



# Understanding Palliative Care and Hospice: A Review for Primary Care Providers

Mary K. Buss, MD, MPH; Laura K. Rock, MD; and Ellen P. McCarthy, PhD, MPH

From the Section of Palliative Care, Division of General Medicine and Primary Care, Division of Hematology-Oncology (M.K.B.), Division of Pulmonary and Critical Care Medicine (L.K.R.), and Research Section, Division of General Medicine and Primary Care (E.P.M.), Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, MA.

## CME Activity

**Target Audience:** The target audience for *Mayo Clinic Proceedings* is primarily internal medicine physicians and other clinicians who wish to advance their current knowledge of clinical medicine and who wish to stay abreast of advances in medical research.

**Statement of Need:** General internists and primary care physicians must maintain an extensive knowledge base on a wide variety of topics covering all body systems as well as common and uncommon disorders. *Mayo Clinic Proceedings* aims to leverage the expertise of its authors to help physicians understand best practices in diagnosis and management of conditions encountered in the clinical setting.

**Accreditation:** Mayo Clinic College of Medicine and Science is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

**Credit Statement:** Mayo Clinic College of Medicine and Science designates this journal-based CME activity for a maximum of 1.0 *AMA PRA Category 1 Credit(s)*.<sup>TM</sup> Physicians should claim only the credit commensurate with the extent of their participation in the activity.

**Credit Statement:** Successful completion of this CME activity, which includes participation in the evaluation component, enables the participant to earn up to 1 MOC points in the American Board of Internal Medicine's (ABIM) Maintenance of Certification (MOC) program. Participants will earn MOC points equivalent to the amount of CME credits claimed for the activity. It is the CME activity provider's responsibility to submit participant completion information to ACCME for the purpose of granting ABIM MOC credit.

**Learning Objectives:** On completion of this article, you should be able to (1) identify benefits of primary palliative care and hospice care for patients and families; (2) distinguish between palliative care and hospice; and (3) give examples of common misconceptions and barriers related to palliative care.

**Disclosures:** As a provider accredited by ACCME, Mayo Clinic College of Medicine and Science (Mayo School of Continuous Professional Development) must ensure balance, independence, objectivity, and scientific rigor

in its educational activities. Course Director(s), Planning Committee members, Faculty, and all others who are in a position to control the content of this educational activity are required to disclose all relevant financial relationships with any commercial interest related to the subject matter of the educational activity. Safeguards against commercial bias have been put in place. Faculty also will disclose any off-label and/or investigational use of pharmaceuticals or instruments discussed in their presentation. Disclosure of this information will be published in course materials so that those participants in the activity may formulate their own judgments regarding the presentation.

In their editorial and administrative roles, William L. Lanier, Jr, MD, Terry L. Jopke, Kimberly D. Sankey, and Nicki M. Smith, MPA, have control of the content of this program but have no relevant financial relationship(s) with industry.

The authors report no competing interests.

**Method of Participation:** In order to claim credit, participants must complete the following:

1. Read the activity.
2. Complete the online CME Test and Evaluation. Participants must achieve a score of 80% on the CME Test. One retake is allowed.

Visit [www.mayoclinicproceedings.org](http://www.mayoclinicproceedings.org), select CME, and then select CME articles to locate this article online to access the online process. On successful completion of the online test and evaluation, you can instantly download and print your certificate of credit.

**Estimated Time:** The estimated time to complete each article is approximately 1 hour.

**Hardware/Software:** PC or MAC with Internet access.

**Date of Release:** 2/1/2017

**Expiration Date:** 1/31/2019 (Credit can no longer be offered after it has passed the expiration date.)

**Privacy Policy:** <http://www.mayoclinic.org/global/privacy.html>

**Questions?** Contact [dletcsupport@mayo.edu](mailto:dletcsupport@mayo.edu).

## Abstract

Palliative care provides invaluable clinical management and support for patients and their families. For most people, palliative care is not provided by hospice and palliative medicine specialists, but rather by their primary care providers. The recognition of hospice and palliative medicine as its own medical subspecialty in 2006 highlighted the importance of palliative care to the practice of medicine, yet many health care professionals harbor misconceptions about palliative care, which may be a barrier to ensuring that the palliative care needs of their patients are identified and met in a timely fashion. When physicians discuss end-of-life concerns proactively, many patients choose more comfort-focused care and receive care more aligned with their values and goals. This article defines palliative care, describes how it differs from hospice, debunks some common myths associated with hospice and palliative care, and offers suggestions on how primary care providers can integrate palliative care into their practice.

© 2016 Mayo Foundation for Medical Education and Research ■ *Mayo Clin Proc.* 2017;92(2):280-286

## WHAT IS PALLIATIVE CARE?

Unlike other medical specialties, the field of palliative care does not address the underlying disease process.

Palliative care addresses symptoms directly to improve how the patient feels, regardless of the cause. As defined by the Center to Advance Palliative Care:

Palliative care, also known as palliative medicine, is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.<sup>1</sup>

Specialty palliative care uses an interdisciplinary team to fully address the needs of patients and families. Nurse practitioners, nurses, social workers, chaplains, and pharmacists work alongside physicians to address psychosocial and spiritual concerns of patients and families in addition to physical symptoms. Symptom management, psychosocial-spiritual support, and facilitation of medical decision making are 3 key domains of palliative care. The Table describes common elements of palliative care in each of these domains. Even with tremendous growth in the past 2 decades, including recognition of hospice and palliative medicine (HPM) as an official subspecialty of the American Board of Medical Subspecialties and the American Osteopathic Association, there remains a shortage of HPM specialists, which is projected to increase as the population ages.<sup>2</sup> Thus, most palliative care is, and arguably should be, provided by non-HPM specialists, including internal medicine, family physicians, and nurse practitioners.<sup>3</sup> Primary care providers (PCPs) are particularly well-suited to deliver primary palliative care. The development of team-based primary care, such as the patient-centered medical home,<sup>4</sup> and the incorporation of population health principles into restructuring primary care should improve outcomes relevant to palliative care.

Palliative care is not well understood by patients or clinicians. A recent Center to Advance Palliative Care<sup>5</sup> survey found that 70% of Americans were “not at all knowledgeable” about palliative care. This lack of awareness creates an opportunity for clinicians to frame the benefits of palliative care for patients and their families. Yet the survey also found that most health care professionals erroneously equated palliative care with end-of-life (EOL) care. Clinicians who perceive palliative care as EOL care, or lack a clear understanding of its benefits, will miss critical opportunities to identify and address

palliative care needs in their patients. Primary palliative care competencies for PCPs include (1) recognition of palliative care needs in patients, (2) prognostication, (3) advance care planning, (4) assessment and management of common symptoms in the seriously ill, (5) referral to specialty palliative, and (6) appropriate and timely referral to hospice.

**RECOGNIZING PALLIATIVE CARE NEEDS IN PRIMARY CARE PATIENTS**

Patients with a serious illness often experience substantial physical burden due to pain and symptoms such as fatigue, anorexia, nausea, and dyspnea. Anxiety and depression are also common after the diagnosis of a life-threatening illness. Any of these symptoms may alter a person’s ability to fulfill roles critical to self-identity, such as athlete, caring spouse, or devoted parent. Through their longitudinal relationship, PCPs can help individuals explore these issues and find ways to adapt and prioritize in the face of a serious illness.

Many PCPs already engage in primary palliative care but may not recognize their actions as palliative care. Primary care providers commonly provide careful assessment of symptoms and recognition of how the symptoms affect that individual’s quality of life. Many also routinely prescribe and titrate opioids for patients in pain.<sup>6</sup> Primary care providers often focus on maximizing quality of life by helping patients and their families find value and meaning, particularly when a patient’s time or function is limited. It is important to help PCPs gain insight into primary palliative care that they already provide, so they may disentangle palliative care and EOL care and integrate palliative care to meet the needs of their patients. Effective symptom management promotes a patient’s ability to remain active in important activities and relationships. When appropriate, palliative care

**TABLE. Key Components of Palliative Care**

Symptom management	Psychosocial-spiritual support	Decision making
Pain	Counseling	Prognostic awareness
Nausea	Social work	Advance care planning
Delirium	Pastoral care	Understanding of outcomes
Fatigue anorexia	Caregiver support	Defining quality of life
Anxiety depression	Bereavement	Eliciting values and goals

counseling by PCPs can extend to family caregivers during active caregiving and into bereavement.

### PROGNOSTICATION AND COMMUNICATION

Patients with a serious illness commonly face difficult medical choices. Patients who realize their prognosis is less than a year often elect to avoid more invasive interventions.<sup>7</sup> However, many patients, even after discussions with their doctors, harbor unrealistic ideas about their prognosis and about the likely benefits of medical treatments.<sup>8</sup> Effective communication allows clinicians to assess patients' informational needs and facilitate clear understanding of their prognosis. A key challenge for PCPs is anticipating palliative care needs in patients before they are in medical crisis. Elderly patients and patients with multiple chronic conditions, but no clear life-threatening diagnosis, can rapidly deteriorate from being spry and independent into a state in which they are too compromised to participate meaningfully in medical decision making. Thus, heightened awareness of patient factors that predict a shortened survival or elevated risks of decline are key palliative care skills. Estimating prognosis is challenging even in illnesses with a defined trajectory, such as malignancy. However, online resources, such as [www.ePrognosis.org](http://www.ePrognosis.org), may help PCPs determine prognostic estimates, particularly for complex patients.<sup>9</sup> PCPs could also adopt "the surprise question," which is a simpler strategy to identify patients at high risk for mortality. Clinicians may ask themselves, "Would I be surprised if this patient died in the next year?" A "No" response to this question has been shown to be strongly associated with an increased likelihood of dying within the next year in various populations.<sup>10</sup>

### ADVANCE CARE PLANNING

As the medical professionals who know their patients best, PCPs are often uniquely suited to help elicit an individual's personal goals, establish priorities, and facilitate informed medical decisions that reflect the patient's values. Most PCPs believe that advance care planning is within their purview, but struggle to find adequate time during patient visits and address competing health conditions

appropriately. In 2016, the Medicare program began reimbursing clinicians for counseling patients about advance care planning. This was an important step toward supporting clinicians for the considerable time it takes to have these crucial conversations. More deliberate prognostication efforts may help PCPs identify their patients for whom advance care planning is a priority.

Advance care planning includes encouraging patients to appoint a health care proxy or surrogate decision maker, facilitating discussions between the patient and their proxy about their wishes in the event of serious illness, and documenting these discussions. Importantly, most patients want information about prognosis in the setting of serious illness.<sup>11</sup> Given the established relationship between PCPs and many of their patients, PCPs are best positioned to help patients make informed decisions about their care. Primary care providers who take time to explore a patient's wishes in light of a life-threatening illness can profoundly influence decisions made and care received near the EOL. Patients who discuss EOL concerns with a physician earlier are more likely to take a comfort-focused approach to care at the EOL.<sup>12</sup> Patients who make their wishes known in advance are more likely to receive care aligned with their preferences.<sup>13</sup> Advance care planning can also improve the mental health outcomes for their family caregivers.<sup>12,14</sup>

### WHEN TO REFER TO SPECIALTY PALLIATIVE CARE

There is no evidence to suggest that early integration of palliative care shortens survival. Yet many patients and health care professionals share an unspoken concern that it may hasten death. This common misconception—combined with the misconception that palliative care is equivalent to EOL care—denies patients and families access to palliative care until late in the illness trajectory. Several prospective randomized controlled trials<sup>15-21</sup> have compared early integration of specialty palliative care with standard care or, in 1 case, later integration of palliative care. These trials, primarily conducted in patients with advanced cancer, have shown improvements in important end points, including patient quality of life, rates of depression or anxiety,

patient or caregiver satisfaction, and utilization of health services at the EOL. Two trials<sup>19,21</sup> have also reported longer survival in the early palliative care arm.

The benefits of palliative care for patients with a serious illness are maximized through early integration in the illness trajectory. These benefits are depleted when palliative care is conceived more narrowly as EOL care. This concept of palliative care as “brink-of-death” care clearly deprives patients and families of the benefits observed with earlier integration (Figure).<sup>22</sup> Although it has not been established whether the benefits derived from early integration by a specialty palliative care team or from high-quality primary palliative care are equivalent, there are reasons to expect they would be. Primary care providers who remain involved in their patient’s care when being followed by other specialists are uniquely positioned to help with coping, symptom management, and navigating complex decisions so that the specialist may remain focused on providing disease-modifying therapy. Primary care providers may then opt to involve specialty palliative care in patients with refractory symptoms or for patients with anxiety, depression, or poor coping skills that might interfere with decision making.

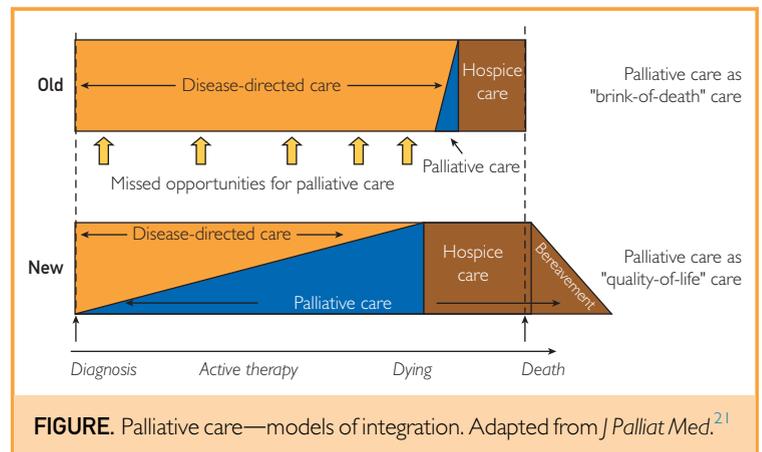
**REFERRING PATIENTS TO HOSPICE**

Historically, the field of palliative care grew out of the hospice movement, shaping a public misconception that they are synonymous. However, the terms *palliative care* and *hospice* should never be used interchangeably. In the United States, hospice is a critical, focused component of palliative care, with specific eligibility requirements driven by the 1983 Medicare hospice benefit. Hospice is usually provided in the patient’s home to allow them to die comfortably surrounded by loved ones. Although fewer than 25% of Americans die at home despite an overwhelming desire to do so, more than 75% of patients on hospice die at home.<sup>23</sup> Thus, hospice is really *the* service that allows patients to die at home, if they choose to do so.

**WHAT HOSPICE SERVICES PROVIDE**

Hospice is a team-based approach to care. Typically hospice is provided by an interdisciplinary team comprising a nurse, social

worker, home health aides, chaplain, volunteers, and hospice medical director. Hospice has 4 levels of care: routine home care, general inpatient care, continuous care, and respite care. Most hospice care (96%) is routine home care, delivered in the patient’s residence to ensure comfort and avoid hospitalization.<sup>24</sup> Members of the team visit the patient’s home to assess symptoms, adjust medications to alleviate or mitigate symptoms, and provide support to the patient and family. Hospice covers durable medical equipment, such as a hospital bed, commode, and supplemental oxygen provided in the home as well as the cost of all medications related to the hospice diagnosis, including schedule II opioid analgesics. Finally, patients on hospice may access a hospice provider, usually a nurse, 24 hours a day, 7 days a week by phone. When phone guidance is insufficient, the hospice provider will come to the patient’s home day or night. Reliable, easy access to an expert provider provides comfort and reassurance to family members, who provide the bulk of care to patients, while helping to avoid emergency department visits and hospitalizations. Occasionally, patients on hospice with complex symptoms, such as refractory pain or agitated delirium, do require hospital care. Such patients can remain on hospice under the general inpatient benefit at either an inpatient hospice facility (if available) or a hospital, in which the hospice team visits them daily and continues to manage their care along with the inpatient hospital team. In contrast, the continuous care hospice benefit provides between 8 and 24 hours of medical care, usually nursing



**FIGURE.** Palliative care—models of integration. Adapted from *J Palliat Med.*<sup>21</sup>

care, in the patient's home. The continuous care benefit is typically used to manage a complicated symptom or to allow a patient to remain at home, during a symptom crisis, with ample medical support. The hospice benefit will also provide up to 5 consecutive days of respite care in a facility, often a skilled nursing facility, to relieve stress of family caregivers. In 2012, continuous care and respite care combined accounted for less than 1% of hospice care delivered in the United States.<sup>24</sup>

When starting hospice, patients choose a primary physician, often their PCP, to oversee their medical care while on hospice. This physician receives updates and changes in the patient's status and gives orders for medications as needed. Many patients fear abandonment by their regular providers when hospice is mentioned. By reassuring their patients that they will remain the physician in charge of their care, PCPs can mitigate this concern. Moreover, able patients on hospice can continue to come in for clinic visits with their PCP and other providers if they desire. However, most hospice benefits do not cover hospitalization unless required for a patient's comfort. In general, hospitalization requires that patients disenroll from hospice and resume prior insurance. Approximately 3% to 6% of patients enrolled in hospice get hospitalized, and many of these patients go on to receive high-intensity care, which indeed may conflict with their preference for comfort measures.<sup>25,26</sup>

### LIMITATIONS OF HOSPICE

To qualify for hospice care, a physician must certify that the patient is expected to die within the next 6 months, if the disease follows its natural course. Once enrolled in hospice, a physician or hospice nurse practitioner must have at least 1 face-to-face visit with the patient in each of the first two 90-day periods, which certifies that the patient continues to meet the prognostic criteria. Patients surviving longer than 6 months require recertification once every 60 days, also accomplished through a face-to-face visit.<sup>27</sup> Occasionally, patients recover unexpectedly and no longer qualify for hospice. Such patients, often dubbed "hospice graduates," disenroll from hospice and resume their prior medical care. Patients often qualify for hospice before

actually being referred. This is partially because physicians notoriously overestimate prognosis,<sup>28</sup> but is also related to readiness of patients and their families to accept hospice. Primary care providers engaged in primary palliative care may help prepare patients and their families for an earlier transition to hospice.

The other major distinction in hospice care is that because of the reimbursement structure, hospice is required only to provide comfort-focused care related to the hospice diagnosis. The Medicare hospice benefit requires patients to forgo treatments aimed at curing their terminal diagnosis. Thus, many hospices will not accept patients receiving disease-directed care (eg, chemotherapy for cancer) because they will not be reimbursed for these therapies, even when the intent is palliative. Such treatments can delay referral to hospice while perpetuating the misconception that hospice is only for the final days of life. Some "open access" hospices allow patients to continue on disease-directed therapy, but this is negotiated on a case-by-case basis. Although receipt of hospice care has increased in recent years, the proportion of patients enrolling within 7 days has also increased.<sup>29</sup> Such late enrollment in hospice deprives patients and families of the chance to derive optimal benefits from hospice services<sup>30</sup>; timely referral to hospice is key to ensuring patients and families can take advantage of hospice benefits.

### OVERCOMING BARRIERS TO HOSPICE USE

Even among patients and health care professionals who understand the value of hospice, many still equate hospice to "giving up" and/or agreeing to shorten one's life. Reframing hospice as a choice to focus on *how* one lives rather than *how long* one lives sometimes can help patients and families accept hospice. Interestingly, care focused on comfort and quality may allow patients to live both better and perhaps a little longer.<sup>31</sup>

When choosing hospice, most patients will also choose to forgo attempts at cardiopulmonary resuscitation (CPR), but a do-not-resuscitate order is not required. Patients who wish for comfort-focused care but, for some reason, still want the option for attempted resuscitation can be enrolled in hospice. The hospice team will continue to address

the issue of code status with the patient and family. Once patients understand the likely outcome of CPR, many choose to forgo it.<sup>32</sup> It is important to highlight the services hospice does provide and not overemphasize the interventions, such as CPR, which are incongruous with hospice goals.

## SUMMARY

The prevalence of progressive chronic illnesses is increasing. The medical community is recognizing the importance of prioritizing medical treatments that promote quality of life along with interventions primarily aimed at prolonging survival. The expansion of primary palliative care delivered by PCPs will greatly promote symptom management and quality of life for patients throughout the course of a life-threatening illness, not just at the end. The development of new models of integrated palliative care will allow patients and families to consider their own personal goals and quality of life when making choices about the direction of their medical care. When attuned to patients' personal values, primary care providers can help individuals find meaning and joy when living with limited function and/or shortened life expectancy.

**Abbreviations and Acronyms:** CPR = cardiopulmonary resuscitation; EOL = end of life; HPM = hospice and palliative medicine; PCP = primary care provider

**Grant Support:** The work was supported in part by the generous donation (E.P.M., M.K.B.) of Missy Carter and Tee Taggart.

**Correspondence:** Address to Mary K. Buss, MD, MPH, Section of Palliative Care, Division of General Medicine and Primary Care, Division of Hematology-Oncology, Beth Israel Deaconess Medical Center, Rose 144, 330 Brookline Ave, Boston, MA 02215 (mbuss@bidmc.harvard.edu).

## REFERENCES

- Center to Advance Palliative Care. About palliative care. <https://www.capc.org/about/palliative-care/>. Accessed December 22, 2016.
- Lupu D. American Academy of Hospice and Palliative Medicine Workforce Task Force. Estimate of current hospice and palliative medicine physician workforce shortage. *J Pain Symptom Manage*. 2010;40(6):899-911.
- Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. *N Engl J Med*. 2013;368(13):1173-1175.
- Rittenhouse DR, Thom DH, Schmittiel JA. Developing a policy-relevant research agenda for the patient-centered medical home: a focus on outcomes. *J Gen Intern Med*. 2010;25(6):593-600.
- Center to Advance Palliative Care. *Public Opinion Research on Palliative Care: A Report Based on Research by Public Opinion Strategies*. New York: Center to Advance Palliative Care; 2011.
- Matlock DD. The pain pendulum swinging again. *J Palliat Med*. 2015;18(9):734-735.
- Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences [published correction appears in *JAMA*. 2000;283(2):203]. *JAMA*. 1998;279(21):1709-1714.
- Temel JS, Greer JA, Admane S, et al. Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer: results of a randomized study of early palliative care. *J Clin Oncol*. 2011;29(17):2319-2326.
- McClymont KM, Lee SJ, Schonberg MA, Wvidera E, Miao Y, Smith AK. Usefulness and effect of online prognostic calculators. *J Am Geriatr Soc*. 2014;62(12):2444-2445.
- Moss AH, Ganjoo J, Sharma S, et al. Utility of the "surprise" question to identify dialysis patients with high mortality. *Clin J Am Soc Nephrol*. 2008;3(5):1379-1384.
- Hagerty RG, Butow PN, Ellis PM, et al. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis [published correction appears in *J Clin Oncol*. 2005;23(15):3652. MacLeod, Craig [corrected to MacLeod, Craig]]. *J Clin Oncol*. 2005;23(6):1278-1288.
- Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300(14):1665-1673.
- Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med*. 2010;362(13):1211-1218.
- Wright AA, Keating NL, Balboni TA, Matulonis UA, Block SD, Prigerson HG. Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol*. 2010;28(29):4457-4464.
- Zimmermann C, Swami N, Krzyzanowska M, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *Lancet*. 2014;383(9930):1721-1730.
- Rabow MW, Dibble SL, Pantilat SZ, McPhee SJ. The comprehensive care team: a controlled trial of outpatient palliative medicine consultation. *Arch Intern Med*. 2004;164(1):83-91.
- Gade G, Venohr I, Conner D, et al. Impact of an inpatient palliative care team: a randomized control trial. *J Palliat Med*. 2008;11(2):180-190.
- Brumley R, Enguidanos S, Jamison P, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. *J Am Geriatr Soc*. 2007;55(7):993-1000.
- Bakitas MA, Tosteson TD, Li Z, et al. Early versus delayed initiation of concurrent palliative oncology care: patient outcomes in the ENABLE III randomized controlled trial. *J Clin Oncol*. 2015;33(13):1438-1445.
- Bakitas M, Lyons KD, Hegel MT, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA*. 2009;302(7):741-749.
- Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363(8):733-742.
- American Academy of Hospice and Palliative Medicine; Center to Advance Palliative Care; Hospice and Palliative Nurses Association; Last Acts Partnership; National Hospice and Palliative Care Organization. National Consensus Project for Quality Palliative Care: Clinical Practice Guidelines for quality palliative care, executive summary. *J Palliat Med*. 2004;7(5):611-627.
- National Hospice and Palliative Care Organization. <http://www.allhealth.org/briefingmaterials/NHPCO-NHPCOsFactsandFigures-2005Findings-760.pdf>. Accessed December 20, 2016.

24. [http://www.nhpco.org/sites/default/files/public/Statistics\\_Research/Hospice\\_Levels\\_of\\_Care.pdf](http://www.nhpco.org/sites/default/files/public/Statistics_Research/Hospice_Levels_of_Care.pdf). Accessed October 31, 2016.
25. Cintron A, Hamel MB, Davis RB, Burns RB, Phillips RS, McCarthy EP. Hospitalization of hospice patients with cancer. *J Palliat Med*. 2003;6(5):757-768.
26. Wang SY, Aldridge MD, Gross CP, et al. Transitions Between Healthcare Settings of Hospice Enrollees at the End of Life. *J Am Geriatr Soc*. 2016;64(2):314-322.
27. Centers for Medicare & Medicaid Services Medicare Hospice Benefit Facts. [https://www.cms.gov/medicare/medicaid-support/materials/pdf/Medicare\\_Hospice\\_Benefit\\_Facts.pdf](https://www.cms.gov/medicare/medicaid-support/materials/pdf/Medicare_Hospice_Benefit_Facts.pdf). Accessed October 31, 2016.
28. Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ*. 2000;320(7233):469-472.
29. Teno JM, Gozalo PL, Bynum JP, et al. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA*. 2013;309(5):470-477.
30. Bradley EH, Prigerson H, Carlson MD, Cherlin E, Johnson-Hurzeler R, Kasl SV. Depression among surviving caregivers: does length of hospice enrollment matter? *Am J Psychiatry*. 2004;161(12):2257-2262.
31. Connor SR, Pyenson B, Fitch K, Spence C, Iwasaki K. Comparing hospice and nonhospice patient survival among patients who die within a three-year window. *J Pain Symptom Manage*. 2007;33(3):238-246.
32. El-Jawahri A, Podgurski LM, Eichler AF, et al. Use of video to facilitate end-of-life discussions with patients with cancer: a randomized controlled trial [published correction appears in *J Clin Oncol*. 2010;28(8):1438]. *J Clin Oncol*. 2010;28(2):305-310.

## CASE REPORTS

Patient 1 is a 26-year-old woman with a medical history of EDS type III (hypermobility type), and asthma, who presented with acute onset of difficulty breathing and stridor after an upper respiratory tract infection. Pulmonary function tests with flow volume loop and a direct laryngoscopy (Figures 1A and 2A, respectively) confirmed the finding of extrathoracic obstruction secondary to arytenoid cartilage prolapse. It was hypothesized that the acute onset of stridor was due to both irritation and resultant edema of the arytenoids and their abnormal movement during inspiration, rather than asthma exacerbation. Her symptoms improved after resolution of the infection and initiating speech therapy.

Patient 2 is a 51-year-old woman with a medical history of EDS hypermobility type, Chiari malformation type 1, asthma, and obstructive sleep apnea. She presented with complaints of hoarseness, chronic cough, and occasional feeling of closing of throat that accompanies upper respiratory tract infections. Both flow volume loop and bronchoscopy showed findings of arytenoids hyperlaxity similar to patient number 1 (Figures 1B and 2B). The patient was referred for speech therapy evaluation.

Patient 3 is a 37-year-old woman with a history of EDS-classic type, Arnold Chiari malformation with syringomyelia, asthma, and central sleep apnea who presented with loss of voice, worsening shortness of breath, and stridor after undergoing general anesthesia for an elective gynecological procedure. Her flow volume loop showed findings similar to the previous 2 patients (Figures 1C and 2C). It was postulated that her fragile arytenoid tissue was weakened by the process of endotracheal intubation, and that physicians need to be aware of this potential complication in the EDS population.

## DISCUSSION

This case series demonstrates the variable presentation of upper respiratory tract symptoms in patients with EDS. Such symptoms include shortness of breath, cough, wheezing, stridor, and abnormal voice and swallowing that exacerbate after recent respiratory infection, elective surgery, or trauma. It was found that these symptoms were due to arytenoid cartilage and upper airway collapse that occur during the respiratory cycle. This collapse was evident in pulmonary function testing and visualized with bronchoscopic airway examination. It occurs because of an increase in tissue distensibility with inadequate connective tissue support to the airways, leading to redundancy as a result of the connective tissue defect. Changes in the mechanical properties of the bronchial airways and lung parenchyma underlie the observed increased tendency of the airways to collapse.<sup>1</sup>

Associated factors that can worsen the symptoms include chest wall deformity, vocal cord dysfunction, asthma, gastroesophageal reflux, obstructive sleep apnea, and allergic rhinitis. All these factors can present separately in 1 patient or can be combined as seen in our patients.

## CONCLUSION

This brief letter demonstrates the presence of arytenoid cartilage prolapse in 3 patients with EDS who presented with shortness of breath and dysphonia, and were previously diagnosed with bronchial asthma. We would like to make physicians aware of this association and the factors that exacerbate it. Larger studies are needed to assess the exact prevalence.

Fadi A. Safi, MD  
 Mohammad A. Alyosif, MD  
 Sarah Imam, BSc  
 Ragheb A. Assaly, MD

University of Toledo Medical Center  
 Toledo, Ohio

1. Morgan AW, Pearson SB, Davies S, Gooi HC, Bird HA. Asthma and airways collapse in two heritable disorders of connective tissue. *Ann Rheum Dis*. 2007;66(10):1369-1373.
2. Hunter A, Morgan AW, Bird HA. A survey of Ehlers-Danlos syndrome: hearing, voice, speech and swallowing difficulties: is there an underlying relationship? *Br J Rheumatol*. 1998; 37(7):803-804.
3. Harris JG, Khiani SJ, Lowe SA, Vora SS. Respiratory symptoms in children with Ehlers-Danlos syndrome. *J Allergy Clin Immunol Pract*. 2013;1(6): 684-686.

<http://dx.doi.org/10.1016/j.mayocp.2017.01.016>

## CORRECTION



In the article titled, “**Understanding Palliative Care and Hospice: A Review for Primary Care Providers**,” published in the February 2017 issue of *Mayo Clinic Proceedings* (*Mayo Clin Proc*. 2017;92(2):280-286), there is an error in the text. The original text read as: Once enrolled in hospice, a physician or hospice nurse practitioner must have at least 1 face-to-face visit with the patient in each of the first two 90-day periods, which certifies that the patient continues to meet the prognostic criteria. Patients surviving longer than 6 months require recertification once every 60 days, also accomplished through a face-to-face visit.<sup>27</sup>

The text should read: At time of enrollment in hospice, the hospice medical director must certify the patient has a prognosis less than six months in each of the first of two 90-day periods, which can be accomplished through chart review. Patients surviving into the third benefit period (6 months if patient is continuously enrolled) require recertification once every 60 days, requiring a face-to-face visit by either the hospice physician or nurse practitioner.

<http://dx.doi.org/10.1016/j.mayocp.2017.04.001>