Update in Hospice and Palliative Care

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Introduction

THE GOAL OF THIS UPDATE in hospice and palliative care is to identify, summarize, and critique journal articles published (electronically or in print) between January 1, 2009 and December 31, 2009 with the highest potential for impact on the clinical practice of hospice and palliative care. We began with a hand search of 21 leading medical journals as well as a keyword search in PubMed using the terms “hospice” and “palliative care.” We also hand-searched the Cochrane Database of Systematic Reviews¹ and Fast Article Critical Summaries for Clinicians in Palliative Care.² Articles were reviewed and ranked based on study quality, scientific merit, and potential for immediate impact on the field of hospice and palliative care. The purpose of this article is to inform clinicians across a broad range of topics, including: spiritual and psychosocial care; palliative care for special populations (pediatrics and geriatrics); symptom management; and clinician self care. Changes to practice resulting from the articles reviewed are summarized in Table 1.

Spiritual and Psychosocial Care

Balboni TA, Paulk ME, Balboni MJ, Phelps AC, Loggers ET, Wright AA, Block SD, Lewis EF, Peteet JR, Prigerson HG: *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.

Summary and main findings

Spiritual care is a core aspect of palliative care and a quality standard,^{3,4} yet the effects of spiritual care on patient outcomes have not been well studied. In this prospective, longitudinal cohort study conducted at seven geographically diverse outpatient sites, the investigators enrolled English-speaking adult patients with advanced cancer who had an informal caregiver. Dependent variables were patients' answers at time of enrollment to the following two questions assessing spiritual care: (1) “To what extent are your religious/spiritual needs being supported by the medical system?” and (2) “Have you received pastoral care services within the clinic or hospital?” Outcome measures were use of hospice and life-sustaining treatments (intensive care unit [ICU], intubation,

resuscitation) in the last week of life and caregivers' rating of patients' quality of life near death.

Of 944 eligible patients, 670 enrolled. Analysis was based on 343 patients who died and had complete spiritual care and postmortem interview data; their mean age was 58 years, 54% were male, and 63% were white. At study enrollment, 60% of patients reported that their spiritual needs were minimally or not at all supported and 54% of patients reported that they had not received pastoral care. Patients who had received pastoral care were much more likely to report that their spiritual needs were supported. In the last week of life, 73% of patients received hospice care and 17% received some form of life-sustaining treatment. Patients whose spiritual needs were largely or completely supported by the medical team were more likely to use hospice (odds ratio [OR] 3.53, 95% confidence interval [CI] 1.53–8.12). Family members rated patients' quality of life near death better for those patients who said that they had greater spiritual support from the medical team.

Strengths and limitations

The strengths of this study include that it was conducted at multiple geographically distinct centers, was prospective, and studied the effects of both pastoral care services and overall spiritual support by the medical team. A limitation is that patients were asked about spiritual care at baseline; their responses could have changed over the course of the study. In addition, the study population's unusually high utilization of hospice may limit generalizability. Finally, because the design was observational, we cannot conclude that the associations between spiritual care and hospice use or quality of life are causal.

Clinical bottom line

Patients with advanced cancer who receive pastoral care are more likely to feel their spiritual needs are supported by the medical team. Supporting patients' spiritual needs may change their utilization of health care and increase their quality of life near death.

Bakitas M, Lyons KD, Hegel MT, Balan S, Brokaw FC, Seville J, Hull JG, Li Z, Tosteson TD, Byock IR, Ahles TA: *Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial.* *JAMA* 2009;302:741–749.

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TABLE 1. RECOMMENDATIONS FOR CLINICAL HOSPICE AND PALLIATIVE CARE PRACTICE EMERGING FROM ARTICLES PUBLISHED IN 2009

<i>Recommendation</i>	<i>Reference</i>
Start	
Providing nursing phone support to rural patients with cancer; it improves their quality of life and decreases depression.	Bakitas et al. ¹⁰
Asking parents of seriously ill children how we can support them in being a "good parent."	Hinds et al. ¹¹
Explaining the relationship between starting dialysis, functional decline, and mortality in nursing home patients.	Kurella Tamura et al. ¹²
Consider	
Helping parents of seriously ill children to plan the location of their child's death; it may change the care the child receives and improve the parent's experience.	Dussel et al. ¹³
Using methods to increase mindfulness for self-care.	Krasner et al. ¹⁴
Continue	
Providing spiritual support for patients with advanced cancer; it improves quality of life at the end of life.	Balboni et al. ¹⁵
Continue exploring proxy knowledge of the course of advanced dementia; it is related to the care the patient receives.	Mitchell et al. ¹⁶
Using the anticholinergic agent of your choice to treat death rattle.	Wildiers et al. ¹⁷

Summary and main findings

The evidence base demonstrating the benefits of palliative care continues to grow, but includes few randomized controlled trials. Bakitas and colleagues report a randomized controlled trial of a multicomponent educational intervention to encourage patient self-management and empowerment in a rural cancer center and a VA medical center. Patients with newly diagnosed advanced cancer were randomly assigned to the intervention or usual care; baseline characteristics were balanced between groups. In the intervention, trained advance practice nurses contacted patients by telephone and conducted four education sessions on: problem-solving; communication and social support; symptom management; and advance care planning and completing unfinished business. Participants and their caregivers were also invited to monthly group medical appointments led by a palliative care physician and nurse practitioner. Core outcomes were validated measures of quality of life, symptom intensity, and depression; secondary outcomes were resource utilization and survival. Patients were assessed at baseline, 1 month, then every 3 months until death or the end of the study.

Of 1222 patients screened, 681 were eligible and 322 enrolled. Analysis of the entire patient sample revealed higher quality of life ($p=0.02$), lower depressed mood ($p=0.02$), and a trend toward lower symptom intensity ($p=0.06$) in the intervention compared to the usual care group; analysis of the subset of patients who died during the study demonstrated a similar pattern. There were no statistically significant differences between the intervention and control groups in the number of days in the hospital or ICU, number of emergency department visits, or survival.

Strengths and limitations

This high-quality randomized controlled trial demonstrates that nursing telephone support may be an effective means for improving quality of life and mental health for advanced cancer patients living in rural or remote areas. That the intervention did not result in clear improvements in

symptom intensity or resource utilization may be the result of limited interface between the intervention and the patients' usual care teams, or the fact that the trial was not powered to detect differences in these outcomes.

Clinical bottom line

Providing rural patients with advanced cancer with nurse-led telephone support and education to encourage patient activation, self-management, and empowerment improves quality of life and decreases rates of depression.

Pediatrics

Dussel V, Kreicbergs U, Hilden JM, Watterson J, Moore C, Turner BG, Weeks JC, Wolfe J: Looking beyond where children die: Determinants and effects of planning a child's location of death. *J Pain Symptom Manage* 2009;37:33-43.

Summary and main findings

The Institute of Medicine recommends that advance care planning for children include planning of location of death.⁵ However, predictors and effects of planning children's location of death have not been empirically investigated. The investigators performed a retrospective cross-sectional study at two tertiary care pediatric hospitals to: (1) identify child, parent, and system-related factors associated with parents planning the location of their child's death and (2) describe associations between planning location of death and end-of-life care as well as parents' experience of the death. Participants were English-speaking parents of children who died of cancer at least one year ago. Parents were interviewed by telephone to assess: (1) whether the parents planned their child's location of death, (2) modifiable factors in the child's care, and (3) whether the child died in the planned location and the parent's experience of the death. The child's medical record was reviewed to describe end-of-life care.

The survey response rate was 64% for a total of 140 parents responding. The interviews were conducted a median of 3 years (range, 1-11) after the children's death. Eight-eight

(63%) parents reported planning the location of their child's death. Two modifiable factors were associated with higher odds of planning: the oncologists clearly explaining all treatment options available at the end of life and the child receiving home care services, OR 3.87 (95% CI 1.3–11.8) and OR 5.34 (95% CI 2.0–14.6), respectively. Children whose parents had planned their location of death were more likely to die at home, 72% versus 8%, $p < 0.001$ and less likely to be hospitalized in their last month of life, 54% versus 98%, $p < 0.001$. In the subset of 73 children who did not die at home, planning the location of the child's death was associated with a lower likelihood of dying in the ICU, 8% versus 47%, $p < 0.001$ and a lower likelihood of being intubated during the last day of life, 21% versus 48%, $p = 0.029$. Parents who planned were more likely to feel very prepared at the time of death (33% versus 12%, $p = 0.007$), very comfortable with the location of death (84% versus 40%, $p < 0.001$), and less likely to have preferred another location of death (2% versus 46%, $p < 0.001$). Similar results were found for the parent experience in the subset of parents whose child did not die at home.

Strengths and limitations

Strengths of this study include the use of parent interviews combined with chart review to describe outcomes of planning as well as the assessment of both child and parent outcomes. Limitations include the possibilities of response and recall bias; only 64% of eligible parents participated, and many interviews occurred a significant amount of time after the child's death. Finally, because the study was observational, it does not prove that routine discussion of location of death with parents of seriously ill children would result in improved outcomes.

Clinical bottom line

Communication about end-of-life treatment options and home care may help parents to plan their child's location of death. Planning may increase home death, decrease use of life sustaining treatments, and improve parents' experience of the death.

Hinds PS, Oakes LL, Hicks J, Powell B, Srivastava DK, Spunt SL, Harper J, Baker JN, West NK, Furman WL: "Trying to be a good parent" as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children. J Clin Oncol 2009;27:5979–5985.

Summary and main findings

Parents cite being a good parent as a key factor in making decisions for their seriously ill children.⁶ However, research has not described parents' conceptualization of being a good parent, or how clinicians' behaviors affect parents' feelings of being a good parent. The authors report the results of their qualitative analysis of interviews performed with parents of children at a cancer research hospital. Eligible parents were English-speaking and had made a major treatment decision for their child in the last 72 hours. In the interview, parents were asked: (1) "Please share with me your definition of being a good parent for your child at this point in your child's life" and (2) "Please describe for me the actions from staff that would help you in your efforts to be a good parent to your

child now." The interviewer transcribed the parents' responses and the parent reviewed them for accuracy before analysis. A content analysis was performed to describe conceptual categories within each of the two questions. A team of researchers developed the coding scheme and multiple coders coded each interview; agreement between coders was 92%.

Sixty-two parents were interviewed: 91% mothers, 45% white, and 12% black. Their children were age 6 months to 22 years, and had been diagnosed with solid tumors (52%), brain tumors (36%), and leukemia (7%). Parents were interviewed after making decisions about: a phase I study (52%, $n = 30/30$ decided yes), do no resuscitate status (31%, $n = 17/18$ decided yes), or terminal care (17%, $n = 9/10$ decided yes). Within parents' definition of being a good parent, 8 distinct themes were identified: doing right by my child (reported by 89% of parents), being there for my child (48%), conveying love to my child (42%), being an advocate for my child (22%), and being a good life example (20%). Within parents' description of how staff can support their efforts to be a good parent, 15 distinct themes were identified, including: all that can be done is being done (reported by 64% of parents), staff respect me and my decisions (33%), staff like our child (30%), staff support my child and me (27%), and staff know our special needs (27%).

Strengths and limitations

All parents readily articulated a view of being a good parent and how clinicians can encourage their efforts, providing further support that being a good parent is a key aspect in parents' decision-making for their seriously ill children. Other strengths are that parents reviewed their responses and there was a high level of agreement between coders of each interview. Limitations are that a nonresponder rate was not cited, and few parents who decided "no" about their respective decision were interviewed.

Clinical bottom line

Clinicians can help parents to cope with the very difficult experience of making decisions for their seriously ill children by learning what it means to them to be a good parent and helping them to achieve that.

Geriatrics and Long-Term Care

Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, Volicer L, Givens JL, Hamel MB: The clinical course of advanced dementia. N Engl J Med 2009;361:1529–1538.

Summary and main findings

Hospice and palliative care providers frequently discuss prognosis and goals of care with families of advanced dementia patients. There is little evidence, however, evaluating the relationship between proxy understanding of prognosis and the type of care advanced dementia patients receive at the end of life. In this prospective cohort study of patients with advanced dementia, the authors describe: (1) prognosis and factors associated with increased mortality, (2) symptom burden, and (3) the relationship between proxy understanding of illness and treatments received at the end of life. Nursing home residents with advanced dementia and their caregivers were recruited from 22 nursing homes with more

than 60 beds each located within 60 miles of Boston. The entry criteria selected for a group of patients with profound deficits, including: being unable to verbally communicate, functionally dependent, incontinent, and unable to ambulate independently. Data were collected from chart reviews, nurse and proxy interviews, and physical examination of the patients.

Of 1763 residents, 572 were eligible and 323 enrolled; their mean age was 85 years, 85% were women, and 90% were white. The median nursing home length of stay was 3 years, and the median time since dementia diagnosis was 6 years. The mean age of the proxies was 60 years; 64% were women, 68% were the child of the patient and 10% the spouse. Of the residents, 55% died over the 18-month course of the study. Their median survival was 478 days, and 94% died in the nursing home. Residents frequently experienced complications of dementia: pneumonia (41%), febrile episode (53%), and eating difficulties (86%). Survival was decreased significantly after developing one of these complications. Residents suffered from a high symptom burden: 46% had dyspnea 5 or more days per month and 39% had pain 5 or more days per month. Agitation developed in 54%, aspiration events were noted in 41% and 39% had a stage II or higher pressure ulcer. Many residents received invasive therapies including parenteral therapies (34%), hospitalization (17%), emergency department visits (10%), and feeding tubes (8%). Although the proxies reported that the main goal of care was comfort for 96% of residents, only 22% were referred to hospice. Proxy understanding of patient's prognosis was poor: in the quarter before the patient's death, only 20% thought the resident had 6 months or less to live. Only 18% of proxies reported receiving information from a nursing home physician about the resident's prognosis. Residents whose proxies believed that their life expectancy was 6 months or less and said they understood the complications of the disease were less likely to undergo interventions in the last 3 months of life (adjusted OR 0.12, 95% CI 0.04–0.37).

Strengths and limitations

This study was a well-designed prospective cohort of nursing home residents with advanced dementia, and the investigators assessed multiple clinically relevant outcomes. Residents were recruited only from nursing homes within the Boston area and it is known that there are regional variations in care provided to nursing home residents⁷; this may limit generalizability.

Clinical bottom line

Nursing home patients with advanced dementia have high morbidity, mortality, and symptom burden. Proxy knowledge and understanding of the clinical course of dementia is associated with decreased interventions near the end of life.

Kurella Tamura M, Covinsky KE, Chertow GM, Chertow GM, Yaffe K, Landefeld CS, McCulloch CE: *Functional status of elderly adults before and after initiation of dialysis*. *N Engl J Med* 2009;361:1539–1547.

Summary and main findings

Palliative care clinicians often help older patients and their families decide whether to start dialysis. Despite the increasing number of elderly patients with end-stage renal disease,⁸

the outcomes of dialysis for nursing home residents have not been determined. The investigators performed a secondary analysis of the United States Renal Data system, which includes all patients who initiate dialysis, linked with the Minimum Data Set, which includes data about functional status for all nursing home residents in the United States. Subjects were nursing home residents who started dialysis either as an outpatient or during a hospital admission. Outcomes were mortality and functional status, measured on a 28-point scale based on 0–4 point ratings for each of the 7 activities of daily living (ADLs): eating, dressing, toileting, walking, personal hygiene, bed mobility, and transferring.⁹ The analysis determined the residents' change in functional status at 3, 6, 9, and 12 months after starting dialysis using the measurement of function closest to but before dialysis initiation as the baseline. The authors defined a decline in function as an increase of 2 or more ADL points on the 28-point scale. Of 3902 residents who started dialysis, 3702 in the combined dataset met study entry criteria and had complete data. Their mean age was 73 years; 60% were female and 64% were white. Most (69%) residents initiated dialysis in the hospital. The mean time from the start of dialysis to first assessment of ADLs was 17 days. The cumulative mortality after starting dialysis was 24% at 3 months, 41% at 6 months, 51% at 9 months, and 58% at 12 months. There was a significant decline in every ADL after starting dialysis ($p < 0.001$ for comparison with scores before starting dialysis) and half of the cohort had a decline in two or more ADLs. Only 1 in 8 residents maintained their functional status after dialysis was started.

Strengths and limitations

A key strength of this study is its use of well-known, large, national datasets. The investigators also used multiple analytic and confirmatory models, including random effects and robustness analyses, to confirm their findings. There was no control group, however, so it is unclear what might have happened to these patients had they not started dialysis. The study does not prove that starting dialysis actually causes functional decline, and the authors provide other potential explanations for their findings. For example, the decline may be a result of hospitalization, or kidney failure may be a reflection of an underlying disease and not a primary cause of the decline in function itself.

Clinical bottom line

The initiation of dialysis in nursing home patients is associated with a rapid decline in functional status and high rates of mortality at 1 year. Presenting this prognostic information may help older nursing home residents and their families to make decisions about the initiation of dialysis that are consistent with their goals and values.

Symptom Management

Wildiers H, Dhaenckint C, Demeulenaere P, Clement PM, Desmet M, Van Nuffelen R, Gielen J, Van Droogenbroeck E, Geurs F, Lobelle JP, Menten J; *Flemish Federation of Palliative Care: Atropine, hyoscine butylbromide, or scopolamine are equally effective for the treatment of death rattle in terminal care*. *J Pain Symptom Manage* 2009;38:124–133.

Summary and main findings

Death rattle is common at the end of life, but there are little data available about the comparative efficacy of the multiple agents available to treat it. The investigators conducted an open-label, prospective, randomized multicenter trial at six residential palliative care units in Belgium to compare three anticholinergic agents: atropine, hyoscine butylbromide, and scopolamine. Eligible patients were terminally ill and had a death rattle that was audible at the end of their bed. Patients were excluded if they had a secondary cause of rattle such as pulmonary edema. Participating patients were randomized by closed-envelope system and medications were delivered as a subcutaneous bolus followed by either intermittent scheduled subcutaneous dosing every 4 hours or a subcutaneous or intravenous infusion. The nurse in charge on each unit evaluated enrolled patients at 30 minutes, 1, 4, 12, and 24 hours, and then every 24 hours until death. If the rattle was audible at the end of the patient's bed at the 12-hour assessment, the bolus dose of the drug was readministered and the maintenance dose doubled; a physician directed further adjustments. The primary study outcome was effectiveness at 1 hour, defined as the rattle only being audible near the patient. The study was powered to detect a 20% difference between the three drugs. Secondary outcomes included effectiveness at other time points and adverse effects including level of consciousness and confusion.

Of 440 patients who were screened, 333 (76%) enrolled. Their median age was 73 years, and 95% had cancer. Consistent with previous research showing that death rattle is a sign of impending death, the median survival was 23.9 hours. At the 1-hour assessment, there was no significant difference in effectiveness between the three drugs; the percentage of patients whose rattle was only audible near them was 42% in the atropine arm, 42% in the hyoscine arm, and 37% in the scopolamine arm, $p = 0.72$. There was no difference in effectiveness between the three drugs up to 48 hours. All drugs were more effective over time, with response rates increasing to 60-70% at 24 hours. In addition, all medications were more likely to be effective if started when the intensity of the rattle was lower. At the beginning of the study, 79% of patients had a level of consciousness of stupor or coma. In the remaining patients, who were alert or somnolent at the beginning of the study, more patients in the scopolamine arm had decreased level of consciousness compared to the other arms at the 12-hour assessment, $p = 0.0076$; this effect did not persist at later assessments. There was no difference in confusion among the arms.

Strengths and limitations

This was a high-quality randomized trial with a large number of patients enrolled at six different sites. A limitation is the lack of blinding and placebo control and that it was not powered to detect differences in adverse effects. Finally, this study only compared the three drugs administered subcutaneously or intravenously, and it is not clear how these results should be extrapolated to other medications or different routes of administration.

Clinical bottom line

In the first 48 hours of treatment subcutaneous or intravenous atropine, scopolamine, and hyoscine are equally effective at treating terminal death rattle.

Self-Care

Krasner MS, Epstein RM, Beckman H, Suchman AL, Chapman B, Mooney CJ, Quill TE: Association of an educational program in mindful communication with burnout, empathy, and attitudes among primary care physicians. *JAMA* 2009;302:1284-1293.

Summary and main findings

Self-care is critical to our ability to do the best for our patients and remain happy in our lives, however few studies have evaluated provider self care interventions. The investigators conducted a pre-/postsurvey evaluation of a Continuing Medical Education program for primary care physicians to determine whether a longitudinal multicomponent mindfulness education program could improve self-reported mindfulness, decrease burnout, and increase empathy. All family medicine, internal medicine, and pediatric physicians practicing in the Greater Rochester Area, New York, were eligible. The authors define mindfulness as "A quality of awareness that includes the ability to pay attention in a particular way: on purpose, in the present moment, and nonjudgmentally." The intervention included: (1) an intensive phase consisting of eight weekly 2.5-hour sessions as well as a 7-hour silent retreat and (2) a maintenance phase consisting of 10 monthly 2.5-hour sessions. Methods used were didactics; narrative and appreciative inquiry; mindfulness, sitting, and walking meditation, and mindful movement; as well as group discussion. Topics included awareness of pleasant or unpleasant sensations, feelings, or thoughts; perceptual biases and filters; burnout; meaning in medicine, boundaries or conflict management; self-care; and being with suffering or end-of-life. Validated survey instruments were used at baseline, 2, 12, and 15 months to assess: mindfulness, burnout, empathy, psychosocial orientation, mood, and personality.

Of 642 eligible physicians, 70 (11%) enrolled. Sixty-eight physicians participated in at least one session; of the 52 total hours in the curriculum, the mean number of hours attended was 34. Survey completion rates were 73%-97%. Mindfulness increased significantly from baseline by 8 weeks, and the increase persisted at the 15-month assessment, $p < 0.001$. The intervention and increases in mindfulness were associated with the following statistically significant outcomes: decreased burnout; increased empathy for patients; increased value of understanding patients' emotional and social life; improved mood; and increased conscientiousness and emotional stability.

Strengths and limitations

Although a small percentage of eligible physicians enrolled, those who participated completed a significant proportion of this very time-intensive behavioral intervention. The outcomes were measured by self-report, but the measures used have been associated with physician behavior with patients in other studies, so it is plausible that the intervention resulted in changes to practice. A limitation is that, because the intervention had multiple components, it is difficult to tell what exactly resulted in the improvements seen. Although all participants were primary care physicians, the methods and topics included in the intervention are not specific to primary care or to physicians, however, and would be applicable to hospice and palliative care providers.

Clinical bottom line

Mindfulness communication training may be an effective means to improve both patient and provider outcomes in hospice and palliative care.

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Author Disclosure Statement

No conflicting financial interests exist.

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