

Quality of Life Matters®

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

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HMO Physicians Praise Hospice Care, Cite Typical Perceived Barriers to Referral

78% of physicians surveyed believe hospice services are underutilized

A recent survey of health maintenance organization (HMO) physicians has found that while all respondents agree that hospice adds quality to patient care at the end of life, physicians perceive the difficulty of estimating 6-month survival to be a barrier to referral, and few can correctly identify hospice referral diagnoses.

“Our study — the first major survey of physician attitudes and practices regarding hospice utilization in an HMO setting — showed that barriers to hospice referral are similar to those in non-HMO settings,” the researchers note.

“Physicians have difficulty predicting life expectancy and lack knowledge of patient eligibility guidelines,” write the

authors in a report published in the *Journal of Palliative Medicine*.

Investigators analyzed the responses of 111 physicians (clinic-based, 71%; hospital-based, 11%; and residents, 18%) who were salaried employees in two internal medicine departments of a large nonprofit HMO in California.

Actual knowledge of appropriate hospice referral was measured by physician ability to correctly identify eight appropriate candidate diagnoses. These diagnoses included acquired immunodeficiency syndrome, liver failure, terminal cancer, dementia, chronic obstructive pulmonary disease, renal failure, congestive heart failure, and severe cerebrovascular accident.

Key findings include:

- **QUALITY CARE.** When asked if hospice adds quality to patients’ care at the end of their lives, 100% of physicians responded “Yes.”
- **HOSPICE UNDERUTILIZED.** 78% of respondents believe that hospice was an underutilized service; 85% stated that they made hospice referrals when appropriate.
- **LACK OF HOSPICE KNOWLEDGE.** Nearly three-quarters (72%) of physicians did not believe that lack of knowledge of hospice services and eligibility requirements hindered their hospice referrals. Of these, however, only 18% correctly identified all eight candidate hospice referral

TOP-RANKED REASONS PHYSICIANS REFER TO HOSPICE

- “Hospice staff can better guide the patient and family through the dying process than I can.”
- Pain control
- Nursing support and psychological support
- Request by patient or family member
- Family not coping well
- Access to benefits, such as home oxygen and durable medical equipment

— Brickner, Scannell, and Ackerson
Journal of Palliative Medicine

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diagnoses. Overall, only 16% of respondents were able to correctly identify all diagnoses.

- **HOSPICE STAFF WELCOME.** Although 78% of physicians believed they had sufficient training to discuss a patient’s death, 74% expressed a desire for hospice staff to be present during an office visit discussion of hospice referral.

The perceived barriers to hospice referral that received the highest rankings by physicians include: Difficulty in accurately predicting death to within 6 months (37%); lack of time for discussing issues of dying and hospice (14%);

Continued on Page 2

Living Wills Linked to Lower Probability of In-Hospital Death

A recent study has found that having a living will is associated with a lower probability of in-hospital death for elderly people living in the community or in a nursing home.

“The findings indicate that people with living wills, both nursing home residents and community-dwelling elderly people, are more likely to die in place than those without living wills,” write the authors.

The team of Pittsburgh researchers conducted a secondary analysis of data from a nationally representative longitudinal study. The sample was based on informants for 539 people who died nontraumatic deaths, representing 1,509,892 people older than 70 years of age who lived at home, in the home of a relative, or in a nursing facility, and who died between 1993 and 1995.

After adjustment, the probability of in-hospital death for people living in the community decreased from 0.65 (95% confidence interval [CI], 0.58 to 0.71) to 0.52 (CI, 0.42 to 0.62). For nursing home residents, the probability of in-hospital death decreased from 0.35 (CI, 0.23 to 0.49) to 0.13 (CI, 0.07 to 0.22).

Compared to those without living wills, decedents with living wills were more likely to have received treatments to keep them pain-free and comfortable, more likely to have had other treatments withheld, and less likely to have received life-sustaining treatments.

The authors note that because no medical records were available, they were unable to determine whether consultation of the

living will was documented. However, most proxy informants reported that the living wills were consulted and that the written directives applied to actual situations.

The association of living wills with lower probability of in-hospital death persisted when the sample was restricted to those decedents who were not involved in decision making or who were severely cognitively impaired.

“These findings suggest that proxy decision makers are influenced by living wills,” note the authors, and that surrogates may “interpret living wills that indicate limiting treatment as implicit instructions to avoid hospitalization.”

In conclusion, the authors point out, **“Physicians should discuss patients’ preferences for location of death during the advance care planning process.”**

Source: “Brief Communication: The Relationship between Having a Living Will and Dying in Place,” Annals of Internal Medicine; July 20, 2004; 141(2):113-117. Degenholtz HB, Rhee Y, Arnold RM; Center for Bioethics and Health Law, University of Pittsburgh, Pittsburgh.

THOSE WITH A LIVING WILL WERE MORE LIKELY TO:

- Receive palliative treatments to keep them pain-free and comfortable.
- Die in a non-hospital setting, in accordance with their wishes.

— Degenholtz, Rhee, and Arnold
Annals of Internal Medicine

HMO Physicians Praise Hospice

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and lack of time secondary to the rapid demise of the patient (13%).

While the above perceived barriers to hospice referral are similar to those cited in studies of non-HMO physicians, the authors identified one potential barrier they believe could be “particularly problematic in HMO settings.” Twenty-eight percent of HMO physicians reported concern that patients and families might construe hospice referral as a cost-saving measure. Eleven percent of physicians said they had been accused of this motivation.

The authors call for an expansion of educational efforts to address all elements of the patient-physician relation-

ship that enhance end-of-life care discussions.

“The emergent situation of our changing population dynamics underscores the urgency...” they write. “Demographic projections indicate that by 2030, almost one in five Americans will be at least 65 years of age, a statistic suggesting that even more people... will be living with terminal conditions and could benefit from hospice care.”

Source: “Barriers to Hospice Care and Referrals: Survey of Physicians’ Knowledge, Attitudes, and Perceptions in a Health Maintenance Organization,” Journal of Palliative Medicine; June 2004; 7(3): 411-418. Brickner L, Scannell K, Marquet S, Ackerson L; Departments of Internal Medicine, Kaiser Permanente Medical Centers, Oakland and Richmond, California; Kaiser Permanente Northern California Ethics Department, and Kaiser Permanente Division of Research, Oakland, California.

Palliative Care Urged for Patients with Heart Failure

Optimal medical management combined with palliative care improves quality of life

Heart failure is a leading cause of death in the U.S. and currently affects 6% to 10% of people aged 65 years and older. Because many patients experience distressing symptoms that can diminish quality of life, and because nearly half of all deaths from heart failure are sudden, **physicians are urged to address issues of palliative care — prognosis, advance directives, symptom management, and hospice care — early in the course of the illness.**

That is according to Steven Z. Pantilat, MD, of the Department of Medicine, University of California, San Francisco, and Anthony E. Steimle, MD, of Kaiser Permanente Northern California in Santa Clara, in their paper published in the *Journal of the American Medical Association*.

“By combining optimal medical management with palliative care, physicians can best care for heart failure patients and their families,” write the authors. “Most patients are cared for by primary care physicians; thus, up-to-date information on palliative care for patients with heart failure is important to all physicians.”

The article offers management strategies for palliating symptoms and comorbidities in patients with heart failure, tables with guidelines for prognostication and for medications to avoid, a list of online physician resources, and suggestions for initiating discussions of prognosis and palliative care issues.

Physicians should address prognosis early in the course of the illness, in order to establish a context for discussing patient wishes and treatment goals, the authors point out. “Contrary to fears that discussions of prognosis will destroy patients’ hope, such discussions can refocus hope more realistically and prevent false hope.”

The authors’ suggestions for addressing palliative care topics with heart failure patients include the following:

AT A GLANCE

- ✓ Heart failure exacts a significant toll on patients and their families. Symptoms can be frightening, and death is often sudden.
- ✓ Hospice care addresses physical, emotional, psychological, spiritual, and existential suffering for the patient and family.
- ✓ The availability of respite care and caregiver support is an appealing and important benefit of hospice.

— Pantilat and Steimle
Journal of the American Medical Association

HOPE AND PROGNOSIS

- **Initiate the discussion.** “When you think about the future, what do you hope for?”
- **Provide a realistic understanding of prognosis.** “Most people with heart failure will ultimately die from it. This can be gradual and anticipated, or sudden and unexpected.” “We know that about half of the people with heart failure like yours will die in the next year. We will work hard to make you one of those who live longer.”

ADVANCE DIRECTIVES

- **Establish a surrogate decision maker.** “If you were to become so ill that you could not talk to me directly, with whom should I speak to help me make decisions about your medical care?”
- **Address individual issues.** In addition to cardiopulmonary resuscitation, discussion of advance directives for heart failure patients should include such topics as invasive procedures, surgery, and

hospitalization. “I would like to talk with you about the kind of care you would want if you became more ill. In particular, I would like to talk about...”

HOSPICE

- **Emphasize the importance of the patient and caregiver support system offered by hospice.** “It sounds like you think your spouse could use more help in caring for you at home. Hospice is one way to get more help for both of you. Have you heard of hospice?”
- **Dispel common misperceptions about hospice care.** According to the authors, these include:

Misperception 1: Electing hospice care means forgoing all treatments. On the contrary, state the authors, because medication helps to manage such symptoms of heart failure as dyspnea and edema, many patients would be expected to continue their medications until death.

Misperception 2: Patients enter hospice to die. Although most hospice enrollees do die, patients who would benefit from hospice care may find that their conditions improve under the comprehensive nature of such care. These patients who “graduate” can re-enroll in the hospice program if they again need help and meet the eligibility criteria.

“Honest and compassionate discussions, focused on optimizing treatment while preparing for an uncertain future, can reap rewards for the patient and physician,” the authors conclude.

Source: “Palliative Care for Patients with Heart Failure,” *Journal of the American Medical Association*; May 26, 2004; 291(20):2476-2482. Pantilat SZ, Steimle AE; Palliative Care Service and Hospitalist Section, Department of Medicine, University of California, San Francisco; Heart Failure Program, Kaiser Permanente Northern California, Santa Clara.

New Prognostic Tool Helps Predict 6-Month Mortality in Advanced Dementia Patients

Boston researchers have created and validated a practical risk score for predicting 6-month mortality in nursing home patients with advanced dementia, according to their report in the *Journal of the American Medical Association*.

“Our risk score offers an improvement over existing prognostic guidelines used in this population because it is based on empiric data, has greater predictive power, and uses standardized, readily available MDS [Minimum Data Set] assessments,” write the investigators, led by Susan L. Mitchell, MD, of the Hebrew Rehabilitation Center for Aged Research and Training Institute and the Harvard Medical School, Boston.

The team conducted a retrospective cohort study of patients with advanced dementia admitted to all Medicare- and Medicaid-certified nursing facilities in New York (derivation cohort, n = 6799) and Michigan (validation cohort, n = 4631) during 1994-1998 and 1998-2000, respectively.

A mortality risk score based on 12 MDS factors associated with 6-month mortality risk identified in the derivation cohort was evaluated in the validation cohort. Six categories of risk

RISK FACTORS

Identified risk factors to be scored for 6-month mortality include:

- Activities of daily living score = 28
- Male sex
- Cancer
- Congestive heart failure
- Oxygen therapy needed in previous 14 days
- Shortness of breath
- Less than 25% of food eaten at most meals
- Unstable medical condition
- Bowel incontinence
- Bedfast
- Age greater than 83 years
- Not awake most of the day

— Mitchell, Kiely, Hamel, et al
Journal of the American Medical Association

of mortality within 6 months were calculated. The authors provide within their report a score sheet for estimating 6-month prognosis and stratifying patients into levels of risk.

When the researchers compared their risk score performance with that of the existing guideline for enrolling patients with a primary diagnosis of dementia into hospice — the cutoff point of 7c (nonambulatory) on the Functional Assessment Staging scale — their risk score was found to demonstrate better discrimination to predict 6-month mortality in these patients.

“Advanced dementia is an incurable, progressive condition for which palliation is often the primary goal of care, regardless of life expectancy,” state the authors. **“High quality palliative care should be available to the large proportion of persons with advanced dementia who will be cared for in nursing homes.”**

Source: “Estimating Prognosis for Nursing Home Residents with Advanced Dementia,” *Journal of the American Medical Association*; June 9, 2004; 291(22):2734-2740. Mitchell S, Kiely D, Hamel M, et al; Hebrew Rehabilitation Center for Aged Research and Training Institute; Department of Medicine and Division of Medicine and Primary Care, Beth Israel Deaconess Medical Center; and Division on Aging, Harvard Medical School, Boston.

DEA and Pain Experts Release Joint Document on Medical Treatment of Pain

The federal Drug Enforcement Administration (DEA), in collaboration with leading experts in the areas of pain treatment and public policy, has issued an educational document addressing the clinical and regulatory issues surrounding the prescribing of controlled drugs for pain.

Intended for primary care clinicians and law enforcement officers, the material aims to promote mutual understanding of effective medical pain management and of efforts to curtail the abuse and diversion of prescription drugs.

“We have two serious societal problems — the undertreatment of pain, and drug abuse and diversion — that are intertwined through prescription pain medications. We address both problems in this document, and hope it will bring some clarity to the issue,” says Russell Portenoy, MD, lead pain expert on the project. Portenoy is chairman of the Department of Pain Medicine and Palliative Care, Beth Israel Medical Center, New York City.

Entitled “Prescription Pain Medications: Frequently Asked Questions and Answers

for Health Care Professionals and Law Enforcement Personnel” (FAQs), the document includes 30 questions and answers, followed by relevant and current references and Internet resources.

Questions include:

- ✓ How can a clinician assess a patient’s pain?
- ✓ When should a primary care physician turn to a pain medicine specialist to manage a patient’s pain?

Continued on Page 5

Close Monitoring Urged for Patients Disenrolled from Hospice

Patient self-report found best predictor of survival

More than one-third of terminally ill patients discharged from hospice die within six months of their disenrollment, a new study has found. Further, the strongest predictor of mortality within six months of hospice discharge is not compatibility with hospice eligibility guidelines, but patient or surrogate report that the patient's condition had worsened.

"Current criteria being used to determine appropriateness of hospice discharge did not consistently predict mortality," write the authors in the August 2004 issue of the *Journal of the American Geriatrics Society*.

Researchers conducted a prospective cohort study of 139 patients with known outcomes who were consecutively discharged from 18 participating hospices in seven states during a one-year period in 2000 and 2001. The participants received monthly follow-up telephone calls for six months after discharge or until death.

KEY FINDINGS INCLUDE:

- 35% of participants died within six months of hospice discharge.
- Of these, 31% died without hospice readmission and thus did not receive hospice care just prior to death.
- The strongest predictor of death within six months of hospice discharge was patient or proxy assessment of worsening condition (hazard ratio for death, 10.2).

No significant associations were found between death within six months of hospice discharge and any of the following patient characteristics: diagnosis, sex, length of hospice service, discharge disposition, admission evidence of prognosis of six-month or less life expectancy, Karnofsky score at admission or change between admission and discharge, and length of hospice care after stabilization.

More than 70% of the study patients had a diagnosis other than cancer. Because noncancer patients tend to have an unpredictable dying trajectory, "it is not surprising that 6% to 8% of hospice patients are discharged alive annually, often because they no longer appear to meet the Medicare eligibility criteria," note the authors. The subsequent death of these patients shortly after discharge is distressing for both families and the hospice staff, they add.

"Close follow-up of patients discharged alive from hospice, perhaps with telephone calls inquiring how the patient (or surrogate) feels he or she is doing, could lead to discovery of unmet needs and potentially more timely hospice re-admission," conclude the authors.

Source: "Outcomes and Characteristics of Patients Discharged Alive from Hospice," Journal of the American Geriatrics Society; August 2004; 52(8):1337-1342. Kutner JS, Meyer SA, Beaty BL, Kassner CT, Nowels DE, Beehler C; Division of General Internal Medicine, Colorado Health Outcomes Program, and Department of Family Medicine, University of Colorado Health Sciences Center, Denver; and Hospice at Riverside and Grant, Columbus, Ohio.

Joint Document on Medical Treatment of Pain

Continued from Page 4

- ✓ What information do patients need about using opioids for chronic pain?
- ✓ Where can clinicians find educational material on prescribing opioid analgesics?
- ✓ How can clinicians assess for risks of abuse, addiction, and diversion and manage their patients accordingly?
- ✓ Under what circumstances will the DEA investigate and prosecute a doctor or pharmacist or refer cases to other agencies?

"We want to answer the types of questions that may be raised by physicians, nurse practitioners, and physician assistants who are not pain management experts, but still treat pain within their practices," explains Portenoy. "Many of them either lack the information they need or are afraid to prescribe these medications for fear of retribution for overprescribing. This leaves countless numbers of people with untreated pain."

Sections of the document include:

- Pain and Its Treatment
- Medical Use of Opioid Analgesics

- Risks in the Medical Use of Opioid Analgesics
- Other Legal and Regulatory Considerations

FAQs was released in August 2004 by the DEA, in collaboration with the Last Acts Partnership and the Pain & Policy Studies Group (PPSG) at the University of Wisconsin. The DEA plans to have the FAQs available in print version and on compact disc in October 2004. Call **202-307-7297**.

The complete document can be accessed free of charge on the PPSG's website. Visit www.medsch.wisc.edu/painpolicy.

PHYSICIAN RESOURCES

Online End-of-Life Care 'Fast Facts' Now Number 121

Go to www.eperc.mcw.edu to download and print these practical summaries

The Fast Facts Index, a list of peer-reviewed, one-page summaries of important clinical information on end-of-life care topics, now includes 121 items within seven categories, all freely accessible on the website of the End of Life/Palliative Education Resource Center (EPERC).

The seven topic areas include clinical interventions; communication; disease categories; ethics; non-pain symptoms/disorders/syndromes; pain; and terminal care/patient's - family's experience. Titles of recently added items include:

- Medicare Hospice Benefit, Parts I to III
- Writing Discharge/Outpatient Opioid Prescriptions
- Opioid Withdrawal
- Oral Transmucosal Fentanyl Citrate (OTFC)
- Cardiac Pacemakers at End of Life
- Implantable Cardioverter Defibrillator (ICD) at End of Life
- Bisphosphonates for Bone Pain
- Pediatric Pain Assessment Scales (Links to websites offering several of the listed scales are provided.)
- Physicians and Prayer Requests

The information is intended for physicians in practice and can also be appropriate for nurses and other health care professionals. After a free, one-time registration, the list can be browsed either in its entirety or by category, and all other end-of-life care educational materials available on the site are searchable by topic.

Selected Fast Facts are featured periodically in the *Journal of Palliative Medicine*, which recently published "Broaching the Topic of a Palliative Care Consultation with Patients and Families." [See summary below.]

The complete collection of Fast Facts is available at www.eperc.mcw.edu.

Broaching the Topic of a Palliative Care Consultation

Physicians may fear that suggesting to patients and families that a palliative care team be consulted will provoke a negative response, due to common misperceptions about the nature of hospice and palliative care. Experts offer the following tips for opening such a discussion:

- **Decide on your reason(s)** for wanting assistance from palliative care experts, such as for help with: symptom assessment and management, difficult decision making, appropriate care planning to meet patient goals, and/or psychological support for the patient/family and health care team.
- **Discuss these reasons with the palliative care team.** Include pertinent information on the patient's history and family support structure, and describe both your own goals and what you perceive to be the goals of the patient/family.
- **Open the patient/family discussion by reviewing the current medical condition and discussing goals of care.** Then introduce the topic of a palliative care team consultation: "To best meet some of the goals we have been discussing,

such as..., I would like to have some members of the palliative care team visit with you. They are experts in treating your symptoms of..., and can also help you and your family deal with the changes brought on by your illness. They can answer your questions about..."

- **Emphasize that you will continue to be involved in the patient's care.** "You and I will talk about the recommendations made by the palliative care experts, and I will see that all of your questions are answered." Explore the reasons for any negative reaction. "What experience do you have with hospice/palliative care?" "What are your concerns?" Stress the positive aspects of palliative care, which has as its goal improving the quality of the patient's and family's life.

SPECIALIZED SUPPORT

- ✓ "...the goal of palliative care is to achieve the best possible quality of life through relief of suffering, control of symptoms, and restoration of functional capacity..."
- ✓ "Palliative care guides the patient and family as they face disease progression and changing goals of care and helps those who wish to address issues of life completion and life closure."

— Arnold and Weissman
Journal of Palliative Medicine

Source: "Broaching the Topic of a Palliative Care Consultation with Patients and Families #42," *Journal of Palliative Medicine*; June 2004; 7(3)472-473. Arnold RM, Weissman DE; University of Pittsburgh Medical Center, Department of Medicine, Pittsburgh; Division of Hematology/Oncology, Medical College of Wisconsin, Milwaukee.

PHYSICIAN RESOURCES

The Written Sympathy Note:

'A Beneficial Act of Closure' for Physician and Bereaved

An expression of sympathy written by the physician to bereaved loved ones following a patient's death serves to further humanize the patient-physician relationship, in that it honors the memory of the deceased while providing comfort to the family, according to a palliative care expert.

"Expressions of sympathy are important aspects of comprehensive patient care," writes Neil M. Ellison, MD, director of the Palliative Medicine Program at Geisinger Medical Center, Danville, Pennsylvania, in the May 3, 2004, issue of the *American Medical News*, a publication of the American Medical Association.

"Sending a condolence note also can be a beneficial act of closure for the physician," he adds. Yet, he notes, physicians rarely write letters of condolence, perhaps out of discomfort and uncertainty about what to say.

"The physician who plays a pivotal role in chronic or acute terminal care of a deceased patient should consider extending a written expression of sympathy to the grieving family, even if he or she interacted with the family for only a few hours in the trauma bay of the emergency department," notes Ellison.

To aid physicians in composing a written letter of condolence, Ellison offers the following suggestions:

ACKNOWLEDGE THE FAMILY'S LOSS AND EXPRESS SYMPATHY

- "I was saddened to find out about...", "It is difficult to find words to express my sorrow...", or "Although I never met...", are helpful phrases in expressing concern for the family.
- When appropriate, mention the importance of the loving care and support provided to the patient by family and friends.

AVOID EUPHEMISMS AND TRITE PHRASES

- It is preferable to use words such as "death" and "died" rather than their euphemistic counterparts.
- Phrases such as "I know how you feel," "He has gone to a better place," and "I'm sure you will do fine" can be perceived as presumptive or incorrect.

MENTION THE DECEASED BY NAME

- If possible, also mention a specific positive quality of the deceased patient, or tell an anecdote about a memorable interaction with the patient or family.

IF AN OFFER OF ASSISTANCE IS MADE, BE PREPARED TO PROVIDE IT WHEN ASKED

- For example, a meeting to review the occurrences in an acute death can help the family's understanding and provide closure.

END WITH A THOUGHTFUL CLOSING

- Conclude with "You are in my thoughts," or "with deepest sympathy."

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 (EPERC)

www.epeconline.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

Center for Palliative Care Studies

www.abcd-caring.org

Americans for Better Care of the Dying

www.lastactspartnership.org

A merger of the resources of the former
Last Acts Coalition and
Partnership for Caring

www.mcw.edu/pallimed/

Palliative Medicine Program at the Medical
College of Wisconsin

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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Karla Wheeler
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Information Technology Specialist

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Tel: 239-513-9907

Toll Free: 1-877-513-0099 (US & Canada)

Fax: 239-513-0088

Email: info@QoLpublishing.com

Quality of Life Publishing Co.
P.O. Box 112050
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