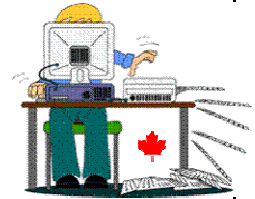


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to [Specialist Publications](#) and 'Palliative care patients' perceptions of the work involved in understanding and managing the network of care provision surrounding them' (p.7), in *BMJ Supportive & Palliative Care*.

Canada

Paramedics to provide palliative home support

NOVA SCOTIA & PRINCE EDWARD ISLAND | CTV News (Halifax, NS) – 30 March 2015 – Paramedics in the two maritime provinces are being trained to ... help people stay at home rather than go into emergency rooms when [for example] experiencing pain. The project will start in early May. <http://www.ctvnews.ca/health/n-s-p-e-i-paramedics-to-provide-palliative-home-support-1.2304001>

[Specialist Publications](#)

""We are strangers walking into their life-changing event"": How pre-hospital providers manage emergency calls at the end of life' (p.9), in *Journal of Pain & Symptom Management*.

Noted in Media Watch, 30 March 2015, #403 (p.3):

- ONTARIO | CBC News (Toronto) – 24 March 2015 – '**Community paramedicine program aims to keep chronic illness patients out of emergency.**' The Community Paramedicine program, which aims to keep people at home and out of the emergency room, allows paramedics to visit patients with chronic and complex illnesses without the prompt of a 911 [emergency] call. <http://www.cbc.ca/news/canada/sudbury/community-paramedicine-program-aims-to-keep-chronic-illness-patients-out-of-emergency-1.3006968>

Noted in Media Watch, 22 July 2013, #315 (p.10):

- *JOURNAL OF PARAMEDIC PRACTICE*, 2013;5(7):394-399. '**End-of-life care in the community: The role of ambulance clinicians.**' The authors outline an online education package in end-of-life care designed specifically for ambulance clinicians in response to training needs. http://www.paramedicpractice.com/cgi-bin/go.pl/library/article.cgi?uid=99703;article=pp_5_7_394_399

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 1 April 2015 – '**Canadian medical schools readying doctors to talk to patients about assisted suicide.**' Canada's medical schools are preparing for what was once unimaginable – teaching medical students and residents how to help patients take their own lives. As the nation moves toward legalized physician-assisted death, Canada's 17 faculties of medicine have begun to consider how they will introduce assisted dying into the curriculum for the next generations of doctors. It is a profound change for medical educators, who have long taught future doctors that it is immoral to end a life intentionally. In its landmark, unanimous ruling in February that swept away Criminal Code prohibitions against doctor-assisted death, the Supreme Court of Canada gave Parliament one year to craft a new law ... that recognizes the right of consenting adults with a "grievous and irremediable" medical condition to seek a doctor's help to end their lives. <http://news.nationalpost.com/health/assisted-death-medical-schools>

Specialist Publications

'Physicians and euthanasia: A Canadian print-media discourse analysis of physician perspectives' (p.12), in *Canadian Medical Association Journal Open*.

U.S.A.

Science and medicine have "publication pollution" problem, according to medical ethicist

SCIENCE DAILY | Online – 3 April 2015 – The scientific community is facing a "pollution problem" in academic publishing, one that poses a serious threat to the "trustworthiness, utility, and value of science and medicine," according to one of the country's leading medical ethicists. Arthur L. Caplan, PhD, director of the Division of Medical Ethics ... at New York University Langone Medical Center, shares these and other observations in a commentary published in the journal *Mayo Clinic Proceedings*.¹ "The pollution of science and medicine by plagiarism, fraud, and predatory publishing is corroding the reliability of research," writes Dr. Caplan. "Yet neither the leadership nor those who rely on the truth of science and medicine are sounding the alarm loudly or moving to fix the problem with appropriate energy." Dr. Caplan describes several causes of publication pollution. [http://www.mayoclinicproceedings.org/article/S0025-6196\(15\)00190-1/fulltext](http://www.mayoclinicproceedings.org/article/S0025-6196(15)00190-1/fulltext)

1. 'The problem of publication-pollution denialism,' *Mayo Clinic Proceedings*, 3 April 2015. [http://www.mayoclinicproceedings.org/article/S0025-6196\(15\)00190-1/fulltext](http://www.mayoclinicproceedings.org/article/S0025-6196(15)00190-1/fulltext)

Noted in Media Watch, 12 January 2015, #392 (p.1):

- CANADA | *The Globe & Mail* – 3 January 2015 – '**Predatory journals take a bite out of scholarship.**' The academic imperative "publish or perish" is so well known people with no intention of entering scholarly life are familiar with it – no tenure for you, my friend, without at least a handful of citations. The journals should be reputable and selective, as all the best ones are, but in the crunch quantity might just trump quality. Alas, now comes this new storm on the horizon of university careerists: predatory journals. <http://www.theglobeandmail.com/globe-debate/predatory-journals-take-a-bite-out-of-scholarship/article22275403/>

N.B. Also noted in this issue of Media Watch: 'Authors and readers beware the dark side of Open Access' in *Journal of Advanced Nursing* (p.10), and 'If it looks like a duck and quacks like a duck ...' in *Oncology Nursing Forum*. (p.10).

Transforming nursing home care

THE NEW YORK TIMES | Online – 1 April 2015 – Nursing homes have evolved from their meager beginnings as part almshouse and part boarding home into a major industry. There are now over 15,000 nursing homes in the U.S., which can house up to 1.7 million people. Today, nearly 70% of Americans with advanced dementia will live their final days in this setting. The problems with nursing homes are well documented. Beginning with a 1986 Institute of Medicine report,¹ the media and academic literature have chronicled the many deficiencies in nursing home care. Although these accounts underscore the urgent need to improve nursing home care, they tend to miss two important points. First, nursing home use is projected to increase dramatically in the coming years, despite these reports and the concerted efforts to keep people with dementia

in their homes. So that means we had better move now to fix what's wrong. Second, many facilities already are trying to "get it right" and have adapted their routines, policies, staffing and physical environment to better meet the individualized needs of their residents. Some of them have succeeded. <http://opinionator.blogs.nytimes.com/2015/04/01/transforming-nursing-home-care/?r=0>

Extract from *The New York Times* article

There are several names for the efforts to transform institutional long-term care... Common to all of them are the principles of palliative care: maximizing comfort and pleasure rather than cure or rehabilitation, and providing care that is consistent with residents' and families' preferences.

1. 'Improving the Quality of Care in Nursing Homes,' Institute of Medicine, January 1986. <https://www.iom.edu/Reports/1986/Improving-the-Quality-of-Care-in-Nursing-Homes.aspx>

Of related interest:

- PENNSYLVANIA | *The Inquirer* (Pennsylvania) – 29 March 2015 – '**At some nursing homes, a changing attitude toward death.**' Even in nursing homes, where hundreds of thousands ... die each year, death has long been a touchy subject. It seemed too depressing to think about how many people were leaving, how many would follow. Attitudes are beginning to change... http://www.philly.com/philly/health/20150329_At_some_nursing_homes_a_changing_attitude_toward_death.html

Noted in Media Watch, 30 March 2015, #403 (p.6):

- *NEW YORK MAGAZINE* | Online – 24 March 2015 – '**Many nursing homes fall short at palliative care.**' In a new study,¹ researchers attempted to see how well directors of nursing responded to questions about both personal knowledge of palliative care practices and about how their facilities handled these issues. Twenty-one percent of the [1,981] directors of nursing surveyed "correctly responded to only one of the knowledge items, and 43% to all items." <http://nymag.com/scienceofus/2015/03/many-nursing-homes-fall-short-at-palliative-care.html>
 1. 'End-of-life care in nursing homes with greater versus less palliative care knowledge and practice,' *Journal of Palliative Medicine*, 16 March 2015. This study included 1,981 nursing homes with complete survey responses and 58,876 residents who died in these facilities. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0393?journalCode=jpm>

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[Media Watch Online](#)

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.13.

Noted in Media Watch, 15 December 2014, #388 (p.12):

- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 3 December 2014 – '**Developing palliative care practice guidelines and standards for nursing home-based palliative care teams: A Delphi study.**' The palliative care guidelines and team standards identified in this study may be helpful in providing practical direction to nursing home administrators and staff looking to improve palliative care practice for their residents. [http://www.jamda.com/article/S1525-8610\(14\)00691-4/abstract](http://www.jamda.com/article/S1525-8610(14)00691-4/abstract)

N.B. In this issue of Media Watch are listed additional articles, noted in past issues of the weekly report, on end-of-life care in nursing homes.

Changes to end-of-life regulations killed in House

NORTH CAROLINA | WRAL-TV5 (Raleigh) - 1 April 2015 – House members ... beat back an attempt to change the rules for health care directives used to make medical and other decisions for patients who are terminally ill, comatose or otherwise near death. State law requires that such directives be signed by both a notary and two witnesses, and House Bill 146 would have made that an either-or proposition instead of requiring both. <http://www.wral.com/changes-to-end-of-life-regulations-killed-in-house/14554505/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MARYLAND | WMDT 47 News (Annapolis) – 2 April 2015 – '**Bill postponed that would give terminally ill people prescription for drugs to speed up death.**' Terminally ill Marylanders will not have the ability to end their own lives with a prescription drug in the near future. <http://www.wmdt.com/news/more-local-news/right-to-die-bill-needs-more-consideration-sent-for-study/32153926>
- NEBRASKA | Net Nebraska – 1 April 2015 – '**Canadian Court OKs doctor-assisted suicide, but who's eligible?**' Four U.S. states, Oregon, Washington, Montana and Vermont, now have laws allowing doctors to help people die, as do a handful of European nations. But no country has ever launched physician-assisted suicide on the scale now under way in Canada. Earlier this year, the Supreme Court there ruled unanimously that all Canadians have a constitutional right to have doctors help them die. The court gave the government just one year to regulate medically assisted death for the entire nation. <http://www.netnebraska.org/node/967241>
- CALIFORNIA | *Kaiser Health News* – 30 March 2015 – '**Hoping to live, these doctors want a choice in how they die.**' Historically, doctors have been some of the most vocal critics of assisted suicide, also called aid-in-dying. The American Medical Association still says "physician-assisted suicide is fundamentally incompatible with the physician's role as healer." Similarly, though it hasn't taken a position on currently proposed legislation, the California Medical Association has said that helping patients die conflicts with doctors' commitment to do no harm. But a recent survey of 21,000 doctors in the U.S. and Europe shows views may be shifting. <http://kaiserhealthnews.org/news/hoping-to-live-these-doctors-want-a-choice-in-how-they-die/>



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>

International

Paupers' funerals in the U.K.

Too poor to die – the shocking story of families who can't afford to bury their loved ones

U.K. | *The Mirror* – 29 March 2015 – New figures show an incredible 305,840 applications were made for funeral payments in Great Britain over the past five years. Of those almost 160,000 were accepted as soaring funeral costs leave hard-pressed families dependent on the [local] council to bury their loved ones. In the last 10 years the Government spent nearly £400 million paying for the funerals of people too poor to be buried otherwise. Last year alone the bill for paupers' burials was an enormous £36 million pounds. <http://www.mirror.co.uk/news/uk-news/poor-die---shocking-story-5419973>

Noted in Media Watch, 27 October 2014, #381 (p.6):

- U.K. | *The Guardian* – 20 October 2014 – '**The return of the pauper's funeral to austerity Britain.**' Funeral poverty is a potent indicator of the combined impact of recession, austerity, low wages and the insecure job market. One in seven people struggle to pay funeral costs. <http://www.theguardian.com/society/2014/oct/20/paupers-funeral-austerity-britain-soaring-costs-bury-loved-ones>

End-of-life care in England

End-of-Life Care: Information for Housing & Care Providers

U.K. (England) | Housing Learning & Improvement Network (Housing LIN) – Accessed 28 March 2015 – This briefing is written for those managing "housing-with-care" so that they can demonstrate and/or develop their role improving the experience of people approaching end of life locally within a housing setting. Housing LIN, formerly responsible for managing the Department of Health's Extra Care Housing capital programme, is the leading "knowledge hub" for a growing network of housing, health and social care professionals in England who are involved in planning, commissioning, designing, funding, building and managing housing with care for older people. http://www.housinglin.org.uk/library/Resources/Housing/Support_materials/Practice_briefings/H_LIN_EoLC_PracticeBriefing.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- COLUMBIA | Columbia Reports (Medellín) – 31 March 2015 – '**Colombia court orders government to regulate euthanasia, 18 years after decriminalization.**' Colombia's constitutional court ... [has] ... ordered the country's government and Congress to come up with legislation to regulate euthanasia... The court decriminalized the practice ... in 1997. However, considering the practice is taboo in the predominantly Catholic country, the country's Congress and administrations have so far failed to propose bills that would regulate euthanasia. <http://colombiareports.co/colombia-court-orders-government-to-regulate-euthanasia-18-years-after-decriminalization/>
- U.K. (Scotland) | *The Herald* (Edinburgh) – 31 March 2015 – '**A troubling lack of clarity in Scots law regarding assisted suicide.**' The debate on the Assisted Suicide (Scotland) Bill has drawn attention to an alarming lack of clarity in Scots law. When the Justice Committee reported on the Bill in January it found itself unable to give any detail about the legal rules applicable to assisting a suicide in Scotland... The absence of either case law or legislative authority in Scotland means that the response to almost any question about the Scottish law applicable to assisted suicide must be only that prosecution is "possible" or "cannot be ruled out." This legal uncertainty is made worse by the absence of any published prosecutorial guidance. <http://www.heraldscotland.com/comment/letters/a-troubling-lack-of-clarity-in-scots-law-regarding-assisted-suicide.122014894>

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

Making decisions to limit treatment in life-limiting and life-threatening conditions in children: A framework for practice

ARCHIVES OF DISEASE IN CHILDHOOD, 2015;100(Suppl 2):1-23. The first edition of the Royal College of Paediatrics & Child Health (RCPCH) document 'Withholding or Withdrawing Life Saving Treatment in Children: A Framework for Practice' was published in 1997 and was one of the first documents produced by the newly-formed College. The first edition followed a series of workshops, public meetings and discussions in the Ethics Advisory Committee. There was consultation with a wide range of clinicians, representatives of faith groups and parents' groups and from individuals with disabilities themselves. Given the difficult and emotive nature of the subject, and the significant number and differing views of those consulted, the original document acknowledged the impossibility of achieving total consensus, but did identify common ground on which a framework could be built. The framework document was widely used; it did inform constructive debate and provided clarification in this difficult and emotive area. The second edition, published in 2004, reflected changes in practice and new legislation but retained the same ethical and legal principles as the first. Its title was changed from "life-saving treatment" to "life-

sustaining treatment" to reflect the fact that the treatment that is often given in these circumstances is not curative but supportive. The need for a revision of the document has been considered over the past 2 years by the Ethics & Law Advisory Committee of the RCPCH. The authors have consulted those who have used the document and have incorporated comments from individuals and groups, in the U.K. and elsewhere. The authors were also mindful of the change in emphasis in decision making with individuals with life-limiting conditions, as exemplified in the General Medical Council document, 'Treatment and care towards the end of life: good practice in decision making'.^{1,2} http://adc.bmj.com/content/100/Suppl_2/s1.full

Extract from *Archives of Disease in Childhood* article

In this extraordinary world of medical miracles, one thing has not changed; the complexity, challenge and pain of that most difficult of decisions: is the treatment we are providing no longer in the best interests of the child?

1. 'Very sick children: Treatment at any cost? New framework to help doctors make tough decisions on end-of-life care,' The Royal College of Paediatrics & Child Health, March 2015. [Noted in Media Watch, 30 March 2015, #403 (p.10)] <http://www.rcpch.ac.uk/news/very-sick-children-treatment-any-cost>
2. 'Treatment and Care Towards the End of Life: Good Practice in Decision Making,' General Medical Council, July 2010. [Noted in Media Watch, 28 July 2010, #155 (p.5)] http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf

Of related interest:

- *HEALTH PSYCHOLOGY*, 2015;34(4):446-452. '**The parents' ability to attend to the "voice of their child" with incurable cancer during the palliative phase.**' The "voice of the child" becomes manifest in the parents' expressions of the child's needs and perceptions. Parents who actively searched to understand their child's inner perspective used direct and indirect strategies. Parents preferred indirect strategies when their child avoided talking or when they considered the conversation as threatening for the child, or for themselves. Even if the parents show an intense involvement in the care and support of their child they can still have difficulty acknowledging the child's perspective. An inability to take into account the child's perspective

Cont.

was largely due to the parents' own struggle to cope with loss. Whether or not the voice of children approaching the end of life is heard, often depends on their parents' ability to give them a voice. Professional caregivers have a difficult task in supporting parents in giving their child his or her voice, while at the same time preserving their, and their parents' ability to cope. <http://psycnet.apa.org/journals/hea/34/4/446/>

Noted in Media Watch, 22 October 2012, #276 (p.9):

- *PROGRESS IN PALLIATIVE CARE* | Online – 15 October 2012 – '**The child's voice in pediatric palliative and end-of-life care.**' Although much is asked clinically and emotionally of children and adolescents receiving treatment for a life-threatening illness, they are not routinely asked how they experience the treatment that is intended to save or prolong their lives. <http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000035>

Noted in Media Watch, 15 October 2012, #275 (p.3):

- *U.S. NEWS & WORLD REPORT* | Online – 9 October 2012 – '**Teens want voice in end-of-life decisions.**' Teens and young adults who are seriously ill should have a chance to be involved in end-of-life decisions, and a new planning guide ... can help, researchers say. <http://health.usnews.com/health-news/news/articles/2012/10/09/teens-want-voice-in-end-of-life-decisions>

Palliative care patients' perceptions of the work involved in understanding and managing the network of care provision surrounding them

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 31 March 2015 – This study explored the work carried out for cancer palliative care patients in understanding and dealing with the often large network of care provision surrounding them. The main theme of "patient work – their strategies and project management" is presented. Sub-themes included: being organised and keeping records; planning ahead and coordinating care; information gathering; understanding the hierarchy and knowing who the key people are; strategies to remember names and roles; understanding and "working the system." Some of the challenges faced by patients and families are identified. These included limited information; uncertainty when care is transferred between different teams or locations; deciding who to contact and how; and negotiating through gatekeepers. <http://spcare.bmj.com/content/early/2015/03/31/bmjspcare-2014-000781.abstract>

Of related interest:

- *JAMA INTERNAL MEDICINE* | Online – 30 March 2015 – '**Variability among U.S. intensive care units in managing the care of patients admitted with pre-existing limits on life-sustaining therapies.**' Although the end-of-life care patients receive is known to vary ... these differences are best explored within a group of patients with presumably similar care preferences. Intensive care units vary dramatically in how they manage care for patients admitted with treatment limitations. Among patients who survive, escalations in the aggressiveness of care are more common during the ICU stay than are de-escalations in aggressiveness. This study cannot directly measure whether care received was consistent with patients' preferences but suggests ICU culture and physicians' practice styles contribute to aggressiveness of care. <http://archinte.jamanetwork.com/article.aspx?articleid=2210886>

[Back Issues of Media Watch](#)

Back issues of Media Watch are available on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

Deathbed phenomena reported by patients in palliative care: Clinical opportunities and responses

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING | Online – 27 March 2015 – Reports from patients on seeing or hearing a dead relative or dreaming a highly significant dream at the end of life can be perplexing for health professionals who may wonder how best to respond. The aim of this study was to systematically review the literature on deathbed phenomena (DBP), and provide suggestions for a clinical response to dying patients' recounts of these hard-to-explain phenomena. Reported prevalence of DBP ranged from 24-51% with common themes described. Distinguishing between DBP and hallucinations was discussed, requiring very different clinical responses. Phenomena were timed most often in the last hours or days before death. Experiencing a DBP was, in most cases, deeply meaningful, bringing comfort, peace and reassurance. Health professionals were not surprised to hear of a DBP, but were not always well prepared to respond appropriately. Rather than simply dismissing DBP as medication related or the physiological effects of dying, the significance of these events and the comfort afforded by them to patients and carers should be recognised. Disclosure of DBP may enable health professionals to discuss more spiritual and existential concerns, which have the potential to offer hope, meaning and connection. <http://www.magonlinelibrary.com/doi/abs/10.12968/ijpn.2015.21.3.117>

Representative sample of articles on deathbed experiences noted in past issues of Media Watch:

- *IRISH MEDICAL NEWS* | Online – 14 June 2011 – **'Visions of dead relatives at deathbed "normal."** Deathbed experiences, an umbrella term for phenomena such as visions in which the dying person reports seeing dead relatives or religious figures, would appear to be a normal part of the dying process and comforting for many patients and relatives, research concludes. [Noted in Media Watch, 20 June 2011, #206 (p.10)] <http://www.imt.ie/news/latest-news/2011/06/visions-of-dead-relatives-at-deathbed-normal.html>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 October 2009 – **'Deathbed phenomena: Its role in peaceful death and terminal restlessness.'** Collective research supports mounting evidence that deathbed visions typically yield peaceful deaths. Yet within the literature, numerous hospice patients experience the symptoms of terminal restlessness and frequently succumb to anguished deaths. Why are some patients and caregivers guided by peaceful deathbed phenomena and others are not? [Noted in Media Watch, 12 October 2009, #118 (p.6)] <http://ajh.sagepub.com/cgi/content/abstract/1049909109347328v1>

Palliative care physicians' attitudes toward patient autonomy and a good death in East Asian countries

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 28 March 2015 – A total of 505, 207 and 211 responses were obtained from Japanese, Taiwanese, and Korean physicians, respectively. Japanese (82%) and Taiwanese (93%) physicians were significantly more likely to agree that the patient should be informed first of a serious medical condition than Korean physicians (74%). Moreover, 41% and 49% of Korean and Taiwanese physicians agreed that the family should be told first, respectively; while 7.4% of Japanese physicians agreed. Physicians' attitudes with respect to patient autonomy were significantly correlated with the country (Japan), male sex, physician specialities of surgery and oncology, longer clinical experience, and physicians having no religion but a specific philosophy. In all 12 components of a good death, there were significant differences by country. Japanese physicians regarded physical comfort and autonomy as significantly more important, and regarded preparation, religion, not being a burden to others, receiving maximum treatment, and dying at home as less important. Taiwanese physicians regarded life completion and being free from tubes and machines as significantly more important. Korean physicians regarded being cognitively intact as significantly more important. [http://www.jpsmjournal.com/article/S0885-3924\(15\)00157-8/abstract](http://www.jpsmjournal.com/article/S0885-3924(15)00157-8/abstract)

"We are strangers walking into their life-changing event": How pre-hospital providers manage emergency calls at the end of life

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 27 March 2015 – Emergency 911 calls are often made when the end stage of an advanced illness is accompanied by alarming symptoms and substantial anxiety for family caregivers, particularly when an approaching death is not anticipated. How pre-hospital providers (paramedics and emergency medical technicians) manage emergency calls near death influences how and where people will die, if their end-of-life choices are upheld and how appropriately health care resources are utilized. Four themes illustrate the nature and dynamics of emergency end-of-life calls: 1) multifocal assessment (e.g., of the patient, family, and environment); 2) family responses (e.g., emotional, behavioral); 3) conflicts (e.g., missing do-not-resuscitate order, patient-family conflicts); and, 4) management of the dying process (e.g., family witnessed resuscitation or asking family to leave, decisions about hospital transport). [http://www.jpsmjournals.com/article/S0885-3924\(15\)00149-9/abstract](http://www.jpsmjournals.com/article/S0885-3924(15)00149-9/abstract)

"Allow Natural Death" [AND] versus "Do Not Resuscitate" [DNR]: What do patients with advanced cancer choose?

JOURNAL OF PALLIATIVE MEDICINE | Online – 31 March 2015 – All 93 of the participants who completed the survey were considered by their attending physician to have a terminal illness, but only 42% of these interviewees believed they were terminally ill. In addition, only 25% of participants thought that their primary oncologist knew their end-of-life wishes. Participants were equally likely to choose either of the "no code" options in all hypothetical scenarios, regardless of age, sex, race, type of cancer, education, or income level. A similar proportion of patients who had a living will chose AND and DNR orders instead of "full code" in all the scenarios. In contrast, among patients who did not have a living will, 52% chose DNR, while 19% opted for AND. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0369>

Noted in Media Watch, 19 January 2015, #393 (p.9):

- *BMJ OPEN* | Online – 13 January 2015 – **'Variation in local trust Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policies: A review of 48 English healthcare trusts.'** There was variation in terminology (85% described documents as policies, 6% procedures, and 8% guidelines). Only one quarter of Trusts used the recommended Resuscitation Council (U.K.) record form (or a modification of the form). There was variation in the terminology used, which included DNAR (do not attempt resuscitation), DNACPR, CPR and AND (allow natural death). <http://bmjopen.bmj.com/content/5/1/e006517.full>

Noted in Media Watch, 5 May 2014, #356 (p.15):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 28 April 2014 – **'A communication training perspective on AND versus DNR directives.'** The term "do not resuscitate" (DNR) is challenging to use in end-of-life discussions because it omits the goals of care. Allow Natural Death (AND) has been proposed as a better way of framing this palliative care discussion. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9247509&fulltextType=CR&fileId=S147895151400039X>

Noted in Media Watch, 9 July 2012, #261 (p.11):

- *HEC FORUMS* | Online – 1 July 2012 – **'Allow natural death orders: Legal, ethical, and practical considerations.'** Conversations with patients and families about the Allow Natural Death (AND) order, along with the standard Do Not Resuscitate (DNR) order during end-of-life decision-making, may create engagement and understanding while promoting care that can be defended using enduring the notions of autonomy, beneficence, and professional duty. <http://www.springerlink.com/content/112qrh2277342362/>

N.B. In this issue of Media Watch are listed additional articles, noted in past issues of the weekly report, on AND and DNR orders.

End-of-life care in Ireland

Call for review of National Children's Palliative Care Policy

THE MEDICAL INDEPENDENT (Ireland) | Online – 31 March 2015 – A number of leading organisations have jointly called for a review of service delivery priorities for the National Children's Palliative Care Policy in light of new figures ... [that] ... show the prevalence of children living with life-limiting conditions is 3,840. The figures, contained in a letter written on behalf of the Health Services Executive's National Development Committee for Children's Palliative Care, appear in the latest edition of the *Irish Medical Journal*.¹ LauraLynn Children's Hospice, Our Lady's Children's Hospital Crumlin, Jack & Jill Foundation, and Irish Hospice Foundation made the joint call for a review. "With only one Consultant Paediatrician with a special interest in paediatric palliative medicine in Ireland and only eight Children's Outreach Nurses, there is a considerable shortage of resources given the true prevalence figures," said Sharon Foley, Irish Hospice Foundation. http://www.medicalindependent.ie/62292/call_for_review_of_national_childrens_palliative_care_policy

1. 'Children with life-limiting conditions: Establishing accurate prevalence figures,' *Irish Medical Journal*, 2015;108(3). <http://www.imj.ie/ViewArticleDetails.aspx?ArticleID=13977>

The last hours of living: Practical advice for clinicians

MEDSCAPE | Online – 24 March 2015 – Clinical competence, willingness to educate, and calm and empathic reassurance are critical to helping patients and families during a loved one's last hours and days of living. Clinical issues that commonly arise in the last hours of living include the management of nutrition and hydration, changes in consciousness, delirium, pain, breathlessness, and secretions. Management principles are the same whether the patient is at home or in a healthcare institution. However, death in an institution requires accommodations that may not be customary to ensure privacy, cultural observances, and communication. In anticipation of the event, inform the family and other professionals about what to do and what to expect. Care does

not end until the family has been supported with their grief reactions and those with complicated grief have been helped to get care. http://www.medscape.com/viewarticle/716463?nlid=79044_1842&src=wnl_edit_med_p_wir&uac=213000DZ&spon=17

Extract from Medscape feature

Many clinicians have little or no formal training in managing the dying process or death. Families usually have even less experience or knowledge about death and dying. From media dramatizations and vivid imaginations, most people have developed an exaggerated sense of what dying and death are like.

Of related interest:

- *INTERNAL MEDICINE JOURNAL* | Online – 31 March 2015 – **'Medical education and law: Withholding/withdrawing treatment from adults without capacity.'** Respondents (to the survey) supported the need to know and follow the law. There were mixed views about its helpfulness in medical decision-making. Over half the respondents conceded poor knowledge of the law; this was mirrored by critical gaps in knowledge that varied by specialty. <http://onlinelibrary.wiley.com/doi/10.1111/imj.12759/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>

Promoting collaboration between hospice and palliative care providers and adult day services for individuals with intellectual and developmental disabilities

OMEGA – JOURNAL OF DEATH & DYING, 2015;70(4):380-403. While end-of-life issues are increasingly gaining more attention, people with intellectual and developmental disabilities (IDD) continue to receive significantly less consideration in research, education, and clinical practice compared with the general population. This is a growing concern especially since the sheer number of persons aging with IDD is expected to double in the next 17 years. Furthermore, policies are shifting to reflect a preference for home and community-based services as an alternative to institutionalization, and it becomes evident that adult day services (ADS) may be ideal settings for receipt of end-of-life care, especially among individuals with IDD. However, end-of-life care and advance planning most commonly occur in long-term care settings for the general population and have historically been less of a priority in ADS and residential services for people with IDD. This article discusses the attitudes of, and collaboration between, ADS and end-of-life providers for aging adults including persons with IDD and explores how ADS may be a great pathway for delivering end-of-life care to the IDD population. Implications and recommendations will also be examined. <http://ome.sagepub.com/content/70/4/380.full.pdf+html>

N.B. Articles on the palliative or end-of-life care needs of individuals with intellectual and developmental disabilities have been noted in several issues of Media Watch, for example, the issues of the weekly report 2 February 2015, #395 (pp.10-11); 29 September 2014, #377 (pp.13-14); 2 June 2014, #360 (pp.10-11); and, 10 March 2014, #348 (pp.809).

[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.

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[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.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *ASIAN BIOETHICS REVIEW*, 2015;7(1):43-61. **'Euthanasia and China: The traditional Chinese moral perspective and its social justice implications.'** This article begins by examining the Chinese relatively liberal stance on suicide. It explains the cultural forces that shaped traditional China's interpretation of life, death and motifs that validate self-sacrifice. To elucidate the Chinese perspective, the article incorporates extensive comparison with Christian viewpoints. It then addresses "self-regarding" euthanasia cases where death is advanced as a measure to relieve personal affliction. Following this are descriptions of the "other regarding" category, where euthanasia is invoked as an altruistic act to benefit the collective. The article then argues that given China's beleaguered public health system, there may be moral justification for some to waive their entitlement to life-prolonging treatment as a measure to curb excesses. It ends by contending that accelerating death, even when constricted by these exceptional instances, is not the favoured recourse. This is because the root causes of the current predicament stem from Beijing's failure to administer equitable care. Instead of pursuing the legitimisation of euthanasia, the stronger ethical response is to reform China's healthcare... http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/asian_bioethics_review/v0077.1.chai.html
- *CANADIAN MEDICAL ASSOCIATION JOURNAL OPEN*, 2015;3(2):e134-e139. **'Physicians and euthanasia: A Canadian print-media discourse analysis of physician perspectives.'** The authors identified 3 predominant discourses about physicians' public views toward euthanasia: 1) contentions about integrating euthanasia within the basic mission of medicine; 2) assertions about whether euthanasia can be distinguished from other end-of-life medical practices; and, 3) palliative care advocacy. Their data showed that although some medical professional bodies appear to be supportive in the media of a movement toward the legalization of euthanasia, individual physicians are represented as mostly opposed. Professional physician organizations and the few physicians who have engaged with the media are de facto representing physicians in public contemporary debates on medical aid in dying, in general, and euthanasia, in particular. It is vital for physicians to be aware of this public debate, how they are being portrayed within it and its potential effects on impending changes to provincial and national policies. <http://www.cmajopen.ca/content/3/2/E134.abstract>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 28 March 2015 – **'When physicians report having used medical drugs to deliberately end a patient's life: Findings of the 'End-of-Life in France' survey.'** The authors selected all the cases where the physicians had "used one or more drugs to intentionally end a patient's life," and compared the decisions and decision-making process with the conditions imposed by French law for decisions to withhold or withdraw life-supporting treatments, and by the Belgian law on euthanasia. Of the 36 cases analyzed, four situations seemed to be deliberate acts following explicit requests from the patients, and only two seemed to fulfill the eligibility and due conditions of the Belgian euthanasia law. Decisions made without any discussion with patients were quite common, and the authors observed inadequate labeling, frequent signs of ambivalence (artificial feeding and hydration not withdrawn, types of drug used), and little inter-professional consultation. Where the patient had requested euthanasia, the emotional burden on the physician was heavy. These findings underscore the pressing need for a clarification of the concepts involved among health professionals, patients and society at large, and better training and support for physicians. [http://www.jpsmjournals.com/article/S0885-3924\(15\)00158-X/abstract](http://www.jpsmjournals.com/article/S0885-3924(15)00158-X/abstract)

N.B. 'End-of-life medical decisions in France,' *Population & Sciences*, #494, November 2012. http://www.ined.fr/fichier/s_rubrique/19162/pesa494.en.pdf

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Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/03/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 | HPC Consultation Services (Waterloo Region/Wellington County): <http://hpcconnection.ca/general-resources/in-the-news/>

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

Europe

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

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

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