

Dying in the Intensive Care Unit: A Candle Vigil Using Illustrations

Elizabeth K.N. Johnson, RN, BSN, and Eelco F.M. Wijdicks, MD, PhD

Abstract

With death and dying in intensive care units, there should be bereavement support for families. We propose placing an illustration of a candle on the door of an unresponsive dying patient, with additional illustrations of votive candles at the nurses' station opposite to the door as a neutral way of identifying these rooms with patients who transitioned to comfort care or who have died. The candle illustrations encourage staff members to modify their words, silence themselves, and reflect. After a 1-year tryout in the neurointensive care unit with a strong positive experience for staff and families, it can be perceived as a symbol of tranquility.

© 2018 THE AUTHORS. Published by Elsevier Inc on behalf of Mayo Foundation for Medical Education and Research. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/) ■ Mayo Clin Proc Inn Qual Out 2018;2(4):378-381

From the Neurosciences Intensive Care Unit, Saint Marys Hospital, Rochester, MN.

he staff of intensive care units (ICUs) recurrently deal with death and dying, but families bear the heavy burden. This realization has led medical institutions to develop bereavement-support programs for families. The common occurrence of unexpected sudden death from catastrophic brain injury is heartbreaking for all involved and makes effective bereavement support essential in neurointensive care units. 1,2 In fact, bereavement-associated posttraumatic stress disorder occurs more frequently in families of patients who die in the ICU and, according to studies performed in the neurointensive care unit, persists up to 6 months in 30% of family members who participated in decision making.3

Within the room of the unresponsive patient, bereavement support involves agreed-upon spiritual ceremonials and guidance. But outside the patient room, the only visible display may be a closed curtain, a do-notenter (stop) sign when the patient has died, or just a verbal admonition by a staff nursenot infrequently at the last moment.

Motivated by an imperative to do better, we propose placing an illustration of a candle on the door of an unresponsive, dying patient, with additional illustrations of candles at the nurses' station opposite to the door. This is a simple and, in our view, solemn and neutral way of identifying rooms in which a patient is dying. The candle illustration on a closed

door helps to set this room apart from the adjacent hurried, often loud ICU environment. The signage is intended not only to identify comfort care patients but also to encourage staff members to adapt their words and actions accordingly.

CANDLE SYMBOLISM

The candle—since its invention as burning wax approximately 3000 years BC—has evolved into a symbol of light in the darkness, a remembrance, a prayer for the dead, and celebration of major religious holidays. The candle functions in bereavement to inspire reflection and tribute. It is prominently used in vigils. People often spontaneously place candles in front of houses of recently deceased public figures or to commemorate deaths caused by natural disasters or acts of terrorism.

Major world religions have used the candle with overlapping meanings. The candle in the Roman Catholic Church signifies the divine savior (*Lumen Christi*). Ages ago, candles were placed in the hands of the dying, and the burning light was a symbol of Christ whom the departed went to meet. Believers in Judaism kindle lights to usher in the Sabbath and festivals, and it is customary to light a candle on the anniversary of a death (*Yahrzeit*) of a close loved one. The National Holocaust Museum has a candle room for remembrance. Muslims do not use candles at funerals, but candlelight vigil is not explicitly



prohibited. Later, most Muslims light candles on the graves of their loved ones and on shrines of prominent religious figures. Moreover, candles decorate areas with light during Ramadan ("Month of Light"). Candles are lit in front of Buddhist shrines or statues as signs

of respect and are commonly used at funerals. Many Hindus incorporate fire in ceremonies that they consider sacred. Diwali (Festival of Lights) symbolizes the triumph of good over evil and light over darkness.⁵

In the modern age, the symbolism of a burning candle is strong and demands serenity. Candles encountered in large numbers cause people to reflect for a moment. For many of us, it requires little explanation. It cannot be expected to offend even if used in peaceful demonstrations.

OUR ADAPTATION OF THE CANDLE

To overcome the usual restrictions against burning candles in a hospital room or ICU, we designed illustrations of a number of candles in coordination with Mayo Clinic Brand Strategy and Creative Studio Department (©2018 Mayo Foundation for Medical Education and Research). We placed an illustration of a single burning candle on the door of the patient's room and illustrations of votive candles on the nurses' station in plastic placeholders opposite or near the room of the patient (Figures 1 and 2). Triggers for placement were a decision to withdraw support in a patient with irrevocable brain injury or in

patients designated as potential organ donors according to brain-death or cardiac-death protocols. The placement of an order set to withdraw support was used as a trigger to place the illustrations, but the nursing staff additionally confirmed this order with physicians to avoid misunderstandings. Families were notified and gave verbal consent for the placement of illustrations. The illustrations remained in place until the family members had said their last goodbyes and left the unit. The door cards were Oxivir wiped, stored, and reused. Our preliminary trial lasted for a year.

THE RESPONSE

The response was immediately supportive. Staff present in the unit rapidly understood the significance of the candle and toned down their conversation while passing the room. Many initially asked what the candle was for but quickly appreciated the symbolism after receiving an explanation. Nursing staff remained motivated to use the illustrations after the pilot study ended. The placeholders did not obstruct administrative traffic. Family members were likewise very appreciative-the spouse of one patient was so moved by the site of the candle door card that she requested to take it home in remembrance of her husband. Others have remarked that the simplicity of the gesture positively impacted the death experience by promoting a more personalized atmosphere and dignity. No negative experiences were identified





FIGURE 2. Drawings of single candle and votive candles. © 2018 Mayo Foundation for Medical Education and Research.

CONCLUSION

The vast number of staff members caring for a patient coupled with the fast-paced, highly technical environment of the ICU can adversely-albeit unintentionally-affect the profoundly personal end-of-life experience for patients and their loved ones. Our neurointensive care unit admits many patients with acute catastrophic brain injury, but in only a fraction-approximately 5 patients per month-the devastating findings and agreed-upon futility of care results in withdrawal of care. When walking through the unit, ICU staff and visiting family members may have to identify which room has a dying (or deceased patient). We have also been struck by the impersonal-but necessary-protocolized management of the deceased (ie, closed curtains and cold stop signs). Our experience with the additional placement of candle illustrations has been very satisfactory. These illustrations may not only bring down noise levels, often related to staff conversations, 6,7 but also serve as a part of holistic care to patients whose lives are drawing to an end. Families and all health care workers with different beliefs (or no belief) appear to appreciate the symbolism of the candle placed outside the room of the dying patient, but it only goes so far to assuage the grief. We do not pretend this placement of candle illustrations alleviates the bereavement process, but we do not envision any negative effect. Despite an increasingly secular world, religious beliefs continue to play a role in managing endof-life care, and the candle illustrations will affirm its symbolism for many. We perceive the candle illustration as a neutral symbol that nevertheless respects faith-based and other interpretations. The candle illustration should not take away hope for a miracle in some family members even after the decision is made to go to comfort measures. The placard should be used only for those patients who transitioned to comfort care and after full agreement to withdrawal of support but also with physicians anticipating early demise.

Our trial was performed in the neurointensive care unit, but we do not foresee concerns when candles are used in other types of ICUs. Its continuing use after the patient is moved out of the ICU to a regular ward may be considered.

Our illustrations have a noticeable color scheme and are large enough for easy notice. The alternative or additional use of battery-operated candles may be physically more difficult, but we have allowed them in patients' rooms at the families' request.

Candles have long symbolized part of the Mayo Clinic model of care. The Sisters of Saint Francis, who founded Saint Marys Hospital and welcomed people from all faiths, believed in prayer as a key component of care. Dr William J. Mayo, who came from a different tradition, respected and honored the Sisters' devotion to patients. He often told the Sisters, "I'll pay for the candles, and you light them."

The sight of a candle often causes individuals to pause, silence themselves, and reflect. In spite of the immense religious symbolism associated with candles, they additionally evoke peace, quiet, and tranquility in the absence of a belief system. Candles are thus both a neutral and universal symbol. In the unit, the door placards and nurses' station signs serve as a visual reminder in a simple and discreet manner that a patient has shifted from life-sustaining interventions to end-of-life care.

ACKNOWLEDGMENTS

We thank Lea and Matt Dacy for suggestions and expert editing. The manuscript was reviewed and approved by Mayo Clinic Values Council and Bereavement Committee. The illustrations can be made available upon emailing Dr Wijdicks at wijde@mayo.edu.

Abbreviations and Acronyms: ICU = intensive care unit

Potential Competing Interests: The authors report no conflicts of interest.

Publication dates: Received for publication August 3, 2018; revisions received August 29, 2018; accepted for publication September 4, 2018.

Correspondence: Address to Eelco F.M. Wijdicks, MD, PhD, Division of Critical Care Neurology, Mayo Clinic, 200 First St, SW, Rochester, MN 55905 (wijde@mayo.edu).

REFERENCES

- Berry M, Brink E, Metaxa V. Time for change? a national audit on bereavement care in intensive care units. J Intensive Care Soc. 2017;18(1):11-16.
- Trevick SA, Lord AS. Post-traumatic stress disorder and complicated grief are common in caregivers of neuro-ICU patients. Neurocrit Care. 2017;26(3):436-443.
- McAdam JL, Erikson A. Bereavement services offered in adult intensive care units in the United States. Am J Crit Care. 2016; 25(2):110-117.
- 4. Theiler H. The Candle as a Symbol and Sacramental in the Catholic Church. New York and Cincinnati: Pustet & Co.; 1909.
- Ford DW. Religion and end-of-life decisions in critical care: where the word meets deed. *Intensive Care Med.* 2012;38(7): 1089-1091.
- Liaschenko J, Peden-McAlpine C, Andrews GJ. Institutional geographies in dying: nurses' actions and observations on dying spaces inside and outside intensive care units. Health Place. 2011;17(3): 814-821.
- Park M, Kohlrausch A, de Bruijn W, de Jager P, Simons K. Analysis of the soundscape in an intensive care unit based on the annotation of an audio recording. J Acoust Soc Am. 2014;135(4):1875-1886.