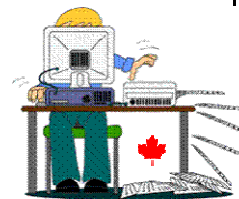


Media Watch...

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

When a patient is deemed incapacitated: Scroll down to [Specialist Publications](#) (p.13) and 'When mediation fails: Identifying and working with inappropriate surrogate decision makers' in *Progress in Palliative Care*.

Canada

Right to refuse potentially life-sustaining treatment

Ontario hospital cannot force chemo on 11-year-old native girl, court rules

ONTARIO | *The Globe & Mail* – 14 November 2014 – In a decision that could affect First Nations people across Canada, a judge in Ontario has ruled that a hospital cannot force a cancer-stricken 11-year-old girl to resume chemotherapy because the Constitution protects her mother's right to treat the child with traditional aboriginal medicine instead. In his decision, Justice Edward, who grew up in Brantford and is a member of the Six Nations band, discussed whether J.J. [as the patient is known] would qualify as a child in need of protection under The Child & Family Services Act in Ontario. Both sides agreed that D.H. [as she is known] is a loving and supportive mother and that only one part of the act might apply, a section that says a child can be deemed in need of protection if "the child requires medical treatment to cure, prevent or alleviate physical harm or suffering and the child's parent or the person having charge of the child does not provide, or refuses or is unavailable or unable to consent to the treatment." Rather than dealing with that issue on its face, Justice Edward turned to an analysis of the aboriginal rights protected by Section 35 of the Constitution. To count as an aboriginal right, he said, a practice must be "integral" to First Nations identity and date back to the time before Europeans arrived in Canada. He concluded that D.H.'s beliefs fit that bill, leading him to dismiss the hospital's application. <http://www.theglobeandmail.com/life/health-and-fitness/health/cancer-patient-has-right-to-use-aboriginal-healing-instead-of-chemo-judge-rules/article21587859/>

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.

Family MDs group pushes Ottawa for home-care strategy...

CANADIAN PRESS | Online – 12 November 2014 – Canada's family doctors are calling on the federal government to develop a national home-care strategy for seniors... In a report released ... at its [recent] annual meeting ... the College of Family Physicians of Canada outlined a suggested road map on how Ottawa could achieve ... [this goal] ...¹ The organization, which represents about 31,000 family doctors across the country, said the health-care system needs to focus more on home- and community-based care under a national home-care strategy, which it wants to see developed and implemented by 2016. Although the federal government has taken small steps in supporting home care for Canadians ... it needs to create a national strategy with the provinces and territories to significantly boost home- and community-based services, while increasing access to long-term care. <http://winnipeg.ctvnews.ca/family-mds-group-pushes-ottawa-for-home-care-strategy-plan-to-end-child-poverty-1.2098797>

1. 'From Red to Green. From Stop to Go. Recommended actions to improve home care and child and youth health,' the College of Family Physicians of Canada, November 2014. http://www.cfpc.ca/uploadedFiles/Health_Policy/PDFs/CFPC_Red_to_Green_2014_EN.pdf

Representative sample of articles on home and community care in Canada noted in recent issues of Media Watch:

- CTV NEWS | Online – 9 September 2014 – '**Home care needs of many Canadians go unmet: Statistics Canada.**' A study by Statistics Canada has found the needs of many Canadians who require home care for long-term illnesses, aging or disabilities aren't being fully met.¹ [Noted in Media Watch, 15 September 2014, #375 (p.2)] <http://www.ctvnews.ca/health/home-care-needs-of-many-canadians-go-unmet-statistics-canada-1.1998250>
 1. 'Canadians with unmet home care needs, 2012,' Statistics Canada, September 2014. <http://www.statcan.gc.ca/daily-quotidien/140909/dq140909a-eng.htm?HPA>
- BRITISH COLUMBIA | *The Vancouver Sun* – 6 September 2014 – '**Seniors' health in the spotlight: High staff turnover plagues home care sector.**' Government and individuals spent \$7-8 billion in 2010 on publicly funded and private home care ... making up about 4% of all health care spending across the country¹ ... an increase from an estimated \$4.3 billion in combined spending in 2003-2004.² [Noted in Media Watch, 15 September 2014, #375 (p.2)] <http://www.vancouversun.com/health/Seniors+health+spotlight+High+staff+turnover+plagues+home+care+sector/10179447/story.html>
 1. 'Home and Community Care in Canada: An Economic Footprint,' Conference Board of Canada, 2012. <http://www.conferenceboard.ca/e-library/abstract.aspx?did=4841>
 2. 'Home Care,' Canadian Institute for Health Information, 2014. <http://www.cihi.ca/cihi-ext-portal/internet/en/tabbedcontent/types+of+care/community+care/home+care/cihi021338>
- CTV NEWS | Online – 18 August 2014 – '**Baby boomers call for national seniors care strategy.**' In the Canadian Medical Association's 2014 National Report Card on health issues, 95% of Canadians aged 45 years and over identified the need for a national strategy for seniors care.¹ The report found that 81% of these Canadians are concerned with the quality of health care they can expect in the future. [Noted in Media Watch, 25 August 2014, #372 (p.1)] <http://www.ctvnews.ca/health/baby-boomers-call-for-national-seniors-care-strategy-1.1964183>
 1. '2014 Annual National Report Card on Health Care,' Canadian Medical Association, August 2014. https://www.cma.ca/En/Lists/Medias/2014_Report_Card-e.pdf

[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.S.A.

Nursing home care levels may be much lower than families think

NBC NEWS | Online – 12 November 2014 – Many U.S. nursing home patients may not be receiving the level of care their loved ones believe they're getting, a Center for Public Integrity probe has found. Staffing levels reported by thousands of nursing homes on a widely-used government website were higher than the staff levels calculated by the [Washington DC-based] Center for Public Integrity through an analysis of annual financial reports submitted by the homes, suggesting that consumers in those facilities may not be getting as many hours of skilled care as they expect. Experts have shown the amount of care provided by nursing homes is linked to the quality of care. More than 80% of the facilities reported higher registered nurse staffing levels on the public website than those the Center calcu-

lated through its analysis of the cost reports. <http://www.nbcnews.com/news/investigations/nursing-home-care-levels-may-be-much-lower-families-think-n246431>

Specialist Publications

'Prevalence and description of palliative care in U.S. nursing homes: A descriptive study' (p.6), *American Journal of Hospice & Palliative Medicine*.

'Hospice family members' perceptions of and experiences with end-of-life care in the nursing home' (p.6), in *Journal of the American Medical Directors Association*.

Ezekiel Emanuel under America Medical Association fire for declaring desire to die at 75

ILLINOIS | *The Chicago Tribune* – 11 November 2014 – Ezekiel Emanuel ... a key figure in health policy circles, came under fire from fellow doctors this week for declaring in a magazine article that he wants to die at the age of 75.¹ In the article ... Emanuel said he plans to refuse life-prolonging and preventive care starting in 2032 because "this manic desperation to endlessly extend life is misguided and potentially destructive." People become less creative as they age, he wrote. A deadline of 75 years "forces each of us to ask whether our consumption is worth our contribution." That sentiment angered some doctors within the American Medical Association [AMA], who said that Emanuel had defied the Chicago-based physician group's code of ethics in suggesting that a human life becomes less valuable with age. With the AMA's House of Delegates convened in Dallas, AMA delegate ... Gregory Pinto proposed a resolution that would have directed the organization to "issue a statement publicly disagreeing" with Emanuel. Emanuel, an oncologist and bioethicist, was a health policy adviser to the White House during the crafting of the Affordable Care Act. <http://www.chicagotribune.com/news/local/breaking/ct-ezekiel-emanuel-ama-met-20141111-story.html>

1. 'Why I hope to die at 75: An argument that society and families – and you – will be better off if nature takes its course swiftly and promptly,' *The Atlantic Monthly*, October 2014. <http://www.theatlantic.com/features/archive/2014/09/why-i-hope-to-die-at-75/379329/>

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>



Hospice patients more likely to die at home, receive efficient care

REUTERS HEALTH | Online – 11 November 2014 – People in hospice are less likely to die in a hospital or nursing home, and less likely to get costly and intensive care, than terminally ill patients who don't opt for hospice care, according to a new study of older Americans with cancer.¹ Hospice patients endured fewer invasive procedures and fewer hospital stays at the end of their lives. Discussing hospice as an option for the terminally ill may prevent that intensive care, the study's lead author said. "There is a lot of evidence that a lot of people don't have these conversations," said Dr. Ziad Obermeyer, a physician at Brigham & Women's Hospital in Boston. "So they get sucked into this intense care option without even talking about it." In the U.S., people with Medicare, the government insurance program for the elderly and disabled, are eligible for hospice benefits if they are not expected to live another six months. For the new study ... the researchers used data on nearly 40,000 Medicare patients with poor-prognosis cancers who died in 2011. Half ... chose hospice

and half didn't. Surprisingly, Obermeyer said, much of the intensive care the patients received was unrelated to their cancers. Patients often don't want intensive care at the end of their lives, the researchers write. <http://www.reuters.com/article/2014/11/11/us-hospice-care-cost-idUSKCN0IV25C20141111>

Specialist Publications

'End-of-life care in critical condition' (p.6), in *American Journal of Public Health*.

'Identifying key priorities for future palliative care research using an innovative analytic approach' (p.7), in *American Journal of Public Health*.

'Quality and costs of end-of-life care: The need for transparency and accountability' (p.10), in *Journal of the American Medical Association*.

1. 'Association between the Medicare Hospice Benefit and health care utilization and costs for patients with poor-prognosis cancer,' *Journal of the American Medical Association*, 2014; 312(18):1888-1996. <http://jama.jamanetwork.com/article.aspx?articleid=1930818>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW JERSEY | Reuters – 13 November 2014 – **'New Jersey state Assembly approves assisted suicide bill.'** The New Jersey state Assembly passed a measure that would allow doctors to prescribe life-ending drugs to terminally ill patients, modeled after the Oregon law... The legislation must still win approval in the New Jersey state Senate, where a companion bill has stalled, and then be signed by Governor Chris Christie. If it passes those hurdles, New Jersey would become the fourth state with a so-called "death with dignity" law. <http://news.yahoo.com/jersey-state-assembly-approves-assisted-suicide-bill-005228434.html>

International

Elder care in the U.K.

MPs attack "shambles" of elderly care home plan that was supposed to save £1 billion – but will only actually reduce bill by £300m

U.K. (England) | *The Daily Mail* – 11 November 2014 – A flagship government policy to improve care for the elderly at home so they don't end up in hospital has been branded a "shambles" by MPs. The Better Care Fund is a series of locally-run schemes to boost services for the elderly at

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home... The policy was first announced by the Government last June but the money – £5.3 billion – will not be made available until next April. In the meantime, local organisations called Health & Wellbeing Boards have been drawing up detailed plans setting out how they will spend their share of the pot. Ministers hope that the scheme will ultimately save the National Health Service money as there will be fewer, expensive admissions to hospital. But MPs on the Committee of Public Accounts who have been scrutinising the local plans estimate it will save just £314 million. <http://www.dailymail.co.uk/news/article-2829339/MPs-attack-shambles-Better-Care-Fund.html>

Noted in Media Watch, 3 November 2014, #382 (p.6):

- U.K. (England) | *The Daily Express* – 30 October 2014 – '**Dignity at last... Millions to get seven-day-a-week health care in their own homes.**' A £5.3 billion package aims to end visits to hospital accident and emergency departments and needless hospital stays. <http://www.express.co.uk/news/uk/529164/Millions-of-elderly-to-get-home-care-due-to-new-pledge>

Paediatric palliative care in Ireland

"Paediatric home-care crisis" emerging in north Dublin

IRELAND | *The Irish Times* (Dublin) – 10 November 2014 – A "paediatric homecare crisis" is emerging in north Dublin as an increasing number of children with life-limiting conditions are being left without homecare, a charity advocating for such families has warned. The Jack and Jill foundation, which provides nursing care to such children in their homes up to the age of four, say the problems they are encountering in north Dublin, when seeking to arrange Health Service Executive nursing hours to replace the hours they provide, are not replicated elsewhere. The charity is reiterating its call, first made over a decade ago, for a national ring-fenced budget for home-care packages for terminally ill children and for a protocol on transferring them to home. <https://www.irishtimes.com/news/social-affairs/paediatric-home-care-crisis-emerging-in-north-dublin-1.1994300>

End-of-life care in New Zealand

Call for more focus on end-of-life care

NEW ZEALAND | Radio New Zealand (Wellington) – 10 November 2014 – Medical specialists say New Zealand is in the grip of a workforce crisis in palliative care, with 55 palliative care specialists, 42 of whom are working full time. The Palliative Medicine Training & Coordination Committee says a stock take it has carried out for the Ministry's Health Workforce New Zealand group shows 12 positions are vacant and 18 more vacancies will occur with five years from retirement. <http://www.radionz.co.nz/news/national/259060/call-for-more-focus-on-end-of-life-care>

Elder care in Wales

Care home life unacceptable, says older people's watchdog

U.K. (Wales) | BBC News – 10 November 2014 – "Too many ... living in care homes quickly become institutionalised. Their personal identity and individuality rapidly diminishes, and they have a lack of choice and control over their lives" [a new report from the Older People's Commission for Wales finds].¹ The review was undertaken using the commissioner's statutory powers, which means care providers and public bodies have to act on the findings. <http://www.bbc.com/news/uk-wales-29976769>

1. 'A Place to Call Home? A Review into the Quality of Life and Care of Older People Living in Care Homes in Wales,' Older People's Commissioner for Wales, November 2014. <http://www.olderpeoplewales.com/Libraries/Uploads/A Place to Call Home - A Review into the Quality of Life and Care of Older People living in Care Homes in Wales.sflb.ashx>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GERMANY | *Deutsche Welle* – 13 November 2014 – **'Strong opposition to organized assisted suicide.'** An unusual, highly emotional debate in German parliament ended with the majority expressing support for prohibiting organized assisted suicide. But not all representatives called for an outright ban of the practice. Such debates are a rarity in the Bundestag. Over the course of five hours, 48 speakers took to the podium – and, there wasn't even a bill up for debate. <http://www.dw.de/strong-opposition-to-organized-assisted-suicide/a-18061620>
- AUSTRALIA | *The Sydney Morning Herald* – 11 November 2014 – **'MPs from both sides back euthanasia reform.'** Parliamentarians from both sides of politics declared their support for voluntary euthanasia ... following a Senate report that could pave the way for a free vote on national right-to-die laws. The Senate Legal & Constitutional Affairs Committee ... recommended a conscience vote following an inquiry on ... proposals for national euthanasia laws. <http://www.smh.com.au/federal-politics/political-news/mps-from-both-sides-back-euthanasia-reform-20141111-11kis9.html>

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

Prevalence and description of palliative care in U.S. nursing homes: A descriptive study

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 12 November 2014 – There is limited availability of palliative type programs in nursing homes and underutilization in those with programs. Hospice is significantly more available than palliative or comfort care programs; also, for-profit facilities, compared to non-profits, are significantly more likely to have palliative care programs and medical directors for palliative care. Social workers and nurses were most likely to suggest palliative type programs. Only 42% of facilities with a palliative program provide consultation by a palliative certified physician. Residents with non-healing pressure ulcers, frequent hospitalizations, or severe/uncontrolled pain or non-pain symptoms were less likely to be referred. <http://ajh.sagepub.com/content/early/2014/11/12/1049909114558585.abstract>

End-of-life care in critical condition

AMERICAN JOURNAL OF PUBLIC HEALTH | Online – 13 November 2013 – Palliative care, comfort measures, hospice – these terms are often used interchangeably among health care professionals and laypeople alike. However, advocates for the dying believe that this "language barrier" is about more than just a semantic debate. It is about popular misconceptions that either delay the provision of compassionate, realistic, end-of-life care or deny it altogether. This prolongs unnecessary misery for people at the end of their lives, puts undue hardship on their loved ones, overburdens the health care system. <http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2014.302189>

Of related interest:

- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION*, 2014;15(10):744-750. **'Hospice family members' perceptions of and experiences with end-of-life care in the nursing home.'** The family members of nursing home residents reported higher quality of life; however, levels of anxiety, depression, perceptions of pain medicine, and health were similar for hospice family members in the nursing home and in the community. Some family members reported positive end-of-life care experiences in the nursing home setting. [http://www.jamda.com/article/S1525-8610\(14\)00340-5/abstract](http://www.jamda.com/article/S1525-8610(14)00340-5/abstract)

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Representative sample of articles on end-of-life care in U.S. nursing homes noted in past issues of Media Watch:

- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION*, 2013;14(10):741-748. **'Site of death among nursing home residents in the U.S.: Changing patterns, 2003-2007.'** The proportion of deaths occurring in nursing homes has been increasing and is expected to reach 40% by 2020. [Noted in Media Watch, 22 September 2014, #376 (p.15)] [http://www.jamda.com/article/S1525-8610\(13\)00140-0/abstract](http://www.jamda.com/article/S1525-8610(13)00140-0/abstract)
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 July 2013 – **'Hospice for nursing home residents: Does ownership type matter?'** More than half of all nursing home residents use hospice at some point. Studies have shown benefits to hospice enrollment for patients; however, the literature on ownership differences in hospice care indicates for-profit hospices offer a narrower scope of services and employ fewer professional staff. [Noted in Media Watch, 12 August 2013, #318 (p.10)] <http://online.liebertpub.com/doi/full/10.1089/jpm.2012.0544>

Identifying key priorities for future palliative care research using an innovative analytic approach

AMERICAN JOURNAL OF PUBLIC HEALTH | Online – 13 November 2014 – Using an innovative approach, the authors identified research priorities in palliative care to guide future research initiatives. The identified research recommendations fell into 2 distinct categories: 1) ways to improve methodological approaches; and, 2) specific topic areas in need of future study. The most commonly cited priority within the theme of methodological approaches was the need for enhanced rigor. <http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2014.302282>

Resilience and death: The nursing professional in the care of children and adolescents with life-limiting illnesses

CIÊNCIA & SAÚDE COLETIVA, 2014; 19(12):4829-4878. The participants of this qualitative research were nursing professionals working in the pediatric ward of a hospital in Rio de Janeiro, Brazil. The relationship between professional resilience and coping with the process of children and adolescent's deaths stood out ... based on data obtained from group and individual interviews. The care given to children and adolescents with life-limiting illnesses triggered resilience-related answers concerning alternatives that oscillate between individual reactions (religious and psychological support), and the search for an incipient collective support based on personal relationships. This ... subject must be strategically handled to train this professional, who must be able to rely on support from the collective environment, presumed within the professional health care training and in the management of humanization at the hospital. <http://www.scielo.br/pdf/csc/v19n12/1413-8123-csc-19-12-04869.pdf>

Witnessing dying and death

Doctors do cry

INDIAN JOURNAL OF MEDICAL ETHICS, 2014; 11(4):249-251. Even though humanity is the cornerstone of medicine, depersonalisation has somehow crept into the physician-patient relationship and crying is considered incompatible with the image of a good physician, who is supposed to be strong, confident and fully in charge. Thus, crying has been equated to weakness and, at times, incompetence. This could be attributed to the fact that our medical curriculum has ingrained in us the belief that emotion clouds rationality and prevents us from being objective while making decisions regarding a patient's clinical progress. Our curriculum fails to teach us how to handle emotional situations, witness the dying process, communicate bad news, interact with the bereaved during the period of grief ... following death, and reduce professional stress involved in working with newly bereaved persons. <http://www.issuesinmedicalethics.org/index.php/ijme/article/view/2150/4634>

N.B. English language article.

Family caregiver education: An Italian experience

LA CLINICA TERAPEUTICA, 2014;165(5):e357-e361. The reliance on family caregivers unprepared for the daily management of the patient's illness may threaten the patients' quality of life and, moreover, increase the burden of care on the caregiver by exposing them to the risk of psychosocial distress. The Nursing Department of the Campus Bio-Medico of Rome have addressed such a need by promoting training courses for family caregivers ... with the goal of supporting families in the acquisition of specific skills related to the health care of patients with chronic conditions. http://www.seu-roma.it/clinica_terapeutica/apps/autos.php?id=1373

N.B. Italian language article (with English language abstract)

Review of evidence about family presence during resuscitation

CRITICAL CARE NURSING CLINICS OF NORTH AMERICA, 2014;26(4):533-550. Family presence during resuscitation (FPDR) has not been implemented consistently as standard practice across health care settings despite the availability of supporting research and recommendations from professional organizations. Health care providers, patients, families, and the public have divergent attitudes about FPDR. Inconsistencies in if, when, and how FPDR is offered can lead to inequities in care. This article presents relevant research on attitudes about FPDR and interventions to help change practice. The authors also share their experience with a project to implement FPDR in a medical intensive care unit. [http://www.ccnursing.theclinics.com/article/S0899-5885\(14\)00055-0/abstract](http://www.ccnursing.theclinics.com/article/S0899-5885(14)00055-0/abstract)

Noted in Media Watch, 17 March 2014, #349 (p.16):

- *YALE JOURNAL OF BIOLOGY & MEDICINE*, 2014;87(1):63-72. **'Family presence during resuscitation: Attitudes of Yale-New Haven hospital staff.'** Seventy-seven percent of staff members favored allowing the option of family presence during resuscitation. Seventy-six percent of staff members believed that family members would want to be present during their loved one's resuscitation. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3941452/>

Noted in Media Watch, 18 March 2013, #297 (p.4):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 March 2013 – **'Family presence during cardiopulmonary resuscitation.'** Relatives [i.e., study participants] who did not witness CPR had symptoms of anxiety and depression more frequently than those who did witness CPR. Family-witnessed CPR did not affect resuscitation characteristics, patient survival, or the level of emotional stress in the medical team, and also did not result in medico-legal claims. http://www.nejm.org/doi/full/10.1056/NEJMoa1203366?query=featured_home

An exploration of factors that hamper better palliative care in sub-Saharan Africa

EUROPEAN JOURNAL OF BIOLOGY & MEDICAL SCIENCE RESEARCH, 2014;2(4):1-16. Palliative care remains significant in health care but its recognition in most sub-Saharan African countries is low. Therefore, to help widen and sustain the scope of palliative care, this article aims to identify the factors that are impeding its development in Ghana. The research employed the use of interviews and questionnaires to retrieve information from a cross-section of health practitioners and general public across the country. The data showed that, many respondents from the general public had little or no knowledge about palliative care even though a similar method of care is provided for terminally ill relatives mostly in their homes. Respondents indicated factors such as; religio-cultural attitudes towards the death and dying, high cost of health care services and lack of funds for the provision of special care, as hampering palliative care in Ghana. As a result, this article prompts that palliative care must be a public health priority and there must be a merger of the general (Western) palliative care concept into that practiced in sub-Saharan Africa (which must adapt to the needs and context of care in Africa). <http://www.eajournals.org/wp-content/uploads/Health-And-Care-Development-An-Exploration-Of-Factors-That-Hamper-Better-Palliative-Care-In-Sub-Saharan-Africa.pdf>

Place of death in populations potentially benefiting from palliative care: A population-level study in 14 countries

EUROPEAN JOURNAL OF PUBLIC HEALTH | Online – 31 October 2014 – The majority of people dying from chronic diseases prefer to die at home, yet many die in hospitals. Cross-national population-level studies on the place of death are scarce although they can provide important evidence to guide the development and evaluation of public health policies for end-of-life care. http://eurpub.oxfordjournals.org/content/24/suppl_2/cku151.014

Of related interest:

- *EUROPEAN JOURNAL OF PUBLIC HEALTH* | Online – 31 October 2014 – '**Hospitalisations at the end of life in four European countries: A cross-national population-based mortality follow back study.**' Most people would prefer to be cared for and to die at home. On the other hand, hospital admissions towards the end of life have been related to aggressive care, higher cost than community care, and they may indicate a low quality of dying. http://eurpub.oxfordjournals.org/content/24/suppl_2/cku151.013.abstract

The language of sedation in end-of-life care: The ethical reasoning of care providers in three countries

HEALTH | Online – 10 November 2014 – In the U.K., an emphasis on titrating doses proportionately against symptoms is more likely, maintaining consciousness where possible. The potential harms of sedation are perceived to be the potential hastening of social as well as biological death. In Belgium and The Netherlands, although there is concern to distinguish the practice from euthanasia, rapid inducement of deep unconsciousness is more acceptable to care providers. This is often perceived to be a proportionate response to unbearable suffering in a context where there is also greater pressure to hasten dying from relatives and others. This means that sedation is more likely to be organised like euthanasia, as the end "moment" is reached, and family farewells are organised before the patient is made unconscious for ever. Medical and nursing practices are partly responses to factors outside the place of care, such as legislation and public sentiment. <http://hea.sagepub.com/content/early/2014/11/09/1363459314555377.abstract>

Continuous sedation in end-of-life care in Belgium, The Netherlands and the U.K. has been the focus recently of several studies, for example:

- *PALLIATIVE MEDICINE* | Online – 25 July 2014 – '**Using continuous sedation until death for cancer patients: A qualitative interview study of physicians' and nurses' practice in three European countries.**' U.K. respondents reported a continuum of practice from the provision of low doses of sedatives to control terminal restlessness to rarely encountered deep sedation. In contrast, Belgian respondents predominantly described the use of deep sedation, emphasizing the importance of responding to the patient's request. Dutch respondents emphasized making an official medical decision informed by the patient's wish and establishing that a refractory symptom was present. [Noted in Media Watch, 28 July 2014, #368 (p.11)] <http://pmj.sagepub.com/content/early/2014/07/24/0269216314543319.abstract>
- *SUPPORTIVE CARE IN CANCER* | Online – 15 July 2014 – '**Making sense of continuous sedation in end-of-life care for cancer patients: An interview study with bereaved relatives in three European countries.**' Relatives' descriptions of the practice referred to the outcome, to practical aspects, and to the goals of sedation. While most relatives believed sedation had contributed to a "good death" for the patient, many expressed concerns. These related to anxieties about the patient's wellbeing, their own wellbeing, and questions about whether continuous sedation had shortened the patient's life or whether an alternative approach would have been better. Such concerns seemed to have been prompted by relatives witnessing unexpected events such as the patient coming to awareness during sedation. [Noted in Media Watch, 21 July 2014, #367 (p.13)] <http://link.springer.com/article/10.1007/s00520-014-2344-7>

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- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 5 June 2014 – '**Descriptions by general practitioners and nurses of their collaboration in continuous sedation until death at home. In-depth qualitative interviews in three European countries.**' The authors found that, in Belgium and The Netherlands, it was the GP who typically made the final decision to use sedation, whereas in the U.K. it was predominantly the nurse who both encouraged the GP to prescribe anticipatory medication and decided when to use the prescription. [Noted in Media Watch, 9 June 2014, #361 (p.13)] [http://www.jpsmjournal.com/article/S0885-3924\(14\)00291-7/abstract](http://www.jpsmjournal.com/article/S0885-3924(14)00291-7/abstract)

Quality and costs of end-of-life care: The need for transparency and accountability

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2014;312(18):1868-1869. Increasing attention to the quality of end-of-life care for seriously ill, dying adults has included evaluation of the site of death, place of care, and health care transitions with an important concern being whether these patterns of care, especially receipt of aggressive care, is consistent with patient preferences and improved quality of life. Choices involving these and other aspects of end-of-life care, such as for hospice care, are complex decisions that involve patients, their families, and their physicians. However, as elegantly stated ... using the metaphor of 'Goldilocks and the Three Bears,' the current dilemma that involves the timing of hospice referral is whether it is too late, too early, or just right. <http://jama.jamanetwork.com/article.aspx?articleid=1930801#jed140096r2>

Improving and validating children's nurses communication skills with standardized patients in end of life care

JOURNAL OF CHILD HEALTH CARE | Online – 13 November 2014 – With regard to end-of-life care, it is has become a challenge to ensure that all students come into contact with a satisfactory range of experience as part of the requirement for competency at the point of registration. The aim of this study was to find out if students at the end of their course were able to use communication skills acquired in their three years of training and adapt and transfer them to a specific palliative care context even if they had never worked in that area of care. Four themes emerged that students identified either inhibited or enabled their communication skills, which included anxiety and fear, the need for professional props, the experience of it being real and feeling empowered. <http://chc.sagepub.com/content/early/2014/11/12/1367493514555588.abstract>

"The present gets in the way of talking about the future."

The future as a series of transitions: Qualitative study of heart failure patients and their informal caregivers

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 11 November 2014 – Patients and their caregivers [i.e., study participants] talked about past and present transitions when asked about the future: The authors identified four common pivotal transitions, including the shock of first being diagnosed with heart failure; learning to adjust to life with heart failure; reframing and taking back control of one's life; and, understanding and accepting that death is inevitable. Concerns about the future were framed based on the most recent transition. By recognizing and educating patients about transitions, identifying transition-specific concerns, and supporting patients and caregivers through transitions, the process of planning for the future as part of advance care planning may be improved. <http://link.springer.com/article/10.1007/s11606-014-3085-5>

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Quotable Quotes

The art of living well and the art of dying well are one. Epicurus (314-270 BC)

Of related interest:

- *FAMILY PRACTICE* | Online – 7 November 2014 – '**Advance care planning in primary care, only for severely ill patients? A structured review.**' To what extent and how primary care providers provide advance care planning in daily practice is largely unknown. Content of planning varied from discussing to refrain from cardiopulmonary resuscitation to existential issues. <http://fampra.oxfordjournals.org/content/early/2014/11/06/fampra.cmu074.short?rss=1>
- *PUBLIC POLICY AGING REPORT*, 2014;24(3):107-111. '**Advance care planning tools that educate, engage, and empower.**' The small sampling of tools and aids described ... demonstrate a growing attention to, and creativity in, effective advance care planning. Many more will likely emerge in the years ahead. The author does expect any one of these tools to become the one way to do it, for a diversity of tools is needed to accommodate the diversity of values, beliefs, attitudes, personal styles, and emotions that we humans have toward the topic of illness and dying. <http://ppar.oxfordjournals.org/content/24/3/107.full>

Hospital-based bereavement services following the death of a child: A mixed study review

PALLIATIVE MEDICINE | Online – 13 November 2014 – Qualitatively, family members described feeling cared for and supported by staff, a reduction in sense of isolation, and improved coping and personal growth. Quantitatively, bereavement services have most effect for parents experiencing more complex mourning. It is recommended that bereavement services be theoretically driven and evidence based, offer continuity of care prior to and following the death of a child, and provide a range of interventions for the "whole family" and flexibility in service delivery. <http://pmj.sagepub.com/content/early/2014/11/12/0269216314556851.abstract>

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 November 2014 – '**An evaluation of a bereavement program in a U.S. research hospital.**' The Bereavement Program at the National Institutes of Health Clinical Center ... makes contact with the next of kin on four occasions post-notification of death. The objective of this analysis was to evaluate program effectiveness for those individuals who were successfully made contact with on all four occasions. <http://ajh.sagepub.com/content/early/2014/11/04/1049909114557538.abstract>

Noted in Media Watch, 20 October 2014, #380 (p.12):

- *OMEGA – JOURNAL OF DEATH & DYING*, 2014;69(4):421-435. '**Pediatric bereavement services: A survey of practices at children's hospitals.**' This article summarizes the ways hospitals follow-up with families, from provision of educational materials to a menu of support services including memorial services, counseling, and community referrals. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue.5.6:journ.1.274:linkingpublicationresults.1:300329.1>

Pediatric advance care planning from the perspective of health care professionals: A qualitative interview study

PALLIATIVE MEDICINE | Online – 11 November 2014 – Conflicts may arise between physicians and non-medical care providers because both avoid taking responsibility for treatment limitations according to a minor's advance directive. Nevertheless, pediatric advance care planning [PACP] is perceived as helpful by providing an action plan for everyone and ensuring that patient/parent wishes are respected. Important requirements for PACP were identified: 1) repeated discussions and shared decision-making with the family; 2) a qualified facilitator who ensures continuity throughout the whole process; and, 3) multi-professional conferences, as well as professional education on ACP. Despite a perceived need for PACP, several barriers to its implementation were identified. <http://pmj.sagepub.com/content/early/2014/11/08/0269216314552091.abstract>

Cont.

Representative sample of articles on advance care planning for children living with a terminal illness noted in past issues of Media Watch:

- *ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 5 December 2013 – **'What parents want from doctors in end-of-life decision-making for children.'** The majority of parents [i.e., study participants] found their child's doctor enabled them to be the ultimate decision maker for their child, which was what they very clearly wanted to be, and consequently enabled them to exercise their parental autonomy. Parents found it problematic when doctors took over decision-making. A less frequently reported, yet significant role for doctors was to affirm decisions after they had been made by parents. [Noted in Media Watch, 9 December 2013, #335 (p.5)] <http://adc.bmj.com/content/early/2013/12/05/archdischild-2013-304249.abstract>
- *FAMILIES, SYSTEMS, & HEALTH*, 2013;31(4):406-413. **'Perspectives of parents on making decisions about the care and treatment of a child with cancer: A review of literature.'** Seventeen articles were identified that focused specifically on the decisions parents make regarding the care and treatment of children with cancer. Coders agreed that the child's quality of life/well-being, parental hope/expectations, support/supportive care, communication, and information were important themes in considering the decisions parents made regarding the care and treatment of children with cancer. [Noted in Media Watch, 6 January 2014, #339 (p.12)] <http://psycnet.apa.org/journals/fsh/31/4/406/>
- *PEDIATRICS* | Online – 11 February 2013 – **'Pediatric advance care planning: A systematic review.'** The authors included 5 qualitative and 8 quantitative studies. Only three pACP [pediatric ACP] programs were identified, all from the U.S. Two were informed by adult programs. Major pACP features are discussions between families and care providers, as well as advance directives. Programs vary in how well they are evaluated; only one was studied by using a randomized controlled trial. Preliminary data suggest that pACP can successfully be implemented and is perceived as helpful. [Noted in Media Watch, 18 February 2013, #293 (p.6)] <http://pediatrics.aappublications.org/content/early/2013/02/05/peds.2012-2394.abstract>

Non-consensual withdrawal of nutrition and hydration in prolonged disorders of consciousness: Authoritarianism and trustworthiness in medicine

PHILOSOPHY, ETHICS & HUMANITIES IN MEDICINE | Online – 7 November 2014 – The Royal College of Physicians of London published the 2013 national clinical guidelines on prolonged disorders of consciousness (PDOC) in vegetative and minimally conscious states.¹ The guidelines acknowledge the rapidly advancing neuro-scientific research and evolving therapeutic modalities in PDOC. However, the guidelines state that end-of-life decisions should be made for patients who do not improve with neuro-rehabilitation within a finite period, and they recommend withdrawal of clinically assisted nutrition and hydration (CANH). This withdrawal is deemed necessary because patients in PDOC can survive for years with continuation of CANH, even when a ceiling on medical care has been imposed, i.e., withholding new treatment such as cardiopulmonary resuscitation for acute life-threatening illness. The authors conclude that these guidelines are not only harmful to patients and families, but they represent the means of non-consensual euthanasia. The latter would constitute a gross violation of the public's trust in the integrity of the medical profession. <http://www.peh-med.com/content/pdf/1747-5341-9-16.pdf>

1. 'Prolonged disorders of consciousness: National clinical guidelines,' The Royal College of Physicians, December 2013. Endorsed by the Association of British Neurologists, Association for Palliative Medicine, British Society of Rehabilitation Medicine, Chartered Society of Physiotherapy, College of Occupational Therapists, Society of British Neurological Surgeons, and Society for Research in Rehabilitation. [Noted in Media Watch, 16 December 2013, #336 (p.6)] http://www.rcplondon.ac.uk/sites/default/files/prolonged_disorders_of_consciousness_national_clinical_guidelines_0.pdf

When mediation fails: Identifying and working with inappropriate surrogate decision makers

PROGRESS IN PALLIATIVE CARE | Online – 13 November 2014 – Patient autonomy and informed consent are cornerstones of medicine, though often clinicians interact directly with surrogate decision makers (SDMs) instead of patients when the latter is deemed incapacitated. Although most SDMs are able to fulfill their duty as proxies, incongruence between SDM role and behavior may occur, even after the best mediation efforts possible by various clinical teams. Instances in which SDMs act inappropriately in their role and fail to respond to such efforts by clinical teams warrant serious consideration of SDM replacement. The authors offer a case series of such instances, describe difficulties faced by SDMs in their role, and offer ethical and legal perspective regarding the challenging and removal of SDMs after thoughtful and collective deliberation. <http://www.maneyonline.com/doi/abs/10.1179/1743291X14Y.000000115>

Of related interest:

- *PROGRESS IN PALLIATIVE CARE* | Online – 13 November 2014 – '**A narrative approach to the ethical dilemmas of surrogate decision making.**' This article explores the ethical challenges of the surrogate decision maker and offers a defense of the surrogate's moral standing. The bioethical principle of respect for autonomy is contrasted with the concept of authenticity. <http://www.maneyonline.com/doi/abs/10.1179/1743291X14Y.000000114>

[Media Watch: Editorial Practice](#)

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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.

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Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/10/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

ALBERTA HOSPICE PALLIATIVE CARE ASSOCIATION: <http://ahpca.ca/> (Scroll down to 'Media Watch')

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

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://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes>

U.K. | Omega, the National Association for End-of-Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>