

Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to [Specialist Publications](#) and 'Preparing for family caregiving in specialized palliative home care: An ongoing process' (p.12), in *Palliative & Supportive Care*.

Canada

Balancing work and caregiving obligations: New guide walks you through it

CANADIAN HUMAN RIGHTS COMMISSION | Online – 11 June 2014 – The Commission has released its *Guide to Balancing Work and Caregiving Obligations: Collaborative Approaches for a Supportive and Well-performing Workplace*. The guide offers employers and employees practical tips on what to do when an employee's family caregiving and work responsibilities come into conflict. http://www.chrc-ccdp.gc.ca/sites/default/files/a_guide_to_balancing_work.pdf

Canada needs national palliative care plan, Canadian Medical Association urges

THE GLOBE & MAIL | Online – 10 June 2014 – The Canadian Medical Association [CMA] is calling for the creation of a national palliative care strategy to ensure people across the country have access to a high-quality, dignified end-of-life experience. The CMA is also warning that strong safeguards must be put in place if physician-assisted dying is legalized in Canada. Last week, Quebec became the first province to allow physician-assisted death. The association made the call in a new national end-of-life report created after speaking to Canadians across the country about their opinions on such highly charged as physician-assisted dying and palliative care.¹ The report urges all Canadians to discuss their end-of-life wishes with family members and create an advance care directive, which sets out what steps should be taken in the event they are incapacitated. The report found Canadians are still sharply divided on issues of assisted suicide. Despite that, there is clear consensus over the fact that access to palliative care needs to be improved... <http://www.theglobeandmail.com/life/health-and-fitness/health/canada-needs-national-palliative-care-plan-cma-urges/article19088848/>

1. 'End-of-life care: A national dialogue,' Canadian Medical Association, based on five town-hall meetings held across Canada conducted in conjunction with *Maclean's* magazine, June 2014. http://www.cma.ca/multimedia/CMA/Content/Images/CMAAdvocacy/EOL_townhall_report_FINAL.pdf

N.B. Several landmark reports, published between 1995 and 2012, on the provision and delivery of end-of-life care in Canada are listed in the issue of Media Watch, 3 March 2014, #347 (p.2). None of these reports are acknowledged or referenced in the CMA report.

Cont.

Noted in Media Watch, 2 June 2014, #360 (p.1):

- CBC NEWS | Online – 28 May 2014 – **'Palliative care strategy call backed by House of Commons.'** In a rare show of near all-party unity, the House of Commons endorsed New Democrat MP Charlie Angus's call for a cross-country strategy on palliative and end-of-life care. <http://www.cbc.ca/news/politics/palliative-care-strategy-call-backed-by-house-of-commons-1.2657151>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- POSTMEDIA NEWS | Online – 10 June 2014 – **'Canadians divided over legalization of euthanasia, doctors' group finds.'** Canadians have watched loved ones suffer "horrible" deaths but the public is divided over whether the federal ban outlawing euthanasia should be overturned, according to a new report from the nation's largest doctors' group. The report, based on the Canadian Medical Association's nationwide consultation with nearly 1,000 Canadians, is calling for a national palliative care strategy and urges all Canadians to prepare "advance care directives" spelling out what life-prolonging treatments they would and would not want should they ever lose the capacity to speak for themselves. But despite opinion polls showing a majority of Canadians support making it legal for doctors to help terminally ill patients kill themselves, the report says the public is split over the emotionally charged issue. <http://www.calgaryherald.com/news/national/Canadians+divided+over+legalization+euthanasia+doctors/9924632/story.html>
- QUEBEC | *The Globe & Mail* (OpEd) – 8 June 2014 – **'The collision course that may lead to change on assisted suicide.'** Quebec [has] become the first province in Canada – and one of the few places in the world – to allow its doctors to facilitate the death of terminally ill patients who wish to end their lives, with a lethal injection. The province should be lauded for passing legislation that snaps the law into line with what a majority of Quebecers – and Canadians – believe: that the terminally ill should be empowered to decide when and how they end their lives. Public opinion may be on the law's side, but Canada's Criminal Code is most definitely not. Quebec has been able to skirt the Criminal Code because the new law treats the right to die as a medical matter – not a criminal one. <http://www.theglobeandmail.com/globe-debate/editorials/the-collision-course-that-may-lead-to-change-on-assisted-suicide/article19057762/>

U.S.A.

End-of-life care in the prison system

Blind prisoner unknowingly signs do not resuscitate order

ALABAMA | Southern Poverty Law Center (SPLC) – 10 June 2014 – The blind prisoner believed he was signing a document related to his transfer. His hand was placed where he needed to sign the form. Prison officials just needed his signature for this small matter. The prisoner later discovered the form was a do not resuscitate order. There is significant evidence that numerous Alabama prisoners have been placed under do not resuscitate orders without their consent or even their knowledge. The SPLC has learned of prisoners being placed under these orders without their consent at the Kilby, St. Clair, Staton and Hamilton facilities. In some cases, doctors have discussed this issue with prisoners, and these prisoners have declined to be placed under a do not resuscitate or allow natural death order, only to be placed under it despite their refusal. One of the most basic health care decisions is when to discontinue treatment for a terminally ill patient. This is a decision that resides with the patient – even in prison. See p.9 of the Center's report: http://media.al.com/news_impact/other/Alabama%20Prison%20Report_final.pdf

Cont.

N.B. There is no mention in the SPLC report of hospice or palliative care; on pp.5,7 there are brief references to the quality of care for prisoners living with a potentially life-limiting or terminal illness. The provision and delivery of end-of-life care in the prison system have been highlighted in Media Watch on a regular basis. A compilation of articles, reports, etc., on this public health issue noted in the weekly report is available online at the Palliative Care Community Network website: <http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons>.

Physician Orders for Life-Sustaining Treatment

Patients' end-of-life wishes granted, study finds

THE WALL STREET JOURNAL | Online – 9 June 2014 – Patients who document their end-of-life wishes using a special medical form get the specific care they want in their final days, according to a study.¹ Researchers at Oregon Health & Science University looked at the growing use of the voluntary form, called Physician Orders for Life-Sustaining Treatment, or POLST. The study is the largest on the topic so far and the first to look at preferences stated in the form and where people actually die. POLST programs have been adopted or are in development in 43 states. Proponents say in addition to giving patients a voice in the face of advanced illness, they can help trim the nation's bill for costly interventions that don't extend life for patients who don't want them. However, the programs remain controversial with some groups in the often-fraught national debate about end-of-life care. The researchers examined death records for 58,000 people who died of natural causes in 2010 and

2011 in Oregon, where the POLST approach was developed in 1991 and which has the most comprehensive data on its use. <http://online.wsj.com/articles/patients-end-of-life-wishes-granted-study-finds-1402285059>

Extract from *Journal of the American Geriatrics Society* article

Nearly 18,000 of the patients, or roughly 30%, had such [POLST] forms on file at time of death. In comparing the location of death with the medical treatment people requested on their forms, only 6.4% of patients who specified "comfort measures only," or allowing for a natural death while relieving pain and suffering, died in a hospital. Meanwhile, 22.4% of patients who chose "limited additional interventions" died in a hospital and 44.2% of patients who chose "full treatment" died there. Of people with no such form, 34.2% died in a hospital.

1. 'Association between physician orders for life-sustaining treatment for scope of treatment and in-hospital death in Oregon,' *Journal of the American Geriatrics Society*, 9 June 2014. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12889/abstract>

Noted in Media Watch, 28 April 2014, #355 (p.10):

- *ANNALS OF EMERGENCY MEDICINE* | Online – 17 April 2014 – '**Physician Orders for Life-Sustaining Treatment and emergency medicine: Ethical considerations, legal issues, and emerging trends.**' Physician Orders for Life-Sustaining Treatment (POLST) is quickly growing in popularity and prevalence as a method of communicating the end-of-life care preferences for the seriously ill and frail nationwide. [http://www.annemergmed.com/article/S0196-0644\(14\)00220-0/abstract](http://www.annemergmed.com/article/S0196-0644(14)00220-0/abstract)

Noted in Media Watch, 20 May 2013, #306 (p.13):

- *THE LINACRE QUARTERLY*, 2013;80(2):103-138. '**The POLST paradigm and form: Facts and analysis.**' The paper offers a critical analysis of POLST, including an analysis of the risks POLST poses to sound clinical and ethical decision-making with recommendations to help Catholic healthcare professionals and institutions address the challenges of end-of-life care. <http://www.maneyonline.com/doi/abs/10.1179/0024363913Z.00000000027?queryID=33%2F291722>

Demographics

The second-largest religion in each state

NATIONAL PUBLIC RADIO | Online – 4 June 2014 – Christianity is by far the largest religion in the U.S.; more than three-quarters of Americans identify as Christians [according to the Association of Statisticians of American Religious Bodies]. A little more than half identify as Protestants, about 23% as Catholic, and about 2% as Mormon. In the Western U.S., Buddhists represent the largest non-Christian religious bloc in most states. In 20 states, mostly in the Midwest and South, Islam is the largest non-Christian faith tradition. And, in 15 states, mostly in the Northeast, Judaism has the most follow-

ers after Christianity. Hindus come in second place in Arizona and Delaware, and there are more practitioners of the Baha'i faith in South Carolina than anywhere else. http://www.washingtonpost.com/blogs/govbeat/wp/2014/06/04/the-second-largest-religion-in-each-state/?tid=pm_pop

Specialist Publications

'End of life-decisions: An Islamic perspective' (p.11), in *Online Journal of Health Ethics*.

International

The "£17,000" cost of dying abroad

U.K. | *The Daily Telegraph* – 13 June 2014 – More than 6,000 Britons die abroad every year, causing travel insurers to increasingly restrict payouts towards the costs of funerals or repatriation. Travellers, particularly older globetrotters, are being advised to read the small print carefully, as some of the wording is far from clear and policies can be riddled with exclusions, leaving bereaved families facing bills for many thousands of pounds. The bodies of nine out of 10 people who die abroad are brought back for funerals near home. Yet repatriation can cost anything up to £17,000... But some insurance policies have introduced strict limits on how much they will pay. <http://www.telegraph.co.uk/finance/personalfinance/insurance/travel/10895307/Travel-insurance-policies-and-the-17000-cost-of-dying-abroad.html>

Elder care in the U.K.

Home care visits for elderly can cost more than a place in a care home

U.K. | *Homecare* – 12 June 2014 – Just a few hours of care visits a day for elderly people in their own homes may be costing the taxpayer more than it would to provide around-the-clock care in a care home, according to a new study. The research, carried out by Four Seasons Health Care, found if a person has a need for more complex nursing care needs or they are receiving supplementary social benefits on top of basic state pension and attendance allowance, then less than two hours of domiciliary care every 24 hours could cost the public purse more than a full time care home place. Authorities tend to offer domiciliary care support ... because it is widely thought to be the least expensive option, but for many elderly people it is not the best way to meet their care needs and, when all the hidden associated costs are added, it is often not best value for the public purse. <http://www.homecare.co.uk/news/article.cfm/id/1563908/home-care-visits-elderly-cost-more-care-home>

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.

Family caregivers in Ireland

Cuts have had big effect on family carers, survey finds

IRELAND | *The Irish Times* (Dublin) – 9 June 2014 – Cuts to the respite grant, changes to medical card provision, and other cutbacks are having a significant impact on family carers of people with neurological conditions, according to a nationwide survey published by the Neurological Alliance of Ireland in association with Care Alliance Ireland.¹ In the survey of more than 170 family carers, 82% reported being impacted by cuts to care packages over the past three years, 77% by cuts to respite services, and 70% by cuts to home help. More than one-fifth of carers could not access any respite services. Some 42% of respondents had given up work to look after the person with a neurological condition, while 64% reported a significant fall in family income since the onset of the condition. Liam O Sullivan of Care Alliance, noted: "It is clear from this survey that successive cuts to supports for family carers are creating a climate of worry, uncertainty and distress. This is very disappointing in the light of the publication in 2012 of the national carers strategy..."² <http://www.irishtimes.com/news/crime-and-law/courts/cuts-have-had-big-effect-on-family-carers-survey-finds-1.1825232>

1. 'Living with a Neurological Condition in Ireland: Report on the Findings of a National Survey,' Neurological Alliance of Ireland, 2014. http://www.nai.ie/assets/72/7FF2BE3A-EF36-3F69-6C4B13B46C81555D_document/NAI_Survey_A4_1_.pdf
2. 'The National Carers' Strategy: Recognized, Supported, Empowered,' Department of Health, 2012. http://www.dohc.ie/publications/pdf/National_Carers_Strategy_en.pdf?direct=1

National Health Service "failing disabled and seriously ill teenagers" transferred to adult services

U.K. (England) | *The Guardian* – 9 June 2014 – The National Health Service is failing disabled and seriously ill teenagers by depriving them of vital services such as pain relief when they become adults, the service's watchdog warns.¹ In a highly critical report the Care Quality Commission (CQC) castigates doctors and hospitals for leaving vulnerable young people confused and stressed when they start being cared for as adults by different health professionals. Too many of the 40,000 under-18s in England with complex and challenging health needs end up losing access to key services they have relied on since childhood ... as they undergo what can be a very difficult "transi-

tion" to being treated as adults, the CQC says. They include young people with sometimes profound physical disabilities, chronic conditions such as diabetes and life-threatening illnesses such as cystic fibrosis. <http://www.theguardian.com/society/2014/jun/09/nhs-failing-disabled-seriously-ill-teenagers-adult-services>

Specialist Publications

'Ethical challenges when caring for dying children' (p.9), in *Nursing Ethics*.

1. 'From the pond into the sea: Children's transition to adult health services,' Care Quality Commission, June 2014. https://admin.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf

Representative sample of articles on the transition to adult services for young people living with a life-threatening or terminal illness noted in past issues of Media Watch:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 December 2013 – '**Palliative care answers the challenges of transitioning serious illness of childhood to adult medicine.**' There is an urgent need to develop approaches that assist with the transition of care from pediatrics to adult medicine. [Noted in Media Watch, 6 January 2014, #339 (p.12)] <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0263>

Cont.

- *PALLIATIVE MEDICINE* | Online – 18 October 2013 – '**Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: A qualitative study.**' Transition to adult services and adulthood is a prospect for young people with life-limiting conditions requiring palliative care. Transition planning [among the study participants] was absent or poorly coordinated; for most families, there were no equivalent adult health/social services. [Noted in Media Watch, 21 October 2013, #328 (p.13)] <http://pmj.sagepub.com/content/early/2013/10/15/0269216313507626.abstract>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- IRELAND | *The Irish Examiner* (Blackpool, Cork) – 9 June 2014 – '**Special report – euthanasia.**' Both euthanasia and assisted suicide are illegal. Under the Criminal Law (Suicide) Act 1993, it is an offence to aid, abet, counsel or procure the suicide or attempted suicide of another person. In practice, this criminal prohibition relates to active euthanasia where the person is helped take their own lives. While assisted suicide remains a crime in Ireland, it is not illegal to remove life support and other treatment should a person or their next of kin request it. <http://www.irishexaminer.com/analysis/special-report--euthanasia-271385.html>
- ISRAEL | *The Jerusalem Post* – 8 June 2014 – '**Euthanasia bill passes initial vote, but struggles to become law.**' The private member's bill that would allow a physician to prescribe a drug that would end a terminal, suffering patient to end his own life, without legal repercussions to the doctor, was passed by a majority vote of the Ministerial Committee on Legislation. Passing the bill in the Knesset will be a struggle due to expected opposition from religious and right-wing opponents. The bill ... is aimed at terminal patients who are not connected to ventilators and thus cannot ask their doctors to turn them off via a delayed-timer mechanism, which is approved but not yet implemented by an existing law on terminally ill patients. <http://www.jpost.com/Health-and-Science/Euthanasia-bill-passes-initial-vote-but-struggles-to-become-law-355677>

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

Students, severe illness, and palliative care: Results from a pilot study on a school-based intervention

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 13 June 2014 – This study was aimed at piloting a school-based intervention on severe illness, within a project focused on spreading knowledge of palliative care among high school students. The intervention entailed the screening of a topic-related movie, two classroom meetings, and the development of a class-based multimedia production. Five classes from five high schools participated, and a before–after evaluation was used to assess intervention feasibility and impact. Valid questionnaires were filled in by 84% (before) and 79% (after) of the 89 students. Concerning students' knowledge on palliative care, the after evaluation showed a significantly higher paired proportions of students reporting on "improving patient quality of life" and "life-threatening illness." Intervention components were deemed helpful by students, and positive feedback on the experience was given. <http://ajh.sagepub.com/content/early/2014/06/12/1049909114539187.abstract>

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>

Caregivers confronted with the withdrawal of artificial nutrition at the end of life: Prevalence of and reasons for experienced difficulties

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 13 June 2014 – Forty-two (25.8%) [of survey respondents] had always or often been affected with ethical dilemmas, and 97 (60%) responded that withdrawing artificial nutrition had always or often been preceded by a multidisciplinary discussion. Items significantly associated with a high level of ethical dilemmas were: 1) existence of differences in opinion within the health care team; 2) lack of information regarding the indication of the withdrawal of artificial nutrition; 3) feeling uncomfortable with the patient and his or her relatives; 4) guilt; 5) feeling of abandonment of care; and, 6) uneasiness. Health care providers seem to have a lack of information and consensus regarding the withdrawal of artificial nutrition at the end of life. The ethical dimension of withdrawing artificial nutrition in palliative care has a strong impact on care providers, regardless of the circumstances of the withdrawal. <http://ajh.sagepub.com/content/early/2014/06/12/1049909114539037.abstract>

Of related interest:

- *BC MEDICAL JOURNAL*, 2014;54(6):292-293. **'Quality of death.'** With the increase in discussion about euthanasia, there has also been confusion around the ethical principles of withholding and withdrawing care. Any treatment that we offer should be medically indicated and based on the clinical situation and knowledge of the patient's values and preferences. A treatment may be withheld or not initiated if it is not medically indicated. While we are not obliged to offer treatments, it is always helpful for the family to understand why that treatment is not being offered. <http://bcmj.org/council-health-promotion/quality-death>

Specialisation in Palliative Medicine for Physicians in Europe 2014: A supplement of the European Association for Palliative care Atlas of Palliative Care in Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (EAPC) | Online – 7 June 2014 – As of January 2014, there are 18 European countries with official Programme(s) on Specialisation in Palliative Medicine [POS-PM], with 10 of them having been started in the last five years. Countries recognised palliative medicine [PM] as a specialty, a subspecialty, a "special area of capacitation" or equivalent. The latter two show no substantial differences in the process. The term palliative medicine is used in most countries' program titles. Professionals in non-speciality programs must possess a previously attained clinical specialty; in five of the countries this can be any clinical specialty, while eight of the countries set a list of qualifying specialties or professional experience in palliative care [PC] and two countries include other clinical specialties. Clinical training varies, with one to two years being the most frequent period. There is a clear trend toward establishing POS-PM as a mandatory condition for obtaining a clinical position in PM within the respective health system, but at the moment it is not mandatory in the majority of the countries. http://www.eapcnet.eu/Portals/0/Organization/Development%20in%20Europe%20TF/Specialisation/2014_SpecialisationPMPhysicianInEurope.pdf

Noted in Media Watch, 3 June 2013, #308 (p.10):

- EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Online – 29 May 2013 – **The EAPC Atlas of Palliative care in Europe 2013.** The Atlas offers a global vision of the services, policies and strategies aimed at improving the end of life attention provided in the 53 countries that make up the European Region of the World Health Organization. The Atlas also contains detailed reports on palliative care in each country that is based on information updated in 2012. http://issuu.com/universidaddenavarra/docs/atlas_europa_full_edition

Quotable Quotes

What has surprised me is how little palliative care has to do with death. The death part is almost irrelevant. Our focus isn't on dying. Our focus is on quality of life. Dr. Balfour Mount

Physician-perceived contradictions in end-of-life communication: Toward a self-report measurement scale

HEALTH COMMUNICATIONS | Online – 9 June 2014 – Communication is undoubtedly a critical element of competent end-of-life care. However, physicians commonly lack communication skills in this particular care context. This study tests and validates a Contradictions in End-of-Life Communication (CEOLC) scale, which disentangles the relational contradictions physicians commonly experience when communicating with end-of-life patients. Analysis confirmed the presence of eight physician-perceived dialectical tensions, reflecting three latent factors of 1) integration; 2) expression; and 3) dominance. A number of significant intercultural differences were found in cross-cultural comparisons of the scale in U.S., Swiss, and Italian physician samples. Thus, this investigation introduces a heuristic assessment tool that aids a better understanding of the dialectical contradictions physicians experience in their interactions with end-of-life patients. The CEOLC scale can be used to gather empirical evidence that may eventually support the development of evidence-based guidelines and skills training toward improved end-of-life care. <http://www.tandfonline.com/doi/abs/10.1080/10410236.2013.841532?queryID=%24%7BresultBean.queryID%7D#.U5cBknJdX8k>

Managing communication tensions and challenges during the end-of-life journey: Perspectives of Māori kaumātua and their whānau

HEALTH COMMUNICATIONS | Online – 6 June 2014 – The purpose of this study is to explore the cultural practices and communication tensions perceived among Māori kaumātua (elders) and their whānaunga (extended family) during the end-of-life journey. Further, the study aims to explore the manner in which the tensions are managed. The study identified three cultural practices (dying at home, prayer, and song) that helped to build connection among the family members and also helped to connect the dying person to the spiritual world. Further, four communication tensions were noted: a) autonomy and connection; b) conflict and connection; c) isolation and connection; and, d) balancing the needs of self and other. To manage these tensions, the following strategies were used: a) coordination conversations; b) inclusion in decision-making conversations; c) emotional support within the whānau; and, d) passing on lessons to the next generation. <http://www.tandfonline.com/doi/abs/10.1080/10410236.2013.861306#.U5b9k3JdX8k>

Noted in Media Watch, 17 March 2014, #349 (p.9):

- *DIVERSITY & EQUALITY IN HEALTH & CARE*, 2014;11(1):61-70. **'Māori perspectives on hospice care.'** A kaupapa [collective philosophical] Māori approach to research shaped this study. Thematic analysis identified: 1) that participants perceived hospice as like a hospital, a place where people died; 2) what they appreciated and wanted from hospice, such as family-centred end-of-life care and respect for Māori cultural practices; 3) what they perceived as problems and barriers to receiving hospice care; and, 4) their potential solutions to these problems, such as community information seminars about the breadth of hospice services. <http://www.ingentaconnect.com/content/rmp/dehc/2014/00000011/00000001/art00006>

When letting-be is more important than actions: Plea for a new culture of dying

HERZ – ZEITSCHRIFT FÜR KARDIOLOGE | Online – 7 June 2014 – Today it has become a common approach to plan death, to organize and to regulate it. We tend to reduce death to a duty of management. With this rationalization of death we try to get within distance of it. Active euthanasia and assisted suicide seem to be the adequate answers to this approach, but is death really well understood if we only try to handle it this way? Is autonomy really the only relevant principle to respect the concerns of dying individuals or desperate people who want to die? This contribution pleads for an emphasis on a new ethics of caring, because a truly human medicine is not possible without caring. It shows that care does not necessarily get in conflict with autonomy but that it is the prerequisite for autonomy. <http://link.springer.com/article/10.1007/s00059-014-4116-z>

N.B. article published in German and English.

Ethical challenges when caring for dying children

NURSING ETHICS | Online – 10 June 2014 – [In this study] the essence of caring for dying children was likened to a musically attuned composition, comprising five constituents: presence, self-knowledge, injustice in dying, own suffering, and in need of others. Presence was found to be a prerequisite for caring when a child is dying. Self-knowledge and support from others can be of help when struggling with emotional pain and injustice. Caring for dying children has been found to be a delicate task for healthcare workers all over the world, and the ethical dimension is emphasized in international research. In this study, emotional pain and suffering accompanied caring, but an atmosphere in which it is possible to give and get support from colleagues and to have time to grieve and time to focus on the patient's needs may ease the burden, as can having time to process thoughts about life and death, and a possibility to grow in self-knowledge. <http://nej.sagepub.com/content/early/2014/06/09/0969733014533234.abstract>

Of related interest:

- *JOURNAL OF MEDICAL ETHICS* | Online – 10 June 2014 – '**Parents who wish no further treatment for their child.**' Sharing end-of-life decisions with parents is a more important duty for physicians than protecting parents from guilt or doubt. Moreover, a request from parents on behalf of their child to discontinue treatment is, and should be, hard to over-rule in cases with significant prognostic uncertainty and/or in cases with divergent opinions within the medical team. <http://jme.bmj.com/content/early/2014/06/10/medethics-2013-101395.abstract>
- *NURSING CHILDREN & YOUNG PEOPLE*, 2014;26(5):21-25. '**Giving hope to families in palliative care and implications for practice.**' Hope plays a crucial role in helping people cope. Healthcare professionals can foster appropriate hopes ethically, while maintaining open and honest communication. If palliative care is discussed with clients and families from the time of diagnosis, they can face realistic decisions better and not feel that they are "giving up." <http://rcnpublishing.com/doi/abs/10.7748/ncyp.26.5.21.e412>
- *PALLIATIVE MEDICINE & CARE: OPEN ACCESS*, 2014;1(2):5. '**Parental refusal of pain management: A potentially unrecognized form of medical neglect.**' While it can be challenging to determine whether a specific refusal rises to the level of neglect, certain cases do meet the criteria of the "harm principle" and thus justify state intervention to protect the child. <http://symbiosisonlinepublishing.com/palliative-medicine-care/palliative-medicine-care07.php>
- *PSYCHO-ONCOLOGY* | Online – 6 June 2014 – '**Pediatric psycho-oncology care: Standards, guidelines, and consensus reports.**' Despite calls by a number of international pediatric oncology and psycho-oncology professional organizations about the urgency of addressing the psychosocial needs of the child with cancer to reduce suffering, there remains a need for development of a widely acceptable, evidence-based and consensus-based, comprehensive standard of care to guide provision of essential psychosocial services to all patients with pediatric cancer. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3589/abstract>



[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>

Limits to relational autonomy: The Singaporean experience

NURSING ETHICS | Online – 9 June 2014 – Recognition that the principle of respect for autonomy fails to work in family-centric societies such as Singapore has recently led to the promotion of relational autonomy as a suitable framework within which to place healthcare decision making. However, empirical data, relating to patient and family opinions and the practices of healthcare professionals in Confucian-inspired Singapore, demonstrate clear limitations on the ability of a relational autonomy framework to provide the anticipated compromise between prevailing family decision-making norms and adopted Western led atomistic concepts of autonomy. Evidence suggests that despite a growing infusion of Western influence, there is still little to indicate any major shift to individual decision making, particularly in light of the way society and healthcare are structured. Similarly, the lack of employing a shared decision-making model and data that discredit the notion that the complex psychosocial and cultural factors that affect the decision making may be considered "content neutral" not only prevents the application of relational autonomy but questions the viability of the values behind the principle of respect for autonomy. Taking into account local data and drawing upon a wider concept of personhood that extends beyond prevailing family-centric ideals along with the complex interests that are focused upon the preservation of the unique nature of personhood that arises from the Ring Theory of Personhood, the authors propose and "operationalize" the employing of an authoritative welfare-based approach, within the confines of best interest decision making, to better meet the current care needs within Singapore. <http://nej.sagepub.com/content/early/2014/06/06/0969733014533239.abstract>

N.B. Noted in Media Watch, 20 January 2014, #341 (p.8): 'Making Difficult Decisions with Patients and Families: A Singapore Casebook.' <http://www.bioethicscasebook.sg/>; sample of content: 'Advance Decision Making in Singapore.' <http://www.bioethicscasebook.sg/background/advance-directives/>

Exploiting loss?: Ethical considerations, boundaries, and opportunities for the study of death and grief online

OMEGA – JOURNAL OF DEATH & DYING, 2014;68(4):315-335. This theoretical article explores the ethical dilemmas, challenges, and opportunities presented to researchers interested in exploring how death and grief are communicated online. Weaving together the literatures of computer-mediated communication and thanatology (dying and death), we discuss the ways in which many common ethical dilemmas uniquely manifest related to death and grief. We also explore the emotional impact studying death and grief online has on researchers and the importance of thinking about researcher emotions on scholars who study these issues. We end with recommendations of how to move forward in the dialogue about ethics and studying death and grief online. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,2,6;journal,1,270;linkingpublicationresults,1:300329,1>

Noted in Media Watch, 17 February 2014, #345 (p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2014;4(1):13-18. '**Palliative social media.**' The uses of social media have become ubiquitous in contemporary society at an astonishingly fast-paced rate. The Internet and in particular platforms such as Facebook, Twitter and YouTube are now part of most people's vocabulary and are starting to replace many face-to-face interactions. <http://spcare.bmj.com/content/4/1/13.abstract>

Noted in Media Watch, 5 March 2012, #243 (p.11):

- *OMEGA – JOURNAL OF DEATH & DYING*, 2012;64(4):275-302. '**Does the Internet change how we die and mourn?**' Part 1 [of this article] describes a range of online practices that may affect dying, the funeral, grief and memorialization, inheritance, and archaeology. Part 2 argues that these online practices have implications for key concepts in death studies. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,1,6;journal,1,255;linkingpublicationresults,1:300329,1>

End of life-decisions: An Islamic perspective

ONLINE JOURNAL OF HEALTH ETHICS | Online – June 2014 – End of life decisions are causing many ethical dilemmas for health care providers, patients, and their families. According to Islam, a doctor or a health care provider should not take away life or help in assisting anyone to end his/her life even when he/she is motivated by mercy. This is prohibited because this is not one of the legitimate indications for killing. Therefore, active euthanasia and physician-assisted suicide are forbidden in Islam. On the other hand, seeking treatment is not a must that every Muslim should do. Therefore, withholding and withdrawing treatment are not considered sins, even though it may lead to the death of the ill person. In some cases, such as in brain death and persistent vegetative state, withdrawing mechanical ventilation from patients is permissible. Others think that withdrawing mechanical ventilation is a must in these cases, since these patients have no hope to be cured and to be brought back to life. Continuing treatment in these cases is considered a waste of scarce resources that might be needed by others who could benefit from it. http://aquila.usm.edu/ojhe/vol10/iss1/4/?utm_source=aquila.usm.edu%2Fojhe%2Fvol10%2Fiss1%2F4&utm_medium=PDF&utm_campaign=PDFCoverPages

Noted in Media Watch, 28 March 2011, #194 (p.10):

- *JOURNAL OF MEDICAL ETHICS* | Online – 23 March 2011 – '**Disclosure of terminal illness to patients and families: Diversity of governing codes in 14 Islamic countries.**' Codes for 14 Islamic countries were located. Five were silent regarding informing the patient, seven allowed concealment, one mandated disclosure, and one prohibited disclosure. Five were silent regarding informing the family, four allowed disclosure and five mandated/recommended disclosure. The Islamic Organization for Medical Sciences code was silent on both issues. <http://jme.bmj.com/content/early/2011/03/22/jme.2010.038497.abstract>

N.B. Additional articles on end-of-life care and Islam law are footnoted in this issue of Media Watch.

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.
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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.

Palliative care development in Latin America: An analysis using *macro indicato*

PALLIATIVE MEDICINE | Online – 12 June 2014 – Recently, the Latin American Association for Palliative Care developed 10 indicators to monitor the development of palliative care and enhance the development of regional and national strategies. [There are 19 Spanish and Portuguese-speaking countries in Latin America.] Indicators significantly associated with the number of palliative care services per million inhabitants included: the proportion of medical schools with palliative care at the undergraduate level, the number of accredited physicians working in palliative care, and opioids consumed *per capita*. Three ranking groups were built to measure palliative care development: Costa Rica, Chile, Mexico, and Argentina ranked in the high group; Bolivia, Honduras, Dominican Republic, and Guatemala ranked in the lowest group. Most of the indicators are useful for assessing national levels of palliative care development. These may be applicable to other world regions. <http://pmj.sagepub.com/content/early/2014/06/12/0269216314538893.abstract>

Palliative care in Latin America

Atlas de Cuidados Paliativos de Latinoamérica, Asociación Latinoamericana de Cuidados Paliativos, 2012. [Noted in Media Watch, 7 January 2013, #287, (p.8)]

Spanish language edition:

<http://cuidadospaliativos.org/uploads/2012/10/atlas/Atlas%20de%20Cuidados%20Paliativos%20en%20Latinoamerica.pdf>;

Portuguese language edition:

<http://cuidadospaliativos.org/uploads/2014/1/Atlas%20Portugues.pdf>;

English language edition:

<http://cuidadospaliativos.org/uploads/2013/12/Atlas%20of%20Palliative%20Care%20in%20Latin%20America.pdf>

Atlas de Cuidados Paliativos de Latinoamérica: Edición Cartográfica 2013, Asociación Latinoamericana de Cuidados Paliativos, 2013. [Noted in Media Watch, 2 December 2013, #334 (p.5)]

Spanish language edition:

<http://cuidadospaliativos.org/uploads/2014/3/Atlas%20Latinoamerica%20-%20edicion%20cartografica.pdf>

The doctor's role in helping dying patients with cancer achieve peace: A qualitative study

PALLIATIVE MEDICINE | Online – 9 June 2014 – Being at peace is important for the quality of life of dying cancer patients, but its features, and the role of the doctor in facilitating peace, are unclear. Patients [i.e., study participants] were asked about the things that gave their life meaning and a sense of peace and how the doctor could support their spiritual well-being. Patients were also questioned about their concerns for their future. They were observed to be along a spectrum between having peace and not having peace. Features of the two extreme positions are described. Spiritual well-being in cancer patients can be promoted by communication from doctors regarding prognosis, which allows them time to prepare for death, and recognition of their fears. However, acceptance of death does not always lead to the patient experiencing peace. <http://pmj.sagepub.com/content/early/2014/05/28/0269216314536455.abstract>

Preparing for family caregiving in specialized palliative home care: An ongoing process

PALLIATIVE & SUPPORTIVE CARE | Online – 9 June 2014 – Family caregivers [i.e., study participants] described their experience of preparing for caregiving as an ongoing process, rather than something done in advance. The process was illustrated through three sub-processes: "awaring" (realizing the seriousness of the situation), "adjusting" (managing a challenging situation), and "anticipating" (planning for the inevitable loss). Knowledge about the process of preparedness for caregiving and its sub-processes could be valuable to healthcare professionals... <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9279476&fulltextType=RA&fileId=S1478951514000558>

Cont.

Noted in Media Watch, 21 April 2014, #354 (p.9):

- *BMC PALLIATIVE CARE* | Online – 17 April 2014 – **"It's alright to ask for help": Findings from a qualitative study exploring the information and support needs of family carers at the end of life.** Family carers experience multiple needs for information and education, but meeting these needs remains a challenge. Three domains could underpin this type of intervention: developing knowledge and competence; facilitating preparedness; and, supporting role recognition and confidence building. <http://www.biomedcentral.com/content/pdf/1472-684X-13-22.pdf>

Noted in Media Watch, 26 July 2010, #159 (p.11, under 'Worth Repeating'):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2004;291(4):483-491. **"They don't know what they don't know": Supporting family caregivers at the end of life.** The amorphous relationship between physicians and the families of patients at the end of life presents both challenges and opportunities for which physicians may be unprepared. Families play important roles in the practical and emotional aspects of patient care and in decision making at the end of life. At the same time, family members may carry significant burdens as a result of their work. Through the perspectives of the wife, daughter, and home care nurse of a patient who died from pancreatic cancer, the authors illustrate the range of family caregiver experiences and suggest potentially helpful physician interventions. <http://jama.ama-assn.org/cgi/content/abstract/291/4/483?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=forgiveness+at+the+end+of+life&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT>

End-of-life expectations and experiences among nursing home patients and their relatives – a synthesis of qualitative studies

PATIENT EDUCATION & COUNSELING | Online – 12 June 2014 – Patients and families emphasized the importance of health personnel anticipating illness trajectories and recognizing the information and palliation needed. Family members who became proxy decision-makers reported uncertainty and distress when guidance from health personnel was lacking. They worried about staff shortage and emphasized doctor availability. Relatives and health personnel seldom recognized patients' ability to consent, and patients' preferences were not always recognized. High-quality end-of-life care in nursing homes relies on organization, funding and skilled staff, including available doctors who are able to recognize illness trajectories and perform individualized advance care planning. [http://www.pec-journal.com/article/S0738-3991\(14\)00230-4/abstract](http://www.pec-journal.com/article/S0738-3991(14)00230-4/abstract)

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *ANTHROPOLOGY TODAY*, 2014;30(3):14-17. **'The death of the right-to-die campaigners.'** The "right-to-die" or assisted suicide debate in the U.K. has recently been dominated by high-profile litigation which has brought to public attention stories of individual suffering. The most recent case is that of Tony Nicklinson who, as a result of his permanent and total paralysis which he said made his life "intolerable," wanted the courts to allow a doctor to end his life. Only six days after a Judicial Review refused Nicklinson's request, Tony died of "natural" causes. This article compares the presentation by the media of Tony's requested death with his actual death and discusses what this reveals more generally about the way in which the right-to-die debate is presented to the public. It argues that in a politicised debate in which the personal stories of the disabled-dying are given airtime because of their didactic or symbolic potential, actual death becomes less important than the rights-rhetoric surrounding death. <http://onlinelibrary.wiley.com/doi/10.1111/1467-8322.12110/abstract;jsessionid=E71FDE73EF70E77A05D31804AE36BF3C.f02t02?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Cont.

- *BRITISH MEDICAL JOURNAL* | Online – 10 June 2014 – '**House of Lords is to consider bill on assisted suicide.**' A majority of the British public say that they support "assisted dying" and within the medical profession there is tacit recognition that many doctors have helped patients to die. Lord Falconer's bill on "assisted dying" would make this legal for terminally ill mentally competent adults, subject to a number of caveats and safeguards, but the debate in the Lords on 18 July will undoubtedly be vigorous as there are strongly held views on both sides. <http://www.bmj.com/content/348/bmj.g3798/rr/701563>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | online – 13 June 2014 – '**Complexities in euthanasia or physician-assisted suicide as perceived by Dutch physicians and patients' relatives.**' Complexities can be categorized into relational difficulties – such as miscommunication, invisible suffering and the absence of a process of growth towards EAS [euthanasia and physician-assisted suicide] – and complexities that arise from unexpected situations, such as the capricious progress of a disease or the obligation to move the patient. The interviews showed that relatives of the patient influence the process towards EAS. [http://www.jpsmjournals.com/article/S0885-3924\(14\)00306-6/abstract](http://www.jpsmjournals.com/article/S0885-3924(14)00306-6/abstract)

Worth Repeating

Last offices neglected in over half of hospital deaths

NURSING TIMES (U.K.) | Online – 11 May 2010 – A dearth of training and guidance means nurses are failing to follow "last offices," the simple procedures for treating dead patients with dignity and respect, a *Nursing Times* investigation has found. In more than half of hospital deaths, nurses neglect to follow procedures such as straightening patients' limbs or closing their eyes and mouth before rigour mortis sets in (see below). Such failures can mean patients have tubes and lines wrongly removed or are left with loose dressings, resulting in fluid leaks which can be distressing for relatives. On occasions patients are not cleaned properly or are left with marks on their bodies. <http://m.nursingtimes.net/5014365.article>

What should last offices involve?

- If the patient is not catheterised, apply gentle pressure over the bladder to allow it to drain
- Remove and record jewellery and any personal items, unless requested or advised otherwise
- Attend to hygiene needs, particularly hair, nail and mouth care
- Replace dentures
- Attempt to close the eyes, using a small piece of clinical tape if required
- Attach identification labels
- Dress the patient in a gown/shroud or own clothes, as required
- Place an incontinence pad under the buttocks to contain any soiling

Source: *Nursing Times*

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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