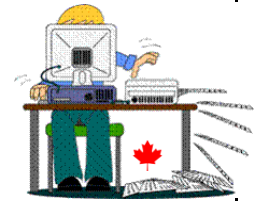


Media Watch...

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 illness experience: Scroll down to [Specialist Publications](#) and 'Family evaluation of hospice care: Examining direct and indirect associations with overall satisfaction and caregiver confidence' (p.10), in *Palliative & Supportive Care*.

Canada

Hospice poised to get regular public funding

BRITISH COLUMBIA | *The Cowichan News Leader* (Duncan) – 1 July 2014 – Cowichan Valley Hospice is thanking the Cowichan Valley Regional District [CVRD] for a decision to recommend a regional service function be created to contribute to hospice care in the community. Hospice services are provided free of charge to more than 800 people a year because of community fundraising, personal and corporate donations and annual grants from gaming and the United Way. [Vancouver] Island Health [Authority] provides a small amount of funding. CVRD

... funding must be approved by all municipal councils and Electoral Area directors, and through a public approval process. <http://www.cowichannewsleader.com/news/263563771.html>

Specialist Publications

'The making of a myth: Unreliable data on access to palliative care in Canada' (p.8), in *Health Law Review*.

Noted in Media Watch, 4 November 2013, #330 (p.2):

- BRITISH COLUMBIA | *The Cowichan News Leader* (Duncan) – 29 October 2013 – '**Proposal to have hospice operations funded by local government rejected...**' Cowichan Valley Hospice and the Cowichan Valley Regional District went all in, asking the provincial government if it would change legislation to fund both local hospice care's capital and operational costs. It didn't get the support it wanted from local government. A motion recently brought to the Union of B.C. Municipalities conference table was passed but stripped of the operational funding portion. <http://www.cowichannewsleader.com/news/229599441.html>

With this issue of Media Watch the weekly report begins its 8th year of publication.

U.S.A.

Hawaii State Center for Nursing celebrates legislation expanding POLST

HAWAII | University of Hawaii at Mānoa – 2 July 2014 – Governor Neil Abercrombie [has] signed a bill into law that expands health care provider signatory authority for POLST [Physician Orders for Life Sustaining Treatment] to include Advanced Practice Registered Nurses (APRNs). The bill language updates references from "physician orders for life-sustaining treatment" to "provider orders for life-sustaining treatment" (POLST). By expanding the signatory authority to include APRNs, the bill allows for patients to continue to have access to completing these orders when the APRN is the care provider and a physician is unavailable for consultation. APRNs in Hawaii are increasingly designated as the primary care provider and educated to begin such con-

versations with their patients and families. <http://www.hawaii.edu/news/article.php?ald=6603>

Specialist Publications

'Family caregiving and palliative care: Closing the policy gap' (p.8), in *Health Affairs*.

'Hospice/palliative care association outlines 5 things physicians should question' (p.8), in *HemOnc Today*.

'Seventeen years of progress for supportive care services: A resurvey of National Cancer Institute-designated comprehensive cancer centers' (p11), in *Palliative & Supportive Care*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW JERSEY | *The Star-Ledger* (Newark) – 28 June 2014 – **'Assembly wise to wait on assisted-suicide bill: Editorial.'** Assemblyman John Burzichelli was smart to pull his assisted-suicide bill... A defeat ... would give too much credence to critics who say the law could put the state's elderly and disabled in mortal danger. The Aid in Dying bill is meant to give terminally ill patients the choice to end their lives with a lethal dose of physician-prescribed drugs. http://www.nj.com/opinion/index.ssf/2014/06/assembly_wise_to_wait_on_assisted_suicide_bill_editorial.html

International

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

Reform of end-of-life care sought

U.K. (England) | *The Belfast Telegraph* (Northern Ireland) – 4 July 2014 –The National Health Service [NHS] could save tens of millions of pounds each year if more was done to allow cancer patients to die at home instead of in hospital...¹ New estimates ... suggest the 36,400 patients who died in hospital in 2012, despite saying they would prefer to be in their own homes, cost the NHS £137 million. The report says that had these patients been treated at home by community care teams, spending would have halved. <http://www.belfasttelegraph.co.uk/news/local-national/uk/reform-of-endoflife-care-sought-30406167.html>

1. 'Can we live with how we're dying? Advancing the case for free social care at the end of life.' Macmillan Cancer Support, July 2014. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Endoflife/EndofLifereport-June2014.pdf>

Cont.

Of related interest:

- U.K. (England) | *The Guardian* – 2 July 2014 – **'NHS cancer care could switch to private contracts in £700m plans.'** Cancer care [including end-of-life care] in the National Health Service could be privatised for the first time in the health service's biggest ever outsourcing of services worth over £1.2 billion. <http://www.theguardian.com/uk-news/2014/jul/02/cancer-care-nhs-outsourcing-ccgs-unison-virgin>
- U.K. (England) | Department of Health– 1 July 2014 – **'Expanding choice and improving the quality of end-of-life care.'** A review has been launched to ... provide advice to government on improving the quality and experience of care for adults at the end of life – their carers, and those who are important to them – by expanding choice. An independently-led board of experts on end-of-life care will present its findings and advice to government in February 2015. <https://www.gov.uk/government/news/expanding-choice-and-improving-the-quality-of-end-of-life-care>
- U.K. (England) | Public Health England (PHE) – 1 July 2014 – **'Results of the National End-of-Life Care Intelligence Network's impact evaluation.'** The survey asked people to rate the impact the network has made since being commissioned in 2010. Over 50% rated it as having a positive impact across all categories, and only five out of an average of 253 people responded that it had made a negative impact. <http://www.endoflifecare-intelligence.org.uk/news/>

End-of-life care in Ireland

Call to extend emergency medical card time limit for dying patients

IRELAND | *The Journal* (Dublin) – 2 July 2014 – The Irish Hospice Foundation [IHF] has called for the HSE [Health Service Executive] to extend the eligibility period of the emergency medical card for people who are approaching the end of life. Currently, people who are terminally ill and are nearing the end of their lives are entitled to a card for six months without a means test, once the prognosis is certified by a medical practitioner. However the IHF said one in five patients who gets medical cards on this basis lives beyond six months and the renewal process may be upsetting for patients and their families. In its submission to the expert group which is reviewing the medical card system, the Foundation said it is concerned that the current focus on specific conditions will "overlook those who may not fit easily into any diagnosis, but for whom life expectancy is still limited, including older people who are becoming increasingly frail." It recommended that the renewal process should involve contacting the certifying doctor for an update rather than a means test form being issued to the patient who is at the end of the life. <http://www.thejournal.ie/medical-card-dying-patients-1548164-Jul2014/>

Noted in Media Watch, 2 December 2013, #334 (p.7):

- IRELAND | *The Irish Times* (Dublin) – 26 November 2013 – **'Health Service Executive has lesson to learn in Fleming medical card case, says Taoiseac.'** Taoiseach [Prime Minister] Kenny said he accepts the Health Service Executive has a lesson to learn following the difficulty terminally ill Multiple Sclerosis sufferer Marie Fleming had in retaining her medical card. <http://www.irishtimes.com/news/ireland/irish-news/hse-has-lesson-to-learn-in-fleming-medical-card-case-says-taoiseach-1.1608142>

[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.14.

Irish Hospice Foundation survey: Interim results

Are you comfortable talking about death and dying?

IRELAND | *The Journal* (Dublin) – 1 July 2014 – The Irish Hospice Foundation is calling for a national conversation on death and dying. Chief executive, Sharon Foley, said, "while talking about death is not easy, we need to create for ourselves the best chance of having a good death and to plan for it." Each year 29,000 people die in Ireland and as many as 290,000 people are left bereaved. Almost half the population die in acute hospitals. Foley said: "Those moments at the end of life are extremely precious and will be re-lived again and again. Excellent communication and a positive, respectful attitude are required from all people associated with the care of the dying person and their loved ones." A new Foundation national survey on attitudes to end of life will be published later this year. The interim results reveal that only one third of the adult population believe discussion around death and dying is sufficient. <http://www.thejournal.ie/irish-hospice-death-1541267-Jun2014/>

Noted in Media Watch, 14 April 2014, #353 (p.10):

- *IRISH MEDICAL TIMES* | Online – 11 April 2014 – '**Doctors' concerns over living wills expressed to Department of Health.**' The development of an advance healthcare directive should require consultation with a healthcare professional, with the directive containing certain minimum information, the Royal College of Physicians of Ireland believes. A healthcare professional is not legally obliged to provide a treatment not clinically indicated, and an advance healthcare directive should not be allowed to mandate provision of a specific intervention that is not clinically indicated. <http://www.imt.ie/features-opinion/2014/04/doctors-concerns-over-living-wills-expressed-to-doh.html>

End-of-life care in Singapore

Higher Medisave withdrawal limits for palliative care

SINGAPORE | Channel AsiaNews – 28 June 2014 – Patients who need palliative care will soon pay less out of their pockets as they will be able to draw more from their Medisave accounts to pay for such services. The Ministry of Health will raise the withdrawal limits from 1 January 2015. Patients can withdraw up to S\$200 per day for inpatient hospice services – S\$40 more than the current S\$160. The lifetime withdrawal limit will be raised to S\$2,500 from the current S\$1,500, and no cap is set for those with terminal illnesses such as cancer or end-stage organ failure. The infrastructure will also be improved, with more beds to be set aside in community hospitals for patients on palliative care. No target is given but the health ministry is working with several community hospitals. Currently, there is one community hospital that caters to patients on palliative care. <http://www.channelnewsasia.com/news/singapore/higher-medisave/1215728.html>

N.B. Medisave is a national medical savings scheme which helps individuals put aside part of their income into their Medisave Accounts to meet their future personal or immediate family's hospitalization, day surgery, and certain outpatient expenses. Under the scheme, every employee contributes 7-9.5% (depending on age group) of their monthly salary to a personal Medisave account. The savings can be withdrawn to pay the hospital bills of the account holder and his immediate family members.

Of related interest:

- SINGAPORE | Channel AsiaNews – 5 July 2014 – '**More manpower needed in palliative care sector.**' In 2020, more than 10,000 Singaporeans are expected to be in need of end-of-life care. To meet this need, the Health Ministry estimates it will have to double manpower capacity in the palliative care sector from the current 150 to 300 by 2020. <http://www.channelnewsasia.com/news/singapore/more-manpower-needed-in/1238510.html>

Transition to adult services

"Forgotten" age group left out of hospice care

U.K. (Scotland) | *The Herald* (Edinburgh) – 27 June 2014 – Young disabled adults in Scotland claim a lack of hospice and respite facilities will leave them either isolated at home or reliant on facilities aimed at much older people. Their concerns are voiced in the Give Us a Break report...¹ It says young disabled people in Scotland have very poor access to hospices or respite facilities once they reach 18. Many children born with life-limiting conditions such as Duchenne muscular dystrophy now live well into adulthood. Yet adult and respite care services in Scotland have not adapted to recognise this, according to MDC, which called on the Scottish Government, local authorities and health boards to launch an urgent review of facilities for this "forgotten" age group. <http://www.heraldscotland.com/news/health/forgotten-age-group-left-out-of-hospice-care.24581785>

1. 'Give Us a Break: Hospice and Respite Care for Young Disabled Adults in Scotland,' Muscular Dystrophy Campaign, London, June 2014. The evidence published in this report outlines the pressing need for the Scottish Government, local authorities and health boards to come together to find a solution to the alarming lack of hospice and respite care for young disabled adults in Scotland. http://www.muscular-dystrophy.org/assets/0004/9845/Give_us_a_Break.pdf

Noted in Media Watch, 17 February 2014, #345 (p.12):

- *NURSING CHILDREN & YOUNG PEOPLE*, 2014;26(1):8-9. **'The challenges faced when leaving a children's hospice.'** The move into adult services can leave young people with life-shortening conditions in Scotland facing an uncertain future as they leave the comfort of children's services behind. <http://rcnpublishing.com/doi/pdfplus/10.7748/ncyp2014.02.26.1.8.s9>

N.B. Footnoted in this issue of Media Watch is a representative sample of articles noted in past issues of the weekly report on the transition to adult services for young people living with a terminal illness.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Daily Telegraph* – 4 July 2014 – **'If "dying with dignity" is legalised, soon it will be expected.'** Lord Falconer ... will bring in a parliamentary Bill for Assisted Dying on 18 July. All of us are dying, of course, and we need assistance in confronting that great fact; but that is not what Lord Falconer is talking about. He means assisting people to kill themselves, which is something else. The use of language is important in this debate, and the pro-killing party is clever at it. "Choice" is favoured. Even more so is "dying with dignity." Whoever thought of that phrase deserves – if euthanasia-supporters admit the concept – immortality. Who, after all, could want people not to die with dignity? The BBC now uses the phrase, unchallenged, in its news coverage of the issue, as if "dying with dignity" were an accepted euphemism for suicide, like "passing away" for death itself. You have to stop a moment to remember that thousands of people die with dignity every day, not by their own hand, but by accepting the course of nature. <http://www.telegraph.co.uk/news/uknews/law-and-order/10946221/If-dying-with-dignity-is-legalised-soon-it-will-be-expected.html>

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[Media Watch posted on Palliative Care Network-e Website](#)

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

- U.K. (England & Wales) | *The Daily Mail* – 2 July 2014 – **'Doctors' fears as leading medical journal backs assisted suicide: Editorial says terminally ill must be allowed to "call time on their lives."** Doctors should be allowed to help terminally ill patients to die, one of Britain's most influential medical journals says today. But the *British Medical Journal's* call for assisted suicide to be legalised provoked immediate alarm and anger in the profession.¹ In an editorial, the publication ... says the terminally ill must be allowed to "call time on their lives" when it is in their best interests. Senior doctors warned that such a change in the law will pressurise the elderly into wanting to end their lives for fear of being a burden on their relatives. The British Medical Association [BMA], Royal College of Physicians and Royal College of GPs all oppose assisted suicide and polls show most doctors share the same view. The journal is owned by the BMA but has editorial independence. <http://www.dailymail.co.uk/health/article-2678619/Doctors-fears-leading-medical-journal-backs-assisted-suicide-Editorial-says-terminally-ill-allowed-call-time-lives.html>

1. 'Dying Bill should become law in England & Wales, *British Medical Journal*, 2 July 2014. <http://www.bmj.com/content/349/bmj.g4349>

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

A follow-up meeting post death is appreciated by family members of deceased patients

ACTA ANAESTHESIOLOGICA SCANDINAVICA | Online – 1 July 2014 – Forty-six out of 84 family members answered and had attended a follow-up meeting post death (FUMPD). Ninety-one percent of the family members thought that we should continue to offer FUMPD. Seventy-eight percent were satisfied with their meeting. Eighty percent felt that they understood the cause of death. The majority wanted the meeting to take place within 6 weeks of death. Ninety-one percent rated the physician as important to be present at the meeting. The social worker was rated more important to attend the meeting than the assistant nurse. Ninety-one percent wanted to discuss the cause of death. Fifty-four out of 84 family members answered. Twenty out of 54 did not want us to contact them again. <http://onlinelibrary.wiley.com/doi/10.1111/aas.12358/abstract>

Palliative care as a human right

CANCER CONTROL | Online – Accessed 30 June 2014 – The right to palliative care is enshrined in many documents and agreements. This article explains how human rights relate to palliative care and where to find the relevant information, as well as the need to remove barriers and integrate palliative care into health care. <http://cancercontrol.info/wp-content/uploads/2014/06/116-121-Gwyther.pdf>

Of related interest:

- *THE LANCET GLOBAL HEALTH*, 2014;2(7):e375-e376. **'Inclusion of end-of-life care in the global health agenda.'** As populations age and societies industrialise, the number of people who will need palliative care to manage the problems associated with chronic progressive illness ... are predicted to increase in low-income and middle-income countries. This increase is compounded by late presentation to medical services and restricted access to potentially curative options. <http://www.thelancet.com/pdfs/journals/langlo/PIIS2214109X14701949.pdf>

Representative sample of articles noted in past issues of Media Watch on access to palliative care as a human rights issue:

- *PROGRESS IN PALLIATIVE CARE* | Online – 13 September 2013 – **'Dignity: A unifying concept for palliative care and human rights.'** Human dignity is a concept that occupies a central place in two disciplines – palliative care and human rights law. [Noted in Media Watch, 16 September 2013, #323 (pp.14-15)] http://www.ingentaconnect.com/content/maney/ppc/pre-prints/content-maney_ppc_167

Cont.

- *PALLIATIVE MEDICINE*, 2013;27(2):101-102. **'The Prague Charter: Urging governments to relieve suffering and ensure the right to palliative care.'** The European Association for Palliative Care, the International Association for Hospice & Palliative Care, the World Palliative Care Alliance, and Human Rights Watch have formulated 'The Prague Charter for Palliative Care as a Human Right.' [Noted in Media Watch, 11 February 2013, #292 (pp.10-11)] <http://pmj.sagepub.com/content/27/2/101.full>

N.B. The Prague Charter: <http://www.eapcnet.eu/Themes/Policy/PragueCharter.aspx>.

- *EDUCATIONAL GERONTOLOGY*, 2013;39(4):241-249. **'Breaking down barriers: Hospice palliative care as a human right in Canada.'** This paper describes numerous barriers that currently exist including ... barriers from geographic location, prognosis, ageism, and constraints from the Canadian medical system that have resulted in unequal access to of a patchwork of services. [Noted in Media Watch, 4 February 2013, #291 (p.7)] <http://www.tandfonline.com/doi/abs/10.1080/03601277.2013.750930>

Of related interest:

- *MCGILL JOURNAL OF LAW & HEALTH*, 2011;5(1):106-160. **'Palliative care: An enforceable Canadian human right?'** This article lays out approaches for establishing an enforceable human right to palliative care in Canada and examines international human rights instruments to which Canada is a signatory, and concludes they offer limited assistance to palliative care advocates. [Noted in Media Watch, 26 September 2011, #220 (p.9)] <http://mjlh.mcgill.ca/pdfs/vol5-1/MJLH%20Vol%20V.,%20No.%201%20-%20Shariff.pdf>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 January 2013 – **'The Lisbon Challenge: Acknowledging palliative care as a human right.'** Access to palliative care has been advocated as a human right by international associations, based on the right to the highest attainable standard of physical and mental health. [Noted in Media Watch, 4 February 2013, #291 (p.7)] <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0394>

N.B. The Lisbon Challenge: <http://www.eapcnet.eu/Themes/Policy/Lisbonchallenge.aspx>

The need for integrating palliative care in ageing and dementia policies

EUROPEAN JOURNAL OF PUBLIC HEALTH | Online – 4 July 2014 – Ageing and dementia is high on policy agendas around the world as is evidenced by recent activities of the European Commission, Council of Europe, World Health Organization, Organization for Economic Cooperation & Development, United Nations, the G8 Dementia Summit and the European Union summit on chronic diseases organized by the European Commission. Motivated by the huge expected increase of the number of people over 80 ... and of older people with reduced physical and mental abilities, these initiatives focus extensively on promoting 'Active and Healthy Ageing' (one of five European Innovation Partnerships in the Europe 2020 Initiatives), protecting the human rights of older persons, preventing and delaying neurodegenerative diseases such as dementia and other chronic diseases and improving quality of life and long-term care for people affected by chronic diseases while ensuring sustainable and affordable health care for everybody. Studying these different policy initiatives, it is highly remarkable how little they focus on the importance and added value of palliative care for older people with chronic and life-threatening diseases... <http://eurpub.oxfordjournals.org/content/early/2014/07/03/eurpub.cku084.extract>



[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>

Family caregiving and palliative care: Closing the policy gap

HEALTH AFFAIRS | Online – 2 July 2014 – In theory palliative care practice supports the principle of person- and family-centered care, which addresses the needs of both the recipient of care and his or her caregiver, promotes communication and shared decision making as well as coordination and collaboration by health care delivery teams. While these concepts have been recognized and included in practice guidelines – for example, those established by the [U.S.] National Consensus Project on Palliative Care¹ – they are often more an ideal than a reality. But the practice arena is far ahead of the policy world. Support for family caregivers has largely been absent from policy discussions of palliative care, which focus on professional, clinical, regulatory, and financial issues. As palliative care moves "upstream," that is, earlier in the course of illness, and into the "mainstream," as part of standard medical care, it is essential to bring family caregivers into the discussion, hear their concerns, and develop meaningful policy responses. <http://healthaffairs.org/blog/2014/07/02/family-caregiving-and-palliative-care-closing-the-policy-gap/>

1. 'National Consensus Project on Palliative Care: Clinical Practice Guidelines for Quality Palliative Care,' 3rd Edition, 2013. http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf

End-of-life care in Canada

The making of a myth: Unreliable data on access to palliative care in Canada

HEALTH LAW REVIEW | Forthcoming – Accessed 5 July 2014 – Assisted death is now the subject of conversation in the media, in public meetings, and around kitchen tables across the country. A frequent part of many conversations about assisted death law reform is access to quality palliative care in Canada. Throughout the literature and other forms of media, the claim is made that only 16-30% of Canadians have access to palliative care (or, its derivative, 70% are without access). The "16-30%" claim has been widely accepted as a fact. But is it, in fact, true? The author is driven to the conclusion that the oft-repeated claim that only 16-30% of Canadians have access to palliative care should be retired. It is based on a misrepresentation of outdated data and it ignores the provision of palliative care outside of the acute care hospital setting. http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2460886

American Academy of Hospice & Palliative Medicine

Hospice/palliative care association outlines 5 things physicians should question

HEMONC TODAY | Online – 30 June 2014 – When it comes to the avoidance of unnecessary tests, procedures or treatments, there is arguably no setting in which it is more important to choose wisely than end-of-life care. Hospice practitioners and palliative care specialists, by definition, seek to avoid unnecessary pain, anxiety, or expense for their patients. It was perhaps an extension of their everyday responsibilities, then, for members of the American Academy of Hospice & Palliative Medicine (AAHPM) to formulate a list of potentially unnecessary treatments and practices in their profession. The list was made as part of the ABIM Foundation's Choosing Wisely initiative, an effort started in 2012 to highlight the issue of overused and unnecessary tests and procedures. Through this collaborative effort, organizations representing a variety of medical specialties compiled and submitted their recommendations. This article presents AAHPM's list of possibly unnecessary or overused practices in the field of hospice care and palliative medicine. <http://www.healio.com/hematology-oncology/palliative-care/news/online/%7Bcc1dd49f-a523-42d5-898b-092025767ffb%7D/hospicepalliative-care-association-outlines-5-things-physicians-should-question>

Cont.

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 2 July 2014 – **'Barriers and strategies to an iterative model of advance care planning communication.'** Barriers included variation among providers in approaches to ACP [advance care planning], lack of useful information about patient values to guide decision making, and ineffective communication between providers across settings. Strategies included eliciting patient values rather than specific treatment choices and an increased role for primary care in the ACP process. <http://ajh.sagepub.com/content/early/2014/07/01/1049909114541513.abstract>
- *ANNALS OF INTERNAL MEDICINE*, 2014;161(1):73-75. **'Patient- and family-centered medical education: The next revolution in medical education?'** In this commentary, the authors propose changes in medical education and the training environment that have the potential to produce clinicians who are better able to address the needs of patients and their families. <http://annals.org/article.aspx?articleid=1862288>
- *BMC MEDICAL ETHICS* | Online – 30 June 2014 – **'To what extent are the wishes of a signatory reflected in their advance directive: A qualitative analysis.'** The non-involvement of a doctor in the process of making an advance directives must be seen as potentially problematic and seeking medical advice should be promoted by politics [sic] and physicians. Standardised forms should encourage amendments and present space for free text entries for all aspects covered. Set phrases need to be defined by the individual to enable them to be translated into a specific course of action. <http://www.biomedcentral.com/1472-6939/15/52/abstract>
- *JOURNAL OF CLINICAL ETHICS*, 2014;25(2):120-130. **'Uncharted terrain: Preference construction at the end of life.'** The author presents a growing body of evidence that suggests the novelty, complexity, and uncertainty of end-of-life circumstances make rational and stable preferences difficult to establish. She argues that an effective decision-making approach for the terminally ill must recognize and respond to the unique characteristics of end-of-life choices... http://www.clinicalethics.com/single_article/9RX5IFQKQXA.html
- *PATIENT EDUCATION & COUNSELING* | Online – 3 July 2014 – **'Twelve myths about shared decision making.'** There are many misconceptions about barriers to shared decision making in practice. The authors investigated the evidence relating to the most common of these. They discuss the twelve most prevalent and summarize the state of the evidence. [http://www.pec-journal.com/article/S0738-3991\(14\)00269-9/abstract](http://www.pec-journal.com/article/S0738-3991(14)00269-9/abstract)

Safety issues at the end of life in the home setting

HOME HEALTHCARE NURSE, 2014;32(7):396-401. Patients who choose care in a home setting at the end of life may be at risk because of their declining cognitive or physical abilities, environmental hazards in the home, or caregiving issues. Although safety concerns in hospitals have been well documented, knowledge about safety issues in the home setting is limited. This study was conducted to understand the safety issues that occur in the home setting from the perspective of home care clinicians who manage these issues for end-of-life patients. http://journals.lww.com/homehealthcarenurseonline/Abstract/2014/07000/Safety_Issues_at_the_End_of_Life_in_the_Home.3.aspx

Noted in Media Watch, 19 May 2014, #358 (p.7):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2014;16(4):200-205. **'Staying at home: Risk, accommodation, and ethics in hospice care.'** Home hospice clinicians frequently care for patients who wish to remain in their homes, even when doing so poses a risk to patients' safety. http://journals.lww.com/jhpn/Abstract/2014/06000/Staying_at_Home_Risk_Accommodation_and_Ethics.3.aspx

Comfort care rounds: A staff capacity-building initiative in long-term care homes

JOURNAL OF GERONTOLOGICAL NURSING | Online – 18 June 2014 – This article reports a pilot evaluation of Comfort Care Rounds (CCRs) – a strategy for addressing long-term care home staff's palliative and end-of-life care educational and support needs. Study participants identified that effective advertising, interest, and assigning staff to attend CCRs facilitated their participation. The key barriers to their attendance included difficulty in balancing heavy workloads and scheduling logistics. Interprofessional team member representation was sought but was not consistent. Study participants recognized the benefits of attending; however, they provided feedback on how the scheduling, content, and focus could be improved. Overall, study participants found CCRs to be beneficial to their palliative and end-of-life care knowledge, practice, and confidence. <http://www.healio.com/nursing/journals/jgn/%7Bcc361834-380d-43c6-9e1d-1e537df636b2%7D/comfort-care-rounds-a-staff-capacity-building-initiative-in-long-term-care-homes#>

Grief after patient death: Direct care staff in nursing homes and homecare

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 3 July 2014 – Grief reactions of staff [i.e., study participants] reflected many of the core grief symptoms reported by bereaved family caregivers in a large-scale caregiving study. Feelings of being "not at all prepared" for the death and struggling with "acceptance of death" were prevalent among staff. Grief was more intense when staff-patient relationships were closer, care was provided for longer, and staff felt emotionally unprepared for the death. [http://www.jpsmjournal.com/article/S0885-3924\(14\)00349-2/abstract](http://www.jpsmjournal.com/article/S0885-3924(14)00349-2/abstract)

District nurse advocacy for choice to live and die at home in rural Australia: A scoping study

NURSING ETHICS | Online – 30 June 2014 – Choice to live and die at home is supported by palliative care policy; however, health resources and access disparity impact on this choice in rural Australia. Thirty-four international studies revealed themes of "the nursing relationship," "environment," "communication," "support" and "the holistic client centred district nursing role." Under-resourcing, medicalisation and emotional relational burden could affect advocacy in rural areas. It is not known how district nurses overcome these circumstances to advocate for choice in end-of-life care. <http://nej.sagepub.com/content/early/2014/06/30/0969733014538889.1.abstract>

Family evaluation of hospice care: Examining direct and indirect associations with overall satisfaction and caregiver confidence

PALLIATIVE & SUPPORTIVE CARE | Online – 3 July 2014 – The Family Evaluation of Hospice Care survey is widely employed by hospices, and several studies have examined this information to help inform and enhance end-of-life services. However, these studies have largely focused on examining relatively straightforward associations between variables and have not tested larger models that could reveal more complex effects. The present study aimed to examine the direct and mediating (i.e., via information/education, patient care, and family support) effects of demographic factors, length of stay, timing of referral, patient symptom severity, location of services, and relationship to caregiver on two outcome variables: overall satisfaction and caregiver confidence. Study participants reporting on racial minority patients, patients with more symptoms, and those referred too late or too early were the most likely to express some discontentment with hospice services. The information/education these individuals received was the only mediating factor significantly associated with caregiver confidence. More positive perceptions of patient care and information/education were both significantly related to greater overall satisfaction. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9296010&fulltextType=RA&fileId=S1478951514000595>

Cont.

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* – 30 June 2014 – **'The stress of sadness: The most stressful symptoms for hospice family caregivers.'** This study investigated the most stressful patient symptoms as reported by 111 hospice family caregivers of cancer and cardiopulmonary patients. Researchers found that the symptoms perceived as most stressful for caregivers were psychological in nature. Study findings suggest that members of the hospice interdisciplinary team should connect patients and their caregivers to various types of support to address psychological symptoms, benefitting patients and caregivers alike. <http://ajh.sagepub.com/content/early/2014/06/27/1049909114540034.abstract>

Seventeen years of progress for supportive care services: A resurvey of [U.S.] National Cancer Institute-designated comprehensive cancer centers

PALLIATIVE & SUPPORTIVE CARE | Online – 3 July 2014 – The authors replicated a 1994 study that surveyed the state of supportive care services due to changes in the field and the increased need for such services. They provide an updated assessment, comparing the changes that have occurred and describing the current status of supportive care services in comprehensive cancer settings. The data revealed increases in the number of cancer beds in the hospitals, the degree of integration of supportive care services, the availability of complementary services, and the number of pain and palliative care services offered. There was also an overall shift toward centers becoming more patient centered, as 65% reported now having a patient and family advisory council. Findings of this study revealed a growing trend to offer distress screening for both outpatients and inpatients. Medical and palliative care directors' evaluations of the supportive care services they offered also significantly improved. However, the results revealed an ongoing gap in services for end-of-life care and timely referrals for hospice services. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9296022&fulltextType=RA&fileId=S1478951514000601>

End-of-life care in South Africa

Paediatric palliative medicine

SOUTH AFRICAN MEDICAL JOURNAL, 2014;104(7):505-506. In November 2013, the International Children's Palliative Care Network ... and the United Nations Children's Fund released 'Assessment of the Need for Palliative Care for Children. Three Country Report: South Africa, Kenya and Zimbabwe.'¹ It reported that, even though an underestimate, >800,000 children in South Africa were in need of generalised palliative care and >300,000 in need of specialised palliative care. Moreover, it was estimated that only 5% of children requiring specialised care were being reached. This low coverage was a result of "inadequate inclusion of children's palliative care within policy and strategy frameworks; widespread lack of knowledge and adequate understanding among health professionals; narrow target focus of services being provided already; the reluctance of health workers to prescribe and/or administer morphine despite the availability of essential palliative care pharmaceutical agents, resulting in a major barrier for access to comprehensive pain management; funding constraints and attendant poor integration of palliative care into the health system." <http://www.samj.org.za/index.php/samj/article/view/8428>

1. 'Significant numbers of sick children suffer and die without access to palliative care,' International Children's Palliative Care Network, 8 November 2013. Less than 1% of children in Kenya and less than 5% of children in South African and Zimbabwe who are in need of palliative care are able to access these services. [Noted in Media Watch, 11 November 2013, #331 (p.15)] <http://www.icpcn.org/significant-numbers-of-sick-children-suffer-and-die-without-access-to-palliative-care/>

Cont.

Also in this issue of the *South African Medical Journal*:

- **'When is the right time? Complex issues around withdrawing life-sustaining treatment in children.'** This article discusses the ethical and legal aspects around the decision to palliate in children. <http://www.samj.org.za/index.php/samj/article/view/8427>
- **'Talking to children: What to do and what not to do.'** Talking to children can be very daunting. Talking to a sick child can be even more daunting. How can we ensure that our message comes across in a way that is suitable and will not cause more harm than good? <http://www.samj.org.za/index.php/samj/article/view/8429>
- **'Basic counselling skills.'** "The single biggest problem in communication is the illusion that it has taken place." In the medical world, and especially one that involves children, this is unfortunately a reality. <http://www.samj.org.za/index.php/samj/article/view/8434>
- **'Managing pain in children at the end of life: What the GP should know.'** Chronically ill children, especially those requiring repeated procedures or admissions, may experience a significant burden of pain. If poorly managed, it has a negative impact on quality of life and parent-child relationships. <http://www.samj.org.za/index.php/samj/article/view/8462>
- **'Physician self-care.'** Moving away from cure to compassionate care of dying patients is a paradigm shift. This can be particularly difficult when caring for children with terminal illness. <http://www.samj.org.za/index.php/samj/article/view/8472>

Of related interest:

- *CANCER CONTROL* | Online – Accessed 30 June 2014 – **'Integrating palliative care into children's oncology service in India.'** The National Cancer Control Programme of India in 1987 referred to palliative care as a priority. However, most large cancer hospitals in India, including 18 of 29 government-designated lead cancer centres, do not have personnel trained in palliative care or are familiar with proper opioid use. In addition, most programmes lack paediatric expertise and thus deprive children and their families of the benefits of palliative care. http://cancercontrol.info/wp-content/uploads/2014/06/122-124-Brown-palliative-care_cc2014.pdf
- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2014;16(6):355-361. **'Supporting children with life-threatening conditions in the schools.'** School nurses are a source of support for teachers who have students with life-threatening conditions, and they provide support to school staff, families, and children. However, little is known regarding the questions they encounter and their desired sources of support, including interest in receiving support from hospice personnel. School nurses [i.e., survey respondents] encountered several types of questions from children with life-threatening conditions, their classmates and families, and school staff. They had questions themselves, in such areas as gaining and disseminating information, promoting understanding of the child's condition and providing support, addressing symptoms in conjunction with school activities, and do-not-resuscitate orders in the school setting. http://journals.lww.com/jhpn/Abstract/2014/08000/Supporting_Children_With_Life_Threatening_8.aspx
- *JOURNAL OF PEDIATRIC NURSING* | Online – 30 June 2014 – **'When a child dies: Parents' experiences of palliative care – An integrative literature review.'** Nine papers met the inclusion criteria. The analysis resulted in five categories: 1) genuine communication; 2) sincere relationships; 3) respect as an expert; 4) and alleviation of suffering; and, 5) need of support... Health professionals need education to provide high-quality pediatric palliative care. They especially need training concerning existential issues, and further studies need to be performed. [http://www.pediatricnursing.org/article/S0882-5963\(14\)00192-4/abstract](http://www.pediatricnursing.org/article/S0882-5963(14)00192-4/abstract)

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *ADVANCES IN PSYCHIATRIC TREATMENT*, 2014;20:250-257. '**Assisted dying – the debate...**' Should the law be changed to allow health professionals to assist mentally competent, terminally ill people to end their own lives? In this article opposing arguments are presented. <http://apt.rcpsych.org/content/20/4/250.abstract>
- *JOURNAL OF MEDICINE & PHILOSOPHY* | Online – 26 June 2014 – '**Rich, white, and vulnerable: Rethinking oppressive socialization in the euthanasia debate.**' Anita Silvers (1998) has criticized those who argue members of marginalized groups are vulnerable to a special threat posed by physician-assisted suicide (PAS) and voluntary active euthanasia (VAE).¹ Paternalistic measures prohibiting PAS/VAE in order to protect these groups only serve to marginalize them further by characterizing them as belonging to a definitively weak class. The author offers a new conception of vulnerability, one that demonstrates how rich, educated, white males, who are typically regarded as having their autonomy enhanced by their social status, are just as, if not more, vulnerable to threats posed by PAS/VAE as a result of the harmful social messages at work just below the surface of contemporary Western culture. <http://jimp.oxfordjournals.org/content/early/2014/06/26/jmp.jhu026.abstract>
 1. *Physician assisted suicide: Expanding the debate.* ISBN 0415920027 (New York: Routledge, 1998)
- *JOURNAL OF THE NEW ZEALAND MEDICAL ASSOCIATION*, 2014;127(1397). '**A critical analysis of the [i.e., New Zealand's] End of Life Choice Bill 2013.**' If passed into legislation, the End of Life Choice Bill will create the most momentous changes to clinical practice and the regulation of certain professional activities of medical practitioners that this country has ever seen. Whether they choose to be or not, sooner or later every medical practitioner will be affected by the legislation. It therefore behoves every medical practitioner to examine and understand this Bill and its implications. <http://journal.nzma.org.nz/journal/abstract.php?id=6198>

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.

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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.
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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.

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/5/media-watch/>

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 | Central Regional Hospice Palliative Care Program: <http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1>

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

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

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

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://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=b623758904ba11300ff6522fd7fb9f0c>

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