Original Article

Family Involvement at the End-of-Life and Receipt of Quality Care

Rebecca L. Sudore, MD, David Casarett, MD, MA, Dawn Smith, MS, Diane M. Richardson, PhD, MS, and Mary Ersek, PhD, RN, FAAN

San Francisco VA Medical Center (R.L.S.) and Division of Geriatrics (R.L.S.), University of California, San Francisco, California; University of Pennsylvania Perelman School of Medicine (D.C.) and School of Nursing (M.E.), Philadelphia, Pennsylvania; and Center for Health Equity Research and Promotion (D.S., D.M.R., M.E.), Department of Veterans Affairs Medical Center, Philadelphia, Pennsylvania, USA

Abstract

Context. Most patients will lose decision-making capacity at the end of life. Little is known about the quality of care received by patients who have family involved in their care.

Objectives. To evaluate differences in the receipt of quality end-of-life care for patients who died with and without family involvement.

Methods. We retrospectively reviewed the charts of 34,290 decedents from 146 acute and long-term care Veterans Affairs facilities between 2010 and 2011. Outcomes included: 1) palliative care consult, 2) chaplain visit, and 3) death in an inpatient hospice or palliative care unit. We also assessed "do not resuscitate" (DNR) orders. Family involvement was defined as documented discussions with the health care team in the last month of life. We used logistic regression adjusted for demographics, comorbidity, and clustered by facility. For chaplain visit, hospice or palliative care unit death, and DNR, we additionally adjusted for palliative care consults.

Results. Mean (SD) age was 74 (±12) years, 98% were men, and 19% were nonwhite. Most decedents (94.2%) had involved family. Veterans with involved family were more likely to have had a palliative care consult, adjusted odds ratio (AOR) 4.31 (95% CI 3.90–4.76); a chaplain visit, AOR 1.18 (95% CI 1.07–1.31); and a DNR order, AOR 4.59 (95% CI 4.08–5.16) but not more likely to die in a hospice or palliative care unit.

Conclusion. Family involvement at the end of life is associated with receipt of palliative care consultation and a chaplain visit and a higher likelihood of a DNR order. Clinicians should support early advance care planning for vulnerable patients who may lack family or friends. J Pain Symptom Manage 2014;48:1108–1116. *Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

Address correspondence to: Rebecca L. Sudore, MD, Division of Geriatrics, San Francisco VA Medical Center, 4150 Clement Street, #151R, San Francisco, CA 94121, USA. E-mail: rebecca.sudore@ucsf.edu

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Key Words
End-of-life care, communication, quality assessment, veterans

Introduction

It is estimated that 25%–75% of seriously ill patients lose capacity to make some or all their medical decisions at the end of life.[1–3] In such cases, it is the ethical and legal standard to have close family or friends (henceforth referred to as family) serve as surrogate decision makers.[4] Ideally, family members work with the patient's clinical team to help interpret advance directives and prior goals of care conversations, when available, and to make medical decisions that align with patients' preferences.[5,6] Even when patients retain the ability to make their own medical decisions, the added support of close family and friends who can help advocate for the patient may relieve stress and provide comfort at the end of life.[1]

However, many patients, up to 25% in some studies, lack a surrogate decision maker[7,8] either because they have no close friends or family members or because suitable surrogates cannot be reached during a crisis.[9,10] For instance, studies in intensive care units have shown that up to one quarter of patients lack both a surrogate decision maker and an advance directive to help guide treatment decisions.[11,12] For patients who lack a family member who can serve as a surrogate, medical decisions are often made with the support of third parties like hospital ethics committees or the courts.[13]

There are concerns that patients without an involved family member who can advocate for the patient may not receive high-quality care at the end of life, such as receipt of a palliative care consultation, visits by a chaplain, and receipt of care that is consistent with patients' goals and preferences.[14–16] However, for a family member to advocate for needed services, he or she must be involved in the patient's care and not just named on a legal document. For instance, Silveira et al.[1] found that a documented durable power of attorney (DPOA) for health care was associated with death outside a hospital and less aggressive care. However, approximately 10% of the actual decision makers for these incapacitated patients were not the documented DPOA.[1] In addition, other studies demonstrate physician frustration in finding the documented DPOA during a medical crisis.[9] What may be more important is not whether a patient has a documented DPOA but whether the patient has involved family who can advocate for the patient and who is actually involved in caring for and helping that person make decisions at the end of life.

Little is known about whether family involvement in health care decisions affects the quality of care that patients receive near the end of life. This is important because many patients who lack involved family may be at risk for poor-quality end-of-life care. Therefore, this study compared the quality of the end-of-life care between patients who had family involved in health care decision making at the end of life vs. those who did not. We hypothesized that patients with involved family members would receive better quality end-of-life care than patients without involved family.

Methods

Setting and Participants

This investigation was part of the Performance Reporting and Outcomes Measurement to Improve the Standard of Care at the End-of-life (PROMISE) Center, an ongoing quality improvement initiative to optimize end-of-life care at 146 Veterans Affairs Medical Centers that had palliative care teams.[17] All Veterans Affairs (VA) facilities with palliative care consultations participate in the PROMISE program and are included in this analysis. The facilities are a mix of acute care and long-term inpatient facilities, including intensive care units, nursing homes, and inpatient hospice units. This study only included veterans who died after >24 hours in a VA inpatient facility between January 2010 and September 2011. Veterans were excluded if they did not have a next of kin documented in the electronic medical record (EMR) or if they died by suicide or outside a VA inpatient facility. Inpatient deaths were retrieved from national VA databases derived from the EMR; this method identifies >95% of decedents.[16,17] Approximately 2% of decedents were selected at random from the largest VA