

Short Communication

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Emerging Quality Improvement Concepts to Enhance the Patient and Family Experience in Hospice and Palliative Care

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ABSTRACT

Most quality improvement in end-of-life care has been related to symptom management, goals of care, cost-effectiveness, and adhering to patient preferences. The patient and family's experience of care, the environment of care, support for surrogate decision-makers, and public engagement related to end-of-life care receive less attention. We describe three new quality improvement models to improve the patient and family experience of care: 1) involvement of the primary care providers (PCP's) throughout the patient's disease course, 2) modeling of decision-making behavior for surrogates using narratives, and 3) increasing engagement with end-of-life care among the public at large. We advocate for the continued development and evaluation of new care models to improve the quality of end-of-life care and the widespread sharing of best practices.

INTRODUCTION

Palliative care refers to symptom management throughout the course of illness while hospice care focuses on management of end-of-life care, typically in the final 6 months of life. The provision of hospice and palliative care is a high priority; however, there are not enough palliative care specialists to provide this care for every individual who needs it. The American Academy of Hospice and Palliative Medicine (AAHPM) reported 7,056 certified hospice and palliative care physicians in 2015¹ and leaders in the field have suggested that generalists can be important contributors to end-of-life care, reducing fragmentation of care and preserving existing therapeutic relationships.² It is critical to patients and families that primary care providers (PCP's) continue to be involved in the provision of end-of-life care for their patients.³

Many quality indicators for hospice and palliative care have been proposed, the majority of these related to symptom management, goals of care, cost-effectiveness, and adhering to patient preferences.⁴ However, the patient and family's experience of care, the environment of care, support for surrogate decision-makers, and public engagement related to end-of-life care are also important considerations but receive less attention. Families and patients usually experience many challenges at the end-of-life including uncertainty, abandonment, hope, trust, and the involvement of multiple medical advance providers.⁵

To promote the use of advance directives, Congress passed the Patient Self-Determination Act in 1990, mandating that all Medicare certified institutions provide written information regarding patients' right to formulate advance directives. However, surveys of the US public suggest that less than 30% have an advance directive.⁶

We describe three model quality improvement demonstrations: 1) promoting continuity of care at end-of-life, 2) model decision-making behavior for surrogates using narratives, and 3) encouraging public appreciation of end-of-life care with participation in informed decisions regarding their own care as well as on behalf of other family members.

1. Notification of Primary Care Providers Regarding Admission to Hospice in a Veterans Administration Facility

The Tennessee Valley Healthcare System Hospice and Palliative Care Service actively involves primary care physicians (PCP’s), routinely contacting PCP’s to obtain information and to discuss the patient’s admission. The Medical Director formulates a care plan and informs patients and families regarding communications with the PCP. We reviewed 37 consecutive admissions to the hospice unit during a 6-month period, July through December 2016, to identify best practices. This study was determined as quality improvement by the Tennessee Valley Healthcare System Institutional Review Board.

We utilized the Bereaved Family Survey (BFS),⁷ a 20 item survey regarding the veteran and family experience of care done following every veteran death as the evaluation tool. We found that 84% of PCP’s were contacted regarding patient admission to the unit, while 16% were not able to be contacted. Barriers to contacting PCP’s included: lack of PCP, homelessness, and residence at a great distance from the medical center. TVHS Hospice and Palliative Care Service has exceeded stretch goals 3 out of the previous 4 years and has always exceeded regional and national benchmarks for quality performance indicators, including 1) proportion of ICU admissions receiving palliative care consultation, 2) proportion of hospital deaths receiving palliative care consultation, and 3) proportion of bereaved families completing the BFS. A comparative hospice program in the same network does not actively contact PCP’s and has met benchmarking only 1 of 4 previous years. TVHS also exceeded the comparative site in 7 of 10 patient care domains identified on the BFS.

PCP notification may be associated with improved patient and family experience of care. Efforts to inform PCP’s during patient admission to hospice may require increased effort, especially for patients residing at a distance from a hospice unit.

2. ICU Story-Web: Narratives of Providers and Caregivers Regarding End-of-Life Care in the ICU

In the US, one in five deaths occurs in an intensive care unit (ICU) but 90% of these deaths involve a decision to limit life support. Patients are usually too sick to participate in these decisions, so clinicians ask for families’ help, based on their understanding of what the patient would want. Participating in life support decisions, places a significant burden on families, even when they follow a loved one’s stated wishes. In the aftermath of making these decisions places family members experience symptoms of depression, anxiety, post-traumatic stress or complicated grief. In 2010, a task force of the Society of Critical Care Medicine proposed a new term for this cluster of symptoms: Post-intensive Care Syndrome – Family (PICSF). Successful strategies are urgently needed to alleviate PICSF among bereaved ICU family members.⁸ The absence of effective and scalable interventions to support healthy grieving in this at risk group is a problem with

wide reaching and significant public health impact.

We collaborated with the University of Pittsburgh, Meharry Medical College, Vanderbilt University, and the Veterans Administration to interview and catalogue narratives from ICU surrogate decision-makers among family survivors as well as caring physicians who provide care to these patients and families. This project was determined as quality improvement by the TVHS IRB. The narratives were included in a curated library of recorded stories from recently bereaved ICU family members to harnesses the power of storytelling to help ICU families to heal. This interactive tool available at icustoryweb.org is designed to help alleviate distress among recently bereaved ICU family members and to model decision-making behavior for surrogates.

3. Honoring Choices® Tennessee-Promoting Advance Care Discussion in the Community

An advance directive for healthcare is a document that informs family, caregivers, and providers of patient preferences for care, should they ever be in a position where they could not make decisions and communicate their problems for themselves. Advance care planning documents include: 1) a Living Will which indicates care preferences, 2) Appointment of Healthcare Agent which includes the medical power of attorney for medical decisions when the patient is not able to do, and 3) the portable directive or medical order which provides documentation to all healthcare providers and EMS personnel regarding the patient’s wishes. This document is signed by the physician, and in different states it is termed Physician Order for Life-Sustaining Treatment (POST or POLST), or Medical Order for Life-Sustaining Treatment (MOLST) (Table 1).

Table 1: Advance Care Planning.

- Living Will - care preferences
- Appointment of Healthcare Agent
- Portable Directive (Medical Order)

Honoring Choices® Tennessee was facilitated by the Tennessee Commission on Aging and Disability and the Tennessee Department of Health and engaged experts to coordinate advance care plan outreach efforts in the community about what matters most prior to an individual becoming seriously ill or being near the end-of-life. Honoring choices Tennessee is affiliated with the Honoring Choices National Network present in a number of other states. The coalition launched the *AdvanceDirectivesTN* initiative to increase knowledge and discourse in the community regarding advance directives for healthcare. The initiative coincided with the National Healthcare Decisions Day (NHDD), an annual event designed to inspire, educate, and empower the public and providers regarding the importance of advance healthcare planning. NHDD is an initiative of the Conversation Project to encourage patients to express their wishes regarding healthcare and for providers and facilities to respect those wishes whatever they may be.⁹

Honoring Choices® Tennessee produced a website <http://advancedirectivestn.org> to enhance public information and provide definitions and resources regarding advance directive documents. Included are personal narratives, testimonials and videos concerning end-of-life care.

DISCUSSION

The therapeutic goals of hospice and palliative care include maintaining dignity, fostering respect, honoring privacy, and helping the patient and family to find spiritual comfort and meaning (Table 2). Care that focuses on these goals enhance the patient and family’s experience during a difficult journey, which family survivors will always remember.

Table 2: Therapeutic Implications of Hospice and Palliative Care.

- Maintaining dignity
- Fostering respect
- Honoring privacy
- Helping find spiritual comfort and meaning

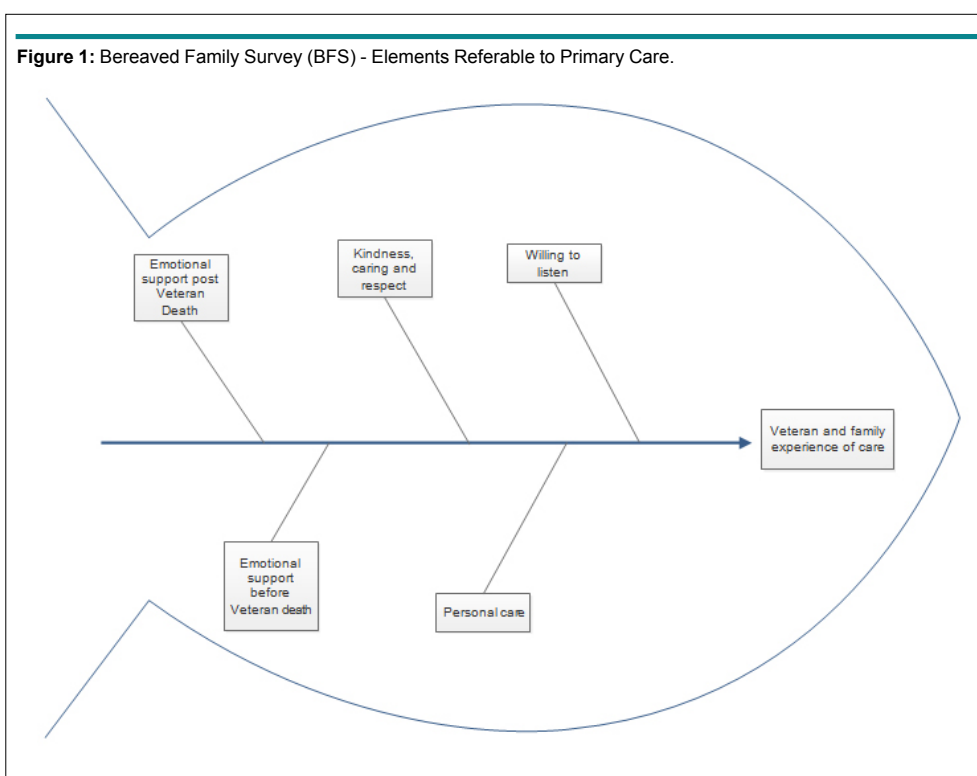
A comprehensive assessment for hospice and palliative care includes the following domains: 1) social and caregiving, 2) existential and spiritual, 3) physical, 4) psychological, and 5) patient-centered goals of care (Table 3).¹⁰ Quality improvement in end-of-life care is appropriately focused on all of these domains. The three models presented touch primarily on three of these domains: social and caregiving, existential and spiritual, and psychological.

Table 3: Comprehensive Patient Assessment.

- Social and caregiving
- Existential and spiritual
- Physical
- Psychological
- Goals of care

The BFS is a quality assessment tool that helps to measure what matters most: to identify factors important to the patient and family experience of care. There are number of elements in the BFS which overlap with primary care concerns including kindness, caring and respect, willingness to listen, personal care, and emotional support before and following death.³ These elements of care are addressed in the care plans of hospice and palliative care programs which seek and value PCP input. They correspond to potential islands of excellence in healthcare delivery. These “bright spots” which exist are associated with improved outcomes and improved patient and family experience of care. While they do not prove causation, in quality improvement efforts these activities may be worthy of emulation and adoption as best practices by other providers.¹¹ Involvement of the PCP, and discussions with patients and families relating to PCP contacts could positively impact the patient and family experience of care (Figure 1).

Practices which address these elements of care are important to patients and families, and may be worthy of dissemination for further evaluation. Involvement of PCPs in hospice care could serve as a best practice to be emulated by other hospice programs.



Categories of care referable to the patient and family experience of care as defined by the BFS.

The sharing of ICU narratives with online availability harnesses the power of storytelling to help support other caregivers in their time of need. The shared experiences of family survivors as well as the perspective of caring hospice and palliative care providers helps support families during and after their experience and addresses concerns common to all. Narratives can help provide modeling for decision-making. Narratives are rich source of values and goals and they provide a context of life experiences that shape and support the surrogate family member's experience.¹² Additional topics included are the Five Wishes (Table 4)¹³ and helping families talk to their loved ones about the things that matter most: 1) please forgive me, 2) I forgive you, 3) thank you, and 4) I love you.¹⁴

Table 4: Five Wishes.

- Who you want to make healthcare decisions for you when you can't make them.
- The kind of medical treatment you want or don't want.
- How comfortable you want to be.
- How you want people to treat you.
- What you want your loved ones to know.

The need to de-medicalize advance care planning and to disseminate information on advance directives to the public is urgent. With whom is it more important to address these issues than with other family members who often serve as surrogate decision-makers? Developing an advance directive is all about personal choice, but it is also about preparing loved ones to make it easier for them to make healthcare decisions when the patient cannot.

Receiving care that is consistent with individual values and having the opportunity to talk and make informed decisions about end-of-life care depends on the recording and sharing of these documents with families and others. The Honoring Choices® Tennessee website provides a link to the State Health Department advance care planning documents. Educating all healthcare workers about the benefits of advance directives is also important so they can also educate patients and their families about end-of-life care.

CONCLUSION

Involvement of the primary care physician, modeling of decision-making behavior using narratives, and public education to promote engagement and discourse regarding end-of-life care may improve the patient and family experience of hospice and palliative care. We advocate for continued development of new quality improvement measures and the widespread sharing of best practices to enhance end-of-life care.

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