

Quality of Life Matters®

End-of-life care news & clinical findings for physicians

Vol. 7, Issue 3 Nov/Dec/Jan 2005-2006

Simple Intervention May Improve Access to Hospice Care in Nursing Homes

Physicians urged to ‘jumpstart’ conversations about ‘the gold standard of end-of-life care’

A simple communication intervention designed to help physicians identify which nursing home residents are appropriate for hospice care may increase rates of hospice referrals and improve family satisfaction with care at the end of life as well as facilitate earlier referrals and decrease utilization of acute care resources.

That is according to a study published in the July 13, 2005, issue of the *Journal of the American Medical Association*.

Although hospice care has been associated with improvements in pain management and other outcomes in nursing home residents, “hospice is underutilized by this population, at least in part because physicians are not aware of their patients’ preferences,” write the authors.

A brief scripted interview and simple criteria to determine hospice appropriateness can be used in any long-term care setting with minimal staff training.

—Casarett, Karlawish, et al
Journal of the American Medical Association

In a randomized controlled trial of 205 residents of three nursing homes with diverse populations, researchers evaluated the impact of a brief scripted interview (five to ten minutes long) employing simple criteria to identify those patients whose goals of care, treatment preferences, and palliative care needs would make them appropriate for hospice care.

Physicians of hospice-appropriate residents in the intervention group were then informed of the interview results and asked whether — if the patient was considered to have a prognosis of six months or less — the nursing home staff should arrange for a hospice informational visit. Hospice-appropriate residents and their families in the control group were simply told about hospice services and how to learn more.

Findings include:

- Subjects in the intervention group were more likely to enroll in hospice within 30 days than were residents in the control group.
- Although only 33% of residents in the

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Families Find Greater Benefits from Longer Hospice Stays

Bereaved family members whose loved ones were enrolled in hospice at least three months before death report receiving nearly 95% of the services they expected and find these services to be of greater help than do families of patients with shorter lengths of stay.

These and other findings from a team of Pennsylvania researchers were published in the May 2005 issue of the *Journal of the American Geriatrics Society*.

The median length of stay in hospices across the nation is about three weeks, with 10% of patients enrolling in the last

day of life, note the study authors.

“When patients enroll in hospice close to the time of death, hospice providers have little time to perform assessments, establish relationships, and initiate effective interventions,” the authors comment.

The team analyzed interviews with a sample of 275 Pennsylvania hospice enrollees and their family members during a one-year period in 2003 and 2004. Both patient characteristics and hospice services were typical of those found nationwide

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intervention group (n = 107) were considered hospice appropriate, 20% of this group had enrolled in hospice within 30 days of the intervention.

- In contrast, 50% of residents in the control group (n = 98) were found to be hospice appropriate, but only one patient (1%) — whose family had contacted the physician directly — was referred to hospice within 30 days.
- Intervention residents were also more likely than usual care residents to enroll in hospice during the six-month follow-up period (25% vs 6%).
- Families of patients in the intervention group rated their loved one's care in the last week of life more highly than did families of control residents (4.1 vs 2.5, on a scale of 1 to 5).
- Intervention residents had fewer acute care admissions and spent fewer days in an acute care setting than did control residents; 90% of acute care admissions in the intervention group occurred when the resident was not enrolled in hospice.

“This study shows that sometimes the best ways to improve end-of-life care are the simplest,” says lead author David Casarett, MD, of the Philadelphia Veterans Affairs Medical Center.

“The brief scripted interview and simple criteria to determine hospice appropriateness ensure that this intervention can be used for an unselected resident population in virtually any long-term care setting, with minimal staff training,” the authors note.

“By ‘jumpstarting’ conversations about hospice, we found that it was possible to give more people access to hospice, earlier in the course of their illness,” Casarett continues. “This seems to be a very effective and efficient way to let more patients and families benefit from hospice, which is the gold standard of end-of-life care.”

Source: “Improving the Use of Hospice Services in Nursing Homes: A Randomized Controlled Trial,” Journal of the American Medical Association; July 13, 2005; 294(2):211-217. Casarett D, Karlawish J, et al; Center for Health Equity Research and Promotion, Philadelphia Veterans Affairs Medical Center; Division of Geriatric Medicine, Center for Bioethics, Leonard Davis Institute of Health Economics, and Center for Clinical Epidemiology and Biostatistics, University of Pennsylvania; Temple University Law School; and Holy Redeemer Home Health and Hospice Care, Philadelphia.

Families Find Greater Benefits from Longer Hospice Stays

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in other hospices, note the authors.

In follow-up interviews, 225 family members of those 252 patients who had died (mean length of stay, 20 days) were asked if they and their loved ones had received the hospice services they anticipated and how helpful these services had been.

The study found that families of patients with longer lengths of hospice stay reported receiving more hospice services and found these services to be of more benefit than did families of patients with shorter stays.

“These results indicate that families feel they receive greater benefits from longer lengths of stay in hospice,” write the authors. “Future efforts to define an ‘optimal’ length of stay in hospice should consider patients’ and families’ perceptions of the benefits that hospice offers.”

Hospice services rated as helpful by study participants:

- Pain and symptom control
- Regular nursing visits
- Help with caregiving
- Emotional and spiritual support
- 24-hour telephone support
- Delivery of medications, medical supplies, and equipment

—Rickerson, Harrold, et al
Journal of the American Geriatrics Society

Findings include:

- Families of hospice patients with a length of stay of one month said they received about 80% of expected helpful services.
- Families whose loved ones enrolled in hospice two months before death reported receiving more than 85% of anticipated services.

- When length of hospice stay was three months or longer, families reported that they received almost 95% of the helpful services they had hoped for.

“Overall, even with a short length of stay, this study found that hospice was able to deliver many services that family members needed and valued,” write the authors. **“Nevertheless, families perceived significantly more benefits with longer lengths of stay.”**

Source: “Timing of Hospice Referral and Families’ Perceptions of Services: Are Earlier Hospice Referrals Better?” Journal of the American Geriatrics Society; May 2005; 53(5):819-823. Rickerson E, Harrold J, Kapo J, Carroll JT, Casarett D; Division of Geriatric Medicine, Center for Bioethics, and Leonard Davis Institute of Health Economics, University of Pennsylvania, Philadelphia; Hospice of Lancaster County, Lancaster, Pennsylvania; Center for Health Equity Research and Promotion, Philadelphia Veterans Affairs Medical Center, Philadelphia.

Good News for An Aging Population: Geriatric Medicine Fellows Feel Prepared to Care for Dying Patients

99% believe physicians should know how to help terminally ill patients prepare for death

A national survey has found that nearly all (98%) of graduating fellows in geriatric medicine believe that learning to care for patients facing the end of life is important, and 99% hold that it is the physician's responsibility to help these patients prepare for death.

Further, those 70% of survey respondents who completed a rotation in palliative care, end-of-life care, or hospice rated their end-of-life education as highly as their overall geriatric training, and reported feeling well prepared to care for seriously ill and dying patients.

That is according to a report published in the April 2005 issue of the *Journal of the American Geriatrics Society*.

"There is hope for the future," the researchers write. By 2030, one in five adults will be aged 65 and older, and the oldest Americans — those aged 85 and older — comprise one of the fastest growing U.S. populations.

"The geriatricians who will care for this burgeoning elderly population must therefore be well trained in palliative and end-of-life care to manage the complex issues of pain and symptom management, evolving goals of care, and psychospiritual support," the authors comment.

A national team of researchers analyzed the end-of-life care training experiences of 188 respondents (male, 45%; white, 44%) completing fellowships in geriatric medicine during 2002 in more than 90 programs in 34 states. A palliative or end-of-life care rotation was found to be strongly associated with receiving both higher quantity and higher quality of teaching about caring for dying patients.

Most respondents received explicit training in:

- Determining when to refer patients to hospice (89%)
- Utilizing other sources of team support (82%)
- Assessing and managing depression (77%) and pain (74%) at the end of life
- Negotiating time-limited trials of interventions (66%)
- Telling a patient that he or she is dying (59%)

However, less than half of respondents said they received instruction in knowing how to say goodbye to patients and how to help patients and/or families with reconciliation (48%) or in responding to requests for physician-assisted suicide (29%).

Geriatrics and end-of-life care share similar philosophical principles:

- Emphasis on interdisciplinary team care
- Focus on caregivers and social support
- Involving patients and families in decision making
- Maximizing functional status or quality of life

— Pan, et al
Journal of the American Geriatrics Society

Nevertheless, only 2.7% of fellows said they felt unprepared to care for dying patients, while 97.3% felt either well prepared (59.7%) or moderately prepared (37.6%).

In multivariate analysis, four factors independently predicted feeling prepared to care for dying patients:

- Rotation in end-of-life or palliative care or hospice
- Female sex
- Education in saying goodbye to patients at the end of life
- Perception that end-of-life care training is important to fellows' attending physicians

Although practitioners in other subspecialties care for patients with a high level of morbidity and mortality, note the authors, the Accreditation Council for Graduate Medical Education requirements call for greater end-of-life care content in geriatrics than in other subspecialties.

"This study suggests that recently trained geriatric fellows feel prepared to care for seriously ill and dying patients," conclude the authors. "Moreover, the apparent success of geriatric medicine fellowships in providing this training may offer a template for other subspecialties that undertake to improve their palliative and end-of-life care educations."

Source: "There Is Hope for the Future: National Survey Results Reveal that Geriatric Medicine Fellows Are Well-Educated in End-of-Life Care," Journal of the American Geriatrics Society; April, 2005; 53(4):705-710. Pan CX, Carmody S, Leipzig RM, Granieri E, Sullivan A, Block SD, Arnold RM; Mount Sinai School of Medicine, New York; Hennepin County Medical Center, Minneapolis; Bronx Veterans Affairs Medical Center Research, Education and Care Center, Bronx; Dana-Farber Cancer Institute and Brigham and Women's Hospital, Boston; and University of Pittsburgh Medical Center, and Institute to Enhance Palliative Care, University of Pittsburgh, Pittsburgh.

Heart Failure Treatment: Integration of Palliative and Hospice Care Recommended

Physicians have a 'mandate to treat the patient during the entire course of illness, even when therapeutic options have been exhausted'

The integration of palliative care with conventional life-prolonging treatment for patients with heart failure should be considered a normal approach to the care of these patients. When further aggressive treatment of advanced disease is inappropriate or declined, patient and family preferences regarding transition to the palliative end-of-life care provided by hospice should be discussed.

That is according to cardiologists Paul J. Hauptman, MD, professor of medicine, Saint Louis University School of Medicine, and Edward P. Havranek, MD, associate professor of medicine, University of Colorado Health Sciences Center, Denver.

"We propose integration of a palliative care approach early in the course of heart failure treatment and a tiered process for selecting patients for hospice care," write the authors in an article published in *Archives of Internal Medicine*, a publication of the American Medical Association.

Palliative care includes:

- Providing the patient and family with information regarding prognosis and treatment options
- Identifying patient and family goals and needs
- Using an interdisciplinary team approach to meeting the identified physical, psychological, and spiritual needs

"In general, **the palliative care approach has improved patient outcomes as judged by symptom control, quality of life, and satisfaction with care,**" comment the authors. However, they note, since the bulk of the evidence on the effectiveness of

palliative care has come from studies of cancer patients, further research specific to heart failure patients is needed.

The article presents an overview of heart failure treatment, addressing the determination of short-term prognosis in advanced heart failure, the range of current and emerging therapeutic options, and available guidelines for determining hospice eligibility.

Also provided in the article is a treatment algorithm for incorporating palliative care into heart failure care early in the course of the disease, as well as for determining the conditions to be met for hospice referral of patients with advanced heart failure.

Hospice care should be considered when:

- The patient is ineligible for advanced therapeutic options or declines therapy
 - The patient is ineligible for or declines destination therapy — such as left ventricular assist device — or heart transplant
 - The patient and family understand the prognosis and desire symptom management, but no further intermittent acute care
- "Heart failure is a condition for which both palliative care and hospice care can be appropriate," the authors conclude. "Failure to acknowledge the importance of this mode of care puts at risk the mandate to treat the patient during the entire course of illness, even when therapeutic options have been exhausted."

Source: "Integrating Palliative Care into Heart Failure Care," Archives of Internal Medicine; February 28, 2005; 165(4):374-378. Hauptman PJ, Havranek EP; Division of Cardiology, Saint Louis University School of Medicine, St. Louis, Missouri; Denver Health Medical Center, Denver.

End-of-Life Preferences Documented for Patients with ALS but Not Cancer

Despite having a significantly worse survival outcome, cancer patients are less likely than patients with amyotrophic lateral sclerosis (ALS) to have evidence of an out-patient discussion about end-of-life treatment preferences, a recent study has found.

Led by Alan B. Astrow, MD, associate chief of hematology and oncology, St. Vincent's Hospital and Medical Center, New York City, a team of researchers reviewed the out-patient charts of 60 patients with advanced cancer and an expected 2-year survival of less than 50%, and 32 recently diagnosed ALS patients.

At 3-month follow-up, ALS patients were significantly more likely

to have documented discussion of wishes regarding ventilator support (35% vs 0%), artificial nutrition and hydration (40% vs 0%), resuscitation (29% vs 0%), and hospice care (25% vs 5%).

Ninety-one percent of ALS patients were alive at six months, compared with 62% of cancer patients. At two years, 63% of ALS patients were alive, while only 23% of cancer patients were still living.

"Patients with advanced cancer need information about treatment options if they are to make informed decisions about end-of-life

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Advance Care Planning, End-of-Life Care Urged for End-Stage Renal Disease Patients

Palliative care for patients with end-stage renal disease (ESRD) must include not only pain and symptom management, but also the support and education of patients and families, with ongoing advance care planning throughout the course of the disease.

That is according to an article published in the March-April issue of *Seminars in Dialysis*, the journal of the American Society of Diagnostic & Interventional Nephrology.

“By incorporating advance care planning in the overall care plan for an ESRD patient, we can improve the lives and deaths of dialysis patients and their families,” writes Jean L. Holley, MD, professor of internal medicine, Nephrology Division, University of Virginia Health System, Charlottesville. **“Asking patients how they want to live will help us to understand how they prefer to die and will provide insight into prioritizing their health care using the palliative care model.”**

Advance care planning

Advance care planning is a dynamic communication process, says Holley, best conducted within the patient-family relationship throughout the disease course. The health care professional’s role is to introduce the topic and focus the discussion on the purpose of advance directives — which is to address not interventions, but acceptable health states.

The topic of a patient’s wishes for end-of-life care and needs for meaningful living can be introduced during discussions of

“Hospice emphasizes supportive care of the patient and family, provides for home nursing and pastoral care, and focuses on treating symptoms while neither prolonging life nor hastening death.”

—J.L. Holley, M.D.
Seminars in Dialysis

prognosis or treatments with a low probability of success, or during any routine assessment of a patient’s problems. Most certainly, says Holley, **end-of-life care should be discussed whenever the physician would not be surprised if this patient died within the next year.**

Hospice care

A major barrier to use of hospice by ESRD patients is the payment structure of the Medicare hospice benefit, which requires hospice programs to pay for all treatments related to the admitting terminal diagnosis. Hospices cannot afford the expense of dialysis treatments. However, notes Holley, if, in addition to ESRD, a patient has a nonrenal terminal condition, both hospice care and dialysis can be provided.

Hospice referral should be considered for:

- Any chronic kidney disease patient who withdraws from dialysis
- Any ESRD patient who chooses not to initiate dialysis
- Any dialysis patient with an alternate terminal diagnosis, a prognosis of six months or less, and the wish to continue dialysis

Bereavement support

Holley notes that because of the close relationships developed between patients and their dialysis providers, these providers often continue contact with patients after discontinuation of dialysis, and later, with their bereaved families. Bereavement support can include a gesture of formal recognition of the death at the dialysis unit, attendance by staff at the memorial service, and a letter of condolence from the nephrologist.

“Renal palliative care encompasses not only end-of-life care, but also the health care that precedes the initiation of dialysis, as well as care of the family and staff following the death of a dialysis patient,” writes Holley.

Source: “Palliative Care in End-Stage Renal Disease: Focus on Advance Care Planning, Hospice Referral, and Bereavement,” *Seminars in Dialysis*; March-April 2005; 18(2):154-156. Holley JL; Department of Medicine, Nephrology Division, University of Virginia Health System, Charlottesville, Virginia.

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care,” note the authors. “The lack of documented discussion of end-of-life treatment options in this group of poor prognosis cancer patients may... leave cancer patients less adequately prepared for end-of-life decision-making and/or forced to confront these difficult issues only when hospitalized and close to death.”

Source: “Discussing End-of-Life Treatment Options: Advanced Cancer vs. Amyotrophic Lateral Sclerosis,” Abstract, American Society of Clinical Oncology Annual Meeting, May 2005, www.asco.org. Astrow AB, Sood JR, Nolan MT, Terry PB, Hughes MT, Kub J, Sulmasy DP; St. Vincent’s Hospital and Medical Center and New York Medical College, New York City.

PHYSICIAN RESOURCES

Saying Goodbye: A Gesture Valuing Both Patient and Physician

A step-wise guide to affirming that the patient has mattered and will be remembered

By saying goodbye — acknowledging the end of the patient-physician relationship with a patient entering the last phase of life — physicians can underscore the importance of that relationship, thereby making the patient feel cared for and valued rather than abandoned. In addition, saying goodbye to a patient can provide physicians with an opportunity to receive patient and family expressions of appreciation for their efforts, reconcile their reactions to the impending death of a patient, and reflect on the meaning of their work.

That is according to an article published in a recent issue of *Annals of Internal Medicine*. “We think saying goodbye is an expert practice worth learning for the sake of both the patient and the physician,” writes lead author Anthony L. Back, MD, of the division of medical oncology, University of Washington School of Medicine, Seattle,

and colleagues.

The common practice of saying nothing to a terminally ill patient who will probably not be making another clinical visit may cause feelings of perplexity and abandonment in patients and their families, note the authors. However, a physician’s authentic goodbye can affirm that the patient has mattered to the physician as a person and will be missed and remembered.

“At that point you are not just the physician, you are a human being in the presence of another human being who’s leaving the corporeal world,” write the authors, quoting a physician who had cared for patients with acquired immunodeficiency syndrome.

Physicians may avoid goodbyes for a number of reasons: uncertainty of what to say, concern about upsetting the patient or

having to deal with an emotional situation, hesitancy about expressing “unprofessional” feelings, and prognostic uncertainty.

The authors offer a step-wise guide to assist physicians in saying goodbye, noting that the approach will be most effective for those clinicians already comfortable with dealing with emotion, expressing empathy, and using silence.

“Saying goodbye is a powerful gesture that values patients and the challenging work of being a physician,” conclude the authors.

Source: “On Saying Goodbye: Acknowledging the End of the Patient-Physician Relationship with Patients Who Are Near Death,” Annals of Internal Medicine; April 19, 2005; 142(8):682-685. Back AL, Arnold RM, Tulskey JA, Baile WF, Fryer-Edwards KA; University of Washington and Fred Hutchinson Cancer Research Center, Seattle; University of Pittsburgh, Pittsburgh; Durham Veterans Affairs Medical Center and Duke University, Durham, North Carolina; and University of Texas M. D. Anderson Cancer Center, Houston.

HOW TO SAY GOODBYE

- **Choose an appropriate time** and a place that allows for privacy. Plan for sufficient time for a meaningful goodbye if the relationship with the patient has been long or significant.
- **Acknowledge that routine contact is ending** and future contact is uncertain. *“I’m not sure we’ll be seeing each other again, so I’d like to say something about our relationship while we’re together now.”*
- **Invite a response** and monitor the patient’s emotions on the topic. *“Would that be okay?”* Or, *“How would you feel about that?”* This allows the patient some control and a moment to prepare for the conversation. Watch for a signal that the patient is ready to proceed.
- **Frame the goodbye as an appreciation.** Create a moment of gratitude for the patient’s contribution to the relationship. *“I just wanted to say how much I’ve enjoyed you and appreciated your flexibility (good spirits, honesty, etc.) and your humor (insights, thoughtfulness).”* If appropriate, acknowledge the loss of the relationship. *“I’ll miss seeing you here and hearing about your family.”*
- **Allow the patient space to reciprocate,** and respond to the patient’s

emotion with empathy. Provide a warm silence if the patient becomes tearful, or ask: *“Would it be too difficult to tell me what your tears are about?”* Patients often express gratitude for the physician’s time and efforts. If this happens, it is a gift, and minimizing it can cause the patient to feel unheard. “Thank you” is the best response.

- **Establish an ongoing commitment to the patient’s care.** *“Of course, you know I remain available to you and that you can still call me. Your hospice nurse will keep me informed about you. I’ll be here if you need me, and I’ll be thinking about you.”*
- **Reflect later on your work with this patient.** Physicians often receive the impression during training that being silent and strong and avoiding discussion of death is part of self-preservation. This may not serve physicians’ professional work or personal growth. It can be worthwhile to ask oneself: *“What meaning do I want to take away from my work with this patient?”*

— Back, et al
Annals of Internal Medicine

PHYSICIAN RESOURCES

Recent Medical Ethics Publications Address End-of-Life Care

— *ACP Ethics Manual, 5th Edition* —

The latest update of the Ethics Manual from the American College of Physicians (ACP) readdresses ethical challenges encountered in clinical practice and medical research and presents expanded guidelines for making ethical decisions related to such issues as end-of-life care, complementary and alternative medicine, and physician-assisted suicide.

Published in the April 5, 2005, issue of the ACP journal *Annals of Internal Medicine*, the manual — an update of the 1998 fourth edition — also raises several new issues, such as health and human rights, and consultation and shared care.

According to the manual, the physician should:

- **Know how to refer patients to appropriate palliative care** specialists and programs
- **Know how to use hospice care**, both home-based and institution-based
- **Be aware of the palliative care abilities of the nursing homes** to which their patients are referred

The manual's appendix presents an end-of-life care scenario as a case method for assisting clinicians in ethical decision making. Other topics addressed in the manual's end-of-life care section include: Advance Care Planning, Do-Not-Resuscitate Orders, and Physician-Assisted Suicide and Euthanasia.

A pocket-sized book version of the Ethics Manual can be purchased by calling ACP customer service at 215-351-2600, or by ordering online at www.acponline.org.

— *Ethics Charter from AAPM* —

The American Academy of Pain Medicine (AAPM) published its Ethics Charter — which calls upon all physicians to work toward improved pain management — in the May 2005 issue of *Pain Medicine*, the official journal of the AAPM. A free, downloadable version of the charter is now available at www.painmed.org.

Topic headings in the charter include: Professional Relationships and the Physician's Duty to the Patient, Clinical Concerns, and Pain Medicine at the End of Life.

The end-of-life care section addresses ethical issues that can pose special difficulties for physicians, such as: comfortable dying, patient self-determination, and euthanasia; and palliative sedation for intractable symptoms.

The ethical imperative to address pain requires that all physicians contribute to advancement in the provision of pain relief, states the charter. Physicians can:

- **Assess the person in pain as a whole person**
- **Treat the pain sufferer with competence and compassion**
- **Advocate for assured access to pain care** and its continuous improvement

"We're dealing with a mind-body field that requires holistic care, not in the alternative sense, but in the literal sense," writes AAPM president Scott Fishman, MD, in his accompanying comment. "We have to be able to look at the whole person, which is not something we're well prepared for in medicine."

End-of-Life Care Websites

www.aahpm.org

American Academy of Hospice and Palliative Medicine

www.eperc.mcw.edu

End of Life/Palliative Education Resource Center (EPEC)

www.epec.net

The EPEC Project (Education on Palliative and End-of-Life Care)

www.nhpco.org

National Hospice & Palliative Care Organization

www.promotingexcellence.org

Promoting Excellence in End-of-Life Care

www.hospicefoundation.org

Hospice Foundation of America

www.americanhospice.org

American Hospice Foundation

www.hpna.org

Hospice and Palliative Nurses Association

www.medicaring.org

Palliative Care Policy Center

www.abcd-caring.org

Americans for Better Care of the Dying

www.mcw.edu/pallmed/

Medical College of Wisconsin
Palliative Care Center

www.medsch.wisc.edu/painpolicy/

University of Wisconsin Pain and Policy Studies Group

www.capcmssm.org

Center to Advance Palliative Care

www.stoppain.org

Pain Medicine & Palliative Care, Beth Israel Medical Center

www.growthhouse.org

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