling blanket but providing some physical comfort.

AV’s environmental needs were many. First, AV wanted to know what time of day it was. The blinds were kept closed because the family and staff members believed a darkened room to be a comfort measure. AV indicated that the darkened room prevented her from remaining oriented to cycles of night and day. Environmental comfort was enhanced when blinds were left open. Second, AV relished quiet, but the noises of the ventilator, monitoring system, and IV pumps were constant irritants. Nurses tried to monitor the equipment more carefully to decrease alarms, and they curtailed their laughter and conversations with each other near AV’s room. Third, privacy needs were acknowledged when family was present. The family demonstrated increased anxiety when nurses were not present. Hence, the need for family reassurance was addressed.

AV demonstrated inward peace about her impending death but had many social and psychospiritual comfort needs related to her inability to communicate this sense of peace to her family. Because of her weakness and mechanical ventilation, she was unable to establish a way to help her family feel better. At times, her frustration at being unable to speak caused real crying that the nurses were able to distinguish from the tearing caused by coughing. They asked AV “yes-no” questions and attended closely to her mouthed conversation. At one point, she looked up at the nurse and mouthed, “I am going to die.” The nurse nodded in agreement for which AV expressed gratefulness and then asked the nurse to tell the family it was “okay.” The mutual acknowledgment of imminent death was extremely comforting to nurses, AV, and her family.

As AV moved closer toward death, she came to understand that her family would be uncomfortable witnessing her final moments and that their discomforts might impede her progress toward dying peacefully. She communicated these beliefs to her nurses who discussed AV and death if the ventilator relieved a AV’s favored comfort before she needs and comfort

COMFORTING DEATH

A “good death” being met well for family. Other and I to find me a bad death interaction welcomed, were involved by dying patient experience the dying [P]. The family consistent participantful, and go life review, for a peace comforts and terminal events that ensure a na
discussed in conference with the family that AV and they might experience an easier death if the family was not present when the ventilator was discontinued. The family was relieved and yet reassured that at least one of AV’s favorite nurses would be attending her constantly, facilitating a “good death.” Total comfort was enhanced for AV and her family before she died. Nurses prioritized emerging needs and implemented deliberately balanced comfort measures to meet those needs.

COMFORT CARE AND “GOOD DEATH”

A “good death” has been described as being meaningful for all, a death that ends well for patient, health care workers, and family. It is a time to say goodbye to each other and to the mortal life of the patient and to find meaning and sum up that life. “Patients should die like they’re being rocked to sleep in their mother’s arms.” Conversely, a bad death was described as an unfulfilling interaction in which feelings of being overwhelmed, helpless, guilty, angry, or anxious were involved. Although these feelings were reported by medical residents working with dying patients, the same feelings can be experienced by any or all participants during the dying process.

The framework of holistic comfort care is consistent with a good death because each participant in the process is proactive, thoughtful, and goal directed. Total comfort entails life review, resolved relationships, and hope for a peaceful release. Ideally, the goal of a comfortable death is articulated by the patient either in advance of, or during, the terminal events. The goal entails assumptions that specific comfort measures will ensure a natural and good death. When the patient has not chosen an advance directive, or when the patient is unable to do so, decisions about instituting specific interventions must be made by a surrogate. The framework of comfort care can direct informed caregivers and families to attend to known comfort needs of the patient and to forego biotechnical interventions that would prolong death. Because total comfort can be assessed through observing patients, the framework is applicable when they are unconscious, very young, or confused.

Although the comfort framework provides a valuable structure for conceptualizing a holistic framework for discussion, decision making, and action, a possible limitation is that comfort care may be perceived as withdrawal of hope by patients, families, and interdisciplinary team members. The variability in the trajectory of critical illnesses contributes to this dilemma; it is not always possible to make definitive decisions about when to change the treatment goal from cure to care. As a guideline in difficult cases such as these, the framework for comfort care informally directs nurses and families to make judgments, not about whether or not death is inevitable, but rather about contributors to or detractors from patient comfort. These are meaningful and productive decisions in and of themselves, and anxiety about probable health outcomes can be relieved in favor of a focus on enhancing the patient’s comfort.

In the second case study, the physician denies the possibility of AV’s death, claiming that it was not yet time to give up hope. This reaction to AV’s progressive deterioration further highlights the role of hope in critical situations. Hope is characterized by the belief in a personal and better tomorrow and the expectation that a better tomorrow is truly possible and important. Hope is often
oriented to immortality rather than mortal life. When hope is defined in terms of the patient, the hopes of the physician (that he or she will be successful in restoring health) and family (that the patient will live) are secondary. Furthermore, creating false hope is likely to create more discomforts for the patient (and family) as the inevitability of death increases. Thus, a patient’s hope that death will be “good” is the realistic goal of holistic comfort care, whether or not legally or formally. If the patient also hopes for a peaceful afterlife, that too is consistent with the reality of the dying patient.

In an earlier article summarizing similar case studies and the findings of ethics committees in each case, the following conclusion was reached: “When the treatment goal is changed from life-prolongation to comfort care, even though the patient is still in the acute hospital setting, it is appropriate to adopt the hospice precept that all treatment decisions should be judged by whether they contribute to patient comfort.” By design, the framework of comfort care is a positive, humanistic guide for caregiving, discussion, and decision making when the need for holistic comfort care is apparent. This article proposes an expanded and articulated sense of comfort care that includes all aspects of comfort. The framework is directed to the patient and family as active participants in the dying process of the patient. When nurses implement the framework in this expanded sense, comfort care strengthens the patient and family and it is positively related to a peaceful death. The result is a family who is empowered to work through and assist in their loved one’s death, and a patient who is allowed and encouraged to meet death with peace, dignity, and comfort.

REFERENCES