REVIEW

Update in Palliative Care - 2011

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INTRODUCTION : The aim of this update is to summarize scientifically rigorous articles published in 2010 that serve to advance the field of palliative medicine and have an impact on clinical practice.

METHOD: We conducted two separate literature searches for articles published between January 1, 2010 and December 31, 2010. We reviewed title pages from the *Annals of Internal Medicine*, *British Medical Journal*, *Journal of the American Geriatrics Society*, *JAMA*, *Journal of Clinical Oncology*, *JGIM*, *Journal of Pain and Symptom Management*, *Journal of Palliative Medicine*, *Lancet*, *New England Journal of Medicine*, *PC-FACS* (Fast Article Critical Summaries for Clinicians in Palliative Care). We also conducted a Medline search with the key words "palliative," "hospice," and "terminal" care. Each author presented approximately 20 abstracts to the group. All authors reviewed these abstracts, and when needed, full text publications. We focused on articles relevant to general internists. We rated the articles individually, eliminating by consensus those that were not deemed of highest priority, and discussed the final choices as a group.

RESULTS: We first identified 126 articles with potential relevance. We presented 20 at the annual SGIM update session, and discuss 11 in this paper.

KEY WORDS: palliative; end-of-life; communication; pain.

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PALLIATIVE CARE AND HOSPICE: HEALTH SERVICES RESEARCH

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;363:733–42.

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What is Already Known?

Metastatic non-small-cell lung cancer (NSCLC) is the leading cause of death from cancer worldwide, and carries a high burden of symptoms as well as a poor quality of life. Traditionally, palliative care has been delivered late in the disease course,¹ as physicians tend to perceive palliative care (PC) as the alternative to life-prolonging or curative care. Studies suggest that late referrals to palliative care are inadequate to alter the quality and delivery of care provided to patients with cancer.^{2,3} Previous research demonstrated that introducing PC soon after diagnosis of metastatic NSCLC was feasible and acceptable among patients.⁴ However, less is known of the effect early integration of palliative care would have on patients' quality of life and end-of-life care.

What This Study Adds

In this randomized controlled study, 151 patients with newly diagnosed metastatic NSCLC were randomly assigned to either receive early integration of PC in addition to standard oncologic care, or oncologic care alone. Patients in the PC group had at least one PC clinic visit per month until death. Guidelines of the visit were in keeping with the National Consensus Guidelines in Palliative Care.⁵ 105 (70%) of patients died. Quality of life (QOL) and mood were assessed at baseline and again at 12 weeks. Compared to patients who received standard care alone, patients assigned to early palliative care had a better QOL (mean score on the Functional Assessment of Cancer Treatment-Lung 98.0 vs. 91.5; $P=0.03$), fewer had depressive symptoms (16% vs. 38%; $P=0.01$). PC patients had longer median survival (11.6 vs. 8.9 months, $p=0.02$) a benefit equivalent to that achieved with a response to first-line chemotherapy.⁶ Standard care patients were more likely to receive aggressive care (54% vs. 33%, $p=0.05$) and less likely to have resuscitation preferences documented (28% vs. 53%, $p=0.05$). These results show that early integration

of palliative care, along with other appropriate and beneficial medical therapies, is appropriate and potentially beneficial.

How Should I Change My Practice?

Based on the outcomes of this study, practitioners should consider the integration of palliative care soon after a patient is diagnosed with NSCLC to improve quality of life, reduce depression and provide a possible survival benefit.

RESOURCE UTILIZATION AND PALLIATIVE CARE

Unroe M, Kahn, JM, Carson, SS et al. One-year trajectories of care and resource utilization for recipients of prolonged mechanical ventilation: a cohort study. *Ann Intern Med* 2010; 153:167–75.

What is Already Known?

For patients who undergo prolonged mechanical ventilation, studies have focused on their survival and initial hospitalization; little is known about their quality of life and healthcare utilization after their initial hospitalization.

What This Study Adds

Unroe and colleagues performed a prospective cohort study of patients who underwent prolonged mechanical ventilation and followed them for 12 months. Patients and their surrogates were interviewed during the initial hospitalization and, for those who survived the hospitalization, at 3 months and 12 months. Out of 126 enrolled patients, 103 (82%) survived the initial hospitalization. They experienced a median of four care transitions each in the subsequent year. By the end of one year, 82 patients (65%) experienced a poor outcome: 56 (44%) of the patients had died, and 9 (11%) were completely functionally dependent. Only 11 patients (9%) were functionally independent. The mean cost of care per patient over the year was \$306,135, amounting to a \$3.5 million cost for each independently functioning survivor.

How Should I Change My Practice?

The study by Unroe and colleagues was the first of its kind to examine the overall healthcare utilization and cost of care for survivors of prolonged mechanical ventilation. For these patients, physicians should include the long-term outcomes in their discussions with surrogates, as the majority of these patients have a markedly poor functional outcome or are dead at one year; this would enhance the informed consent process.

Penrod JD, Partha D, Dellenbaugh C et al. Hospital-based palliative care consultation: effects on hospital cost. *J Palliat Med*. 2010;13:973–979.

What is Already Known?

Penrod et al. present an observational study examining the direct VA hospital costs and ICU utilization of patients during a 2-year period from 2004 through 2006 at five different VA hospital sites. For patients with advanced disease, palliative care consultation decreased overall direct hospital costs and ICU utilization compared to usual care by \$464 per hospital day. Palliative care patients were 43.7% less likely to be admitted to the ICU during their hospitalizations.

What This Study Adds

Palliative care consultation has been demonstrated to improve the quality of hospital care for patients with advanced disease and is also thought to decrease the cost of care, but only a few studies have examined the relationship between palliative care consultation and healthcare cost and utilization.

How Should I Change My Practice?

Regarding overall healthcare utilization for patients with advanced illness, this large VA study demonstrates that palliative care consultation should be considered in patients with advanced illness as it both improves the quality of care as well as avoids unwanted and costly care.

QUALITY OF LIFE AND TERMINAL CARE

Balboni T.A., Paulk M.E., Balboni M.J. et al. Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. *J Clin Oncol*. 2010; 28:445–52.

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: 4457–64.

What is Already Known?

These analyses address two important factors in determining quality of life at the end of life: provision of spiritual care by the medical team and location of death. The Coping with Cancer study, the source of both these papers,

prospectively follows a cohort of terminally ill patients with cancer and their caregivers from seven different centers over time to determine how psychosocial factors influence patient care and outcomes. The study follows over 330 patient-caregiver dyads from enrollment to death (a median of 4.5 months) and includes after-death assessments of bereaved caregivers.

Religion and spirituality are known to be important to many patients with advanced illness, and may be more important among ethnic minorities. Religion and spirituality are associated with improved coping and quality of life; and for patients with high religious coping, higher likelihood of receiving hospice care at the end of life.⁷

Location of death is associated improved satisfaction, with family members reporting having received excellent care if patients die at home with hospice rather than in a hospital, nursing home, or at home with non-hospice home health services.⁸

What These Studies Add

The first paper found that when patients near death reported that their spiritual needs were met by the medical team or through receipt of pastoral care services they also scored higher on the McGill Quality of Life instrument (20.0 [95% CI, 18.8–21.1] vs. 17.3 [95%CI, 15.9–18.8]). Patients whose spiritual needs were supported were more likely to use hospice care (adjusted odds ratio 3.53, $p=0.003$) and those patients with high religious coping were also less likely to receive aggressive end-of-life (EOL) care (adjusted odds ratio 0.18, $p=0.02$). Unfortunately only 46% of patients reported receiving pastoral care services and only 40% reported that their spiritual needs were supported, although patients were more likely to report that their needs were supported if they received pastoral care services.

The second paper found that 56.8% of patients died at home with hospice services, 7.5% died at home without hospice services, 25.5% died in a hospital, and 8.4% died in an ICU. In interviews 2 weeks post mortem, caregivers of patients who died in hospital or in ICU rated patients quality of life ($p=0.003$), physical comfort ($p<0.0001$), and psychological well being ($p=0.02$) as worse than those who died at home with or without hospice services. A significant finding from this study is the quantification of caregiver burden associated with death in hospital and ICU. Compared with deaths in home hospice, ICU deaths were associated with higher rates of post-traumatic stress disorder (PTSD) in bereaved caregivers (adjusted odds ratio 5, $p=0.02$). Similarly, hospital deaths were associated with higher odds of prolonged grief disorder (adjusted odds ratio 8.83, $p=0.02$) at the 6-month post mortem assessment.

As the authors readily acknowledge, when interpreting results from the Coping with Cancer Study, readers must remember that it is an observational study which demon-

strates association, not causation, and that the findings apply best to patients with advanced cancer.

How Should I Change My Practice?

Health professionals should be aware that it is common for patients to have unmet religious or spiritual needs. When available, referral to pastoral care services for such patients is indicated. This may be particularly salient when working with members of minority groups who may rely more heavily on religious coping. Health professionals should also be aware of the increased risk of PTSD associated with ICU deaths, and prolonged grief disorder associated with hospital deaths.

PAIN AND DISTRESSING SYMPTOMS

Smith AK, Cenzer IS, Knight SJ, et al. The Epidemiology of Pain During the Last 2 Years of Life. *Ann Intern Med.* 2010;153:563–569.

What is Already Known?

Addressing pain is an important part of clinical care. While data suggest that pain is prevalent at the end of life^{8–10}, little population-based data for the prevalence of pain are available.

What This Study Adds

Using data from the Health and Retirement Study (HRS) for 4703 community-dwelling decedents with a mean age of 76 years who died between 1994 and 2006, the investigators measured the prevalence of moderate to severe pain in the last two years of life. Patients in the study cohort suffered from the following illnesses: heart disease (29.7%), cancer (27.6%), sudden death (16.7%), other causes (14.2%), and frailty (11.8%). They found that the prevalence of pain was 26% (CI, 23% to 30%) 2 years before death and increased 6% per month in the last four months of life to 46%. The authors also reported that controlling for other factors, older age, female sex, lower net worth, the presence of a proxy interviewer, and presence of arthritis were all associated with higher levels of pain. Controlling for other factors, being black (as compared to being white or Hispanic) was associated with fewer reports of moderate-to-severe pain.

How Should I Change My Practice?

This data suggest that pain is prevalent in older adults with a variety of chronic illnesses. Physicians should assess pain routinely in all of their patients, not only in patients at the end of life.

Dunn KM, Saunders KW, Rutter CM, et al. Opioid Prescriptions for Chronic Pain and Overdose. *Ann Intern Med* 2010;152:85–92.

What is Already Known?

When non-opioid therapies are ineffective, long-term opioid therapy may be instituted for chronic pain. As with any treatment, use of opioids for chronic pain requires consideration of alternative therapies' as well as risks and benefits' before initiation of the treatment.^{11,12} The authors were interested in investigating the prevalence of overdose as a potential risk of prescribing opioids for patients with chronic pain.

What This Study Adds

The authors used data from the Consortium to Study Opioid Risks and Trends (CONSORT) study. The cohort of patients studied included patients diagnosed with chronic pain, 18 years or older who started treatment with opioids and continued use for at least 90 days from 1997 through 2005. Patients with cancer were excluded from the study. Overdose was conservatively defined by ICD-9 codes and from vital statistics data from the Washington mortality registry. Medical record review was used to determine the severity of the overdose. The study found that 51 of 9940 (0.005%) adults in this cohort experienced an overdose event and 6 (0.0006%) of them died as a result of an overdose. The authors report that patients receiving higher doses of opiates were more likely to have an overdose; however the observational nature of the data limited interpretations of this association.

How Should I Change My Practice?

Patients for whom opioid therapy is being considered to treat their chronic pain can be counseled about the real (but relatively rare) risk of overdose. As always, patients receiving opioids should be monitored carefully and should receive education about opioid management.

Abernethy AP, McDonald CF, Frith PA et al., Effect of palliative oxygen versus room air in relief of breathlessness in patients with refractory dyspnoea: a double-blind, randomised controlled trial. *Lancet* 2011;376:784–793.

What is Already Known?

Dyspnea is defined as “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations

varying in intensity.”¹³ It is common in patients with advanced illness and associated with worse quality of life as well as poorer physical and psychological functioning. Unfortunately, its pathophysiology is not well understood; while acute hypoxia is typically associated with dyspnea, many terminally ill patients are dyspneic but not hypoxic. Despite this, palliative oxygen is frequently prescribed to manage dyspnea irrespective of partial pressure of oxygen in arterial blood (PaO₂) and the lack of evidence-based guidelines.¹⁴ This study attempts to determine the effect of oxygen compared to room air, both delivered through nasal cannula, in dyspneic non-hypoxic patients.

What These Studies Add

In this international, multi-center, randomized controlled, double-blinded study, 239 patients with life limiting illnesses (mostly pulmonary disorders and cancer) and PaO₂>55 mm HG were given either oxygen or room air through nasal cannula at 2 liters per minute for 7 days, ≥ 15 hours per day. The primary outcome, the change in “breathlessness right now” over the time of the study, was measured using a numerical rating scale and assessed twice a day. There was no difference in breathlessness between the two groups, either in the morning (oxygen arm 95% CI, -1.3 to -0.5 vs. room air arm 95% CI, -1.2 to -0.2) or the evening (oxygen arm 95% CI, -0.7 to 0.1 vs. room air arm 95% CI, -0.9 to -0.1). There also was no difference in quality of life between the two groups. Side-effect frequencies were minimal and similar across the groups.

How Should I Change My Practice?

This study provides definitive evidence that oxygen is no more effective than room air in relieving the sensation of dyspnea when both are given by nasal cannula from a concentrator. This study should not be interpreted as showing that ambient room air is comparable to oxygen or room air delivered by cannula. There is data that air movement across the face and nares is associated with dyspnea relief.¹⁵ Given the practical problem ordering room air by nasal cannula and oxygen's symbolic power, consider prescribing oxygen to patient/families who request it. On the other hand, this study might lead patient/families to be more willing not to use oxygen given the practical problems associated with concentrators.

COMMUNICATION AND DECISION-MAKING AT THE END OF LIFE

Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med*. 2010;362:1211–8.

What is Already Known?

Although popularity of advance directives has grown over the last few decades, there remains a debate about their effectiveness.¹⁶ Recently, studies have shown that advance directives are associated with patients receiving less life-sustaining treatment and of dying at home vs. dying in a hospital,^{17,18} but it was unclear if these outcomes were consistent with patient wishes. Furthermore, it has never been determined how often patients are placed in a circumstance where advance directives could guide care.

What The Study Adds

The investigators used a nationally representative sample of 3746 patients ≥ 60 years old from the Health and Retirement Study who died between 2000 and 2006. They measured the prevalence of the need for decision making and lost decision-making capacity. They also measured the association between preferences documented vs. outcomes of surrogate decision-making. They found that 42.5% required decision making, of whom 70.3% lacked decision-making capacity. Of those without capacity, 67.6% had advance directives. Based on surrogate interviews, the care received was strongly associated with prior preferences: 83.2% of subjects who requested limited care and 97.1% of subjects who requested comfort care received care consistent with their preferences. Only a minority of patients with advance directives requested all possible care; they were more likely to receive aggressive therapy.

How Should I Change My Practice?

Practitioners should assess their patients' advance directives before patients lose the capacity to convey their wishes, as advanced conversations are associated with receiving their preferences at the end of life.

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. *J Clin Oncol*. 2010. 28:305–10.

What is Already Known?

Poor health literacy is a prevalent problem and may impair decision making at the end of life.¹⁹ Video images have been shown to improve the communication of health information and the description of health states.^{20–24}

What This Study Adds

In this study 50 participants with malignant glioma were randomly assigned to either a verbal narrative of goals-of-

care options at the end of life (life-prolonging care, e.g. cardiopulmonary resuscitation [CPR], ventilation), basic care (hospitalization, no CPR, and comfort care) or verbal narrative (as above) plus an informational video. Participants who viewed the goals-of-care video were more likely to prefer comfort care and avoid CPR (91.3% vs. 22% for comfort care, 0 vs. 25.9% for CPR), and were more certain of their end-of-life decision making. Participants reported feeling comfortable watching the video. These results support the potential usefulness and high patient acceptance of a novel way of assessing patients' end-of-life care preferences.

How Should I Change My Practice?

Practitioners should be open to the use of multimedia methods to improve their patients' understanding of health outcomes and treatment options at the end of life, particularly for patients with low medical literacy who might find verbal descriptions difficult.

Boyd EA, Lo B, Evans LR et al. "It's not just what the doctor tells me:" factors that influence surrogate decision-makers' perceptions of prognosis. *Crit Care Med*. 2010; 38:1270–5.

What is Already Known?

A number of studies have shown that surrogates' estimates of prognosis are often discordant with their physicians'.^{25,26} Several authors have postulated that poor communication may be the cause of this discordance.^{27–29} Little is known about the thought processes surrogates employ to arrive at their estimates.

What This Study Adds

Using face-to-face, semi-structured interviews with 179 surrogates of 142 incapacitated, critically ill patients in four intensive care units, the investigators recorded the surrogates' beliefs about prognosis. Less than 2% of the surrogates reported that their beliefs about prognosis hinged exclusively on prognostic information provided by physicians. The majority cited other factors, such as their loved one's strength of character, will to live, unique history of illness and survival, their appearance, the surrogate's belief that their presence may improve prognosis as well as the surrogate's optimism, intuition, and faith. For some surrogates these other sources of knowledge were more important than the physician's prognostication. Most surrogates balanced the above factors and physician prognostication.

How Should I Change My Practice?

Surrogates use diverse types of knowledge when estimating their loved ones' prognoses. Physicians may be unaware of these other factors, and should inquire about the decision-making process among surrogates. Recognition of the factors that influence surrogate decision-making may help physicians address specific beliefs that the surrogate holds, as well as specific issues that surrogates may be misinterpreting. Finally, physician recognition of these other factors may help the physician understand apparently paradoxical decision-making on the part of surrogate surrogates.

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