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Embrace Hope: An End-of-Life Intervention to Support Neurological Critical Care Patients and Their Families

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PRIME POINTS

- Because of the acute nature of most neurological events, families are often faced with rapid processing of the illness with little time to realize that their loved one is going to die.

- Embrace Hope is a structured multidisciplinary delineation of end-of-life interactions that include educational and support information to be received soon after the patient has died.

- Staff feedback indicates that coordinating an end-of-life plan enabled a decrease in the moral distress of staff.

Watching the dying process of patients in acute care settings can be unsettling for both patients’ families and staff. The neurocritical care unit at Riverside Methodist Hospital in Columbus, Ohio, wanted to offer help to families and patients traveling this difficult path. To support this goal, an organized, intentional, and flexible end-of-life intervention was needed. Using subjective data gathered from our neurocritical care staff and client families, we developed a plan of care called “Embrace Hope” to help patients and their families through the dying process. In this article, we provide an overview of the specific items that

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This article has been designated for CE credit. A closed-book, multiple-choice examination follows this article, which tests your knowledge of the following objectives:

1. Discuss relevant research findings in end-of-life care
2. Define the term “good death” as outlined in research findings and identify the components that affect patient and family perceptions of a “good death”
3. Describe the interventions included in the Embrace Hope plan of care

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made up the Embrace Hope intervention, and we use DJ’s story as an example of how the new intervention was applied.

**Literature**

More than 50% of deaths in the United States occur in hospitals. More than 4 million patients are admitted to intensive care units in the United States annually, and of those admitted, approximately 500,000 or 10% to 20% die. As the population ages and technological support advances, needs related to end-of-life care increase. In an attempt to address this growing need, multiple organizations gathered in January 2005 to support a national consensus project for end-of-life care. The global goal of this group was to establish care standards for the period around the end of life. To achieve this goal, the group’s focus included symptom management and support of patients and their families during the dying process via adequate communication and decision making. This multiorganizational group identified the need to increase structural support in institutional settings and to identify areas for palliative care.

In a study performed by Teno et al., a mortality follow-back survey of approximately 1500 surrogates (next of kin) occurred. The focus of the study was to evaluate the dying experience of persons in the United States at home and in an institutional setting. Results indicated that people in the United States who died in institutions died with unmet needs for symptom amelioration, physician communication, emotional support, and respectful treatment.

A 2-year prospective observational study with more than 4300 end-of-life patients occurred from 1989 to 1991. The objectives of this study were to improve end-of-life decision making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying. The study was focused on obtaining information from dying patients about treatment preferences and patterns of decision making among critically ill patients. Results of this study indicated shortcomings in practitioner communication, frequency of aggressive treatment, and family report of patients experiencing severe to moderate pain at the end of life.

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of life. Of the patients included in the study, 38% had spent at least 10 days in the intensive care unit.

Mosenthal et al did a prospective, observational study of 42 trauma deaths before an intervention and 52 trauma deaths after an intervention. In that study, care was evaluated before a structured palliative care intervention was integrated into standard intensive care. Results from after the intervention indicated an ability to integrate palliative care interventions within this environment leading to earlier consensus on goals of care for dying trauma patients.

In 2001, the Society of Critical Care Medicine (SCCM) published recommendations for end-of-life treatment in the intensive care unit. The recommendations acknowledged the emerging perspective that palliative and intensive care are not mutually exclusive. Although some patients benefit from the transition to other care settings, others are so dependent on critical care technology that transfer is not possible. Therefore, SCCM recommended a series of interventions necessary for clinicians in intensive care units to ensure transition to death. Examples include preparing the team, ensuring patients’ comfort, offering a variety of ventilator withdrawal techniques, and learning communication skills to support patients’ families.

The American Academy of Critical Care Medicine in 2008 released a consensus document for end-of-life recommendations that update the 2001 version. Acknowledging that 95% of patients may not be able to make decisions themselves because of illness, patient- and family-centered decision making was acknowledged as the comprehensive ideal for end-of-life care. With this concept as the foundation, conflict resolution, family communication strategies, interdisciplinary team rounds, and practical considerations for withdrawal of care were discussed.

In 2006, the American Association of Critical-Care Nurses printed protocols for end-of-life issues in critical care. In this document, 5 major areas for end-of-life care were highlighted: symptom management, family issues, withdrawing or withholding support, communication and conflict resolution techniques, and caring for the caregiver.

Background

Although the literature is compelling, situations similar to DJ’s were what prompted the NCC staff to focus on improving end-of-life care within our unit. About a year before DJ’s death, the unit had experienced 3 deaths of patients within 4 days, leaving the unit staff emotionally drained. As several bedside staff lamented that emotional support provided to families currently was perhaps not enough, an informal debriefing session began between multidisciplinary staff, bedside nurses, and advanced practice nurses. A vision of providing optimal end-of-life care to our patients and families through an organized intervention was formed. Driven by the desire of NCC staff and the needs of patients and their families in end-of-life situations, a multidisciplinary team gathered, literature was reviewed, and the concept of an end-of-life intervention that would enable families to embrace hope despite life-changing and life-ending circumstances was born.

Although neuroscience practice involves aggressively treating patients and supporting their families during acute illness, death is also a reality. Because of the acute nature of most neurological events, families are often faced with rapid processing of the illness with little time to transition into the realization that their loved one is going to die. Additional stress occurs as catastrophic neurological injuries often leave patients incapable of making end-of-life decisions. These choices are then deferred to families that may never have discussed final wishes with their loved one. In these situations, practitioners are faced with the challenge of not only actively caring for patients, but also supporting families as they transition through the grieving process. Therefore, practitioners must learn to balance the difficult task of resuscitation with the art of compassionate end-of-life care.

Intervention Planning/ Process

Team Members

In order to ensure that the literature supported a comprehensive approach to our end-of-life care, a multidisciplinary team was selected to review the literature and assist in creating a unit-specific process. The team consisted of several bedside nurses, a patient care technician, a unit clerk, a case manager, a neurological social worker, a palliative care social worker, palliative care and hospice nurses, a unit-based family communication liaison, an intensivist, a neurosurgeon, 2 pastoral care representatives, and
a neurological nurse practitioner team leader. Before moving forward, permission for monthly meetings was sought from and granted by the unit’s leaders.

The name of the intervention, Embrace Hope, was selected. Despite the devastation of the death of their loved one, our goal was to provide immediate comfort as well as lasting memories that were not clouded by awkward or disorganized interactions with hospital staff. We wanted to relay our respect for their loved one, while giving families the freedom to customize the death to meet their family’s preferences by providing resources to support hope for the future. Building on the research that outlined a “good death” as one that provides physical and emotional support, creates shared decision making, and treats the dying person/family with respect, the group worked to create interventions that would span the continuum. The following sections provide an overview of this formalization process while using DJ’s case study to provide examples of the interventions designed to support NCC families.

**Multidisciplinary Algorithm**

Appreciating the literature support for a multidisciplinary approach to end-of-life care, the group began work to solidify this approach. It became clear after the first several meetings that the group first needed to designate the roles and responsibilities among the involved disciplines. The goal was to optimize multidisciplinary skill sets and minimize duplication of tasks while spreading the emotional toll and workload between the involved disciplines. A flowsheet was developed to visually guide physicians, nurses, nurse practitioners, unit clerks, pastoral caregivers, social workers, communication liaisons, palliative caregivers, and hospice staff into potential roles at each phase of the Embrace Hope process.

The Embrace Hope intervention did not begin until the physician indicated that the patient’s clinical condition had deteriorated to a futile situation. Often several conversations were necessary for family members to process the news and be able to make a decision about withdrawal of life support. These initial conversations were presented by either the attending physician or the nurse practitioner as directed by the attending physician. Early in the process of flowcharting the intervention, it became clear that many items could be accomplished by a number of staff. Through debate, the group reached consensus on lead individuals for given tasks indicated by an asterisk on the diagram. This person was responsible for driving the completion on this item or communicating the need for a replacement if he or she were unavailable. Having multiple people qualified for each item ensured that the process would not break down if death occurred during off hours or if other clinical situations pulled someone in a different direction.

**Educational Foundation**

As outlined by the Academy of Critical Care Medicine, competent practitioners require specific end-of-life education. The Institute of Medicine states that poor end-of-life care sometimes happens because health care professionals are not trained well. The NCC end-of-life team believed similarly and proactively sought to train providers on end-of-life care. To achieve this educational foundation, 4 hours of content was crafted by the multidisciplinary team. Management of the NCC required that all full-time and part-time patient care technicians and nursing staff participate in the training. A total of 5 repeat sessions were taught by members of the Embrace Hope

**Case Study**

Once DJ was declared do-not-resuscitate/comfort care, her family was approached by the neurological nurse practitioner, nurse, and organ procurement representative to discuss the next steps, which included waiting for further clinical progression to brain death to enable organ donation or immediate cessation of technological and pharmacological support. DJ’s family opted to wait for progression to brain death to enable organ donation. After this plan was determined, the neurological nurse practitioner and the nurse verbally described the Embrace Hope packet and indicated that when the logistics of organ donation were adequately reviewed, NCC staff would approach them again regarding how they envisioned DJ’s respectful death. When asked, Jim (DJ’s husband) initially refused a visit from the hospital’s pastoral care representative, indicating that the patient’s pastor had already been notified.
team at various times of day to accommodate day and off-shift schedules. One session was taped so that new hires could also receive the training. Nurse and technician training included content on the components of the Embrace Hope structured process, symptom onset/management during terminal stages, communication techniques during grief, cultural considerations of dying, and institutional resources available to support end-of-life care. Content from the 2001 End-of-Life Nursing Education Consortium was used in all educational sections except the institution-specific topics.\(^1^2\) Physician education was 1 hour and included a brief overview of the Embrace Hope intervention and evidence-based symptom management given by the palliative care physician. The suggestions related to symptom management that were presented corresponded to recommendations and guidelines from the SCCM and the American Academy of Critical Care Medicine.\(^7^8\)

**Signs**

In a busy intensive care unit, it is important for all team members to be engaged in the end-of-life process. As outlined in the SCCM guidelines, ensuring an environment conducive to emotional and physical intimacy is also a goal.\(^7^9\) To create this environment, minimization of potential disruptions of family time with the patient were needed. To this end, 2 types of signs were created that notified hospital workers of the situation. The first sign contains the words “Please See Nurse Prior to Entering Room.” This paper sign was stored with other Embrace Hope paperwork to facilitate placement on the patient’s door after the end-of-life decision has been made. The second form of notification is a magnet with the letters EH, for Embrace Hope. This magnet is placed next to the patient’s name on the unit’s communication board. These 2 simple measures ensure that staff at all levels of service will be aware that additional sensitivity with activities is needed for these patients and their families.

**The Setting/The Envelope**

As stated in the SCCM end-of-life recommendations, attention to detail can make an enormous difference in how the patient and the patient’s family perceive the final

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**Case Study**

As the family spent quiet time together in the family conference room, DJ’s nurse notified the unit clerk to please place the magnet on the communication board as she obtained the Embrace Hope envelope with paperwork and hung the sign on DJ’s hospital door. Coffee and juice were also delivered to the family in the conference room to provide physical comfort to the family as they processed the next steps related to DJ’s care. While this occurred, the neurological nurse practitioner went to daily multidisciplinary rounds, where all patients’ daily plans were discussed. Social service, communication liaison, charge nurses, unit management, and case management staff were among those present during this meeting, and all were made aware of the end-of-life plan for DJ.

After DJ’s husband had finished the organ donation interview, the family returned to DJ’s bedside with questions about next steps. DJ’s nurse retrieved the cloth envelope and obtained the cultural assessment. Using the questions on the form, the nurse learned that her girls wanted to paint their mother’s toenails bright pink (her favorite color) before her death. Given the special needs of her small children, the unit clerk notified the communication liaison to assist the girls in purchasing nail polish from the hospital gift shop. Able to focus more fully on DJ with the brief absence of the girls, DJ’s mother expressed her desire for the presence of the hospital pastor to provide prayer at DJ’s bedside. The unit clerk called our pastoral care representative, who met with the family and was able to assist with contact of their clergy. The hospital’s pastor remained with the family until the arrival of the patient’s pastor. During the conversation with the hospital’s pastoral care representative, DJ’s love of gospel music was mentioned. A CD player was allowed into the room and tunes such as “Amazing Grace” filled the air as the nurse and nurse practitioner focused efforts on maintaining hemodynamic stability and euvoledia.

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moments. The Embrace Hope care team developed a number of interventions to assist staff in supporting patients’ family members as they transitioned through the grieving process. The process began in the family conference room. This closed room contained multiple chairs and couches, tissue boxes, water, phone access, and a wall quilt to create a private, comfortable setting to receive updates. This attention to detail addresses the family’s physical comfort as they emotionally process the death of their loved one.

Once the family’s physical needs were tended to, an organized rollout of the end-of-life tools needed to be created to support efficient and compassionate execution by staff. The team decided on a fabric envelope that would be stocked with intervention materials and centrally stored (Figure 1). The concept of the envelope came from a pastoral intern who was included on the team and who had experience with a similar item in a hospital in Toledo, Ohio. A local fabric dealer, Boone Fabrics in Columbus, Ohio, was approached and graciously agreed to donate fabric on an ongoing basis. Cloth pouches were created by Riverside Methodist Hospital’s sewing guild. The fabric design was selected for the huggable nature of the product that also afforded room to place cards, pictures, and additional mementos that may have accumulated throughout the patient’s stay in the NCC. Paperwork to be completed by the staff or given to the family was separated into 2 sections. The first section was to be used right away, and the family could refer to the second section immediately or after they returned home.

Embrace Hope Checklist

In January 2006, the Joint Commission outlined a national safety goal to improve handoffs of patients. Although this concept is not generally thought to apply to a withdrawal situation, staff in the NCC decided that a communication handoff tool would be useful to standardize end-of-life care. Appreciating the number of staff that might be involved in providing various interventions, a paper checklist was created and served to support an organized transition for staff and for patients’ families (Figure 2). The checklist is kept with the bedside paperwork and can be written on by staff from any discipline.

As actual care does not always follow a planned algorithm, the checklist ensures that all components

Case Study

DJ’s physician arrived at the patient’s bedside and was updated on events to date. Jim had gone off the unit with his daughters to get something to eat. The doctor reviewed the physical deterioration to brain death and the plan for getting a second opinion from the neurologist to verify the clinical progression to brain death with DJ’s mother. DJ’s nurse was able to provide the “What to expect—Brain death” educational sheet to Jim upon his return, and DJ’s mother used it to describe what the neurosurgeon had reviewed with her. Side rails were lowered, DJ’s hands were made accessible, tissue boxes were provided, and technology was hidden or removed as appropriate to further increase accessibility of the patient.
focus care and enables staff to feel confident that all the necessary steps have been taken for the patient, leaving more time to spend comforting the family.

Cultural/Spiritual Assessment

An additional way to provide comfort is to involve the patient and the patient’s family in defining what a “good death” means to them. This process begins by staff understanding the family’s cultural beliefs and expectations.9 Evidence shows that families are more satisfied when clinicians spend time listening to and valuing the families’ input regarding their desires for their loved one during the dying process.

Spirituality also plays an important role in end-of-life coping and should not be strictly defined as religion.8 In order to respect and honor the dignity of each family’s cultural and spiritual beliefs, the NCC staff developed a cultural needs assessment. Through baseline subjective data obtained from staff, it was clear that beginning these conversations was challenging for some NCC nurses. To minimize this discomfort, a structured format was created to begin the process of engaging the family in defining what they needed from us to support the respectful death they wanted. As we aimed for a succinct process, The End Of Life/Cultural Assessment was developed by using the pastoral care department’s cultural expertise and contacts (Figure 3—available online only).

The assessment addresses 3 main topics: religious/spiritual practices, specific beliefs about illness/death, and what is most important to the patient/family at this time? Generally this assessment is reviewed by the physician/neurological nurse practitioner/nurse initially but as other disciplines interact with the family, additional requests often surface. The awareness and use of family preferences assist all staff in implementing the plan of care to make the journey through death a positive experience for the patient’s family.

of the Embrace Hope intervention are completed, no matter the order of implementation or the shift providing the care. The checklist consists of 12 items that are completed from start to finish but in any order. This time is very emotional for all family and staff involved in the care of the patient. This checklist helps

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**Embrace Hope Checklist:**

- 1. NCC information given to family
- 2. Cultural Assessment and Evaluation of family readiness form completed and placed in blue bedside chart
- 3. DNR status determined
- 4. Brain death determined or decision to withdraw made
- 5. Pastoral Care/LOOP notified
- 6. Evaluate need for palliative care
- 7. “What to Expect During This Transition” brochure given to family
- 8. Embrace Hope cloth envelope with patient ID label placed on shelf over thinned charts (envelope includes “Hope in Remembering” poem, hand-tracing card, and “A Lock of Love” packet)
- 9. Sign placed on patient room door and magnet placed on white board identifying “Embrace Hope” patient
- 10. Explanation of hand tracing and/or “A Lock of Love” provided to family and verbal consent documented on flow sheets as appropriate. Obtain snippet of hair/hand tracing for family with as little or as much family participation as they desire.
- 11. At time of death, after patient has been pronounced, Pastoral Care Bereavement packet added to Embrace Hope cloth envelope. Remove patient ID label from front of envelope and give to primary family contact. (Pastoral care will provide parking passes to family.)
- 12. Unit sympathy card with seed packet attached to the violet tab in the blue chart for signatures, and after the patient discharges will be kept in metal bin by UC desk and mailed to family by UC or communication liaison 5 days after patient is discharged from unit.

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**Figure 2** Shift checklist.

Abbreviations: DNR, do not resuscitate; ID, identification; LOOP, Lifeline of Ohio Organ Procurement, Inc; NCC, neurocritical care unit; UC, unit clerk.
Symptom Brochure

Providing physical, emotional, and spiritual care for dying patients and their families can be quite overwhelming to staff members. Clear and explicit explanations from the clinician on what to expect next may alleviate anxiety and refocus family members’ expectations. Communication that focuses on preparing the patient and the patient’s family for the withdrawal process is therefore essential. With DJ’s physical and spiritual needs addressed for the moment, the staff focused on teaching Jim and DJ’s family about what to expect as time progressed. To assist with this dialog, a brochure (Figure 4—available online only) was designed by the Embrace Hope team to help families understand simple physiological changes that can occur during the transition from life to death. For some families, this may be their first experience of loss. For others, this experience may trigger past emotional turmoil, regret, or unresolved grief. Some may see death as a welcome relief from suffering; others may focus on small external details to help them cope during this time.

Although each patient’s circumstance is unique, the brochure discusses common signs and symptoms of the dying process such as pain, confusion, decreased responsiveness, and changes in breathing and vital signs. In situations where withdrawal or withholding of care is expected, this brochure is reviewed and customized by the staff to reflect the patient’s unique situation.

After an initial pilot of this brochure, the Embrace Hope committee realized that brain death required a separate educational sheet, given the unique progression of events. This sheet also was created (Figure 5—available online only). Whether brain death, withdrawal, or withholding care are the circumstances surrounding death, practical comfort measures are incorporated during this review and families are encouraged to participate in their loved one’s care as they wish. Families were taught about what to expect during the dying process, and staff modeled supportive behaviors during this time. With this support and education, the goal was to support families in offering the gift of presence that can be so meaningful as they look back on this time in their lives. To this end, siderails are lowered, monitoring devices are removed or blocked within the room, and opportunities for families to provide care or engage in reminiscing dialog are encouraged.

Love Locks

To continue perfecting the idea and project plan of the Embrace Hope intervention, the multidisciplinary team met on many occasions to decide what they could do to give families tangible positive memories of their loved one. The team decided that something that family members could hold in their hand or that could be placed in the soft quilted folder to hug would be something that could be cherished over time. The idea developed into having family members remove a lock of hair as a remembrance of their loved one.

Removing a lock of hair from a dying loved one was a common practice in the Victorian era. The hair was then braided and placed into lockets or made into other remembrance keepsakes. At our institution, this method was modernized in the labor and delivery area with infant death. Emulating this concept, the team decided to use a “Love Lock” card.

Appreciating the diversity of the families that we would be supporting, the team decided to make it mandatory to obtain and document verbal consent from the family to remove the lock of hair. Doing so would prevent any misunderstanding and emphasize respect for cultural or religious practices that may disapprove of the removal or cutting...
of the patient's hair. Selection of discrete areas, such as the back of the patient's head, and limiting the number of samples to 1 or 2 served to minimize the cosmetic impact of this procedure.

Handprints

Given the limitation of potential hair samples, another process was conceptualized to provide lasting memories for large families such as DJ's. One of these ways was to offer to create a handprint of a loved one (Figure 6—available online only). After the hospital noise is gone and there are only memories, continued grieving occurs. Times of reflection can be helpful and healing. View the handprint of one whom we loved can generate thoughts of how that person touched our life. A poem, created by an Embrace Hope team member, was included in the background of the handprint to encourage the hope that can happen in remembering.

Five poem sheets were added to each premade packet with extra poems available in a central area should additional copies be necessary. The boldness of the printed background poem was adjusted down so that it did not overpower the loved one's handprint. Cardstock in lavender and blue was acquired to support the handprint and improve its longevity. The color of the paper enabled contrast to the Versamark oil print that became the template for the volunteers and is permanently kept in a plastic filing box for ongoing reference. “Extra” items needed for families, such as “Lock of Love” cards, “Embrace Hope” poem cards for handprints, and additional tools are also kept in the plastic file folder housed at the unit clerk's desk. (Versamark stamp pads are available in craft stores. One hundred seed packets can be purchased for $1.50 per packet from Forever Wildflower, Inc, Westcliffe, Colorado.)

Grief Information/Family Note/Seed Packet

Often the hardest aspect of the grieving process comes later, as families return home to their lives, where they are greeted with constant reminders of loved ones. In accordance with JCAHO recommendations for bereavement processes, the members of the Embrace Hope team wanted to support this transition to home after a loved one's death. The first solution was to provide a 2-pocket folder filled with practical items and grief support information. Practical items included how to create an obituary, create memorials, and manage holidays/anniversaries/special occasions (available from www.ohiohealth.org/embracehope). Local grief support groups and their phone numbers were also included for reference; these were anticipated to be useful after the activity of postdeath care had calmed and when the concept of the family's new reality might hit.

In addition to these practical tools, the staff wanted to communicate to the families that we cared enough to remember their loved one. To accomplish this, 2 items are removed from the quitted packet and saved until after the families have gone home. These items are a condolecence card for the family (Figure 7—available online only) and a packet of seeds (see Figure 1). The condolecence card (a concept supported in the SCCM guidelines) carries the same quilt pattern as the rest of the items in the packet and is kept on the unit for a period of 1 to 2 weeks after the patient's death. This time frame gives staff time to sign the card. Additionally, sending the card 2 weeks after the death increases the chance that receipt will occur during a time less likely to be filled with postmortem activities. Placed inside the card was a small packet of wildflower seeds encased in a dark blue velvet bag. The seed packet was selected by the Embrace Hope team as a live remembrance that would live, grow, and flourish in honor of their lost family member.

Ordering/Preparing the Packet

The concept of Embrace Hope was unique, but actualization of the process was daunting at times. In addition to outlining the implementation of care, a process to sustain the preparation of support material needed to occur. Preparing the packets for the families is possibly the most time-consuming portion of this initiative. An administrative assistant who oversaw a group of our hospital volunteers coordinated the packet preparation. A sample packet was created as a template for the volunteers and is permanently kept in a plastic filing box for ongoing reference. “Extra” items needed for families, such as “Lock of Love” cards, “Embrace Hope” poem cards for handprints, and additional tools are also kept in the plastic file folder housed at the unit clerk's desk. (Versamark stamp pads are available in craft stores. One hundred seed packets can be purchased for $1.50 per packet from Forever Wildflower, Inc, Westcliffe, Colorado.)

Future Directions

After successful implementation of the Embrace Hope intervention in the NCC, a pilot for a formalized order set for withdrawal of care was established (Figure 8). Evaluations before and after the Embrace Hope intervention were completed by staff (physicians, nurses, technicians) and indicated statistically significant changes in staff members' perceived ability to provide a "good death."
## Critical Care Withdrawal Physician Orders

### I. End of Life Care (e.g., < 72 hours)
- Begin Embrace Hope Packet
- Code Status: □ DNRCC – Comfort Care
- If patient admitted within 24 hours (coroner’s case)
  - DO NOT discontinue invasive catheters/lines.
- Discontinue vital signs. Observational vital signs only.
- Discontinue telemetry, pulse oximetry, medications, labs, x-rays and scans, TED Hose, Sequential Compression Devices, restraints, respiratory treatments, Physical Therapy, Occupational Therapy and Speech Therapy.
- Maintain IV fluids at KVO
- Discontinue OG/NG and tube feeds
- Intracranial Pressure Monitoring:
  - Clamp and discontinue monitoring of veniceulostomy
  - Discontinue Camino monitoring
- At time of death, RN may note absence of vital signs and notify physician. Physician may give telephone order to pronounce patient’s death. Notify attending physician of patient’s death. (Policy P-120-R)
- Open visitation
- Pet visitation p.r.n. (Policy I-640-R)
- Notify eICU to change level of care
- Artificial tears to both eyes p.r.n. dryness
- Artificial saliva p.r.n. mouth dryness

### II. Pain / Dyspnea
- Heat or cold application p.r.n.
- Hydromorphone (Dilaudid) 1 mg IV SQ 15 minutes prior to extubation and then every 3 hours ATC. May repeat dose every 10 minutes p.r.n. signs of pain/dyspnea
- Morphine 6 mg IV SQ 15 minutes prior to extubation and then every 10 minutes p.r.n. signs of pain/dyspnea
- Morphine 10 mg IV SQ 15 minutes prior to extubation and then every 10 minutes p.r.n. signs of pain/dyspnea

### III. Anxiety / Agitation / Dyspnea
- Haloperidol (Haldol) 1 mg IV SQ 15 minutes prior to extubation and then every 3 hours ATC. May repeat dose every 15 minutes p.r.n. anxiety/agitation/dyspnea
- Ativan 2 mg IV SQ 15 minutes prior to extubation and then every 10 minutes p.r.n. anxiety/agitation/dyspnea
  OR
- Valium 10 mg IVP 15 minutes prior to extubation then every 1 hour p.r.n. anxiety/agitation/dyspnea
  OR if concern of seizure:
- Glycopyrrolate (Robinul) 0.2 mg IV SQ 15 minutes prior to extubation and then every one hour p.r.n terminal secretions
  OR
- Atropine Ophthalmic Drops 1% Two drops SL 15 minutes prior to extubation and every one hour p.r.n terminal secretions

### IV. Secretions / Airway
- Discontinue ventilator and terminally extubate. Titrated supplemental oxygen (FiO2) per nasal cannula/mask/rebreather mask as needed for dyspnea/comfort care
- Oral suction per patient/family comfort p.r.n.
- Glycopyrrolate (Robinul) 0.2 mg IV SQ 15 minutes prior to extubation and then every one hour p.r.n terminal secretions
  OR
- Atropine Ophthalmic Drops 1% Two drops SL 15 minutes prior to extubation and every one hour p.r.n terminal secretions

### V. Consults
- Pastoral Care
- Social Services
- Palliative Care

### VI. Additional Orders

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**Figure 8** Withdrawal order set.
A "good death" was defined as a death that was free from avoidable pain and suffering, consistent with a patient’s wishes, and consistent with ethical, cultural, and clinical standards. After the end-of-life intervention was implemented, practitioners also noted a statistically significant decrease in perceived barriers to their ability to provide end-of-life care (see Table). A total of 74 surrogates, (the patient’s next of kin) were also queried about the end-of-life care provided in the NCC. Thirty-eight surrogates completed surveys before the intervention and 36 surrogates completed surveys after the intervention. Statistically significant changes in the perceived emotional support and overall care provided were noted on follow-up surveys. Decreased variability was noted by surrogates in regard to symptom control, communication, and emotional support provided by NCC staff (Figure 9). We intend to publish detailed research results, but that work is still underway.

The success of the Embrace Hope intervention and the pilot process of the withdrawal order set within the NCC has prompted other units within the hospital to create similar processes to support their patients. Currently the inpatient palliative care unit and several other critical care units are customizing the process to reflect the personnel available and the needs of their specific populations of patients.

### Conclusions

Through hard work and emphasis on supporting patients and their families at the end of life, quality care can be provided within the walls of inpatient critical care units. Emphasizing the skill sets of an entire multidisciplinary team enables a structured intervention that optimizes caring while enabling a manageable workflow for team members. Formal staff feedback from the intervention indicates that providing a structured intervention served to coordinate an end-of-life plan that enabled a decrease in the moral distress of staff. In the words of Dame Cicely Saunders, "How one dies remains in the memories of those who live on." Through the transition of critical care to caring critically, our...
Case Study

At DJ’s memorial, a nephew read the handprint poem aloud, reflecting that her death enabled others to embrace hope for a better life. The girls told stories of their nail polish selection with friends. “Amazing Grace” played softly in the background as the priest shared stories he had heard about DJ as he stood alongside family in the final hours at the hospital. Family members laughed as he spoke of her pie-eating antics when she was a young girl at a family picnic. They smiled when he spoke of her compassion for others and sense of humor. Tears flowed when he spoke of the life taken too soon. In a letter to the unit several weeks after DJ’s death, Jim shared his appreciation for the gentle, consistent care that the NCC had provided to his wife and family in those final hours. We could not alter the ultimate outcome, but we did ease the process through our caring professionalism. Hope for a future was still a dim thought, but the glimmer was there for him to embrace as time healed.

Figure 9  Mean response to domain F questions by 38 surrogates before and 36 surrogates after the intervention. Asterisk indicates significant difference between groups (P < .05).

desire is to share our success to enable more positive memories for families of intensive care patients receiving end-of-life care so that they too can Embrace Hope. CCN

Financial Disclosures
None reported.

References
1. What percentage of patients admitted to intensive care units in the United States die annually?
   a. 5% to 10%
   b. 10% to 15%
   c. 10% to 20%
   d. 20% to 25%

2. The 2008 consensus document released by the American Academy of Critical Care Medicine identified which of the following as the comprehensive ideal for end-of-life care?
   a. Specific intensive care team for patient deaths
   b. Offering a variety of ventilator withdrawal techniques
   c. Learning communication skills to support patients and families
   d. Patient- and family-centered decision making

3. As part of implementation of the Embrace Hope intervention, education regarding end-of-life care was provided to which groups?
   a. Patient care technicians, nursing staff, and physicians
   b. Patient care technicians and nursing staff only
   c. Nursing staff and physicians only
   d. All members of the neurological critical care unit staff

4. Which of the following best describes the checklist used with the Embrace Hope intervention?
   a. The items on the checklist are listed in order of importance and are to be completed in that order.
   b. The items in the checklist can be completed in any order.
   c. The neurological nurse practitioner is responsible for completion of the checklist.
   d. The checklist applies to nursing staff only, and is not a tool used by staff from other disciplines.

5. Questions related to the families’ specific beliefs about illness and death are part of which Embrace Hope intervention activity?
   a. Background information collection tool
   b. Multidisciplinary algorithm
   c. Cultural/spiritual assessment tool
   d. Symptom brochure and information guide

6. Which activities are performed specifically to support families in offering the gift of presence to their dying loved ones?
   a. Lowering side rails and removing monitoring devices
   b. Allowing family pets to be present in the patient’s room
   c. Allowing family members to be present when the patient is extubated
   d. Removing a lock of hair from the patient

7. In addition to the “What to Expect” brochure for patients’ families, the Embrace Hope team created a separate educational sheet to explain what process?
   a. Transitioning from resuscitation to dying
   b. Brain death
   c. Withholding care
   d. Withdrawal of care

8. What specific reason did the Institute of Medicine identify to explain why poor end-of-life care sometimes occurs?
   a. Health care clinicians are too busy to provide the necessary emotional support.
   b. Intensive care units are too noisy and impersonal to allow families the needed privacy and personal time.
   c. Health care professionals are not trained well in providing care at this particular time.
   d. Families are not allowed to participate in decision making as much as they desire.

9. In order to minimize potential disruptions of family time with the patient, the neurological critical care unit staff did what?
   a. Removed restrictions to visiting hours, number of visitors, and age limitations
   b. Placed a special sign on the patient’s door
   c. Moved the patient receiving end-of-life care to a more secluded area of the unit
   d. Provided meals and snacks for families in the unit’s conference room

10. The Embrace Hope paperwork is divided into what sections?
    a. What is used immediately and what is used as a reference for the family after the patient’s death
    b. What is to be filled out by the staff and what is to be filled out by the patient’s family
    c. What is to be completed by the nursing staff and what is to be completed by the other members of the multidisciplinary team
    d. What is used when support is withheld and what is used when support is being withdrawn

11. Which of the following statements is true regarding the “Love Locks” portion of the Embrace Hope intervention?
    a. Although nursing staff may assist in the process, a member of the patient’s family must cut the lock of hair.
    b. This method of creating a remembrance keepsake was chosen because it is universally accepted by all religions and cultures.
    c. Removal of a lock of hair for this purpose requires only verbal consent be obtained and documented.
    d. Locks of hair are removed in patients who are 16 years of age or younger only.

12. The folder sent home with Embrace Hope families includes which of the following?
    a. A framed copy of their loved one’s handprint with the poem background
    b. A condolence card signed by members of the neurological critical care unit staff
    c. Ideas and suggestions for creating memorials
    d. A small packet of wildflower seeds in a blue velvet bag

Test answers: Mark only one box for your answer to each question. You may photocopy this form.

1. [ ] a  [ ] b  [ ] c  [ ] d
2. [ ] a  [ ] b  [ ] c  [ ] d
3. [ ] a  [ ] b  [ ] c  [ ] d
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6. [ ] a  [ ] b  [ ] c  [ ] d

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Program evaluation

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City ______________ State ___ ZIP _____________
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