

Quality of Life Matters™

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

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Institute of Medicine Urges Improvements in Palliative and End-of-Life Cancer Care

Recommendations include revision of the Medicare hospice benefit

Major changes in the nation's health care system—from public research agencies to private insurers—are urgently needed to **overcome the barriers that prevent cancer patients from receiving adequate symptom control and supportive therapies, particularly at the end of life.**

That is the recommendation of a report released in June by the National Cancer Policy Board, a committee of experts assembled by the Institute of Medicine (IOM) and the National Research Council.

“Nine million Americans, or 3% of the population, are living with a diagnosis of cancer,” says co-editor Kathleen M. Foley, MD, director of the Project on Death in America, the Open

Society Institute, and chair of the Society of Memorial Sloan-Kettering Cancer Center, New York City.

“In our dogged pursuit of cure, we have almost ignored the need for palliative care to reduce the needless suffering from the physical and emotional symptoms of cancer and cancer treatment,” says Foley.

Due to barriers existing across the health care system, **about half of the 550,000 Americans expected to die from cancer this year will have suffered from a range of distressing symptoms during the course of their disease and especially as they near death,** says the report.

Among the barriers to good care identified in the report are:

- ✓ **Absence of research** in the fields of palliative and end-of-life care
- ✓ **Inadequate training** among health care professionals
- ✓ **Lack of standards** for treating many physical and psychosocial symptoms
- ✓ **Restrictive reimbursement policies** for palliative and hospice care
- ✓ **Absence of patient-oriented information** on cancer treatment and survival
- ✓ **Disparities in care** across socioeconomic and age groups—especially among racial minorities and children

The report, entitled “Improving Palliative Care for Cancer,” proposes steps that private insurers and government

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Physician Communication Skills Span Spectrum of Care for Terminally Ill Patients

Suggested techniques for physician-patient communication in the medical literature tend to focus on the giving of bad news as a “single event” in the care of a terminally ill patient, note the authors of a recent study. **“However, physicians often must give their patients a spectrum of bad news that begins with the initial terminal diagnosis and continues through the eventuality of failed treatments, physical decline, and ultimately, death,”** they write in their report in the March 26, 2001, issue of the *Archives of Internal Medicine*.

To determine which aspects of communication are important to dying patients and their families, a team from the University of Washington School of Medicine, Seattle, assessed findings from a series of local focus groups on physician skill in end-of-life care. The 137 participants included: patients with a terminal diagno-

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Institute of Medicine *(from Page 1)*

agencies, particularly the National Cancer Institute (NCI) and the Centers for Medicare and Medicaid Services (CMS), can take to overcome these barriers. The CMS, formerly known as the Health Care Financing Administration, is the federal agency responsible for Medicare.

The report's recommendations include:

√ **The NCI should dedicate a larger portion of its budget to palliative and end-of-life care** and designate certain “centers of excellence” to advance research and develop models of care for adults and children. These centers should collaborate with local hospice organizations, and provide in-service training in innovative palliative care techniques to local hospice staff.

√ **The CMS should revise the Medicare hospice benefit to allow the integration of active treatment of disease with palliative or hospice care**, so that patients are no longer forced to choose between potentially life-prolonging treatment and comfort care.

√ **Private insurers should provide reimbursement for end-of-life care and compensate physicians equitably for care that is not aggressive**, such as counseling and pain management.

√ **Organizations that disseminate patient-oriented information about cancer and other disease-specific treatments should include comprehensive and accurate information on palliative care** in their materials. Also, cancer patients need easier access to reliable statistics on survival by type and stage of disease.

“Until recently, most cancer funding and programs emphasized winning our national war against cancer, with all the effort devoted to treatment, prevention, and survivorship,” says Joanne Lynn, MD, director of the RAND Center to Improve Care of the Dying, and a contributor to the report. “These new recommendations offer hope that the nation is coming to terms with the fact that some people still will die.”

“All people suffering from serious and fatal disease will benefit from programs and policies that meet the medical, financial, and social needs of dying patients and their families,” adds Lynn.

The full report can be accessed online by selecting “Recent Reports” on the IOM website at www.iom.edu. Printed copies can be purchased either online, or by calling the National Academy Press at **800-624-6242**.

Physician Communication *(from Page 1)*

sis; recently bereaved family members; health care professionals from hospice or acute care settings; and physicians identified by participating nurses as experts in end-of-life care.

Overall, communication with patients was the most frequently identified domain related to physician competence at end-of-life care. Within that domain, several areas of central importance to patients and family members emerged. *[See bullets below.]*

“A terminal diagnosis introduces a period of great complexity in the lives of patients and their families. They must cope not only with choices and decisions about treatment and subsequent tests, procedures, and treatment regimens, but also the many psychological, spiritual, interpersonal, and practical issues associated with dying,” write the authors.

“The voices of the participants in this study highlight the importance of improving the quality of physician-patient communication throughout the spectrum of medical care at the end of life,” they conclude.

Physician Skills Important for Communicating with Dying Patients Include:

□ **Talking with patients in an honest and straightforward way.** This encompasses alleviating uncertainty about a patient’s medical condition, explaining all available options clearly and directly, and being candid about prognosis. When the question is, “How long do I have?” noted one health professional, the patient is really asking, “What are the statistics for my condition?”

□ **Being willing to discuss dying** in a skillful and open manner. This provides patients and families with the information necessary for making plans, plus the considerable comfort of knowing that they will not be abandoned.

□ **Giving bad news sensitively** yet realistically involves choosing the appropriate time and place, being honest but not blunt, and maintaining hope. “If cure is not an option, then hope may be oriented toward maximizing quality of life,” suggest the authors.

□ **Asking open-ended questions**, listening with interest, and encouraging questions from the patient are excellent ways for the physician to demonstrate active concern. “If you keep your mouth shut, you’ll probably accomplish more than if you talk too much,” commented one physician.

□ **Knowing when patients are ready to talk about dying** requires judgment on the part of the physician as to how much information a patient can assimilate, based on previous discussions. This allows each patient the chance to come to terms with death in his or her own way.

Community-Wide Project Targets Pain Management

Pain Assessment Scale Available for Use by Clinicians and Patients

A task force for the Missoula Demonstration Project (MDP) is concluding a 3-year research project to improve pain management in the local community by **developing a process for professional health care providers, health institutions, and the local population to use the same pain assessment scale in all settings**, researchers report.

The nonprofit MDP, based in Missoula, Montana, was begun in 1996 to examine factors influencing the end-of-life experience, and to improve care for dying patients and their families through a community approach.

Led by Ira R. Byock, MD, of the University of Montana, Missoula, the MDP's Pain as the Fifth Vital Sign Task Force surveyed health professionals and the general population of Missoula to establish baseline measurements of pain-related knowledge, skills, and attitudes.

Initial Surveys Revealed:

GENERAL POPULATION: 86% of local residents said they were moderately or extremely fearful of dying painfully.

PHYSICIANS. Although 82% of physicians believed that inadequate assessment of both pain and pain relief is a significant barrier to pain management, only 25% used formal pain-assessment tools in their practice.

NURSES. While 93% of nurses knew that the four vital signs alone are not reliable indicators of pain, 75% said that vital signs moderately or greatly influenced their decision to implement treatment for pain

INSTITUTIONS. Not one health care institution measured patient satisfaction with pain management.

When local residents were asked to agree or disagree with erroneous statements about pain control:

√ 42% of residents agreed that it is important to take the lowest dose of pain medication possible, saving larger doses for severe pain.

√ 42% agreed that people often receive too much pain medication.

√ 32% thought that most people taking pain medication will be become addicted over time.

KEY ELEMENTS OF PAIN ASSESSMENT FOR USE BY CLINICIANS

SELF-REPORTED INDICATORS

History, location, intensity, quality, pattern, aggravating or relieving factors, and functional effect

PHYSIOLOGICAL INDICATORS

Vital signs, level of consciousness, and functional status

BEHAVIORAL INDICATORS

Muscle tensing, rigid posture, pallor/flushing, agitation/restlessness, and crying/moaning

For more information on the project, or to obtain copies of the complete pain assessment scale, contact the MDP at 406-728-1613 or visit www.missoulademonstration.org.

The task force designed a bookmark-sized pain assessment scale, which it distributes in two versions to clinicians and patients. *[See box above for excerpts.]*

Educational sessions on pain management were incorporated into regularly scheduled provider workshops, and citizen groups were addressed on the importance of taking individual responsibility for their pain management.

The team reports "signs of success" in the initiative's third year. Pain is monitored as a vital sign in area hospitals and several other facilities; participating institutions use the MDP pain assessment scale and have developed a continuous-quality-improvement process. In addition, patients have been observed using the scale in both public and clinical settings.

Follow-up surveys of clinicians, institutions, and the community are pending or in progress. Meanwhile, says the report, which was published in the February 2001 issue of the *American Journal of Nursing*, "**Nurses, physicians, and patients have begun to speak the 'language of pain.'**"

Terminally Ill Patients Willing to Tolerate Pain to Avoid Therapy Side Effects

New research has found that although half of terminally ill patients report experiencing moderate to severe pain, most do not want additional pain therapy, citing aversion to the effects of treatment as the major reason. **“We found that most patients were willing to tolerate pain, even when substantial. Among dying patients, other factors were more important than pain relief,”** write investigators.

The team surveyed 988 terminally ill patients during 1996 and 1997 at 6 geographically diverse locations in the United States. Just over half (51%) had cancer, 18% had heart disease, and 11% had chronic obstructive pulmonary disease.

While poor physical functioning, depressive symptoms, and low income level were all independently associated with experiencing moderate to severe pain, no association between type of terminal illness and degree of pain was found.

“Pain is as prevalent among those with heart disease, chronic obstructive pulmonary disease, and other non-cancer illnesses as in patients with cancer,” state the investigators. **“Thus, cardiologists, pulmonologists, and other non-oncologists must receive adequate training in pain management.”**

During the 4 weeks prior to being interviewed, 52% of the study patients had consulted their primary care physician for treatment of pain.

Although 73% of these patients were in moderate to severe pain, only 29% wanted their pain therapy increased, while 62% wanted it to remain the same and 9% wanted it reduced.

The team found that avoidance of the side effects of opioid analgesia, such as constipation and confusion, was named by about one-third of

patients as their primary reason for refusing additional treatment. **The researchers urge that physician training in pain assessment and management include the management of side effects of opioids.** “Additionally, the development of pain treatments that do not produce the common side effects of opioids should be a high research priority.”

Major Reasons Patients Refused Additional Pain Medication:

- Dislike of mental or physical side effects
- Fear of addiction
- Not wanting more pills or injections

Fear of addiction was also seen in about one-third of patients, a finding consistent with previous studies, the investigators note. **“Therefore, physicians must communicate more effectively that addiction to opioids for pain relief is a myth, and remove this belief as a barrier to adequate analgesia.”**

Source: “Understanding the Experience of Pain in Terminally Ill Patients,” The Lancet; April 28, 2001; 357:1311-1315. Weiss SC, Emanuel LL, Fairclough DL, Emanuel EJ; Department of Clinical Bioethics, Warren G. Magnuson Clinical Center, National Institutes of Health, Bethesda, MD; Northwestern University School of Medicine, Chicago; and Center for Research Methodology and Biometrics, AMC Cancer Research Center, Denver.

Prognostic Index May Aid Clinicians in Discussing Goals of Care

Researchers have developed and validated a prognostic index for predicting 1-year mortality in elderly patients following hospitalization, often a time of major health transition requiring reassessment of goals of care in this population.

The prognostic estimates provided by the index may be useful when counseling patients and their families about the utility of treatment interventions and the initiation of palliative care, investigators suggest. “One use of objective prognostic indices may be to increase clinicians’ confidence in their own prognostic estimates, enhancing their willingness to discuss prognosis with their patients.”

The researchers developed the prognostic index in 1,495 patients aged 70 years or older discharged from the general medical service of an Ohio tertiary care hospital between 1993 and 1997. An independent sample of 1,427 elderly patients discharged during the same time period from a separate hospital in Ohio was then used to validate the index.

Risk factors known at hospital discharge and an additive point system were used to stratify patients according to 1-year mortality.

The 6 factors found to be independently associated with mortality were: male sex, number of dependencies in activities of daily living, cancer, congestive heart failure, renal insufficiency, and hypoalbuminemia.

Source: “Development and Validation of a Prognostic Index for 1-Year Mortality in Older Adults after Hospitalization,” Journal of the American Medical Association; June 20, 2001; 285(23):2987-2994. Walter LC, Brand RJ, Counsell SR, et al; Division of Geriatrics, San Francisco VA Medical Center and University of California, San Francisco; Department of Epidemiology and Biostatistics, University of California, San Francisco; Division of General Internal Medicine and Geriatrics, Indiana University School of Medicine, Indianapolis.

Advance Directives Can Lessen Stress of Families' End-of-Life Decision-Making

The presence of advance directives (ADs) can greatly relieve the high levels of stress experienced by families making the decision to withdraw life support from their incapacitated, hospitalized loved ones, a research team has found. The authors urge health care professionals to encourage their patients to complete ADs earlier.

“Nurses and doctors can play a strong role in encouraging patients before they become gravely ill to

complete advance directives and to discuss them with their families. This will reduce stress on their families down the road,” note the authors, who are with the Center for Ethics in Health Care at Oregon Health Sciences University (OHSU), Portland.

Because most decisions to initiate or withdraw life support occur in hospitals, the OHSU team studied 74 family members of patients who had died recently in one of four Portland hospitals. Family stress levels were measured at

ventions, even in the face of their relative’s suffering and lack of response to treatment.

“With advance directives, families are able to concentrate on improving the patient’s quality of life during the time left, rather than futilely prolonging life, with high risk of making patients suffer unnecessarily,” says lead author Virginia Tilden, DNSc, RN, professor of nursing at OHSU and associate director of the Center for Ethics in Health Care.

“While better communication within families can do a lot to relieve stress, our study found that **communication and support by doctors and nurses profoundly impacts the experience of families,**” adds Tolle. “Families emphasized the need for [professional] caregivers to be truthful about the possible benefits of life-sustaining treatments and not to offer false hope. Following family decisions to remove life support, it’s important for [professional] caregivers to support family decisions,” she adds, which may help reduce any long-term feelings of guilt.

Source: “Family Decision-Making to Withdraw Life-Sustaining Treatments from Hospitalized Patients,” Nursing Research; March-April, 2001; 50(2):105-115. Tilden VP, Tolle SW, Nelson CA, Fields J; School of Nursing and Center for Ethics in Health Care, Oregon Health Sciences University, Portland.

Key Findings:

HIGH STRESS

Families of patients who **had not provided an Advance Directive (AD)** experienced the **highest stress levels.**

MODERATE STRESS

Those who had received a **verbal AD** from their dying relatives reported more **moderate stress** after the death.

LOW STRESS

Family members whose loved ones had completed a **written AD** experienced the **lowest levels of stress.** These families reported “**a sense of peacefulness**” in having done the right thing.

both 1 to 2 months and 6 to 9 months following the death.

Reported levels of stress in all families were extremely high, similar to levels found in people who had survived disasters, and twice as high as levels reported by those whose homes had been destroyed recently by fire. Moreover, levels remained high for as long as 6 months after the hospitalized relative’s death.

The researchers also found that **families with no ADs to guide them were more likely than either clinicians or other families to favor futile, life-prolonging inter-**

Median Survival for Dementia May Be Shorter Than Previously Thought

Estimated median survival after the onset of dementia in elderly persons may be only 3.3 years, similar to the median survival for some of the most malignant diseases, says a Canadian research team. Previous studies of people with existing dementia have estimated survival at between 5 and 9.3 years, note the authors.

Because earlier studies may have excluded those with rapidly progressive dementia who died too soon after diagnosis to be included, the researchers estimated duration of survival from the onset of symptoms (derived mainly from the patient’s first presentation to a physician), and used a statistical adjustment to account for this “length bias.”

The team screened for cognitive impairment among all 10,263 participants in the Canadian Study of Health and Aging, a multicenter study of health problems in those 65 years of age and older, which was conducted across Canada in two phases between 1991 and 1996.

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RESEARCH MONITOR

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Of the 821 identified subjects (mean age, 83.8 years), 396 had probable Alzheimer's disease, 252 had possible Alzheimer's disease, and 173 had vascular dementia. While the unadjusted median survival for the group as a whole was 6.6 years, after adjustment, this dropped to 3.1 years.

After adjustment for length bias, median survival for the 3 groups was:

- 3.1 years (probable Alzheimer's disease)
- 3.5 years (possible Alzheimer's disease)
- 3.3 years (vascular dementia)

in the United States is predicted to quadruple in the next 50 years to include 1 in every 45 Americans. Therefore, there is a need for clarification not only of duration of survival, but also of the duration of each stage of dementia; current screening instruments may exclude mild cases or more slowly progressive disease. "Future progress in meeting the public health challenges of dementia should be measured not merely by the extension of the life expectancy of patients with severe dementia, but by improvements in the **quality of life for patients and their caregivers,**" they urge.

Source: "A Reevaluation of the Duration of Survival after the Onset of Dementia," *The New England Journal of Medicine*; April 12, 2001; 344(15):1111-1116. Wolfson C, Wolfson DB, Asgharian M, et al, for the *Clinical Progression of Dementia Study Group*; McGill University, Montreal. "Aging and the Public Health Effects of Dementia," *The New England Journal of Medicine*; April 12, 2001; 344(15):1160-1161. Kawas CH, Brookmeyer R; University of California, Irvine; Johns Hopkins University, Baltimore.

Informed Consent Process for Gastrostomy Tube Placement Found Inadequate

The quality of informed consent obtained for placement of gastrostomy tubes in patients near the end of life was found to be inadequate in a study of the process in a large community teaching hospital, **a finding that investigators believe can be generalized to other settings.**

South Carolina researchers retrospectively reviewed in detail the medical records of 154 consecutive adult patients (mean age, 71 years; female, 57%) who underwent placement of gastrostomy tubes in the context of chronic pro-

gressive illness between July 1, 1997 and June 30, 1998.

More than two-thirds of the patients had neurological diagnoses (acute stroke, 36%; chronic dementia, 20%; other, 15%). The non-neurological conditions (29%) included terminal cancer and advanced failure of one or more organ systems. Inhospital mortality was 17%; the cumulative 1-year mortality for the cohort was 50%.

"Our close reading of all medical chart notes suggested an inevitability about gastrostomy placement, with no consideration of alternatives," write the study authors. They note that the study hospital provided only a generic surgical consent form, with no space in which to record specific benefits, burdens, and alternatives related to a procedure such as permanent gastrostomy tube placement. "Although the written consent form is no substitute for meaningful discussions between physicians and patients or surrogates, a form requiring procedure-specific details could at least trigger such discussions more consistently," the authors observe.

They recommend that institutions offer preprinted informational materials to patients and families, noting that **other studies have shown that fully informed patients or their surrogates might decline tube feeding more often than expected.**

The authors also urge professional organizations to develop **educational campaigns to enhance physicians' understanding of the medical evidence, as well as the ethical and legal issues, surrounding medically administered nutrition at the end of life.**

Source: "The Adequacy of Informed Consent for Placement of Gastrostomy Tubes," *Archives of Internal Medicine*; March 12, 2001; Brett AS, Rosenberg JC; Center for Bioethics, University of South Carolina, and Department of Medicine, University of South Carolina School of Medicine, Columbia.

Key Findings:

Only 1 of the 154 medical records contained a physician's progress note documenting a discussion with the patient or surrogate decision-maker regarding the benefits and burdens of, and the alternatives to, permanent gastrostomy tube feedings.

Although 33 patients were judged to be clearly or probably competent, only 12 of these signed their own consent form; a surrogate decision-maker signed the consent form in the other 21 cases.

Of the 142 surrogate decision-makers authorizing gastrostomy placement, 34 did so by telephone, with a nurse signing the consent form, although the procedure was elective and most surrogates were family members living nearby.

PHYSICIAN RESOURCES

Palliative Care for Children: Resources for Pediatric Clinicians

Recent awareness of the need to improve the quality of care delivered to children with life-threatening disease has led a number of organizations to make best-known practices in the field of pediatric palliative care more widely available. Below are resources newly offered to health professionals caring for terminally ill children.

CANCER PAIN MANAGEMENT IN CHILDREN

www.childcancerpain.org/home.cfm

This website, funded by the Texas Cancer Council, presents up-to-date information on the assessment, management, and treatment of pain—including both pharmacological and nonpharmacological interventions—for health care providers working with children who have cancer. The content was created by pediatric palliative care experts from Texas Children's Hospital and Baylor College of Medicine, Houston.

Online sections include:

- What Is Pain?
- Etiology of Cancer Pain in Children
- Barriers to Effective Pain Management
- Assessment of Pain
- Pharmacologic Pain Management
- Procedure-Related Pain Management
- Nonpharmacological Pain Intervention
- The Dying Child

Most of the website contents are available in collected form as a printable handbook, "Pain Management in Children with Cancer."

COMPENDIUM OF PEDIATRIC PALLIATIVE CARE

This reference work was compiled by the Children's International Project on Palliative/Hospice Services, a project of the National Hospice and Palliative Care Organization (NHPCO). It offers comprehensive information on the care of children living with life-threatening conditions, and includes such topics as: defining the need for palliative care; program development; ethics and decision-making; and grief and bereavement.

The work is divided into four sections:

- Models of pediatric palliative care
- Communication
- Management of pain and other symptoms
- Psychosocial and spiritual care

The compendium can be purchased through the NHPCO's website, www.nhpco.org.

End-of-Life Care Websites

www.eperc.mcw.edu

End of Life Physician Education
Center (EPERC)

www.aahpm.org

American Academy of Hospice &
Palliative Medicine

www.epec.net

The EPEC Project (Education for
Physicians on End-of-Life Care)

www.nhpco.org

National Hospice & Palliative Care
Organization (formerly the NHO)

www.hospicefoundation.org

Hospice Foundation of America

www.americanhospice.org

American Hospice Foundation

www.hpna.org

The Hospice and Palliative Care
Nurses Association

www.medicaring.org

Center to Improve Care of the Dying

www.abcd-caring.org

Americans for Better Care
of the Dying

www.lastacts.org

Last Acts Coalition

www.mcw.edu/pallmed/

Palliative Medicine Program at the
Medical College of Wisconsin

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

Online community for end-of-life care

www.partnershipforcaring.org

America's Voices for the Dying

Upcoming Meetings for Clinicians Interested in End-of-Life Care Education

16th Management and Leadership Conference, Hospice and Palliative Care: Evidence, Advocacy and Action. September 23-26, 2001, Hyatt Regency Crystal City, Arlington, VA. Sponsor: National Hospice and Palliative Care Organization. Phone: 703-837-1500. Website: www.nhpc.org

Palliative Care Fall Forum 2001. October 7-9, 2001, Chicago Downtown Marriott Hotel, Chicago. Sponsor: Center to Advance Palliative Care. Phone: 212-241-9090. Website: www.capcmssm.org

American Board of Hospice and Palliative Medicine Certification Exam in Hospice and Palliative Medicine. October 13, 2001, multiple US cities. Sponsor: ABHPM; Website: www.abhpm.org. Contact: Professional Testing Corporation; Phone: 212-356-0660; Website: www.ptcny.com

Canadian Palliative Care Conference 2001: An Odyssey — Personal and Professional Journeys in Hospice Palliative Care. October 21-24, 2001, Victoria Conference Centre, Victoria, BC. Sponsor: Victoria Hospice Society. Contact: Focus Conferences; Fax: 250-598-4863.

Program in Palliative Care Education and Practice. November 14-20, 2001, Boston, MA. Sponsor: Harvard Medical School. Contact: Eve Panzera; Fax: 617-726-2691; E-mail: epanzera@partners.org; Website: www.hms.harvard.edu/cdi/pallcare

21st Annual Scientific Meeting of the American Pain Society. March 14-17, 2002, Baltimore Convention Center, Baltimore MD. Sponsor: American Pain Society. Phone: 847-375-4715; Fax: 877-734-8758; Website: www.ampainsoc.org/meeting

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