

# Quality of Life Matters™

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

Vol. 1, Issue 2 Aug/Sept/Oct 1999

## AMA Seeks to Extend Prognosis for Hospice Eligibility

### ***Patients Are Entered Into Hospice Programs Too Late: AMA Delegates***

Acknowledging that, unfortunately, a major rewrite of Medicare is not likely to happen soon, the House of Delegates of the American Medical Association (AMA) is aiming to make numerous improvements in the program, reports the July 12, 1999, issue of *American Medical News*, published by the AMA.

Among the many recommendations made at the delegates meeting in June was the direction that the AMA extend the prognosis necessary to approve a patient's placement in hos-

pice from six months to 12 months.

Because of the difficulty of determining how long a patient with a terminal illness will live, many patients are entered into a hospice program much too late, the delegates noted.

On the other hand, physicians worry that if patients live longer than the allotted six months they will lose their hospice benefits.

For detailed information, call the AMA at **312-464-4430**.

## Physicians Can Take Steps to Improve End-of-Life Care 'Next Week,' Expert Says

Identifying the bottom line of health care as "the care," Don Berwick, MD, President and CEO of the non-profit Institute for HealthCare Improvement based in Boston, called for physicians to initiate immediate changes in their approach to end-of-life care.

As part of his keynote address to the American College of Physicians-American Society of Internal Medicine (ACP-ASIM) Annual Session held in New Orleans in April, Berwick presented the assemblage with "20 Improvements in End of Life Care—Changes Internists Could Do Next Week!" This document, prepared by Americans for Better Care of the Dying (ABCD), lists practical ways for internists to improve end-of-life care in their daily practices.

### **STEPS TO IMPROVE CARE AT THE END OF LIFE**

*Summary of a presentation by Don Berwick, MD*

- **Identify** those among your patients who are "sick enough to die." Ask yourself as you see each patient, "Would I be surprised if this patient died in the next few months?"
- **Explain** to your "sick enough to die" patients what is likely to happen; this eliminates anxiety and fear. Start counseling and planning around the possibility. **Discover** what they know, and share information: "Tell

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# NEWSLINE

## Poll: 90% unaware hospice care is covered by Medicare

A nationwide public survey of 1250 adults aged 45 and over was conducted in April for the National Hospice Foundation. In reply to the question “How is hospice care paid for?” 44% of the respondents said, “Don’t know,” while only 9% answered, “Medicare/Government.” No significant variation in this response was noted after adjusting for age, race, income, or education.

## Managed care challenged to improve end-of-life care

The National Task Force on End-of-Life in Managed Care, whose members include leaders in managed care, palliative care experts, ethicists, and quality improvement specialists, issued a report in May calling for the managed care industry to take the initiative on improving care for the dying, and urged action in three specific areas: access, accountability, and payment methods.

Among the panel’s recommendations are: basing access to hospice on severity of need, not estimated life expectancy; the development of valid, standardized measures for assessing quality of end-of-life care; and the study of alternative payment methods to ensure providers and plans are properly compensated for the care of the gravely ill.

The report was prepared by the Center for Applied Ethics and Professional Practice at Education Development Center, Inc. of Newton, Mass.

## ACP-ASIM publishes landmark end-of-life care series

The American College of Physicians-American Society of Internal Medicine (ACP-ASIM) has launched a series of articles on end-of-life care for physicians and clinicians who are not specialists in palliative care and do not provide care for dying patients on a regular basis.

Developed by the College’s Consensus Panel on End-of-Life Care, the series—projected to run for a year or more in the ACP-ASIM’s journal *Annals of Internal Medicine*—began with the publication of the paper, “Discussing Palliative Care with Patients,” in the May 4, 1999,

issue. Also appearing in that issue was the panel’s accompanying editorial “Care at the End of Life: Guiding Practice Where There Are No Easy Answers.”

According to the ACP-ASIM, the panel has identified as its key issues:

- better relief of physical symptoms;
- improved decision-making about life-sustaining interventions;
- more meaningful discussions with patients and families about end-of-life issues such as sadness, grief, and fear of the unknown.

To date, two papers have followed: “A Consensus-Based Approach To Providing Palliative Care to Patients Who Lack Decision-Making Capacity,” published in the May 18 issue, and “Management of Pain and Spinal Cord Compression in Patients with Advanced Cancer,” which appeared in the July 6 issue.

Projected titles include: “Dying Patients in the ICU: Forgoing Treatment, Maintaining Care,” “Beyond Good Symptom Management: Opportunities Within Palliative and End-of-Life Care,” and “Legal Barriers to End-of-Life Care: Myths, Realities, and Grains of Truth.”

For more information, access the section on the Center for Ethics and Professionalism on the ACP-ASIM website at [www.acponline.org](http://www.acponline.org).

## Congress to address three palliative care and pain initiatives

Advocates for improved pain and symptom relief have three legislative proposals on the table this session.

*The Advance Planning and Compassionate Care Act of 1999* (S 628/HR 1149) aims to strengthen the effectiveness of advance directives across state lines and to fund innovations in end-of-life care.

*The Conquering Pain Act of 1999* (S 941/HR 2188) recognizes federal responsibility for insuring the best possible care for patients suffering from pain, and recommends both short- and long-term approaches to pain management.

*The Pain Relief Promotion Act of 1999* (S 1272/HR 2260) directs the Agency for Health Care Policy and Research to collect and disseminate protocols and best practices for palliative care, with emphasis on pain management.

## Council of Europe Rejects Euthanasia, Supports Legal Entitlement to Palliative Care

The Council of Europe, a 41-member international governmental organization based in Strasbourg, France, adopted at its June assembly a strongly worded resolution advocating the protection of the human rights and dignity of terminally ill and dying patients, according to a report in the July 17, 1999, issue of the *British Medical Journal*.

The resolution urges European governments and the medical profession to give higher priority to providing effective palliative care and pain treatment to the terminally ill and dying, along with social and psychological support to the patients and their

*Advances in medical technology and economic pressures must not be allowed to rob patients of their peace and human dignity, the advisory assembly warns. As a result of the ability to prolong survival, "the quality of life of the dying is often ignored, as is their loneliness, their suffering, and that of their families and caregivers," the resolution states.*

families. At the same time, the assembly rejected a call for euthanasia, firmly supporting the existing prohibition against it.

Among the range of legal and social measures recommended by the council is the establishment of specialized palliative care units and hospices, along with a network of hospice teams for providing care at home. The medical community is urged to provide effective pain control for the dying, even if the treatment may shorten the patient's life.

The Council of Europe is a parliamentary body founded in 1949 to deal with humanitarian, cultural, and social problems. Part of its mandate is to protect the rights of individuals in member nations against arbitrary government action.

## STEPS TO IMPROVE CARE AT THE END OF LIFE

*Summary of a presentation by Don Berwick, MD*

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- me what you know about (your disease). Tell me what you know about what other people go through with this disease.”
- **Understand** the needs of these patients and their caregivers. Ask, “What do you hope for, as you live with this condition? What do you fear?” Ask about their home lives: “How are things going for you and your family?”
  - **Prioritize** their concerns, such as symptom relief, continuity, spirituality, family support, and advance care planning. (If discussing advance directives seems difficult, try asking, “If at sometime you can’t speak for yourself, who should speak for you about health care matters? Do they know this, and do they know what you would want?”)
  - **Anticipate** the expectable complications, and work to have plans for them in place. Ask your patients who are “sick enough to die” whether anything for which they were not prepared has happened recently with regard to their medical conditions.
  - **Arrange** care plans to reflect the patients’ priorities. If, for example, they would be most comfortable at home or in a nursing facility, discover the quality services in your area [such as hospice], and work with these services to fill any gaps in the patients’ care preferences.
  - **Praise** the caregivers who are doing a good job, and **follow up** after a death: make a supportive phone call, arrange a visit to answer questions and console, or at least send a card to affirm the value of the life which has just ended.

The entire text of “20 Improvements” can be viewed on-line on the ABCD website at [www.abcd-caring.com/tools/intern.htm](http://www.abcd-caring.com/tools/intern.htm).

# RESEARCH MONITOR

## Large Study Finds WHO Pain Guidelines Effective for Home Care of Cancer Patients

By following the guidelines of the World Health Organization (WHO), health professionals can rapidly control pain and maintain pain relief for prolonged periods during home care of patients in the advanced stages of cancer, a recent Italian study has shown.

In an open prospective study over a 9-year period, Sebastiano Mercadante, MD, of Fatebenefatelli Hospital in Palermo, followed 3678 consecutive patients with advanced cancer who were referred to a home palliative care program. All members of the interdisciplinary hospice team attending the patients had at least 5 years experience in palliative care.

The patients were treated with analgesia therapy following the 3-step WHO approach to drug administration, which advises progression from nonopioid analgesics to strong opioids according to the intensity of the patient's pain. [See box.] Drugs for other symptom relief were also administered as required.

The study recorded patient age, gender, Eastern Co-

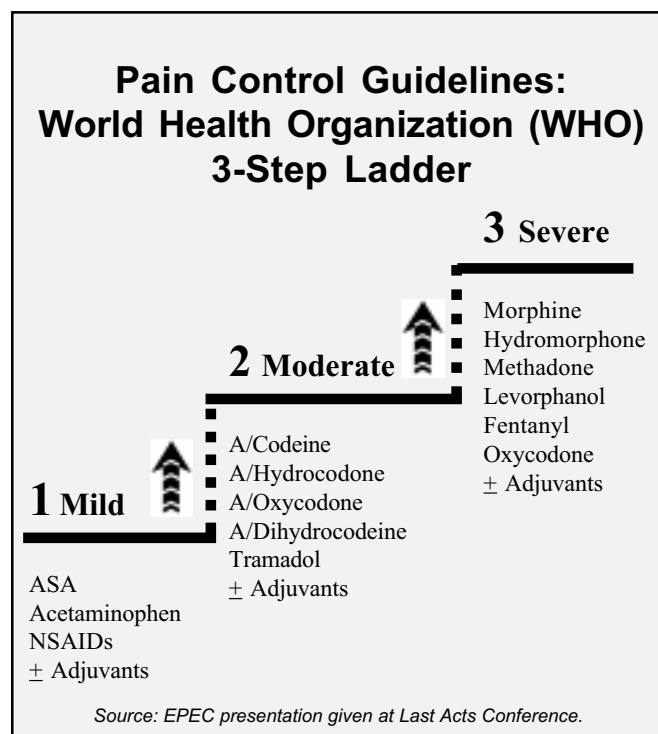
operative Oncology Group performance status, and pain mechanism at referral; pain and symptom intensity, and doses and days of drug administration during the course of the treatment were monitored at regular intervals.

Of the 3557 patients who were followed until their deaths, 70.3% required analgesia therapy for a mean duration of 64 days (range: 1 to 812 days). The mean duration periods of the 3 steps (nonopioid drugs, moderate opioids, and strong opioids) were 18, 27, and 19 days, respectively. In the last week of life, the percentage of patients in each drug category was 16%, 49%, and 35%, respectively. A minority of the patients (2.65%) underwent such invasive procedures as celiac plexus block or epidural analgesia.

"At referral, most patients received inadequate treatment," Mercadante notes. After pain treatment according to the WHO guidelines was initiated, "improvement in pain intensity was clinically relevant, statistically significant, rapid, and protracted until death in most patients," he writes.

In an editorial accompanying the report of the study in the April 15, 1999, issue of *Cancer*, Janet L. Abraham, MD, of the University of Pennsylvania School of Medicine, Philadelphia, calls for oncologists to become more familiar with palliative care and symptom management, so they may offer these services themselves; and to collaborate more closely with hospice personnel, nurse specialists, and other nonphysician colleagues, so that patients will not be denied "the significant resources and quality-of-life improvements a hospice can offer."

Sources: "Pain Treatment and Outcomes for Patients with Advanced Cancer Who Receive Follow-Up Care at Home," *Cancer*; April 15, 1999; 85:1849-1858. Mercadante S; *Pain Relief and Palliative Care, SAMOT, Palermo, Italy*; Department of Anesthesia and Intensive Care, Pain Relief and Palliative Care, La Maddalena Clinic, Palermo, Italy. "The Oncologist's Expanding Role," *Cancer*; April 15, 1999; 85:1645-1648. Abraham J; University of Pennsylvania School of Medicine, Philadelphia.



# RESEARCH MONITOR

## Research Needed to Assist Physicians in Timely Hospice Referral

Late enrollment in hospice care prevents patients from realizing the full benefits of humane and clinically appropriate palliative care, according to a Chicago study. Late enrollment can be disruptive and stressful for providers, patients, and their caregivers; and yet the majority of patients are enrolling in hospice too late, says Nicholas A. Christakis, MD, PhD, MPH, Associate Professor of Medicine and Sociology, University of Chicago.

In his study of prognostication, Christakis looks at physician difficulty with predicting patient survival as one of a number of barriers to timely hospice referral.

“Little is known about the accuracy and mechanism of physician prognostication in terminally ill outpatients in general and in those referred to hospice in particular,” says Christakis. Although prior studies have often neglected or oversimplified the relationship between diagnosis and length of survival after referral, he notes, recent studies have shown that patients with non-cancer diagnoses live longer after hospice referral than do patients with cancer. However, research linking the timing of hospice referral to physician specialty has been inconclusive or contradictory.

To assist physicians in decreasing prognostic uncertainty, Christakis recommends prognostic staging systems for patients with an intermediate survival expectation (up to one year), both in general and for specific diseases. And he suggests research into a number of areas regarding physician behavior:

- The effectiveness of providing physicians with feedback on their patients’ survival after hospice referral;
- The use physicians make of prognostic information;
- The qualities (experience, specialty) that make physicians better prognosticators; and
- Geographic variation in physician behavior regarding hospice referral.

*Source: “Predicting Patient Survival Before and After Hospice Enrollment,” The Hospice Journal; March 1998; Vol.13, No. 1/2; and A Good Dying: Shaping Health Care for the Last Months of Life (ed: Joan K. Harrold and Joanne Lynn), The Haworth Press, Inc., 1998. Christakis NA; Departments of Medicine and Sociology, University of Chicago, Chicago.*

## Comfort Assessment Tool Measures Both Pain and Suffering

Noting that patients perceive suffering and pain as separate entities, two palliative care experts presented the 14th Senior Management and Leadership Conference of the National Hospice Organization with a practical tool for assessing and relieving suffering in end-of-life care.

Barry Baines, MD, of HealthPartners, Inc., of Minneapolis, and Rebecca Eck, CRNH, of Hospice of the Lakes, Minneapolis, reported on the use of the Comfort Assessment, a two-part questionnaire that encourages patients to identify and rate their pain, suffering, and ability to cope.

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**Barry Baines, MD,  
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The assessment asks patients to rate their pain on a 0-10 scale, and to indicate its characteristics. The patients are next requested to use the same 0-10 pain-rating scale to determine the level of their suffering in three areas: physical, spiritual, and personal/family. Patients are then asked, “Do you want any help in these areas?”

Patients are unlikely to mention suffering unless asked, Baines and Eck said, but just being asked can relieve some of the burden of suffering. And the staff administering the questionnaire found that it opened discussions in areas that might otherwise have been overlooked in a focus only on the relief of physical symptoms.

Although the proclaimed mission of medicine from its

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# RESEARCH MONITOR

Continued from Page 5

earliest days has been to relieve human suffering, the two experts noted, little attention has been paid in health care research, education, or practice to suffering, which they defined as "the state of severe distress associated with events that threaten the intactness of a person as a complex social and psychological entity."

Source: "Relief of Suffering at the End of Life," presentation at the National Hospice Organization's 14th Senior Management and Leadership Conference: "Emerging Models in End-of-Life Care," May 1999, Arlington, Va. Baines B, Eck R; Continuing Care Department, HealthPartners, Inc., Minneapolis; Hospice of the Lakes, Minneapolis.

## Charcoal Dressing May Improve Care of Fungating Tumors

The management of malodorous wounds may be significantly improved with the use of a recently available design of dressings with an absorbent contact layer bonded to an outer layer of activated charcoal, according to a trial directed by Vicki Muller, RN, MSN, CETN, of the Mountain States Tumor Institute, Boise, Idaho. Muller presented her findings at the Ninth Annual Palliative Care Conference held by Humber College, Toronto.

Results from the multicenter clinical trial reported positive patient and caregiver satisfaction for odor control, drainage control, and ease of application. Although research on the incidence and prevalence of malodorous wounds is scarce, said Muller, "it is estimated that 5-10% of persons with metastatic disease will develop skin involvement within the last six months of life."

In a related presentation, Valerie Schulz, MD, University of Alberta, St. Albert, reported on a study in which one of the objectives was to determine the number of patients referred to cancer centers with cutaneous spread of malignancy. Of 287 referrals to the symptom clinic at the London Regional Cancer Centre, London, Ont., from December 1996 to December 1998, said Schulz, 49 (17%) were patients with malignant cutaneous wounds.

Sources: "Fungating Malignant Tumors: A New Treatment for Odor and Drainage Containment," Muller V, Murray D, Earhart K; Mountain States Tumor Institute, Boise, Idaho.

"The Role of the Cancer Center in Cutaneous Malignant Wound Management," Schulz V, Kligman L; University of Alberta, St. Albert, Alta., Canada. Poster Presentations, Ninth Annual Palliative Care Conference, Humber College, Toronto, April 1999. Journal of Palliative Medicine; Spring 1999; Vol. 2, No. 1.

## 'Years of Healthy Life' Preferred to 'Survival' as Study Endpoint

Medical interventions intended to improve patients' health are often evaluated in studies designed with survival as the primary outcome, when it may be more appropriate to use measures adjusted for quality of survival, such as years of healthy life (YHL). So says a recently published study that looked at the use of both measures to determine which was the more powerful study endpoint in cases where either would be appropriate.

Researchers considered 156 different health conditions in a cohort of 1909 older adults and calculated the sample sizes and lengths of follow-up required for each outcome measure with

**YHL requires lower sample sizes, shorter length of study, and fewer follow-ups.**

P. Diehr, MD, et al

each health condition. They found that YHL is better than survival for the majority of the health conditions and twice as good for 54 conditions; survival is twice as good for only 22 conditions. Further, YHL requires lower sample sizes, shorter length of study, and fewer follow-ups.

"We have shown that trials with YHL as an outcome can often be shorter than those based on survival, and that the number of follow-up measurements need not be large... investigators should consider using YHL as the primary outcome measurement," the researchers conclude.

Source: "Survival Versus Years of Healthy Life. Which Is More Powerful as a Study Outcome?" Controlled Clinical Trials; June 1999; 20:267-279. Diehr P, Patrick DL, Burke GL, Williamson J; Department of Biostatistics and Health Services, University of Washington, Seattle; Department of Public Health Science, School of Medicine and the J. Paul Sticht Center on Aging, Wake Forest University, Winston-Salem, N.C.

# PHYSICIAN RESOURCES

## Popular Living Will Available On-Line

"*Five Wishes*," the nationally popular living will that is valid in 33 states and useful for end-of-life care discussion and as a preference guide in all states, can be obtained free at [www.agingwithdignity.org](http://www.agingwithdignity.org), or by mailing a \$4 check or money order to: Aging with Dignity, P.O. Box 1661, Tallahassee, FL, 32302-1661.

## VA Project Offers On-Line Resources

As part of a two-year initiative to improve end-of-life and palliative care nationwide, the **Veterans Administration (VA) Faculty Leaders Project for Improved Care at the End of Life** has established a website that includes a monthly newsletter with updates on the project and related topics and links to end-of-life care resources on-line.

The project, funded by the Robert Wood Johnson Foundation, aimed in the first year to develop and implement benchmark curricula for training resident physicians in the care of the seriously ill and dying. To this

end, the VA designated end-of-life faculty leaders at 31 affiliated residency programs and created action plans that addressed five topic domains: pain, communication skills, personal reflection, clinical end-of-life experiences, and faculty development.

An on-line discussion group, "Improving End-of-Life Care Forum," has been created to stimulate ideas on integrating end-of-life care into post-graduate physician education programs. Access the VA Project website at [www.va.gov/oa/flp](http://www.va.gov/oa/flp).

## Upcoming Meetings

**6th Congress of the European Association for Palliative Care.** September 22-24, 1999, Geneva, Switzerland. Contact: Secretariat, Kuoni Congress, Rue de Berne 7, 1201 Geneva, Switzerland. Phone: 41 (22) 908-1855; Fax: 41 (22) 908-1835; e-mail: [eapc.congress@kuoni.ch](mailto:eapc.congress@kuoni.ch)

**Doctors, Death, & Dignity II: Regaining Lost Ground.** September 24-25, 1999, Chautauqua, New York. Sponsors: Hamot Second Century Fund and the Center for Hospice and Palliative Care in Buffalo, New York. Contact: Hamot Medical Center. Phone: 800-352-2553. URL: [www.hamot.org](http://www.hamot.org)

**12th World Congress: Completing the Circle of Care.** November 3-6, 1999, Vienna, Austria. Sponsor: Children's Hospice International. Phone: 800-24CHILD or 703-684-0330.

**Palliative Care 2000.** March 19-23, 2000, Jerusalem, Israel. Sponsors: the European Association for Palliative Care and Israel Association of Palliative Care, P.O. Box 50006, Tel Aviv 61500, Israel. Phone: 972 (3) 514-0000; Fax: 972 (3) 517-5674; e-mail: [palliative@kenes.com](mailto:palliative@kenes.com)

## End-of-Life Care Websites

[www.aahpm.org](http://www.aahpm.org)

American Academy of Hospice & Palliative Medicine.

[www.nho.org](http://www.nho.org)

National Hospice Organization.

[www.hospicefoundation.org](http://www.hospicefoundation.org)

Hospice Foundation of America.

[www.americanhospice.org](http://www.americanhospice.org)

American Hospice Foundation.

[www.gwu.edu/~cicd](http://www.gwu.edu/~cicd)

Center to Improve Care of the Dying, George Washington University.

[www.abcd-caring.com](http://www.abcd-caring.com)

Americans for Better Care of the Dying. Website includes *Exchange*, a monthly publication of news and innovative practices in end-of-life care.

[www.lastacts.org](http://www.lastacts.org)

Last Acts, care and caring at the end of life. Website includes "Innovations in End-of-Life Care," an international journal and online forum.

[www.mcw.edu/pallmed/](http://www.mcw.edu/pallmed/)

Palliative Medicine Program at the Medical College of Wisconsin. Website includes the educational tool, "Improving End-of-Life Care: a Resource for Physician Education."

[www.chcr.brown.edu](http://www.chcr.brown.edu)

Center for Gerontology and Health Care Research.

[www.halcyon.com/iasp/](http://www.halcyon.com/iasp/)

International Association for the Study of Pain.

[www.medsch.wisc.edu/painpolicy](http://www.medsch.wisc.edu/painpolicy)

University of Wisconsin Pain and Policy Studies Group.

# EPEC Project Enters Second Phase

## *AMA Continues Educating Physicians Nationwide in Care for Dying Patients*

The Institute for Ethics of the American Medical Association (AMA) and the staff of the **EPEC (Education for Physicians on End-of-Life Care) Project** have announced that the Robert Wood Johnson Foundation has provided funding for the continuation of the AMA initiative, whose core curriculum has been the training of select groups to educate practicing physicians in the basic knowledge and skills needed for appropriate care of dying patients.

The EPEC curriculum, offered in a two-day conference format, consists of four plenary modules and 12 workshop modules, which include such topics as: whole patient assessment, communicating bad news, pain management, medical futility, physician-assisted suicide, and the last hours of living.

In addition, the project offers several companion products: the Speaker's List, Resource Guide, and Compendium, which are available upon request or through the AMA website. New this year is the EPEC Monograph, a self-directed learning manual that physicians can complete for CME credit eligibility.

EPEC II is intended to build on the achievements of the 1997-1999 EPEC initiative, the AMA said. Over the next year, EPEC II will aim to facilitate further implementation of materials, track the use of EPEC, evaluate educational outcomes, and update materials to keep them current. For more information, call the EPEC Project at **312-464-4979** or visit their website at [www.ama-assn.org/ethic/epec](http://www.ama-assn.org/ethic/epec).

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- *The quality of each life MATTERS, particularly at the end of life; and*
- *Everyone has the right to die pain free and with dignity.*

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