

## A Comfortable Place to Say Goodbye

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### **Article:**

#### SCENARIO

Bill had suffered severe trauma, the type of injury even a 46-year-old healthy man does not survive. A helicopter transferred Bill to tertiary trauma facility miles from his home. Nurses and physicians worked for hours to stabilize him. Throughout the day, family members arrived, some in tears, some angry, all confused and distraught over Bill's tragic accident. The afternoon of Bill's arrival, the physician had a meeting with the family. The physician was honest, direct, and compassionate with the family. Bill would not likely survive this trauma; however, he discussed the supportive process of comfort care. The family wrestled with their emotions and with the reality of Bill's eminent death for several hours. The family finally agreed to stop the futile treatments and allow Bill to experience a peaceful death. The comfort care protocol for Bill involved continuing mechanical ventilation, continuous intravenous sedation, and pain medications. Family members took turns in their vigil at Bill's bedside, each coping in his/her own way and toward his/her own acceptance of Bill's death, some in tears, some still angry at the unfairness of life. Bill was still alive the next morning, and the nurse from the day before resumed his care. The family's emotional journey culminated that morning with Bill's death, with loved ones surrounding his bedside, holding hands, and singing hymns as Bill's heart rate slowed and eventually stopped. There were tears in everyone's eyes, but there was also relief on their faces. Death had finally come, and Bill had never exhibited any signs of pain or suffering. No death is easy, but we all hope to die peacefully, with our loved ones surrounding us, comforted by each other's presence, and the knowledge that the right decision has been made.

Bill's story illustrates what many people hope and strive for: a comfortable place to say goodbye. The family was not in despair; the environment was comfortable emotionally, psychologically, and physically for the family. They had a large room allowing the family to stay comfortably at Bill's side. The healthcare team maintained open and honest communication with the family throughout the ordeal and helped the family accept that the right decision had been made. It appeared to all that Bill was comfortable in his last hours and did not suffer. He received medication for anxiety and pain and was not struggling to breathe. His loving family remained at his side. It was emotionally and professionally comfortable for the physicians and nurses to know that Bill was receiving the care and comfort he needed most. All of this gave peace to Bill's death. One might ask then why all death experiences in the intensive care unit (ICU) are not like Bill's. End-of-life care in ICUs has been extensively advocated in both nursing and medical critical care literature. Contemporary ICU care does institute end-of-life issues. Yet, our personal experience (the authors) is that peaceful end-of-life care in the ICU is the exception rather than the rule. Several problems may interfere with implementing this type of end-of-life care.

#### PROBLEMS ENCOUNTERED WITH END-OF-LIFE CARE IN THE ICU

Caregivers and family members often have unrealistic expectations that a patient admitted to the ICU will be

cured and may consider death a failure of modern medicine. Boyle et al 1 noted that admissions to an ICU are often not anticipated by the patient and family. End-of-life discussions have not been held, and patients may be unable to make decisions or even discuss their desired care. Families may not realize or may not accept that death is eminent. This may require further and ongoing communication by healthcare providers to explain the patient's treatments and condition or any possible conflict with the patient's or family's wishes.<sup>2</sup>

Studies have found that end-of-life care was implemented earlier for patients with certain chronic disease when physicians initiated conversation about advance directives in the outpatient setting or before the patient became too ill to discuss. Transitions to end-of-life care were made more easily if honest discussions on the severity of the patient's condition were held at the time of admission to an ICU. Much stress and many problems were reduced by early discussion and planning involving all parties.<sup>3-5</sup>

End-of-life care is palliative. It changes the focus from curing the disease to addressing the spiritual, emotional, and psychological needs of the patient. Optimal symptom management and pain control are vital in end-of-life care.<sup>4</sup> Some critical care nurses may have limited knowledge of end-of-life care and may be ill prepared to change their thought processes from acute or curative to facilitator of a comfortable death.<sup>6</sup> Efforts should be made to include end-of-life issues in all ICU orientation programs. Changes in the focus of care are often based on the patient's advance directives. Nurses traditionally are the advocates for patient wishes and must understand the advance directive and desired end-of-life care of each patient as an individual. Nursing staff members may then find themselves facing challenges as they advocate for the patient's stated wishes. Rady and Johnson<sup>4</sup> found that many patients with predictors of the likelihood of a poor survival were often transferred by physicians to the ICU for aggressive care despite the fact that these patients had voiced a desire for comfort care only. Most often, these physicians were junior house staff or first and second year resident physicians in large teaching hospitals. Less experienced physicians tended to pursue aggressive treatment options and had little experience in initiating discussions and the enactment of end-of-life care.<sup>4</sup>

Beckstrand et al<sup>6</sup> studied issues encountered by critical care nurses in implementing end-of-life care in the ICU. They identified themes of (1) unrealistic expectations of survivability by families, (2) lack of communication between all parties, and (3) physicians who were not ready to "admit defeat." Family members often have conflicting opinions, both between one another and with the patient's own wishes regarding treatment options. The ICU, with its lack of privacy and limited visiting hours, can be a difficult place for quality end-of-life care. The nursing shortage has caused heavy patient assignments that often leave nurses with insufficient time to devote to dying patients and their loved one.<sup>2,3,5</sup>

It is challenging for the ICU team to educate the family to understand that instituting end-of-life care in the ICU does not mean giving up hope but rather instills hope for a "good death". A "good death," which means being pain-free, with loved ones rejoicing in the patient's life, actually gives a renewed sense of hope for the family.<sup>7</sup>

The ICU nurse assists families in making the decision in stopping treatment by understanding advance directives and as the patient makes the transition from curing to palliative care. The entire ICU team can provide supportive, end-of-life care and promote hope for a comfortable and compassionate place to say goodbye for the patient and his/her loved ones.

## MAKING THE DECISION TO STOP TREATMENT

Studies have found that communication is key to making an informed decision to forego treatments that will likely be futile and allow a peaceful death in the ICU. The patient (when able), loved ones, physicians, and nursing staff must all engage in an honest and effective communication for this decision to be made.<sup>1,8</sup>

We often think family members are the decision makers for very ill patients. More often, however, individuals

closest to them are not necessarily related but are linked by love. It is vital to the well-being of patients and those who love them that this bond be understood and honored. Dracup and Bryan-Brown<sup>8</sup> noted that decisions were more easily made if loved ones had a clear understanding of a patient's wishes, either from previous discussions or existing advance directive documents. Loved ones should know the location of any advance directive documents. Communication among the healthcare team members increases the understanding of a patient's condition as well as treatment goals. The healthcare team must identify the goals of each patient on a daily basis and share the information with the patient's loved ones. These discussions should review the patient's prognosis and weigh patient suffering versus quality of life. Loved ones have a better acceptance and long-term peace of mind when decisions are made based on informed communication.<sup>1</sup> Communication with patients and families is one of the key ways to maintain hope and family integrity in critical care settings.<sup>9,10</sup>

The critical condition of the patient in the ICU may force loved ones into the position of making end-of-life decisions. This may lead to lasting feelings of uncertainty and guilt about the decisions they made. Nurses may prevent or lessen the guilt by encouraging the loved ones to talk about the patient. Describing and remembering the patient's life and his/her hobbies and favorite activities help the family realize the futility of current treatments and the inevitability of death.<sup>11,12</sup>

It is equally important for nurses, physicians, and all healthcare providers to understand and respect the wishes of dying patients. Listening to what patients are saying requires practice, focus, and sensitivity. Patients may say "I just want to die," but upon questioning, the patient may mean to say that he/she needs better pain relief. Patients want to be heard and understood and assisted in achieving a comfortable death. They need to be certain that their final wishes are respected.<sup>13</sup> Interviews with dying patients have revealed a common desire to have an ample time for honest and informative communication with healthcare providers regarding the patient's condition, prognosis, and strategies of care. Patients want a compassionate bedside manner and empathy in care. They are adamant that healthcare workers treat patients as they themselves would wish to be treated. Advance directives initiate an avenue for discussions with the patient and loved ones, ensuring that all participants have full understanding of the stated wishes.<sup>14</sup>

## ASSISTING FAMILIES AND PATIENTS WITH ADVANCE DIRECTIVES

The right of patients to accept or refuse treatment is guaranteed by the Patient Self-Determination Act. This right is operationalized as either an advance directive or durable power of attorney. The durable power of attorney or healthcare proxy designates a representative chosen by the patient who will make healthcare decisions for him/her when he/she is unable to do so. The advance directive or living will is a legal document that allows a patient to specify desired care and treatment when he/she is unable to do so.

Kass-Bartelmes et al,<sup>15</sup> with the Agency for Healthcare Research and Quality, found that less than 50% of patients had completed an advance directive, and for those who did, less than half had their directives followed. The representatives named by patients were often unwilling to make treatment decisions even when they clearly understood the patient's desires. Physicians may not discuss advance directives with their chronically ill patients and often did not inform the patients of the terminal status of their illnesses. The study also found that patients who had discussed and instituted an advance directive were less anxious and fearful about their end-of-life care, feeling that their physicians and representatives understood their wishes. Patients who had established an advance directive were also more likely to have open and ongoing discussions with their loved ones clarifying these wishes. Kass-Bartelmes et al<sup>15</sup> suggest a 5-part process for healthcare providers to facilitate discussion with patients and family members:

1. Initiate a discussion using hypothetical situations and noting the patient's preferences on whether he/she wants to be treated. This also allows clarification of patient understanding of specific treatments and situations.

2. Begin discussion of an advance directive far in advance of the expected need. It should be noted that this is not always possible in the ICU. This allows the patients an opportunity to gain a better understanding of their rights and more fully explore their wishes and desires. It also allows time to have open discussions with family members before facing a crisis.
3. Have the proper documents completed with explicit details, including wishes for intubation, vasopressors, cardiopulmonary resuscitation, and invasive procedures.
4. An advance directive should be reviewed with patients on a regular basis. As an illness progresses, patients often change their mind about certain treatment options.
5. Honor the decisions that the patient has made. There may be conflicts between the treatments that the physician desires to give and those requested by the patient. There is no easy way to say when the application of an advance directive should be activated, and it is based on the knowledge of the physician and the emotions of the patients and family members.

Most people will die from chronic illness. It is vital to quality end-of-life care that discussions regarding care choices be initiated early, while patients still have the mental and emotional capacity to understand, discuss, differentiate, and decide on the course of end-of-life care that they desire.<sup>15</sup>

## MAKING THE TRANSITION FROM CURING TO CARING

The transition from curative, aggressive treatment to comfort care involves several important elements. It is best if families are provided with unlimited access to the patient in as private a setting as possible.<sup>9</sup> A private room should be available for both condition conferences with healthcare providers and a place where grieving family members can seek refuge. Supportive services of clergy or hospital bereavement counselors should be offered. Families often express appreciation for continuity of care when they have the same nurse, one who is familiar with the patient and all aspects of care.<sup>2,16</sup> Although some nurses find that taking care of the same patient day after day is taxing, retaining the same nurse fosters hope for a comfortable death in the patient and family. Two hospice nurses, Callanan and Kelley,<sup>17</sup> point out in their book, *Final Gifts*, that nurses who are with a patient and family in the days and hours leading to death experience awe. Callanan and Kelley<sup>17</sup> show how nurses and family members can learn to recognize, understand, and respond to a dying patient's requests rather than perceive the patient's death as a negative experience that some nurses may dread. This experience may provide ICU nurses with a sense of renewal and provide both the inspiration and desire to come back "and do it all again tomorrow."

The dying patient's physical, emotional, and psychological comfort take priority for the ICU nurse. Nurses are strong advocates for patient comfort, pain, and anxiety management, and they ensure that the patient's desires are met. The nurse's role is to assess and inform the patient as to how medication can help. A patient may desire to forego medications for a period to be more lucid in the last days with loved ones. The refusal of life-sustaining or life-prolonging treatments is the competent patient's right and must be honored.<sup>2</sup>

Dying patients have stated that being kept clean and experiencing physical touch were important to them in their end-of-life care. The simple task of washing a patient's hair may be fondly remembered forever by family members. Being without pain, shortness of breath, or anxiety, is also important to these patients. Basic nursing care includes ensuring that the patient is clean with combed hair, shaved face, and clean mouth and has clean gown and linens. The simple tasks of nursing care preserve the dignity of the dying person when he/she has little control over anything else.<sup>7,10</sup> Preserving dignity increases a patient's control and helps the patient maintain hope for a comfortable death. Having dignity and feeling empowered and in control are essential to a peaceful death.<sup>11,18</sup>

## INCREASING NURSING COMPETENCE IN PROVIDING END-OF-LIFE CARE

With the aging population and chronic disease processes, nurses face an increasing number of end-of-life patients in the ICU. Nurses should increase their clinical as well as psychological skills related to end-of-life care. Gross<sup>2</sup> suggests that end-of-life care should be included as one of the core competencies in ICU and critical care nursing education programs. Hospitals increasingly have palliative care units or teams who are available to provide in-service education. Short-term educational assignments for nursing staff on palliative care units have also been proposed.

We serve as patient advocates for honoring advance directives and, thus, must be able to clearly explain the importance of such documents to both patients and families. Nurses may facilitate discussion of these issues between patients and loved ones before they are confronted with making these difficult decisions. End-of-life care and death in the ICU can be compassionate. This is best accomplished when nurses are comfortable with their own hopes, beliefs, and feelings regarding death. Nurses must work together on difficult patient care tasks, support one another through peer counseling and debriefing, and, most importantly, be of comfort and hope to each other.<sup>17,19</sup>

## CONCLUSION

In summary, factors were identified that made Bill's death comfortable for him and his family, nurses, and physicians: comfort in the correct decision made, comfort in the knowledge that Bill received optimal care and was without pain and anxiety, and comfort for the family. Today's nurses can provide a high level of comfort to all patients, their families, and fellow healthcare providers when faced with their own "Bills".

All critical care nurses should be educated in compassionate care during the orientation period. The ultimate goal for end-of-life care is to allow the individual a dignified death, ethically intact and as pain-free as possible.<sup>18</sup> This can be achieved through remembering to treat patients and their loved ones as you yourself would wish to be treated. As nurses, we are frequently confronted with thoughts of how we would like to die. We would all choose to die surrounded by loved ones and pain-free. We would want to make the ICU a comfortable place to say goodbye.

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