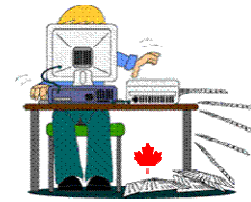


Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice, palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry.

30 November Edition | Issue #125



Compilation of Media Watch 2008, 2009 ©

Compiled & Annotated by Barry R. Ashpole

Death and dying: Scroll down to [Specialist Publications](#) for selected articles published in a theme-specific issue of the *British Medical Journal*. (p.6)

Canada

Patients weigh in on hospital-to-home transitions

ONTARIO | The Change Foundation online posting – 28 October 2009 – After listening to elderly patients and caregivers describe what works – and doesn't – during the move from hospital to home or long-term care, and learning from an analysis of all the steps and decisions in those transitions ... hospitals and community care access centres involved in a quality improvement project in two regions in Ontario have introduced changes to ease patient transitions and provide better value and better care.¹ <http://www.changefoundation.ca/news.html#HTS>

1. *Having their say and choosing their way: Helping patients and caregivers move from hospital to home:* <http://www.changefoundation.ca/docs/HTScommentary.pdf>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NOVA SCOTIA | *Chronicle-Herald* – 29 November 2009 – **'Death tourism just one worry of opponents to euthanasia bill.'** Canada might be a popular destination for "death tourism" if a private member's bill that would legalize euthanasia and assisted suicide is approved by the House of Commons, a public meeting in Halifax heard Saturday. <http://thechronicleherald.ca/Metro/1155152.html>
- ONTARIO | *The Interim* – 25 November 2009 – **'Expert in palliative care discusses realities of euthanasia, assisted suicide.'** The week before a parliamentary debate took place on euthanasia and assisted suicide [see sidebar] one of the country's experts on palliative care spoke to a group of concerned citizens in Ottawa about the issue. <http://www.theinterim.com/issues/expert-in-palliative-care-discusses-realities-of-euthanasia-assisted-suicide/>

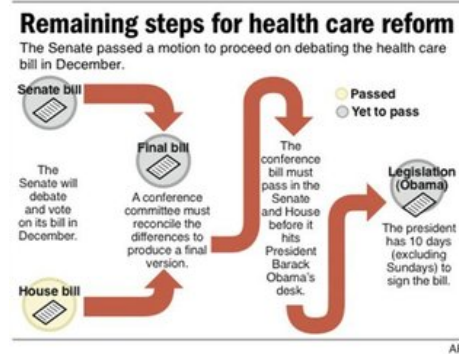
Parliamentary note

The second hour of debate on the Private Member's Bill C-384 that would decriminalize assisted suicide has been rescheduled and will take now place 2 February 2010, with the vote the following day.

U.S.A.

Understanding the pros and cons of health overhaul

WASHINGTON DC | Association Press – 28 November 2009 – Maybe you've been reading the health care bill in your spare time. Then perhaps you can answer this question: If Congress makes history and puts a bill on President Barack Obama's desk by Christmas, how long before the uninsured get medical coverage? If you said three years or more, you'd be right. Yet many people don't realize that to keep costs down, lawmakers made compromises that might not appeal to consumers. "There's going to be a long period of great expectations and very modest deliveries," said economist Robert Reischauer, president of the Urban Institute public policy center. <http://www.miamiherald.com/living/health/healthAP/story/1355405.html>



Families can't afford cost of dying

NEW MEXICO | KRQE (Albuquerque) – 24 November 2009 – In a sign of how tough times are for some people, the Office of the Medical Investigator [OMI] reports it is being forced to keep corpses longer than usual because more families cannot afford funerals. On average, OMI holds around 75 sets of remains that are waiting to be claimed. But recently they've had as many as 110. <http://www.krqe.com/dpp/news/business/families-cant-afford-cost-of-dying>

Hope vs. acceptance

Patients who don't accept state of illness can get depressed

FLORIDA | *Palm Beach Daily News* – 23 November 2009 – People who never give up can hope themselves into a deep hole. A new study ... supports this assumption.¹ The authors found that those who gave up hope that their medical condition would change led happier lives. The study concluded that people who believe their situations can or will change don't accept the reality they are in. That's the wrong approach, says Dr. Gail Austin Cooney, the president of the American Academy of Hospice & Palliative Medicine. "I think the authors err in describing the difference as being a 'loss of hope.' It has much more to do with the positive virtue of acceptance." http://www.palmbeachdailynews.com/news/content/news/2009/11/23/HEALTH_SusmanPatientHope_1124.html

1. *HEALTH PSYCHOLOGY*, 2009;28(6):787-791. '**Happily hopeless: Adaptation to a permanent, but not to a temporary, disability.**' Knowing an adverse situation is temporary can interfere with adaptation, leading to a paradoxical situation in which people who are better off objectively are worse off subjectively. <http://psycnet.apa.org/index.cfm?fa=buy.optionToBuy&id=2009-20990-017&CFID=26275091&CFTOKEN=14389928>

Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/>

Elders happier with family care vs. professional

VIRGINIA | *News Leader* – 23 November 2009 – Lots of families, at some point, will battle with a decision about how best to provide long-term care for an elderly parent. A new study co-authored by University of Virginia economics professor Steven Stern suggests that you shouldn't assume a home-care professional can better care for your parent than you can.¹ Elder parents are more likely to describe themselves as "happy" when they are receiving informal in-home care than when they receive formal in-home care from a nurse, home health aide or other home care professional. <http://www.newsleader.com/article/20091123/NEWS01/91123003/1002/news01/Elders+happier+with+family+care+vs.+professional>

1. *International Economic Review*, 2009;50(4):1205-1242. **'Formal home health care, informal care and family decision making.'** <http://www3.interscience.wiley.com/journal/122663094/abstract>

Of related interest:

- NEW JERSEY NEWS ROOM | Online report – 27 November 2009 – **'The Sandwich Generation: Modern dilemma of elder care.'** More than 25% of American families are involved in elder/parent care at some level. Today, the baby boomers are the "heart" of the sandwich generation. To understand the significance of the Sandwich Generation, one needs to realize that the Sandwich Generation is the largest segment of our population. Who are these sandwich generationers? <http://www.newjerseynewsroom.com/healthquest/the-sandwich-generation-the-modern-dilemma-of-elder-care>

International

Children's palliative care plea

AUSTRALIA | *The Age* – 30 November 2009 – Victorian children are suffering more than they should because of a lack of funding for pain management programs at the Royal Children's Hospital. Pediatric rheumatologist, Jane Munro, told a bioethics conference last week that although pain management had improved significantly at the hospital in recent years, a key barrier was lack of funding for specialist programs. Dr Munro said that in recent years, doctors had argued for more money for the specialty without success, and that hospital staff could and should be doing more to ease children's pain. <http://www.theage.com.au/national/childrens-palliative-care-plea-20091129-jywl.html>

Saving the dying from futile care

AUSTRALIA | *Sydney Morning Herald* (OpEd) – 30 November 2009 – There are many ways for the dying to die. As the South Australian Parliament wrestles with voluntary euthanasia ... perhaps we should also examine options that are presently lawful to save the dying from devotion that they don't need or want. Voluntary euthanasia was rejected in South Australia by vote of 11 to 9 in the Legislative Council so we need to look at other options. Other than euthanasia, there are two main escapes for the dying from pointless and invasive medical intervention. The first is the voluntary refusal of medical treatment and the second is the doctor made decisions about withholding futile treatment. <http://www.smh.com.au/opinion/blogs/godless-gross/saving-the-dying-from-futile-care/20091127-jw5y.html>

Quotable Quotes

Get a feedback loop and listen to it. Your feedback loop can be this dorky spreadsheet thing I did, or it can just be one great man who tells you what you need to hear. The hard part is the listening to it. Randy Pausch (1960-2008)

Discovering life in vegetative patients

THE NETHERLANDS | NRC Handelsblad – 25 November 2009 – For 23 years, doctors thought Rom Houben was brain dead. But, neurologist Steven Laureys found the Belgian was very much awake. Experts say up to 40% of those thought to be in a persistent vegetative state are ... quite conscious. http://www.nrc.nl/international/Features/article2422536.ece/Discovering_life_in_vegetative_patients

Of related interest:

- KOREA | *Korea Times* – 29 November 2009 – '**Law unnecessary for treatment of comatose.**' The Constitutional Court ... rejected a petition seeking legislation that would allow suspension of medical treatment for a comatose patient with little chance of recovery. In rejecting the petition, the court said the suspension of treatment should be determined by the patient, not by law. http://www.koreatimes.co.kr/www/news/nation/2009/11/117_56355.html

Cost of providing free care for elderly up 11%

U.K. (SCOTLAND) | *Times* – 24 November 2009 – [There has been] a significant rise in the costs of free care for the elderly in Scotland ... with expenditure on elderly people living in their own homes up 15% in the last year, and almost double what it was four years ago. The total cost of providing the policy, both at home and in nursing establishments, rose by 11% in the last year to £358 million. The figures appear to add weight to those who claim that the policy is unsustainable in the long term, especially if public spending falls in the coming years. Shona Robison, the Public Health Minister, defended the figures, saying the policy improved the lives of more than 50,000 vulnerable elderly people. <http://www.timesonline.co.uk/tol/news/uk/scotland/article6929850.ece>

Liverpool Pathway

Fighting for a peaceful, pain-free death

U.K. | *Daily Telegraph* – 23 November 2009 – The [Liverpool] Pathway [LCP] was caught in a blaze of controversy ... when a group of doctors wrote to *The Daily Telegraph* claiming it was the cause of elderly and sick patients dying prematurely. The option to withdraw food and fluids became a particular focus for public concern, leaving many elderly and terminally ill people ... frightened they might spend their last days starved and dehydrated. In a further disturbing twist, a national audit of the LCP revealed ... that more than a quarter of families were not informed when their relatives were moved onto the Pathway. The architects of the LCP are seeking to address these concerns with a revised version of the guidelines. They will include the requirement that patients and their families are consulted before the LCP is commenced, and will stipulate that food, fluids and non-palliative medication should be withdrawn only if they are harmful or burdensome to a dying patient. <http://www.telegraph.co.uk/health/6613732/Fighting-for-a-peaceful-pain-free-death.html>

Of related interest:

- U.K. | *Nursing Times* – 24 November 2009 – '**Call for mandatory training in care of the dying patient.**' End of life care experts are to call for all healthcare staff to receive mandatory training in how to care for patients nearing the end of their lives. <http://www.nursingtimes.net/whats-new-in-nursing/primary-care/call-for-mandatory-training-in-care-of-the-dying-patient/5008729.article>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NETHERLANDS | NRC Handelsblad – 30 November 2009 – **'Euthanasia law is no cure-all for Dutch doctors.'** Anthropologist and lawyer Anne-Marie talks about the Dutch euthanasia law in practice. http://www.nrc.nl/international/Features/article2425897.ece/Euthanasia_law_is_no_cure-all_for_Dutch_doctors
- FRANCE | Panorama – 27 November 2009 – **'France against euthanasia.'** Parliamentarians rejected the draft of a law to make euthanasia legal. 326 French deputies voted against the draft and 202 for. <http://www.panorama.am/en/society/2009/11/25/french-parliament/>
- RADIO NETHERLANDS | Online report – 26 November 2009 – **'Euthanasia still a taboo for mental patients...'** People suffering from an incurable mental disease have the same legal right to euthanasia as physically terminally ill patients in The Netherlands, but they almost never get it. <http://www.rnw.nl/english/article/euthanasia-still-taboo-mental-patients-even-netherlands>
- U.K. | *Times* – 25 November 2009 – **'Legalise assisted...'** Contradicting the Church's official stance on the issue, the Rev. Dr John Cameron praised the work of Dignitas, the Swiss-based assisted suicide group, and accused Britain of "exporting" its ethical dilemma overseas. <http://www.timesonline.co.uk/tol/news/uk/scotland/article6930246.ece>

Specialist Publications (e.g., in-print and online journal articles, reports, etc.)

U.S. health care reform

Home is where the health is: Advancing team-based care in chronic disease management

ARCHIVES OF INTERNAL MEDICINE, 2009;169(21):1945-1948. As the nation once again engages in discussions of health reform, issues of quality and cost containment are high on the agenda. One approach to addressing these challenges is team-based delivery of health care services, including physicians and allied health professionals working collaboratively. The imperative to consider team-based care is fueled by the unrelenting escalation in health care costs in the care of the chronically ill covered by Medicare; in the error-prone features of the current fragmented delivery system; and by the shortage of primary care physicians. In 2003, the Institute of Medicine recommended that "all health professionals should be educated to deliver patient-centered care as members of an interdisciplinary team, emphasizing evidence-based practice, quality improvement approaches, and informatics." <http://archinte.ama-assn.org/cgi/content/extract/169/21/1945>

Of related interest:

- BMC PALLIATIVE CARE | Online article – 28 November 2009 – **'Out-of-hours palliative care provided by GP co-operatives: availability, content and effect of transferred information.'** Out-of-hours GP care in England, Denmark and the Netherlands has been reorganised and is now provided by large scale GP co-operatives. Adequate transfer of information is necessary in order to assure continuity of care, which is of major importance in palliative care. The authors conducted a study to assess the availability, content and effect of information transferred to the GP co-operatives. <http://www.biomedcentral.com/content/pdf/1472-684x-8-17.pdf>
- *JOURNAL OF PROFESSIONAL NURSING*, 2009;25(6):363-368. **'Policy issues in end-of-life care.'** The purpose of this policy brief is to bring attention to the urgent systems-level matters that impede progress in improving end-of-life care in the U.S. Recommendations for policy changes are suggested, and nursing's role in advocating for policy change is explored. [http://www.professionalnursing.org/article/S8755-7223\(09\)00137-9/abstract](http://www.professionalnursing.org/article/S8755-7223(09)00137-9/abstract)

Death and dying

BRITISH MEDICAL JOURNAL, 2009;339(7732). The main theme of this issue is death and dying containing several articles that add to the debate about public policy and also throw light on to the nuances of private thoughts and behaviour:

- **Editorial:** 'Dying and death.' http://www.bmj.com/cgi/content/extract/339/nov26_1/b5044
- **OpEd:** 'New interim guidance on assisted suicide.' http://www.bmj.com/cgi/content/extract/339/nov26_1/b4900
- **Letters (The Liverpool Pathway):** 'The price of silence: 18 Liverpool consultants reply.' http://www.bmj.com/cgi/content/extract/339/nov24_3/b4981
 - **Author's reply:** http://www.bmj.com/cgi/content/extract/339/nov24_3/b4986
- **News:** 'Dutch legal protection scheme for doctors involved in mercy killing of babies receives first report.' <http://www.bmj.com/current.dtl>
- **Analysis:** 'Are advance directives legally binding or simply the starting point for discussion on patients' best interests?'
 - Case study: http://www.bmj.com/cgi/content/extract/339/nov26_1/b4667
 - Medical opinion: http://www.bmj.com/cgi/content/extract/339/nov26_1/b4697
 - Legal advice: http://www.bmj.com/cgi/content/extract/339/nov26_1/b4693
 - Ethical view: http://www.bmj.com/cgi/content/extract/339/nov26_1/b4695
- **Research:** 'Concept of unbearable suffering in context of ungranted requests for euthanasia: qualitative interviews with patients and physicians.' http://www.bmj.com/cgi/content/abstract/339/nov16_1/b4362
- **Personal view:** 'Letting go.' http://www.bmj.com/cgi/content/extract/339/nov24_2/b4982

Care alternatives in prison systems

CRIMINAL JUSTICE & BEHAVIOR, 2009;36(6):620-634. The authors examined age at the end of prison sentence, race, and psychosocial factors on end-of-life treatment preferences among ... male inmates ... from the Alabama Aged & Infirm Correctional Facility. All measures ... were administered in an interview format. A significant amount of variance in treatment preferences for cardiopulmonary resuscitation, feeding tube, and palliative care was predicted by race, lifer status, and death anxiety. Inmates who were members of minority groups, non-lifers, and those with high death anxiety expressed greater desire for a feeding tube, whereas inmates who were Caucasian or lifers expressed a greater desire for palliative care. Given the aging of the inmate population and increasing health care costs ... exploration of end-of-life treatment preferences among older inmates is warranted. <http://cjb.sagepub.com/cgi/content/abstract/36/6/620>

Of related interest:

- **USA TODAY** | Online report – 30 November 2009 – '**Inmates assist ill and dying fellow prisoners in hospices.**' Four times a week, [Animal] Durbin, 51, who's serving 140 years for armed robbery at Louisiana State Penitentiary, meets with frail, dying inmates at the prison's Treatment Center. He bathes them, provides other personal care and often squeezes skeletal hands as their bodies succumb to shriveled livers or stomach cancer. It's the best job he has ever had, he said. http://www.usatoday.com/news/nation/2009-11-29-prison-hospices_N.htm

N.B. Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. For those interested in prison hospice, a compilation of these articles and reports in a single document is available on request.

The right to die: does the state lose an interest in a dying patient's life?

INTERNATIONAL JOURNAL OF LIABILITY & SCIENTIFIC ENQUIRY, 2009;2(4):447-470. In 2008, Washington approved a Death with Dignity Act modelled after a similar law enacted in Oregon in 1993. These laws allow terminally ill patients to seek Physician Assisted Suicide. The U.S. Supreme Court has not acknowledged a fundamental right to die and opponents of the [two] ... Acts have sought to strike these statutes down as being unconstitutional. This comment evaluates the similarities between Washington and Oregon's statute and proposes that the U.S. Supreme Court recognise that the state may have a declining interest in a terminally ill patient's life. http://www.inderscience.com/search/index.php?action=record&rec_id=29355&prevQuery=&ps=10&m=or

Of related interest:

- *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2009;181(11):825-826. **'Euthanasia debate reignited.'** It is notable that after all the years of discussions that followed the Sue Rodriguez case, we are still insinuating that "pain so intense" (which painkillers do not alleviate) leads near-death patients to ask that their life be ended. <http://www.cmaj.ca/cgi/reprint/181/11/825-c>
- *ONCOLOGY ISSUES*, 2009;November-December:8-11. **'At the very end of life.'** Empowering terminally ill cancer patients with the option of aid in dying. http://www.accc-cancer.org/oncology_issues/articles/novdec09/ND09-Issues.pdf

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy tool or change document.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Paradoxes in advance care planning: The complex relationship of oncology patients, their physicians, and advance medical directives

JOURNAL OF CLINICAL ONCOLOGY | Online article – 23 November 2009 – Many seriously ill patients with cancer do not discuss prognosis or advance directives (ADs), which may lead to inappropriate and/or unwanted aggressive care at the end of life. Ten years ago, patients with cancer said they would not like to discuss ADs with their oncologist but would be willing to discuss them with an admitting physician. The authors assessed whether this point of view still held. Fewer than half of seriously ill patients with cancer [interviewed] admitted to an oncology service have an AD. Only 23% would like to discuss their ADs with their oncologist but nearly all supported a policy of discussing ADs with their admitting physician. However, fully 48% actually preferred to discuss advance directives with their oncologist if AD discussion was necessary. <http://jco.ascopubs.org/cgi/content/abstract/JCO.2009.24.6397v1>

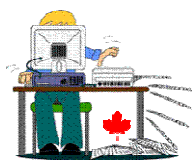
Factors that influence the presence of a hospice in a rural community

JOURNAL OF NURSING SCHOLARSHIP, 2009;41(4):420-428. Given the increasing numbers of patients and families who will be facing end-of-life care issues across the globe, access to hospice care is a significant end-of-life outcome. The most rural communities are least likely to have a Medicare-certified hospice. The higher the physician rate, the more likely a county is to have a Medicare-certified hospice. The Medicare Hospice Benefit's regulations requiring a physician's certification of terminal illness may be creating a barrier to hospice care, especially in rural communities. In this study, racial-ethnic diversity decreased as the rural-urban classification progressed from metropolitan (least rural) to rural-adjacent to metro to rural-nonadjacent (the most rural). The availability of Medicare-certified hospices in the metro and rural nonadjacent counties was influenced by the minority composition of the county. More research is needed on how the interaction of rurality, race-ethnicity, and physician access may affect access to hospice in rural communities. <http://www3.interscience.wiley.com/journal/123190031/abstract>

Of related interest:

- *THEORETICAL MEDICINE & BIOETHICS* | Online article – 27 November 2009 – '**On the notion of home and the goals of palliative care.**' This paper is based upon the intuitively positive connotation of the term "home." By metaphorically describing the goal of palliative care as "the patient's coming home," it wants to contribute to a medical humanities approach of medicine. It is argued that this metaphor can enrich our understanding of the goals of palliative care and its proper objectives. http://www.ncbi.nlm.nih.gov/pubmed/19943192?itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum&ordinalpos=1
- UNIVERSITY OF IOWA CENTER ON AGING | Online report – Accessed 27 November 2009 – '**Elder caregiving in rural communities.**' This recent U.S. report provides an overview of the rural caregiving population, information about the role of technology in delivering services ... [and] examples of promising practices ... and policy implications for helping elders and their caregivers. <http://www.centeronaging.uiowa.edu/archive/pubs/Elder%20Caregiving%20in%20Rural%20Communities.htm>

Barry R. Ashpole



My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops, for frontline care providers.

Worth Repeating

Reciprocal suffering

The need to improve family caregivers' quality of life through palliative care

JOURNAL OF PALLIATIVE MEDICINE, 2009;1(4):357-366. There is growing recognition of the reciprocity of suffering by patients and families experiencing terminal illness and the need to improve the quality of their lives as the patient's illness progresses. Research is presented that addresses the importance of a dyadic perspective in recognizing patients' and families' stress and adjustment and the related physical, emotional, social, spiritual and financial needs at the end-of-life. These aspects of quality of life are specifically addressed by palliative care. The philosophy and goals of palliative care are described, as is its role in promoting the best possible quality of life for patients and their families experiencing terminal illness. This article addresses the importance of assessing the dynamics of the family caregiving system and potential palliative care interventions to enhance the quality of life of family caregivers. Implications for research are also discussed. <http://www.liebertonline.com/doi/abs/10.1089/jpm.1998.1.357>

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