Media Watch...
is intended as an advocacy and research tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in hospice and palliative care, and in the quality of end-of-life care in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

25 November 2013 Edition | Issue #333


Compiled & Annotated by Barry R. Ashpole

Canada

Patient rights vs. health provider obligations

Nursing staff who stop feeding woman risk charges: Lawyer

BRITISH COLUMBIA | The Vancouver Sun – 19 November 2013 – Nursing home staff would be helping an Abbotsford Alzheimer’s patient commit suicide if they stopped feeding her, risking criminal charges of culpable homicide, a lawyer representing the provincial government in a B.C. Supreme Court case says. "To the extent that (the patient's living will) constitutes an instruction to assist her in committing suicide, it cannot be enforced without the commission of an offence."

"The lawsuit is expected to be precedent-setting as it should clarify end-of-life rights of patients and obligations of health providers."

http://www.vancouversun.com/health/Patient+family+sues+B.C.+as+nursing+home+keeps+her+alive+against+her+wishes/8756167/story.html

Specialist Publications

'Commentary on 'The standard of care and conflicts at the end of life: A review of decisions by the Ontario Consent & Capacity Board' (p.13), in Journal of Critical Care.'
**U.S.A.**

Views on end-of-life medical treatments

Growing minority of Americans say doctors should do everything possible to keep patients alive

PEW RESEARCH CENTER | Online – 21 November 2013 – At a time of national debate over health care costs and insurance, a Pew Research Center survey on end-of-life decisions finds most Americans say there are some circumstances in which doctors and nurses should allow a patient to die. At the same time, however, a growing minority says medical professionals should do everything possible to save a patient's life in all circumstances. When asked about end-of-life decisions for other people, two-thirds of Americans say there are at least some situations in which a patient should be allowed to die, while nearly a third say medical professionals always should do everything possible to save a patient's life. Over the last 25 years, the balance of opinion has moved modestly away from the majority position on this issue. While still a minority, the share of the public that says doctors and nurses should do everything possible to save a patient's life has gone up 9 percentage points since 2005 and 16 points since 1990.

http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/

Who will care for America's aging population?

THE WASHINGTON POST | Online OpEd – 21 November 2013 – Nearly 70% of Americans who reach age 65 will, at some point, be unable to care for themselves without assistance. Issues of long-term care also affect millions of younger people with significant cognitive or physical functional limitations. Yet long-term care gets neither the public attention nor the policy focus that it deserves. The scope of the challenge before our nation was summed up by the Commission on Long-Term Care. In its final report to Congress, the federally appointed bipartisan group wrote that in today's system, services and supports "are highly fragmented and difficult for individuals and family caregivers to access" and that the system "lack[s] the focus and coordination across agencies and providers necessary to ensure the best outcomes for the person and family." Services are also "provided in ways that can be expensive and inefficient."


Specialist Publications


'Futile treatment in intensive care burdens other patients' (p.12), in Medscape Medical News.

'Few U.S. public health schools offer courses on palliative and end-of-life care policy' (p.14), in Journal of Palliative Medicine.
1. ‘Commission on Long-Term Care,’ Report to Congress, September 2013. 
   http://www.ltccommission.senate.gov/Commission%20on%20Long-Term%20Care-
   %20Final%20Report%209-26-13.pdf

Of related interest:

- **THE NEW YORK TIMES** | Online – 21 November 2013 – *Work, women and caregiving.*
  Trying to hold onto a job while caring for a family member is a tough juggling act. Caregivers 
  sometimes have to arrive late or leave early, cut back to part-time work, and decline travel and 
  promotions. For women, these competing responsibilities may prove particularly perilous, a re-
  cent study suggests. Women who are caregivers are also significantly less likely to be in the 
  labour force, compared to women who are not caregivers. Yet, for men, caregiving has no im-
  caregiving/?ref=health&_r=0

1. ‘More caregiving, less working: Caregiving roles and gender difference,’ Journal of Applied 
   Gerontology, published online 5 November 2013. Findings of this study have implications 
   for supporting caregivers, especially women, to balance work and caregiving commitments. 
   http://jag.sagepub.com/content/early/2013/10/29/0733464813508649.abstract

**Preserving voicemails helps modern grieving process**

MASSACHUSETTS | The Boston Globe – 20 November 2013 – If grief has a modern form, 
mourning the lost voicemail is surely it. The very technology that allows bereaved friends and 
relatives to feel, if only temporarily, closer to the departed can just as easily sweep away that 
connection. There are ways to permanently save voicemails, but most people do not think like 
archivists. Messages disappear in system upgrades. They are deleted by companies intent on 
keeping subscribers’ inboxes within preset limits. They go missing during carrier-to-carrier 
switches. Sometimes they are there, somewhere, but wrongly believed irretrievable. Within the 
past decade, voicemail has become reviled as a time waster in the age of texts and e-mail. But at 
the same time, holding onto a lost loved one’s voice has become so important that many people 
save and resave messages for years to prevent automatic deletion. Others pay to keep alive a 
dead relative’s phone contract so they can listen – and listen again – to the outgoing message. 
http://www.bostonglobe.com/lifestyle/style/2013/11/20/grief-has-modern-form-mourning-lost-
voicemail-from-deceased-loved-one-surely/RQDlIvFuavZbzTxQEAIyJ/story.html

“do not hospitalize”

**A misunderstood directive**

THE NEW YORK TIMES | Online – 20 November 2013 – Dr. [Michael] Rothberg stopped to col-
lect himself as he spoke about this dementia patient, his father-in-law. After another difficult hos-
pitalization, this time for pneumonia, the family decided they didn’t want this vulnerable, dis-
tressed relative transferred from the nursing home again if he took ill. They asked that a "do not 
hospitalize" order be communicated to staff and placed in his medical record. Several months 
later, the patient stopped eating and drinking and passed away. Now, Dr. Rothberg and col-
leagues in Pennsylvania and Massachusetts have written a new paper on this little known, poorly 
understood medical directive.1 The key findings? Often, proxies are confused about how "do not 
hospitalize" orders work. Several proxies believed, mistakenly, that such an order was equivalent 
to a request to withhold medical intervention altogether.” And a physician’s willingness to recom-
 mend it makes a difference. http://newoldage.blogs.nytimes.com/2013/11/20/a-misunderstood-
directive/

1. ‘Do-not-hospitalize orders for individuals with advanced dementia: Healthcare proxies’ per-
Patient-centered care: Pairing medicine, compassion

CALIFORNIA | San Francisco Chronicle (Commentary) – 19 November 2013 – The 80-year-old woman was so riddled with cancer that her entire rib cage snapped as my co-resident performed CPR. We had all known that she would die during this stay in the hospital, but our attending physician had not signed a "Do not resuscitate" order. Without this order, we felt obliged to engage in this final act of futility. This story didn't end well. The woman remained dead as we continued to compress her tiny chest and flood her body with chemicals designed to jump-start her heart. By the time we called for the code to end, she lay on the bed, naked and exposed, looking like the victim of an assault. Something changed in me that day. As I continued my critical care training, I became increasingly distressed by the ethos in the intensive care unit that life should be prolonged over all other considerations. We believed that our role was to stretch every patient's life span to its physiologic limit. I always felt uncomfortable with cases like these, but I didn't know there were other options. Then, during my early years as an ICU attending physician, I was introduced to the concept of patient-centered care. http://www.sfgate.com/health/article/Patient-centered-care-pairing-medicine-4994529.php

Specialist Publications

'Compassion in healthcare' (p.10), in Clinical Ethics.

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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 and research tool.

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.
How doctors die: Showing others the way

THE NEW YORK TIMES |Online – 19 November 2013 – Brave. You hear that word a lot when people are sick. It's all about the fight, the survival instinct, the courage. But when Dr. Elizabeth D. McKinley's family and friends talk about bravery, it is not so much about the way Dr. McKinley, a 53-year-old internist from Cleveland, battled breast cancer for 17 years. It is about the courage she has shown in doing something so few of us are able to do: stop fighting. When it comes to dying, doctors, of course, are ultimately no different from the rest of us. And their emotional and physical struggles are surely every bit as wrenching. But they have a clear advantage over many of us. They have seen death up close. They understand their choices, and they have access to the best that medicine has to offer. There is no statistical proof that doctors enjoy a better quality of life than the rest of us. But research indicates they are better planners. But without some basic understanding of the road ahead, Dr. Anthony L. Back, a University of Washington professor and palliative care specialist, said even sophisticated patients could end up where they least want to be: the ICU. "They haven't realized the implications of saying 'Yeah, I'll have one more treatment. Yeah, I'll have chemotherapy,'" Dr. Black said. But the end-of-life choices Americans make are slowly shifting. Medicare figures show that fewer people are dying in hospital – nearly a 10% dip in this last decade – and that there has been a modest increase in hospice care. At the same time, palliative care is being embraced on a broad scale, with most large hospitals offering services. [http://www.nytimes.com/2013/11/20/your-money/how-doctors-die.html](http://www.nytimes.com/2013/11/20/your-money/how-doctors-die.html)

Physician perspectives on end-of-life care

'How to die like a doctor,' Forbes, 7 March 2012. [Noted in Media Watch, 12 March 2012, #244 (p.3)]
http://www.forbes.com/sites/carolynmcclanahan/2012/03/07/how-to-die-like-a-doctor/

'Doctors do die differently...' Forbes, 2 March 2012. [Noted in Media Watch, 5 March 2012, #243 (p.2)]
http://www.forbes.com/sites/carolynmcclanahan/2012/03/02/doctors-do-die-differently-how-we-make-certain/

The second Forbes article cites 'Why doctors die differently,' The Wall Street Journal, 25 February 2012.
http://online.wsj.com/article/SB1000142405297020391830457724332124283962.html

'How doctors choose to die,' The Guardian (U.K.), 19 February 2012. [Noted in Media Watch, 27 February 2012, #242, p.8]
http://www.guardian.co.uk/theguardian/shortcuts/2012/feb/19/death-and-dying-doctors

'Why MOST doctors like me would rather DIE than endure the pain of treatment we inflict on others for terminal diseases: Insider smashes medicine's big taboo,' The Daily Mail (U.K.), 14 February 2012. [Noted in Media Watch, 27 February 2012, #242 (p.8)]

'Terminal illness: What doctors don't tell you,' The Star (South Africa), 15 February 2012. [Noted in Media Watch, 20 February 2012, #241, (p.5)]
http://www.iol.co.za/the-star/terminal-illness-what-doctors-don-t-tell-you-1.1234701

'What doctors know – and we can learn – about dying,' Time Magazine (U.S.), 16 January 2012. [Noted in Media Watch, 23 January 2012, #237 (p.2)]
http://ideas.time.com/2012/01/16/what-doctors-know-and-we-can-learn-about-dying/?xid=gonewsedit

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Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a 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 college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: [http://www.ipcrrc.net/barry-r-ashpole.php](http://www.ipcrrc.net/barry-r-ashpole.php)
End-of-life care in Australia

Call to end inequity in palliative care

AUSTRALIA | Australian Ageing Agenda – 20 November 2013 – Palliative Care Australia has called for end of life care to be delivered according to need rather than disease type, following new statistics showing a high concentration of services among cancer patients. According to an Australian Institute of Health & Welfare report, 58% of palliative care patients in hospital had a principal diagnosis of cancer, compared with just 0.4% of patients with dementia. Dementia is Australia's third leading cause of death. "It is vital that referring clinicians recognise that palliative care can benefit those with a variety of diseases, and equally vital that services are funded to provide this care," said CEO of Palliative Care Australia, Dr. Yvonne Luxford. She said heart disease is Australia's leading cause of death yet it accounted for only 14.6% of palliative care admissions to hospital. Dr. Luxford said the latest international research shows that around 70% of people who die each year would benefit from access to palliative care services but Australia was falling below this benchmark.


GPs [in the U.K.] take on extra role for frailest patients

U.K. (ENGLAND) | BBC News – 15 November 2013 – The million most frail patients in England are to be identified and given a named GP to co-ordinate their care. The move has been agreed to by the British Medical Association and NHS [National Health Service] England in talks over next year's GP contract. Ministers had been pushing for doctors to take greater responsibility for the most vulnerable patients in society to relieve pressure on hospitals. A third of emergency admissions are among the over-75s – many of which could be avoided if they received earlier and better care in the community. http://www.bbc.co.uk/news/health-24945134

Noted in Media Watch, 21 January 2013, #289 (p.8):

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **IRELAND | The Irish Times** (Dublin) – 22 November 2013 – *'Cabinet may set up expert group on assisted suicide, Gilmore says.'* Tánaiste [deputy prime minister] Eamon Gilmore has said he will discuss with Cabinet colleagues commissioning an expert report on assisted suicide. Mr. Gilmore was responding in the Dáil [lower house of the Irish parliament] to Independent TD [Teachta Dála, a member of the lower house] Stephen Donnelly, who suggested the expert report. The Tánaiste said he agreed members of the House should deal with the issue as legislators. [http://www.irishtimes.com/news/politics/oireachtas/cabinet-may-set-up-expert-group-on-assisted-suicide-gilmore-says-1.1602665](http://www.irishtimes.com/news/politics/oireachtas/cabinet-may-set-up-expert-group-on-assisted-suicide-gilmore-says-1.1602665)

- **IRELAND | ITV News** (Dublin) – 20 November 2013 – *'Irish woman faces trial over assisted suicide.'* A woman is to stand trial in Ireland charged with assisting the suicide of a multiple sclerosis sufferer in what is believed to be the first case of its kind in the country. In Ireland, a conviction for assisted suicide can carry a sentence of up to 14 years. The Irish Supreme Court ruled in May that there is no right to assisted suicide in the country. [http://www.itv.com/news/update/2013-11-20/irish-woman-faces-trial-over-assisted-suicide/](http://www.itv.com/news/update/2013-11-20/irish-woman-faces-trial-over-assisted-suicide/)

- **U.K. | BBC News** – 19 November 2013 – *'Assisted Dying Bill takes a rest.'* Former lord chancellor Lord Falconer’s Assisted Dying Bill won’t make it to the wicket in this parliamentary session; but it’s in pole position for the new parliamentary year which beings in May. The Labour peer tabled his bill last May, but it was too low in the batting order to get a worthwhile debating slot. He's traded the chance of a late second reading debate, which would not go much further, for assurances from the House authorities of a better chance of full discussion in the next session – perhaps even the opportunity to send a bill to the Commons, or even have a parallel bill debated by MPs at the same time. [http://www.bbc.co.uk/news/uk-politics-25021131](http://www.bbc.co.uk/news/uk-politics-25021131)

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

Estimates of the need for palliative care consultation across U.S. ICUs using a trigger-based model

**AMERICAN JOURNAL OF RESPIRATORY & CRITICAL CARE MEDICINE |** Online – 21 November 2013 – Use of triggers for palliative care consultation has been advocated in intensive care units (ICUs) to ensure appropriate specialist involvement for patients at high-risk of unmet palliative care needs. The volume of patients meeting these triggers, and thus the potential workload for providers is unknown. [In this retrospective cohort study] approximately one in seven ICU admissions met triggers for palliative care consultation using a single set of triggers, with an upper estimate of one in five patients using multiple sets of triggers; these estimates were consistent across different types of ICUs and individual units. Results may inform staffing requirements for providers to ensure delivery of specialized palliative care to ICU patients nationally. [http://www.atsjournals.org/doi/abs/10.1164/rccm.201307-1229OC](http://www.atsjournals.org/doi/abs/10.1164/rccm.201307-1229OC)

Music at the end of life: Bringing comfort and saying goodbye through song and story

**ANNALS OF LONG-TERM CARE: CLINICAL CARE & AGING,** 2013;21(11):24-29. Although the formal and structured use of music as a component of care for individuals in end-of-life palliative care and hospice systems is relatively new in the world of contemporary medicine its use is growing rapidly and is appreciated by both those providing the music and those receiving the benefits of the music, including patients and their families. This article provides a review of some of the current uses of music therapy ... and illuminates the benefits and potential uses of music through a case example. [http://www.annalsoflongtermcare.com/content/music-end-life-song-story](http://www.annalsoflongtermcare.com/content/music-end-life-song-story)
Identifying changes in the support networks of end-of-life carers using social network analysis

**BMJ SUPPORTIVE & PALLIATIVE CARE** | Online – 19 November 2013 – End-of-life caring is often associated with reduced social networks for both the dying person and for the carer. However, those adopting a community participation and development approach, see the potential for the expansion and strengthening of networks. This paper ... analyses the caring networks of people with a terminal illness who are being cared for at home and identifies changes in these caring networks that occurred over the period of caring. The analysis used key concepts from social network analysis ... together with qualitative analyses of the group's reflections on the maps. The results showed an increase in the size of the networks and that ties between the original members of the network strengthened. The qualitative data revealed the importance between core and peripheral network members and the diverse contributions of the network members. The research supports the value of third generation social network analysis and the potential for end-of-life caring to build social capital. [http://spcare.bmj.com/content/early/2013/11/19/bmjspcare-2012-000257.full](http://spcare.bmj.com/content/early/2013/11/19/bmjspcare-2012-000257.full)

Policy for home or hospice as the preferred place of death from cancer: Scottish Health & Ethnicity Linkage Study population cohort shows challenges across all ethnic groups in Scotland

**BMJ SUPPORTIVE & PALLIATIVE CARE** | Online – 19 November 2013 – Cancer deaths occur most often in hospital (52.3%) for all ethnic groups. Regardless of the socioeconomic indicator used, more affluent Scottish White patients were less likely to die in hospital; existing socioeconomic indicators detected no clear trend for the non-White population. Regardless of ethnic group, significant work is required to achieve more people dying at home or the setting of their choice. [http://spcare.bmj.com/content/early/2013/11/19/bmjspcare-2013-000485.abstract](http://spcare.bmj.com/content/early/2013/11/19/bmjspcare-2013-000485.abstract)

Of related interest:

**PEDIATRIC BLOOD & CANCER** | Online – 21 November 2013 – ‘Parent and clinician preferences for location of end-of-life care: Home, hospital or freestanding hospice?’ Parents and clinicians prefer home as the location for EOL [end-of-life care] and death for children with cancer. Hospital based palliative care is a preferred alternative if home is not desired. Freestanding pediatric hospice is a relatively recent phenomena and further research needs to be directed towards understanding its cost benefit in comparison to home and hospital-based EOL care. [http://onlinelibrary.wiley.com/doi/10.1002/pbc.24872/abstract](http://onlinelibrary.wiley.com/doi/10.1002/pbc.24872/abstract)
"Not yet" and "Just ask": Barriers and facilitators to advance care planning – a qualitative descriptive study of the perspectives of seriously ill, older patients and their families

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 19 November 2013 – The authors explored seriously ill, older hospitalised patients' and their family members' perspectives on the barriers and facilitators of advance care planning (ACP). Three main categories described these: 1) person (beliefs, attitudes, experiences, health status); 2) access (to doctors and healthcare providers, information, tools and infrastructure to communicate ACP preferences); and, 3) the interaction with the doctor (who and how initiated, location, timing, quality of communication, relationship with doctor). The authors suggest strategies for both healthcare systems and individual healthcare providers to improve the quality and quantity of ACP with this population. These include assessing readiness for participation in ACP and personalising relevance of ACP to each individual, routinely offering scheduled family meetings for exploring a person's own goals and sharing information, ensuring systems and policies are in place to access previous ACP documentation and ensuring doctors' education includes communication skills. http://spcare.bmj.com/content/early/2013/11/19/bmjspcare-2013-000487.abstract

Making medical decisions for patients without surrogates

NEW ENGLAND JOURNAL OF MEDICINE, 2013;369(21):1976-1978. People who are decisionally incapacitated but haven't provided advance directives for their health care and have no health care surrogates – sometimes called the "unbefriended" or "unrepresented" – are some of the most powerless and marginalized members of society. Most of the unrepresented are elderly, homeless, mentally disabled, or socially alienated. Yet medical decision making for these vulnerable patients often lacks even minimally sufficient safeguards and protections. Consequently, health care decisions made on their behalf are at risk of being biased, arbitrary, corrupt or careless. http://www.nejm.org/doi/full/10.1056/NEJMp1308197?query=featured_home

Of related interest:

- JOURNAL OF COMMUNITY HEALTH, 2013;38(6):995-996. 'It is time for a gender specific discussion on advanced directives with female patients during routine health visits.' The article explains the importance of advanced directives (ADs) to ... health care services to women. Data show a low number of ADs in women diagnosed with terminal illnesses and HIV infections. Family physicians are advised to help initiate a gender specific discussion regarding an AD during routine medical visits. http://link.springer.com/article/10.1007/s10900-013-9723-8

- PATIENT EDUCATION & COUNSELING | Online – 19 November 2013 – 'Decision-making styles of seriously ill male veterans for end-of-life care, autonomists, altruists, authorizers, absolute trusters, and avoiders.' This article describes self-reported decision-making styles and associated pathways through end-of-life (EOL) decision-making for African-American, Caucasian, and Hispanic seriously ill male Veterans, and examines potential relationships of race/ethnicity on these styles. Patients [i.e., study participants] described two main decision-making styles, deciding for oneself and letting others decide, leading to five variants that we labeled Autonomists, Altruists, Authorizers, Absolute Trusters, and Avoiders. These variants, with exception of avoiders (not found among White patients), were found across all racial/ethnic groups. The variants suggested different "implementation strategies," i.e., how clear patients made decisions and whether or not they then effectively communicated them. http://www.sciencedirect.com/science/article/pii/S0738399113004540

Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-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, exchange of ideas, information and materials. http://www.pcn-e.com/community/pg/file/owner/MediaWatch
A clinical method for physicians in palliative care: The four points of agreement vital to a consultation – context, issues, story, plan

**BMJ SUPPORTIVE & PALLIATIVE CARE** | Online – 19 November 2013 – In palliative care, where interactions cross clinical, pathological, psychological, social and spiritual considerations, it may be useful to take a minimal approach and avoid an overcomplicated or formulaic structure for the consultation. The authors focus on points in the encounter where doctor and patient with or without family or carers need to be in agreement. Whether a consultation is based on a structured interview, a cue-based assessment or a narrative approach, the points of agreement or concordance need to cover four key areas; missing any of these has grave consequences for the clinical relationship. Without concordance, patients may be right to conclude that you don't know why you're all there (context), you don't know what's the matter (issues), you don't know what's going on (story) or you don't know what you're doing (plan). These four elements may serve also as a guide to the quality and effectiveness of an encounter among a doctor, patient and carers.

http://spcare.bmj.com/content/early/2013/11/19/bmjspcare-2013-000519.abstract

What tools are available to identify patients with palliative care needs in primary care: A systematic literature review and survey of European practice

**BMJ SUPPORTIVE & PALLIATIVE CARE**, 2013;3(4):444-451. It can be difficult to identify when a palliative care approach should be started both in malignant, and particularly, in non-malignant disease, ideally to run alongside disease-modifying care. A structured method or tool may be useful to help general practitioners (GPs) identify patients for early palliative care and trigger assessment and care planning. The literature search identified four tools. A questionnaire survey identified a further three in current use and found in current practice identification is largely based on a GP's own clinical judgement and information received from the hospital: tools are rarely used. Although several identification tools have been developed, none of these have been validated or widely implemented in Europe.

http://spcare.bmj.com/content/3/4/444.short

Noted in Media Watch, 16 September 2013, #323 (p.6):


**N.B.** Access to the European Journal of Palliative Care requires a subscription. Contents page:

Compassion in healthcare

**CLINICAL ETHICS**, 2013;8(4):87-90. "Compassion" is very much the catchword in current healthcare discourse. The government's preliminary response to the Mid Staffordshire Public Inquiry [in the U.K.] contains the words "compassion" or "compassionate" 59 times in less than 70 pages of text. Of late, numerous articles, public statements and conferences reinforce the necessity for compassion in healthcare, offering strategies for its promotion or for preventing "compassion fatigue" or "compassion deficit." But what do we mean by compassion? Is there a risk that the word becomes overused or misused such that it loses its power and becomes a synthetic or insipid simulacrum? Unfortunately, there are considerable semantic confusions and discrepancies in defining the words "compassion," "empathy" and "sympathy" in the literature, and this is to a certain extent reflected in some of the articles in this issue. Furthermore, compassion resists conventional measures.

http://cet.sagepub.com/content/8/4/87.full

http://www.midstaffspublicinquiry.com/report
Pain management and outcomes in cancer patients: Comparison between oncological and palliative sets of care

*EPIDEMIOLOGY BIOSTATISTICS & PUBLIC HEALTH* | Online – Accessed 19 November 2013
– This study indicates how much oncologists and palliative care physicians differ in managing cancer pain. The observational nature of this study reflects the natural and unaffected choice of the professionals. The study only describes their behaviors without a stringent comparative evaluation.  
http://ebph.it/article/view/8698/8206

**Atlas of palliative care in Europe**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(5):297. The Atlas is the product of the EAPC Taskforce on the Development of Palliative Care in Europe, which has been working on aspects of palliative care development across the countries of the WHO European Region. The new Atlas gives up-to-date information on palliative care services, policies and strategies in the 53 countries that make up the region.1,2 The information presented shows, for each jurisdiction, the relationship between the establishment of palliative care programmes and scores on the Human Development Index or indicators related to national expenditure on health. It also contains detailed reports on palliative care in each country, based on information updated in 2012.

1. Full edition: http://dspace.unav.es/dspace/handle/10171/29291

**N.B.** Access to the *European Journal of Palliative Care* requires a subscription. Contents page:

Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: A randomised controlled trial

*FOCUS*, 2013;11(4):576-587.165 of 441 patients were assigned to dignity therapy, 140 standard palliative care, and 136 client-centred care. No significant differences were noted in the distress levels before and after completion of the study. For the secondary outcomes, patients reported that dignity therapy was significantly more likely than the other two interventions to have been helpful, improve quality of life, increase sense of dignity, change how their family saw and appreciated them, and be helpful to their family. Dignity therapy was significantly better than client-centred care in improving spiritual wellbeing, and was significantly better than standard palliative care in terms of lessening sadness or depression; significantly more patients who had received dignity therapy reported that the study group had been satisfactory, compared with those who received standard palliative care.

http://focus.psychiatryonline.org/article.aspx?articleID=1769661

**Extract from Focus article**

Although the ability of dignity therapy to mitigate outright distress, such as depression, desire for death or suicidality, has yet to be proven, its benefits in terms of self-reported end-of-life experiences support its clinical application for patients nearing death.

Noted in Media Watch, 4 June 2012, #256 (p.16):

- *WRITTEN COMMUNICATIONS*, 2012;29(2):111-141, 'Creating discursive order at the end of life: The role of genres in palliative care settings.' Dignity therapy is a psychotherapeutic intervention that its proponents assert has clinically significant positive impacts on dying patients.
http://wcx.sagepub.com/content/29/2/111.short
THE LANCET ONCOLOGY, 2011;12(8):753-762. 'Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: A randomised controlled trial.' Dignity therapy is a unique, individualised, short-term psychotherapy that was developed for patients living with life-threatening or life-limiting illness. Although its ability to mitigate outright distress, such as depression, desire for death or suicidality, has yet to be proven, its benefits in terms of self-reported end-of-life experiences support its clinical application for patients nearing death. http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(11)70153-X/abstract

Comprehensive Health Enhancement Support System

CHESS improves cancer caregivers' burden and mood: Results of an eHealth RCT

HEALTH PSYCHOLOGY | Online – 18 November 2013 – Informal caregivers (family and friends) of people with cancer are often unprepared for their caregiving role, leading to increased burden or distress. Comprehensive Health Enhancement Support System (CHESS) is a Web-based lung cancer information, communication, and coaching system for caregivers. This randomized trial reports the impact on caregiver burden, disruptiveness, and mood of providing caregivers access to CHESS versus the Internet with a list of recommended lung cancer websites. Although caring for someone with a terminal illness will always exact a toll on caregivers, eHealth interventions like CHESS may improve caregivers' understanding and coping skills and, as a result, ease their burden and mood. http://psycnet.apa.org/psycinfo/2013-39991-001/

Association of healthcare expenditures with aggressive versus palliative care for cancer patients at the end of life: A cross-sectional study using claims data in Japan

INTERNATIONAL JOURNAL FOR QUALITY IN HEALTH CARE | Online – 13 November – The authors analyzed 3,143 decedents from 54 hospitals. Median expenditure per patient during the last 3 months was US$13,030. Higher expenditures were associated with the aggressive care indicators of higher mortality at acute-care hospitals and use of chemotherapy in the last month of life, as well as with the palliative care indicators of increased hospice care and opioid use in the last 3 months of life. However, increased physician home care in the last 3 months was associated with lower expenditure. Indicators of both aggressive and palliative end-of-life care were associated with higher healthcare expenditures. Results may support the coherent development of measures to optimize aggressive care and reduce financial burdens of terminal cancer care. http://intqhc.oxfordjournals.org/content/early/2013/11/12/intqhc.mzt081.short

Futile treatment in intensive care burdens other patients

MEDSCAPE MEDICAL NEWS | Online – 20 November 2013 – Critical care is resource-intensive and limited, and the burdens of futile treatment extend beyond the patients who receive it, researchers report. "It negatively affects not only the patient who receives futile treatment, but also patients whose care is delayed or unavailable because futile treatment is being provided. Because futile treatment is not beneficial, we need to develop mechanisms that will reorient care to better serve our patients" [says Thanh Huynh, MD, from the University of California at Los Angeles]. Her team gathered a focus group of physicians who developed a definition of futile treatment. The physicians agreed that treatment is futile when death is imminent, when the patient is permanently unconscious, when the patient will never survive outside intensive care, and when treatment cannot achieve goals [of care]. http://www.medscape.com/viewarticle/814754

Of related interest:

BMJ SUPPORTIVE & PALLIATIVE CARE, 2013;3(4):389-398. 'Can palliative care reduce futile treatment? A systematic review.' Evidence that palliative interventions cut costs, without reducing quality of life, by minimising futile medical acts is limited. Further research, including both observational studies and controlled trials, should be conducted to collect empirical data in this field. http://spcare.bmj.com/content/3/4/389.abstract

Cont.
Medical futility is an area that many people probably believe will never affect them. Yet there is no way of predicting whether it will affect us, or our loved ones, in the future. The question we need to ask ourselves is: who would we like to decide our fates if we were unfortunate enough to find ourselves in that situation? By medical professionals bound by rigid and stringent legislation or by medical professionals governed by adaptable guidelines, combined with the court's oversight where possible? This paper seeks to demonstrate that the latter is much more adequate in dealing with the ever-changing area of medical futility.

http://atp.uclan.ac.uk/buddypress/diffusion/?p=1808

Commentary on 'The standard of care and conflicts at the end of life: A review of decisions by the Ontario Consent & Capacity Board'

JOURNAL OF CRITICAL CARE, 2013;28(6):1105. In this edition of the Journal of Critical Care, medical ethicists grapple with the complex issue of how the "standard of care" (SOC) is addressed legally in Canadian end-of-life decisions. In legal terms, the SOC for physicians may be defined as "The level at which a prudent physician having the same training and experience in good standing in a same or similar community would practice under the same or similar circumstances." Disputes and conflicts concerning how the SOC might be applied to individual patients at the end of life in intensive care units (ICUs) are usually confined to physician/patient/family congress. In Canadian medical practice, a higher recourse in identifying the SOC exists when conflicts occur: an escalation to binding court arbitration, amounting to an appeals court, with some degree of authority to mediate a final decision as to continuing end-of-life treatment. The authors imply that the need for the finality of court action exists because the problem by its nature is inherently not solvable at lower levels. Providers are not culturally allowed to "say no," and surrogates have the principle of autonomy on their side. Because none of the conflicting factions have authority to come to a final binding decision, any conflict can eventually escalate to a standoff under the noonday sun, each daring the other to draw. The authors suggest that this "court of last resort" has the potential to adulterate the SOC and familial/patient wish standards to a more jurisprudence-friendly "best interest of the patient" standard. This may dilute the entire concept of the medical "standard of care" to a legal framework that satisfies only dry legal principles and may invoke the Principle of Unintended Consequences. http://www.jccjournal.org/article/S0883-9441(13)00252-9/fulltext#bb0005


Noted in Media Watch, 5 August 2013, #317 (p.9):

- MCGILL JOURNAL OF LAW & HEALTH, 2013;7(1):123-128. 'Informed consent and patient comprehension: The law [in Canada] and the evidence.' In Canada, several well-known Supreme Court cases, and, in some provinces, health care consent laws, provide that physicians must obtain the informed consent of patients prior to providing medical treatment. While the basic parameters of informed consent law are clear, confusion remains about the extent of the duty of physicians to ensure that patients understand the information provided. http://mjlh.mcgill.ca/pdfs/vol7-1/vol7_issue1_Burningham.pdf

Noted in Media Watch, 17 December 2012, #284 (p.10):

- JOURNAL OF CRITICAL CARE, 2013;28(1):22-27. 'Best interests at end of life: An updated review of decisions made by the Consent & Capacity Board of Ontario.' There was a significant increase (235%) in decisions from this tribunal between 2009 and 2011. Substitute decision makers rely on an appeal to their own values or religion in their interpretation of best interests; physicians rely on clinical conditions; board emphasizes alignment with Health Care Consent Act. [http://www.sciencedirect.com/science/article/pii/S0883944112003152]
Few U.S. public health schools offer courses on palliative and end-of-life care policy

JOURNAL OF PALLIATIVE MEDICINE | Online – 20 November 2013 – Palliative care has been identified by the World Health Organization as a critical policy element for the relief of suffering, yet palliative care policy receives minimal attention in mainstream U.S. public health journals, conferences, or textbooks. In the '90s, documentation of the lack of attention to end-of-life and palliative care in medical and nursing curricula led to concerted efforts to improve medical and nursing education in palliative care. No such educational effort has yet been directed toward public health professionals. For academic years 2011/2012 and 2012/2013, 3 (6%) of the 49 accredited U.S. schools of public health offered a full course covering public health issues in palliative care. Six schools (12%) included some palliative care content in related courses such as gerontology policy. [Link]

Noted in Media Watch, 18 November 2013, #332 (p.3):

- GOVERNMENT HEALTH IT | Online – 11 November 2013 – 'American Public Health Association seeks to improve and rebrand public health.' The American Public Health Association is envisioning public health models of palliative care that incorporate patient-centered medical home design, investments in the palliative care workforce, and public education campaigns explaining patient rights in pain management and end-of-life care. [Link]

Acute hospital admissions of hospice patients

JOURNAL OF PALLIATIVE MEDICINE | Online – 9 November 2013 – This study, of a large and undifferentiated hospice population, revealed several important new findings regarding AHA [acute hospital admissions]. The authors found these previously unreported factors associated with elevated AHA rates: 1) hospice diagnoses of terminal heart and lung disease compared with other diagnoses; and, 2) the home care setting compared with the nursing home setting. Moreover, previous studies had not looked in detail at the timing of AHA over the course of hospice care or related the timing of AHA to the reason for AHA. The future agenda for research on AHA of hospice patients should include studies of large and undifferentiated hospice populations like the authors' own, but designed to capture data on socio-economic status (SES), religion, race/ethnicity, the details of supportive care in place, and a look at specific factors surrounding individual AHAs. [Link]

Of related interest:

- BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 19 November 2013 – 'Healthcare professionals’ perspectives on delivering end-of-life care within acute hospital trusts: A qualitative study.' Staff acknowledged that the diagnosis of dying was often made late; this was partly due to prognostic uncertainty but compounded by a culture that did not acknowledge death as a possible outcome until death was imminent. Both the medical and nursing staff found the EOL [end of life] tool useful as a means of communicating ceilings of care, ensuring appropriate prescribing for EOL symptoms, and giving nurses permission to approach the bedside of a dying patient. [Link]

- PALLIATIVE & SUPPORTIVE CARE | Online – 19 November 2013 – 'The provision of end-of-life care by medical-surgical nurses working in acute care: A literature review.' Managerial and organizational support that recognize the centrality of emotional work nurses provide to dying patients is needed. Research exploring ways to improve communication among nurses and medical colleagues is essential. A critical examination of the ideological assumptions guiding nurses’ practice of end-of-life care within the context of acute care is recommended... [Link]
End-of-life care pathways

Do palliative care health professionals settle for low level evidence?

PALLIATIVE MEDICINE | In Press – Accessed 19 November 2013 – The findings of the recent independent review of the U.K. Liverpool Care Pathway (LCP), following substantial concerns raised by members of the public and health professionals found that the implementation of the LCP is often associated with poor care. The Neuberger Report highlighted the complexity of various ethical, safety, clinical practice and negligence issues associated with pathway usage and how, despite technological advances, diagnosing dying continues to be challenging.\(^1\) The U.K. Government's decision to phase out the LCP as policy following these findings, has generated considerable debate both within and beyond the U.K. However, another key issue raised by the Neuberger's report is the issue of the palliative care community’s perceived willingness to readily adopt new clinical practices in the absence of evidence. It is this translational issue that this editorial explores. [http://eprints.qut.edu.au/64198/](http://eprints.qut.edu.au/64198/)


Of related interest:

- COCHRANE DATABASE OF SYSTEMATIC REVIEWS | Online – 18 November 2013 – ‘End-of-life care pathways for improving outcomes in caring for the dying.’ With sustained concerns about the safety of the pathway implementation and the lack of available evidence on important patient and relative outcomes, recommendations for the use of end-of-life pathways in caring for the dying cannot be made. No new studies met criteria for inclusion in the review update.\(^1\) With recently documented concerns related to the potential adverse effects associated with Liverpool Care Pathway (the most commonly used end-of-life care pathway), the authors do not recommend decision making based on indirect or low-quality evidence. All health services using end-of-life care pathways are encouraged to have their use of the pathway, to date, independently audited. Any subsequent use should be based on carefully documented evaluations. [http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD008006.pub3/abstract](http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD008006.pub3/abstract)

1. The original review identified 920 titles. The updated search found 2042 potentially relevant titles (including the original 920), but no additional studies met criteria for inclusion in the review update.

Noted in Media Watch, 11 November 2013, #331 (p.12):

- JOURNAL OF PALLIATIVE MEDICINE | Online – 7 November 2013 – ‘A health economics response to the review of The Liverpool Care Pathway.’ This paper explores the economic implications of the [Palliative Care Funding Review's] recommendations and links these to inadequacies with the current economic framework currently recommended for use in the U.K. by the National Institute for Health & Care Excellence, before highlighting aspects of ongoing research aimed at addressing these inadequacies. While there is a need for increased funding in the short term (highlighted in recent reviews), increasing funding to services that have little evidence base appears to be an irresponsible long-term strategy. Hence there should also be increased investment in research and increased emphasis in particular on developing economic tools to evaluate services. [http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0464](http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0464)
World AIDS Day: Together we will stop HIV transmission and conquer AIDS

RETROVIROLOGY | Online – 15 November 2013 – It is fair to say that the HIV/AIDS epidemic is unprecedented for a number of different reasons. As another World AIDS Day approaches [on 1 December], it behooves us to take stock of the progress that has been made and reflect on the road that still lies ahead. First, who can remember another disease that arose as quickly as HIV did in the early 1980s to infect millions of people around the world, almost all of whom succumbed to their illnesses at a time that anti-retroviral (ARV) drugs were non-available. Second, the development of safe and well-tolerated ARVs over the past 25 years has now resulted in a situation in which almost all infected persons, who are fortunate to live in wealthy countries, can aspire to live for many years, as HIV disease has been transformed into a chronic manageable condition. Of course, many problems remain, not the least of which is that HIV continues to spread to millions more people each year. In addition, people who live in developing countries are often treated with inferior drugs compared to those that are now available in wealthier settings and are, therefore, less likely to fully benefit from the treatment advances that have taken place. Against this background, there is now a widespread consensus that the only truly effective way to deal with the HIV epidemic over the long term will be to find a cure. First, although the global programmes that exist to provide ARVs to people in developing countries (who could not otherwise afford them) have been successful, they may well be unsustainable over the long term for reasons of cost. Simply put, the total costs may well exceed hundreds of billions of dollars over the next decade and many health care economists have sounded the alarm that the West may not be able to provide this necessary assistance unless the worldwide economy improves. Second, it is no panacea for anyone to need to take drugs every day for the rest of their life. And, so far at least, the quest for an effective HIV vaccine has fallen flat, in spite of valiant and insightful efforts by scientists throughout the world. http://www.retrovirology.com/content/10/1/129

N.B. Noted in Media Watch, 18 November 2013, #332 (p.7), are several recent articles on different aspects of HIV/AIDS.

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- **CURRENT OPINION IN CRITICAL CARE**, 2013;19(6):636-641. 'The ethics of hastening death during terminal weaning.' Withdrawal of life-sustaining medical treatment is under scrutiny as next-of-kin challenge medical decision-making in the courts and established end-of-life pathways are withdrawn in the face of public criticism. With persistent lobbying for medically assisted dying as the other side of the coin and professional advice that doctors distance themselves from this activity, the fine line between defensible palliative care and hastening a death needs to be unambiguously defined... The medical literature ... is dominated by ethical debate on euthanasia and medically assisted dying rather than defensibility within intensive care at the point of withdrawal of life-sustaining medical treatment. http://journals.lww.com/co-criticalcare/Abstract/2013/12000/The_ethics_of_hastening_death_during_terminal.19.aspx

- **PULSE (U.K.)** | Online – 20 November 2013 – 'More than two-thirds of GPs think RCGP should change stance on assisted dying.' More than two-thirds of GPs are in favour of the RCGP [Royal College of General Practitioners] dropping its opposition to assisted dying when it finishes its consultation exercise, a Pulse survey has revealed. The survey questions ... found that 38% of 689 GP respondents said they favoured the college adopting a neutral stance on assisted dying, while 31% said the college should go even further and support a change in the law to allow doctors to help the terminally ill patients to die in the U.K. http://www.pulsetoday.co.uk/clinical/therapy-areas/elderly-care/more-than-two-thirds-of-gps-think-rcgp-should-change-stance-on-assisted-dying/20005114.article
Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/newsletter/2013/11/media-watch/


PALLIATIVE CARE NETWORK COMMUNITY: http://www.pcn-e.com/community/pg/file/owner/MediaWatch

PALLIMED (Hospice & Palliative Medicine Blog): http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html (Scroll down to ‘Aggregators’ and Barry Ashpole and Media Watch)

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://centres.sg/updates/international-palliative-care-resource-center-media-watch/

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: http://palliativecarewa.asn.au/site/helpful-resources/ (Scroll down to ‘International Websites’ and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report)

Canada

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx (Click on ‘Current Issue’ under ‘Media Watch’)

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://www.hpcconnection.ca/newsletter/ithenews.html

ONTARIO | Mississauga Halton Palliative Care Network: http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1

ONTARIO | Palliative Care Consultation Program (Oakville): http://www.palliativecareconsultation.ca/?q=mediawatch

ONTARIO | Toronto Central Hospice Palliative Care Network: http://www.tcpcn.ca/news-events

Europe

HUNGARY | Hungarian Hospice Foundation: http://www.hospicehaz.hu/en/training/ (Scroll down to ‘Media Watch’)

U.K. | Omega, the National Association for End of Life Care: http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ffe522fd7fb9f0c

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