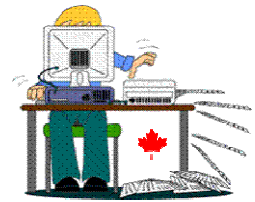## Media Watch...

is intended as an advocacy, research and teaching 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.

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Compiled & Annotated by Barry R. Ashpole

The ethics of hope: Scroll down to Specialist Publications and 'Solicitude: Balancing compassion and empowerment in a relational ethics of hope – an empirical-ethical study in palliative care' (p.12), in *Medicine, Health Care & Philosophy*.

Canada

A continuum of care, before a natural death

QUEBEC | Online – *The Montreal Gazette* – 8 April 2015 – In Canada's fragile discussions around end-of-life care, three statistics lie submerged in the rhetorical tension, dissension and fear. The first two numbers are from a 2013 Harris Decima Survey and a 2011 report by the Canadian Institute for Health Information.[1,2] They show, respectively, that 75% of Canadians would prefer to die at home, and that 70% of Canadians instead die in hospital. The third number is from a new Nanos Research poll commissioned by Cardus, which showed that 73% of Canadians fear their end-of-life wishes will not be respected in whatever setting they pass their final days.[3] A conclusion: Almost three-quarters of Canadians are not getting what they want from the care system set up to usher them over death's threshold, and while living are denied peace of mind. This is no reflection on the skill and best intentions of those on the front lines or in the administrative roles of that system. Rather, as the Cardus report on re-framing the end of life conversation in Canada makes clear, it is a function of a system that has many overlapping, and frequently contrary, approaches and objectives. http://montrealgazette.com/news/national/opinion-a-continuum-of-care-before-a-natural-death

1. 'What Canadians Say: The Way Forward Survey Report,' Canadian Hospice Palliative Care Association. 2013. [Noted in Media Watch, 27 January 2014, #342 (p.1)] http://hpcintegration.ca/media/51032/The%20Way%20Forward%20-%20What%20Canadians%20Say%20-%20Survey%20Report%20Final%20Dec%202013.pdf

2. 'Report on Seniors & Aging,' Canadian Institute for Health Information, 2011. https://secure.cihi.ca/free_products/HCIC_2011_seniors_report_en.pdf

3. 'Death is natural: Reframing the end-of-life conversation in Canada,' Cardus, April 2015. [Noted in Media Watch, 4 May 2015, #408 (p.2)] https://www.cardus.ca/store/nocharge/

Palliative care nursing set to experience a seismic shift

ONTARIO | *The Toronto Star* – 7 May 2015 – Palliative care in Ontario is about to experience a shift of seismic proportions; the recent historic ruling by the Supreme Court of Canada legalizing physician-assisted suicides for the terminally ill has redefined what's legal and ethical in palliative care. Statistics from the Canadian Hospice Palliative Care Association estimate less than 30% of Canadians receive any palliative or end-of-life care – and even that depends on where you live. Certainly, the demand for end-of-life care in Ontario is growing fast. Within 20 years, people over 65 will double to four million, making up almost a quarter of this province's population. Today, Ontario provides palliative care through a maze of sources: hospitals; 14 Local Health Integration Networks (LHINs); community care access centres; 32 hospices, and 60 other agencies providing companionship visits. But, the bottom line, according to a critical report by the Ontario Auditor-General,[1] is far from encouraging; the auditor-general estimates Ontario needs between 484 and 809 new hospice beds to meet demand. The province now has 271 and some LHINs have no beds at all. http://www.thestar.com/life/nursing/2015/05/07/nursing-week-palliative-care-nursing-set-to-experience-a-seismic-shift.html

1. '2014 Report of the Office of the Auditor General of Ontario (Chapter 3: Ministry of Health & Long Term Care – Palliative Care, pp.258-288),' 9 December 2014. [Noted In Media Watch, 15 December 2014, #388 (p.2)] http://www.auditor.on.ca/en/reports_en/en14/308en14.pdf

Palliative care should be offered sooner, not only at the end of life

QUEBEC | *The Montreal Gazette* – 4 May 2015 – Over time, some words take on meanings that can change dramatically how they "matter" to people. One of those words is "palliative." To most, it is now linked exclusively to the provision of non-curative care to people in the last days of their lives... But it's time to reclaim the full meaning of the word and thus broaden what constitutes "palliative care" as our population ages and faces more chronic and life-threatening diseases. The broader definition of palliative is "to make the effects of something (such as an illness) less painful, harmful or harsh" (Merriam-Webster dictionary) while not necessarily curing the illness. This recognizes that patients with serious diseases have many other physical, emotional and social needs that deserve attention to make their lives "less painful, harmful or harsh." They need palliative care in addition to their cura- tive care. Our health system, however, is set up almost exclusively to provide curative care, with only a few supportive services available. It is generally only after curative care is deemed futile that palliative care is instituted for the final days of life – if the patient is lucky. Some 70% of Canadians don't have any access to palliative care services at all. http://montrealgazette.com/news/local-news/opinion-palliative-care-should-be-offered-sooner-not-only-at-the-end-of-life

U.S.A.

Why African American seniors are less likely to use hospice

PBS NEWSHOUR | Online – 5 May 2015 – Black seniors are more likely than whites and Latinos to forgo hospice care. Due to deeply felt religious beliefs and a long history of discrimination in the U.S., African American patients are often reluctant to plan for the end of their lives, and more skeptical when doctors suggest stopping treatment. http://www.pbs.org/newshour/bb/african-american-seniors-less-likely-use-hospice/

The space between life and death

FLORIDA | *The Tampa Bay Times* (St. Petersburg) – 3 May 2015 – Why would anyone want to spend their days with dying people? What is it like to know the end is always near? And what happens to people, and families, when they agree to stop looking for a cure? For six months, journalist Lane DeGregory and photographer Melissa Lyttle followed the workers of Suncoast Hospice's Purple Team and three patients in their care as they worked together to navigate that space between life and death. http://www.tampabay.com/projects/2015/features/hospice/

It's not just about "quality of life"

THE NEW YORK TIMES | Online – 2 May 2015 – Of all the situations a doctor can encounter in a hospital, perhaps none is as nerve-racking as a so-called futility case. It has been estimated that there are at least 12,000 such cases in the U.S. every year, each typically costing hundreds of thousands of dollars.[1] A vast majority are settled through discussions between doctors and patients' families or mediation by a medical ethics team. But a large number cannot be resolved. For most doctors, these cases present a crisis of conscience. How can we obey a central pillar of our profession – to do no harm – when we are forced to provide treatment that will only prolong suffering? http://www.nytimes.com/2015/05/03/opinion/sunday/sandeep-jauhar-its-not-just-about-quality-of-life.html?_r=0

Specialist Publications

'**Changes in Medicare costs with the growth of hospice care in nursing homes**' (p.12), in *New England Journal of Medicine.*

'**Applying palliative care principles to transform geriatric emergency care may reduce hospital admissions**' (p.13), in *News Medical.*

Extract from *The New York Times* article:

Far better for us to decide that we cannot afford to pay for non-beneficial care. We need to have this discussion without alarmist rhetoric about "death panels." Rational judgments about end-of-life issues should not give way to idiosyncratic desires.

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1. 'Dispute resolution mechanisms for intractable medical futility disputes,' *The New York Law School Law Review*, 2013/2014;58(2):347-368. http://www.nylslawreview.com/wp-content/uploads/sites/16/2014/01/NYLS_Law_Review.Volume-58_Issue-2_Pope-article.pdf

   N.B. The focus of this issue is 'Freedom of choice at the end of life: Patients' rights in a shifting legal and political landscape.' Contents page: http://www.nylslawreview.com/201314-volume-58-number-2/

Noted in Media Watch, 8 December 2014, #387 (p.10):

▪ *CHEST*, 2014;146(6):1667-1672. '**Medical futility: A new look at an old problem.**' Efforts to answer the question of whether or when physicians may unilaterally refuse to provide treatments they deem medically futile, but that are nonetheless demanded by patients or their surrogates, have been characterized as intractable failures. The authors propose a new look at this old problem and suggest reframing the debate in terms of the implicit social contract, in healthy democracies, between the medical profession and the society it serves. This ever-evolving contract is predicated upon providing patients with beneficial and desired medical care within the constraints of scarce resources and the characteristics of our health-care system. http://journal.publications.chestnet.org/article.aspx?articleid=1983728

Assisted (or facilitated) death

Representative sample of recent news media coverage:

▪ *HASTINGS CENTER REPORT*, 2015;45(3):11-12. '**"Aid in dying" in the courts.**' Three states – Oregon, Washington, and Vermont – have used straightforwardly democratic means to legalize the practice formerly known as "physician-assisted suicide," but now termed "aid-in-dying." In two states – Montana and New Mexico – aid-in-dying has been declared legal neither by directly democratic action by citizens nor by representatively democratic action by the legislature, but by court rulings in cases brought by aid-in-dying activists. The court case in New Mexico (*Morris v. New Mexico, 2014*) is undoubtedly of greater significance to the rest of the states. http://onlinelibrary.wiley.com/doi/10.1002/hast.443/abstract

International

Home care in Australia

**Thousands of seniors on nationally funded at-home care
packages to be forced to pay more or move into nursing homes**

AUSTRALIA | ABC News (Canberra) – 9 May 2015 – Seniors on Federal Government in-home care plans have been told they will have to pay more or consider moving into nursing homes if their services are cut when they are forced on to new packages in July. More than 60,000 seniors who currently receive in-home care through federally funded Home Care Packages are set to be moved to Consumer Directed Care (CDC)... Under CDC packages, the recipient has more choice about how their care is delivered; consumers are told how much their package is worth, and can negotiate with their care provider about what kind of care they receive. However, it has been estimated up to 20% of those being transitioned to the program will suffer serious care shortfalls. http://www.abc.net.au/news/2015-05-09/changes-coming-to-in-home-care-spark-fear-for-thousands/6456604

End-of-life care in Australia

Victoria end-of-life inquiry set up

AUSTRALIA (Victoria) | Channel 9 News (Melbourne) – 7 May 2015 – Victoria's state parliament has voted to launch an inquiry into end-of-life issues and palliative care. The upper house decided on the action ... after an original bid to hand the task to the Victorian Law Reform Commission failed. The inquiry will deliver a report back to the parliament by the end of March next year. http://www.9news.com.au/national/2015/05/07/12/29/vic-mps-examine-voluntary-euthanasia

Noted in Media Watch, 20 April 2015, #406 (p.5):

▪ AUSTRALIA (Victoria) | *Sydney Morning Herald* – 15 April 2015 – '**Palliative care services in Victoria overwhelmed: Auditor-General report finds.**' Dying people in Victoria are facing waiting lists of up to six weeks for specialist care to relieve their pain and suffering and many who want to die at home are not able to because palliative care services are overwhelmed.[1] http://www.smh.com.au/national/health/palliative-care-services-in-victoria-overwhelmed-auditorgeneral-report-finds-20150415-1mltei.html

1. 'Palliative Care,' Victorian Auditor-General's Office, April 2015. The audit examined policies and procedures of the Department of Health & Human Services and four health services. http://www.audit.vic.gov.au/publications/20150415-Palliative-care/20150415-Palliative-care.pdf

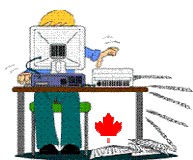**Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- SOUTH AFRICA | *Business Day Live* (Johannesburg) – 5 May 2015 – **'Judge calls on MPs to look at stalled '98 euthanasia bill.'** In a written judgment explaining his reasons for allowing Robin Stransham-Ford to have the assistance of a doctor to help him die, Pretoria High Court Judge Hans Fabricius suggested that the bill presented for debate be based on the Law Reform Commission report [of 1998] on assisted suicide and viewed through the lens of the Constitution's Bill of Rights.[1] http://www.bdlive.co.za/national/law/2015/05/05/judge-calls-on-mps-to-look-at-stalled-98-euthanasia-bill

  1. Report of the South African Law Commission on the investigation into euthanasia and the artificial preservation of life, November 1998. Submitted to Minister of Justice, Dr. Am Omar. http://www.justice.gov.za/salrc/reports/r_prj86_euthen_1998nov.pdf

  Noted in Media Watch, 4 May 2015, #408 (p.8):

  - SOUTH AFRICA | BBC News – 30 April 2015 – **'South African court grants man "right to die."'** [In a landmark ruling] the Pretoria High Court ruled that Robin Stransham-Ford, 65, who was diagnosed with terminal prostate cancer in 2013, could allow a doctor to help him end his life. Judge Hans Fabricius said that the doctor treating him could not now be prosecuted or face disciplinary action. http://m.bbc.com/news/world-africa-32530580

- U.K. (Scotland) | *The Press & Journal* (Aberdeen) – 2 May 2015 – **'Holyrood committee: Assisted suicide proposals are flawed.'** Controversial proposals to legalise assisted suicide in Scotland contain "significant flaws," according to Holyrood's health committee. Members noted the British Medical Association's observation that there was no way to guarantee the "absence of coercion" in any new legislation to allow those with terminal or life-shortening illnesses to obtain help in ending their suffering. The committee said ... that while the majority of its members did not support the general principles of the Assisted Suicide Bill, it would make no formal recommendation to parliament as it was a matter of conscience. The report raised concerns that the proposals had the potential to undermine suicide prevention messages by "softening cultural perceptions of suicide at the perimeters". Bob Doris, deputy convener of the committee, said: "Our intention was to inform the debate and not influence the outcome as that is a matter of conscience for the parliament when they vote later this month." https://www.pressandjournal.co.uk/fp/news/politics/holyrood/565885/assisted-suicide-proposals-flawed/

  1. 'Report on Assisted Suicide (Scotland) Bill,' Parliament of Scotland, 30 April 2015. http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/88982.aspx

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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.ipcrc.net/barry-r-ashpole.php

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Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.15.

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

Conflict escalation in paediatric services: Findings from a qualitative study

ARCHIVES OF DISEASE IN CHILDHOOD | Online – 4 May 2015 – Conflicts escalate in a predictable manner. Clearly identifiable behaviours by both clinicians and parents are defined as mild, moderate and severe. Mild describes features like the insensitive use of language and a history of unresolved conflict. Moderate involves a deterioration of trust, and a breakdown of communication and relationships. Severe marks disintegration of working relationships, characterised by behavioural changes including aggression, and a shift in focus from the child's best interests to the conflict itself. Though conflicts may remain at one level, those which escalated tended to move sequentially from one level to the next. Understanding ... [this] ... provides clinicians with a practical, evidence-based framework to identify the warning signs of conflict in paediatrics. http://adc.bmj.com/content/early/2015/05/03/archdischild-2014-307780.abstract

End-of-life care in the U.K.

Development of the care programme for the last days of life for older patients in acute geriatric hospital wards: A phase 0-1 study according to the Medical Research Council Framework

BMC PALLIATIVE CARE | Online – 9 May 2015 – The effects of the Liverpool Care Pathway (LCP) have never been investigated in older patients dying in acute geriatric hospital wards and its content and implementation have never been adapted to this specific setting. Moreover, the LCP has recently been phased out in the U.K. hospitals. For that reason, this study aims to develop a new care programme to improve care in the last days of life for older patients dying in acute geriatric wards. Phase 0 consisted of a review of existing LCP programmes from the U.K., Italy, and The Netherlands, a literature review to identify key factors for a successful LCP implementation and an analysis of the concerns raised in the UK. In phase 1, the authors developed a care programme for the last days of life for older patients dying in acute geriatric wards based on the results of phase 0. Results of Phase 0 resulted in the identification of nine important components within the LCP programmes, five key factors for a successful LCP implementation, and a summary of the LCP concerns raised in the U.K. Based on these findings the authors developed a new care programme consisting of: 1) an adapted LCP document or Care Guide for the older patients dying in an acute geriatric ward; 2) supportive documentation; and, 3) an implementation guide to assist health care staff in implementing the care programme on the acute geriatric ward. http://www.biomedcentral.com/content/pdf/s12904-015-0025-z.pdf

End-of-life care in psychiatry: "One chance to get it right"

BRITISH JOURNAL OF PSYCHIATRY BULLETIN, 2015;1-3. In June 2014, the Leadership Alliance for the Care of Dying People [in the U.K.] published 'One Chance to Get it Right.'[1] This nationally accepted guidance replaces previous end-of-life care pathways ... and outlines how dying patients should be managed irrespective of setting. Increasingly, patients with mental health problems are entering their final days of life within psychiatric in-patient or acute hospital settings, and psychiatrists need to be aware of the new guidance and ready to implement it within psychiatric practice. http://pb.rcpsych.org/content/pbrcpsych/early/2015/04/26/pb.bp.114.049684.full.pdf

1. 'One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life,' Leadership Alliance for the Care of Dying People, June 2014. [Noted in Media Watch, 30 June 2014, #364 (p.7)] https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations

Noted in Media Watch, 20 April 2015, #406 (p.8):

▪ *AGING & MENTAL HEALTH* | Online – 14 April 2015 – **'Is death our business? Philosophical conflicts over the end-of-life in old age psychiatry.'** Two ... themes were identified [in this study]. Death is not our business reflected participants' experience of working in a mental health framework and incorporated: 1) death should not occur in psychiatry; 2) working in a psychiatric treatment model; 3) keeping a distance from death; and, 4) unexpected death is a negative experience. Death is our business reflected participants' experience of working in an aged care context and incorporated: 1) death is part of life; 2) encountering the EOL through dementia care; 3) doing EOL work; and, 4) expected death is a positive experience. Participants reported conflict because of the contradictory domains in which they work. http://www.tandfonline.com/doi/abs/10.1080/13607863.2015.1031636#.VS5fXWdFCos

Phenomenology in end-of-life care: Implications for philosophy and clinical practice

CLINICAL SOCIAL WORK JOURNAL | Online – 30 April 2015 – Support to family, as well as the patient, is implicit in hospice care, adding to the reach and impact of the hospice social worker's role. As people age and approach the end of life, they may encounter changes in their experience of time, space and of the material world. They often have to redefine the role of hope in their day to day lives. Based on these changing experiences and perceptions, phenomenology, with its focus on a patient's subjective, lived experience, has implications for end-of-life care. The role of empathy and compassion are explored in relation to existential experiences of the terminally ill through the lens of phenomenology and Eastern philosophy. To complement the Western biomedical model of care for the dying, insight from Eastern philosophical traditions, which view living and dying on the same continuum, and provide an expanded view of suffering bring comfort and understanding to how living and dying are processed within the phenomenology of patient experience and the hospice model of care. Case vignettes demonstrate social work theory and practice at the intersection of various interrelated phenomena when caring for those facing end of life. http://link.springer.com/article/10.1007/s10615-015-0536-3

The carer persona:
Masking individual identities

PERSONA STUDIES, 2015;1(1): This paper argues that in caring for loved one, a compromise takes place between individual selves and the social caring role. The "carer persona" can mask a carer's individual identities and their associated needs. The potential complexity of caring roles is explored, with an emphasis on acknowledging the personal needs and identities of carers beyond their caring roles. This has implications for service delivery and policy development regarding carers and those for whom they care. https://ojs.deakin.edu.au/index.php/ps/article/view/392

Of related interest:

▪ *PALLIATIVE MEDICINE* | Online – 5 May 2015 – **'Bereaved carers' accounts of the end of life and the role of care providers in a "good death": A qualitative study.'** Six themes were identified as attributes of a good death in which care providers had a key role: 1) social engagement and connection to identity; 2) care provider characteristics and actions 3) carer's confidence and ability to care; 4) preparation and awareness of death; 5) presentation of the patient at death; and, 6) support after death for protected grieving. Care providers played a much wider role in social aspects of care at the end of life than previously considered. http://pmj.sagepub.com/content/early/2015/05/04/0269216315584865.abstract

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Identifying palliative and end-of-life care research priorities: A U.K. approach to consult end users

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2015;22(3):114-117. Launched in 2013 ... [the] ... Palliative and end of life care Priority Setting Partnership (PeolcPSP) has enabled end users of research – patients, carers and clinicians – to identify their priorities in order to inform future end-of-life care research. More than 1,400 patients, carers and health- and social- care professionals completed a survey, and a list of ten top research priorities was compiled from the responses. A "long list" of 83 questions was compiled and 1,300 patients, current and bereaved carers and healthcare professionals took part in the second phase of the survey to select their most important priorities among these 83 questions. This was again a public survey conducted online and available in print on request. It was disseminated via the same networks as in the first phase. A "short list" of 28 evidence uncertainties was produced on the basis of the results of the second phase. Finally, the top ten research priorities were determined in a workshop involving 24 patients, carers and health- and social- care professionals who had volunteered to take part. Most of them had heard about the workshop through Marie Curie or our partner organisations. In the surveys, respondents were asked whether they would be interested in taking part, and we contacted those who said they were. The results of this 18-month public consultation and prioritisation exercise have recently been announced. The top ten research priorities are shown [above].

Box 1. The top 10 identified priorities for palliative and end-of-life care research

- 1. What are the best ways of providing palliative care **outside of working hours** to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support for patients, carers and families
- 2. How can access to palliative care services be improved for **everyone regardless of where they are in the UK?**
- 3. What are the benefits of **advance care planning** and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?
- 4. What **information and training** do carers and families need to provide the best care for their loved one who is dying, including training for giving medicines at home?
- 5. How can it be ensured that staff, including healthcare assistants, are **adequately trained** to deliver palliative care, no matter where the care is being delivered? Does increasing the number of staff increase the quality of care provided in all settings? To what extent does funding affect these issues?
- 6. What are the best ways to determine a person's palliative care needs and then initiate and deliver care for patients with **non-cancer diseases** (such as chronic obstructive pulmonary disease, heart failure, motor neurone disease, AIDS, multiple sclerosis, Crohn's disease, Parkinson's disease, dementia and stroke)?
- 7. What are the **core palliative care services** that should be provided no matter what the patients' diagnoses are?
- 8. What are the benefits and best ways of **providing care in the patient's home** and how can home care be maintained as long as possible? Does good co-ordination of services affect this?
- 9. What are the best ways to make sure there is **continuity for patients at the end of life** in terms of the staff that they have contact with, and does this improve the quality of palliative care? Would having a designated case co-ordinator improve this process?
- 10. What are the best ways to assess and treat **pain and discomfort** in people at the end of life with communication and/or cognitive difficulties, due for example to motor neurone disease, dementia, Parkinson's disease, brain tumour (including glioblastoma) or head and neck cancer?

those who said they were. The results of this 18-month public consultation and prioritisation exercise have recently been announced. The top ten research priorities are shown [above].

Of related interest:

- *ARCHIVES OF CHILDHOOD DISEASES* | Online – Accessed 7 May 2015 – **'End-of-life care decisions: Differing decision making processes.'** The majority of the literature on the topic ... includes children with both life-limiting illnesses [LLI] and life-threatening illnesses (LTI). Although there may be some overlap in the decision making processes, this study although limited by its sample, has shown that decisions may differ for children with LLI as compared to children with LTI, suggesting that perhaps these populations should be researched separately. http://adc.bmj.com/content/100/Suppl_3/A91.1.abstract

- *PALLIATIVE MEDICINE* | Online – 30 April 2015 – **'Results of a transparent expert consultation on patient and public involvement in palliative care research.'** Support and evidence for patient, unpaid caregiver and public involvement in research are growing. Consensus on how best to involve users in palliative care research is lacking. For involvement in palliative care research to succeed, early and flexible involvement is required. Researchers should advertise opportunities for involvement and promote impact of involvement via dissemination plans. Users should prioritise adding value to research through enhancing productivity, quality and relevance. More research is needed not only to inform implementation and ensure effectiveness but also to investigate the cost-effectiveness of involvement in palliative care research. http://pmj.sagepub.com/content/early/2015/04/29/0269216315584875.abstract

Spiritual care education: Results from an European Association for Palliative Care survey

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2015;22(2):91-95. The Association's White Paper on palliative care education states that, to adequately support patients and their families, "palliative care professionals should be able to: 1) demonstrate the reflective capacity to consider the importance of spiritual and existential dimensions in their own live; 2) integrate the patients' and families' spiritual, existential and religious needs in the care plan, respecting their choice not to focus on this aspect of care if they so wish; 3) provide opportunities for patients and families to express the spiritual and/or existential dimensions of their lives in a supportive and respectful manner; 4) be conscious of the boundaries that may need to be respected in terms of cultural taboos, values and choices." Palliative care professionals need to be trained in recognising spiritual issues and in delivering spiritual care. Every professional or volunteer working with patients, families and caregivers must be able to open a dialogue about meaning, purpose and change. The confidence to do so can be developed through training courses, which provide a space for participants to reflect on their personal understandings of spirituality, and a place where theoretical learning and skills practice come together. Training in spiritual care is a crucial component of any form of palliative care education, whether as a stand-alone course or as part of a broader programme.

Access to the contents of the *European Journal of Palliative Care* requires a subscription.

May/June issue – contents page:
http://www.haywardpublishing.co.uk/_year_search_review.aspx?JID=4&Year=2015&Edition=536

March/April issue – contents page:
http://www.haywardpublishing.co.uk/_year_search_review.aspx?JID=4&Year=2015&Edition=533

Of related interest:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2015;22(3):130-132 **'Delivering spiritual care: A resource to train hospice staff in New Zealand.'** Hospices have an ethical, evidence-informed and principle-based mandate to attend to the spiritual needs of people at the end of life. It is what makes hospice care different. However, in hospices, spirituality is broadly understood, but not always well articulated or assessed. When they deliver care, hospice team members need to acknowledge the unique culture and spirituality of each individual, being mindful of, and responsive to, them. In creating this programme, we tried to recognise that one size does not fit all and propose a diversity of resources to allow all future participants' needs to be met.

"We cannot do it without you" – the impact of volunteers in U.K. hospices

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2015;22(2):80-83. Hospices and hospice volunteering in the U.K. are undergoing significant change. It is important that the role and impact of volunteering on such organisations is understood if the planning of, and approach to, future services are to be both holistic and effective. This paper gives a brief overview of a research study that explored volunteering from a strategic perspective and considered its impact on a number of key organisational viability factors. The findings gained from respondents (trustees, senior staff and volunteers) indicate that volunteers are understood to be a key strategic resource and to be important in helping organisations to achieve their goals. Volunteers, however, were not always involved in contributing to strategy development and there was little evidence of planning for volunteer involvement. While respondents agreed that most hospice trustees are volunteers, there was little recognition of the significant responsibilities of volunteers in organisational governance. Although trustees indicated that they had an effective level of engagement both with volunteers and with staff, the perceptions of staff and volunteers indicated otherwise.

N.B. Listed in Media Watch, 16 February 2015, #397 (pp.8-9) are several articles on hospice volunteers noted in past issue of the weekly report.

Communications with the public, politicians, and the news media

OXFORD TEXTBOOK OF PALLIATIVE MEDICINE (5th Edition). In many countries, the philosophy and practice of palliative medicine is being embraced well beyond the care and support for those living with a terminal illness. This stage in palliative medicine's evolution is running parallel with a growing elderly population (a global trend), a corresponding increase in the incidence of chronic or long-term illness, and the fiscal challenge facing many governments in sustaining current levels and standards of health care while, at the same time, projecting future demands on both health and social services. Significantly, a relatively recent development is a merging – or a proposed merging – in some countries of the last mentioned to improve the provision and delivery of care and support in the community and, in particular, in the home. The current state of affairs has created a somewhat turbulent environment in which to effectively communicate, not only on the individual needs of patients (their families and loved ones), but also, in the public arena, on the broader issues related to the overall quality of health care and social support at all stages of life, not just for those living with a shortened life expectancy. This chapter discusses the prevailing communications environment, the language of end-of-life care in public discussion, and engaging in a dialogue with politicians and the news media. Offered is a preparedness plan to enhance existing communications skills and to also assist health professionals in general to engage in advocacy – to facilitate and focus public discussion, and to inform the decision and policy making processes. ***Barry R. Ashpole***

Print edition: Preview content of the new edition of the textbook:
http://fdslive.oup.com/www.oup.com/academic/pdf/13/9780199656097.pdf

Online edition: Communication in Palliative Medicine (see Section 6.4, pp.357-359).
http://oxfordmedicine.com/view/10.1093/med/9780199656097.001.0001/med-9780199656097-part-6

"Right to try" laws: The gap between experts and advocates

HASTINGS CENTER REPORT, 2015;45(3):9-10. 2014 brought a new development in the bioethics "laboratory of the states." Five states adopted "right to try" laws intended to promote terminally ill patients' access to investigational drugs. Many more state legislatures are considering such laws. The campaign for right to try laws is the latest move in an ongoing effort to give seriously ill patients access to drugs whose safety and effectiveness remain largely unknown. http://onlinelibrary.wiley.com/doi/10.1002/hast.442/abstract

Noted in Media Watch, 27 April 2015, #407 (p.12):

▪ *HEMONC TODAY* | Online – 25 April 2015 – **'Expansion of "right to try" legislation raises ethical, safety concerns.'** Since 2014, thirteen states have passed right to try laws, and legislators in 20 more states have plans to introduce similar legislation this year. "When an individual has a life-threatening illness and a terrible cancer, there is a natural sympathy," [says] Ezekiel J. Emanuel, MD, PhD, professor of medical ethics and health policy in the Perelman School of Medicine at the University of Pennsylvania... http://www.healio.com/hematology-oncology/practice-management/news/print/hemonc-today/%7Bc801b6ee-318e-4fce-9dfa-a29c597028b9%7D/expansion-of-right-to-try-legislation-raises-ethical-safety-concerns

Rapid palliative discharge home

INNOVAIT | Online – 30 April 2015 – Unfortunately, in a national health service [i.e., in the U.K.] that is under increasing pressure, and in which staff are feeling the effects of financial cutbacks and professional burnout, the community resources available to manage and support patients and families will vary greatly from area to area. Given these difficulties, how can we optimise our chances of a good outcome? The key to successful discharge to the community for imminently dying patients is good communication and good forward planning. This article aims to outline an approach to the dying patient who is rapidly discharged without prior involvement of the GP. http://ino.sagepub.com/content/early/2015/04/29/1755738015579293.abstract

Finding privacy from a public death: A qualitative exploration of how a dedicated space for end-of-life care in an acute hospital impacts on dying patients and their families

JOURNAL OF CLINICAL NURSING | Online – 4 May 2015 – Dying in hospital is a common out-come for people across the world. However, noise and activity in acute environments present barriers to quality end-of-life care. This is of concern because care provided to dying patients has been shown to affect both the patients and the bereaved families. Interviews were conducted with 17 multidisciplinary staff and seven families... Analysis generated three categories describing dying in an hospital: The [hospital's] Lotus Room was seen as a large, private and, ultimately, safe space for patients and families within the public hospital environment. Family feedback supported staff perspectives that the Lotus Room facilitated family presence and communication. http://onlinelibrary.wiley.com/doi/10.1111/jocn.12845/abstract

"On good conscience": Conscience-based exemptions and proper medical treatment

MEDICAL LAW REVIEW | Online – 5 May 2015 – Lack of clarity about the proper limits of conscientious refusal to participate in particular healthcare practices has given rise to fears that, in the absence of clear parameters, conscience-based exemptions may become increasingly widespread, leading to intolerable burdens on health professionals, patients, and institutions. The authors identify three factors which clarify the proper scope of conscience-based exemptions: the liminal zone of "proper medical treatment" as their territorial extent; some criteria for genuine conscientiousness; and, the fact that the exercise of a valid conscience-based exemption carries certain duties with it. http://medlaw.oxfordjournals.org/content/early/2015/05/04/medlaw.fwv007.abstract

> **The changing landscape of care: Does ethics education have a new role to play in health practice?**
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> *BMC MEDICAL ETHICS* | Online – 8 May 2015 – This paper proposes that ethics education has a new contribution to make, in supporting and promoting ethical practice – as it is defined in and by the everyday actions and decisions of practitioners and people who need health services. Ethics education that promotes moral agency, rather than problem solving approaches, would explore not only clinical problems, but also the difficult and contested arenas in which they occur. http://www.biomedcentral.com/content/pdf/s12910-015-0005-0.pdf

Of related interest:

- *MEDICAL LAW REVIEW* | Online – 8 May 2015 – **'Voices of discontent? Conscience, compromise, and assisted dying.'** If some form of assisted dying is legalised, we are likely to hear voices of discontent, not least from the medical profession and some of its members, who might be expected to provide the service. The profession generally favours a position of opposition, premised on an ethic of "caring not killing," which might be said to convey its "professional conscience." There will, of course, also be individual conscientious objectors. The authors initially explore the nature and sources of conscience and we argue that conscience does merit respect. They also recognise that professionals ... are bound to serve their patients, some of whom will want (and may be entitled to) that which their doctors do not wish to provide. http://medlaw.oxfordjournals.org/content/early/2015/05/07/medlaw.fwv008.abstract

Noted in Media Watch, 2 March 2015, #399 (p.5):

- *CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS* | Online – 25 February 2015 – **'Conscientious objection and the standard of care.'** Recently the scope of protections afforded those healthcare professionals and institutions that refuse to provide certain interventions on the grounds of conscience have expanded, in some instances insulating providers (institutional and individual) from liability or sanction for harms that patients experience as a result. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9572319&fulltextType=RA&fileId=S0963180114000528

Cont.

Noted in Media Watch, 26 January 2015, #394 (p.8):

- *AMERICAN JOURNAL OF RESPIRATORY & CRITICAL CARE MEDICINE*, 2015;191(2):219-227. **'Managing conscientious objections in intensive care medicine.'** The [American Thoracic Society Policy statement is] based on the dual goals of protecting patients' access to medical services and of protecting the moral integrity of clinicians. Conceptually, accommodating conscientious objections should be considered a "shield" to protect individual clinicians' moral integrity rather than as a "sword" to impose clinicians' judgments on patients. http://www.atsjournals.org/doi/abs/10.1164/rccm.201410-1916ST#.VL5XHtLF_YR

Solicitude: Balancing compassion and empowerment in a relational ethics of hope – an empirical-ethical study in palliative care

MEDICINE, HEALTH CARE & PHILOSOPHY | Online – 6 May 2015 – The ethics of hope has often been understood as a conflict between duties: do not lie versus do not destroy hope. However, such a way of framing the ethics of hope may easily place healthcare professionals at the side of realism and patients at the side of (false) hope. That leaves unexamined relational dimensions of hope. The objective of this study was to describe a relational ethics of hope based on the perspectives of palliative care patients, their family members and their healthcare professionals. Semi-structured interviews on hope were conducted with twenty-nine palliative care patients, nineteen friends or family members, and fifty-two healthcare professionals, which were recorded and transcribed. When participants spoke about hope, they referred to power and empowerment, like the powerful bonding of hope between patients and physicians. They also associated hope with the loss of hope and suffering. Several participating healthcare professionals tried to balance both sides, which involved acknowledgment of hope and suffering. Hope and power were reflected in the ethical concept of empowerment, whereas suffering and the loss of hope were reflected in the ethical concept of compassion. Empowerment and compassion can be balanced in solicitude. In conclusion, a relational ethics of hope requires solicitude, in which healthcare professionals are able to weigh empowerment and compassion within particular relationships. http://link.springer.com/article/10.1007/s11019-015-9642-9

Of related interest:

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 4 May 2015 – **'Reflections on hope and its implications for end-of-life care.'** Physicians caring for individuals with life-altering, incurable illnesses often have a desire to convey a sense of hope while also helping their patients prepare for the end of life to minimize unnecessary suffering and grief. Unfortunately, in the U.S., most people receive more-aggressive treatments toward the end of life than studies would suggest that they desire. This reflects the challenging task of balancing optimism and realism, and how providing a false sense of hope for a cure for too long a time while avoiding advance care planning may contribute significantly to the problem. http://onlinelibrary.wiley.com/doi/10.1111/jgs.13392/abstract

Changes in Medicare costs with the growth of hospice care in nursing homes

NEW ENGLAND JOURNAL OF MEDICINE, 2015;372(19):1823-1831. Nursing home residents' use of hospice has substantially increased. Whether this increase ... reduces end-of-life expenditures is unknown. Of 786,328 nursing home decedents, 27.6% in 2004 and 39.8% in 2009 elected to use hospice. The 2004 and 2009 matched hospice and non-hospice cohorts were similar (mean age, 85 years; 35% male; 25% with cancer). The increase in hospice use was associated with significant decreases in the rates of hospital transfers, feeding-tube use, and ICU use. The mean length of stay in hospice increased from 72.1 days in 2004 to 92.6 days in 2009. Between 2004 and 2009, the expansion of hospice was associated with a mean net increase in Medicare expenditures of $6,761, reflecting greater additional spending on hospice care ($10,191) than reduced spending on hospital and other care ($3,430). Growth in hospice care for nursing home residents was associated with less aggressive care near death but at an overall increase in Medicare expenditures. http://www.nejm.org/doi/full/10.1056/NEJMsa1408705

**Applying palliative care principles to transform
geriatric emergency care may reduce hospital admissions**

NEWS MEDICAL | Online – 5 May 2015 – Applying palliative care principles to emergency departments may reduce the number of geriatric patients admitted to intensive care units, possibly extending lives and reducing Medicare costs, according to a three-year analysis by Mount Sinai researchers...[1] "Data show that more than half of Americans ages 65 and older are seen in the emergency department in the last month of their lives, and that the number and rate of admissions to intensive care units among older adults who are seen in the ED have also increased," said Corita Grudzen MD, the lead author of the study and former Mount Sinai Health System physician. "Our findings suggest that early palliative care inpatient consultation can improve care for older patients, decrease hospital lengths-of-stay and costs, and even extend life." http://www.news-medical.net/news/20150505/Applying-palliative-care-principles-to-transform-geriatric-emergency-care-may-reduce-hospital-admissions.aspx

1. 'Redesigned geriatric emergency care may have helped reduce admissions of older adults to intensive care units,' *Health Affairs*, 2015;34(5):788-795.
http://content.healthaffairs.org/content/34/5/788.abstract

**Examining palliative care program use and place of death in rural and
urban contexts: A Canadian population-based study using linked data**

RURAL & REMOTE HEALTH | Online – Accessed 6 May 2015 – Palliative care has been both more available and more heavily researched in urban than in rural areas. Importantly, rather than simply comparing between urban and rural areas, this paper examines how the effects of demographic, geographic, and socioeconomic factors differ across service delivery settings within the Canadian province of Nova Scotia. The study examined 23,860 adult residents of three district health authorities, who died from 2003 to 2009 with a terminal illness, organ failure, or frailty and who were not nursing home residents. Demographic, geographic, and socioeconomic predictors of palliative care program (PCP) enrolment and place of death were investigated... Overall, 40.3% of the study subjects were enrolled in a PCP, and 73.4% died in hospital. Odds of PCP enrolment were highest for females, persons aged 50-64, and persons with a terminal disease, such as cancer... Geographic patterns of PCP enrolment and place of death differed by district, as did the impact of economic and social deprivation. Analysis and reporting of population-based indicators of access should be grounded in an understanding of the characteristics of geographic areas and local context of health services. Though more research is needed, these findings show promise that disparities in access between urban and rural settings are not unavoidable, and positive aspects of rural and remote communities may be leveraged to improve care at end of life. http://www.rrh.org.au/articles/showabstractearly.asp?ArticleID=3134

Of related interest:

▪ *RURAL & REMOTE HEALTH* | Online – 4 May 2015 – **'Feasibility of a rural palliative supportive service.'** The Rural Palliative Supportive Service model has the potential to smooth transitions and enhance quality of life along the disease trajectory and across locations of care by providing a consistent source of support and education. This type of continuity has the potential to foster the patient- and family-centered approach to care that is the ideal of a palliative approach. Further, the use of a rural community capacity-building approach may contribute to sustainability, which is a particularly important part of rural health service delivery. http://www.rrh.org.au/articles/showarticlenew.asp?ArticleID=3116

N.B. Listed in Media Watch, 30 June 2014, #364 (p.15) are several articles on the provision and delivery of end-of-life care in rural communities and remote regions noted in past issue of the weekly report.

How to discuss goals of care with patients

TRENDS IN CARDIOVASCULAR MEDICINE | Online – Accessed 4 May 2015 – Engaging patients in meaningful, empathic communication not only fulfills an ethical imperative for our work as clinicians but also leads to increased patient satisfaction with their own care and improved clinical outcomes. While these same imperatives and benefits exist for discussing goals of care and end-of-life, communicating with patients about these topics can be particularly daunting. While clinicians receive extensive training on how to identify and treat illness, communication techniques, especially those centering around emotion-laden topics such as end-of-life care, receive short shrift medical education. Fortunately, communication techniques can be taught and learned through deliberate practice, and in this article, we seek to discuss a framework, drawn from published literature and our own experience, for approaching goals-of-care discussions in patients with cardiovascular disease. http://www.tcmonline.org/article/S1050-1738(15)00115-2/abstract

Of related interest:

▪ *PALLIATIVE MEDICINE*, 2015;27(5):418-427. **'To be involved or not to be involved: A survey of public preferences for self-involvement in decision-making involving mental capacity (competency) within Europe.'** Self-involvement in decision-making is important to the European public. However, a large proportion of the public prefer to not make decisions about their care in advance of incapacity. Financial hardship, educational attainment, age, and preferences regarding quality and quantity of life require further examination; these factors should be considered in relation to policy. http://pmj.sagepub.com/content/27/5/418.abstract

Noted In Media Watch, 9 February 2015, #396 (p.2):

▪ *JAMA INTERNAL MEDICINE* | Online – 2 February 2015 – **'Goals of care discussion: How hard it can be.'** Dying used to be less complicated when unaccompanied by decisions about high-tech interventions. Recent studies show that more patients fill out advance directives and consider end-of-life care options, but few report having discussions with their clinicians. http://archinte.jamanetwork.com/article.aspx?articleid=2107606

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http://www.ipcrc.net/archive-global-palliative-care-news.php

Assisted (or facilitated) death

Representative sample of recent news media coverage:

▪ *JOURNAL OF MEDICAL ETHICS* | Online – 2 May 2015 – **'Treatment-resistant major depressive disorder and assisted dying.'** Competent patients suffering from treatment-resistant depressive disorder should be treated no different in the context of assisted dying to other patients suffering from chronic conditions that render their lives permanently not worth living to them. Jurisdictions that are considering, or that have, decriminalised assisted dying are discriminating unfairly against patients suffering from treatment-resistant depression if they exclude such patients from the class of citizens entitled to receive assistance in dying. http://jme.bmj.com/content/early/2015/05/02/medethics-2014-102458.abstract

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Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/newsletter/2015/04/media-watch/#lived

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://www.ipcrc.net/archive-global-palliative-care-news.php

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 | HPC Consultation Services (Waterloo Region/Wellington County): http://hpcconnection.ca/general-resources/in-the-news/

ONTARIO | Palliative Care Consultation Program (Oakville): http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/ [Scroll down to 'Additional Resources']

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: http://www.eapcnet.eu/Themes/Organization/Links.aspx [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes

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=b623758904ba11300ff6522fd7fb9f0c

Worth Repeating

"We will remember them": A mixed-method study to explore which post-funeral remembrance activities are most significant and important to bereaved people living with loss, and why those particular activities are chosen

PALLIATIVE MEDICINE, 2009;23(6):537-544. In an increasingly secular age in which society no longer offers a code of behaviour for those who are bereaved as in Victorian times, the majority of people do not seek support from church-based rituals of remembrance. Most hospices provide religious services of remembrance and thanksgiving or non-faith remembrance gatherings for families and friends, and although these are usually well attended, the average number of families represented is usually less than 20% raising the question of whether alternative support should be offered to the remaining majority of families. This study explored which post-funeral remembrance activities are most significant and important to people living with death-related loss, and why those particular activities are chosen. Results indicated that although formal remembrance events are valued, informal rituals created by the bereaved are more important and significant to them: rituals to maintain a "direct link," or those undertaken "for" the deceased rituals that remember the deceased within the community, and those viewed as an act of remembrance. The most common reason for choosing a ritual was to keep a bond with the deceased or ensure that the deceased was remembered by others. Remembrance and ritual is personal to each individual and is dynamic, altering from day to day. Remembrance appears to be a journey made up of many small daily rituals, some of which are generic to bereaved people and some of which are highly individualistic. http://pmj.sagepub.com/content/23/6/537.abstract

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