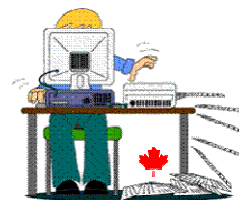


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Transition to palliative care: Scroll down to [Specialist Publications](#) and 'The troubles of telling: Managing communication about the end of life' (p.12), in *Qualitative Health Research*.

Canada

Health care consent and advance care planning in Ontario: Legal capacity, decision-making and guardianship

ONTARIO | Law Commission of Ontario – Accessed 31 January 2014 – This paper focuses on the interrelationship between health care consent and advance care planning under Ontario law, and on related misconceptions of health practitioners and health care organizations. At common law and under Ontario legislation, informed consent is required before a health practitioner can provide treatment to a patient. Importantly, where a patient is incapable, the requirement to obtain informed consent is not abrogated, but instead the informed consent is obtained from communications with substitute decision-makers. There has been an increasing emphasis in Ontario, and other common law jurisdictions, on encouraging patients to pre-plan for future treatments that may become necessary if and when the patient becomes incapable. This often means that health practitioners will solicit patients' wishes, values and beliefs relevant to future care decisions, and then record such wishes, values and beliefs in the patient's health record. Unfortunately, at the time of these future care discussions, health practitioners and patients do not always turn their minds to how these wishes, values and beliefs will affect future health care decision-making. Similarly, health practitioners do not always provide patients with sufficient information in order to express informed and robust wishes about future care. In Part 1 of this paper, the authors explain their concerns arising from this trend.¹ <http://lco-cdo.org/en/capacity-guardianship-commissioned-paper-ace-ddo>

1. The increasing emphasis on uninformed future care wishes that can create a tension between two sides of the principle of patient autonomy is discussed in **Part 2**. **Part 3** is an in-depth summary of the law of Ontario on health care consent, capacity and substitute decision-making. **Part 4** explores how advance planning fits into Ontario's laws on health care consent, and summarize how different examples of advance care planning have been interpreted by Ontario Courts and administrative tribunals. **Part 5** examines the relationship between health care consent and advance care planning in several extra-provincial (i.e., **Alberta, British Columbia, Nova Scotia, Saskatchewan**) and international jurisdictions. **Part 6** describes the operationalization of the law of health care consent and advance care planning in Ontario. **Part 7** identifies concerns arising from the authors' research into the operationalization of the law of health care consent and advance care planning in Part 6. **Part 8** details recommendations for addressing the issues identified in Part 7.

U.S.A.

A decision deferred: Turning off the pacemaker

THE NEW YORK TIMES | Online – 29 January 2014 – No-body really knows exactly how many Americans are walking around with pacemakers and defibrillators. But with surgeons implanting at least 225,000 pacemakers and 133,000 defibrillators each year, "there probably are a couple of million" out there now, said Dr. Paul S. Mueller, a Mayo Clinic general internist and bioethicist. The devices prolong lives, but "all those people will face decisions down the road," Dr. Mueller said. "Do I keep it going? Do I turn it off?" Physicians have similar questions, including what kinds of patients confront these choices and who usually winds up making these decisions. We know a bit more now that Dr. Mueller and his colleagues have reviewed the medical records of 150 Mayo Clinic patients who, over four years, requested that their devices be deactivated – the largest group of such patients examined to date.¹ What the data show is that these patients are mostly male, quite old, very sick – and unprepared to deal with this issue. "These patients typically are very ill. They're approaching death," said Dr. Mueller. Yet the majority hadn't recorded their desire to deactivate their cardiac devices. More than half ... had done what health care providers perennially urge and prepared advance directives, but only one of those documents made any mention of cardiac technology. http://newoldage.blogs.nytimes.com/2014/01/29/a-decision-deferred-turning-off-the-pacemaker/?_php=true&_type=blogs&ref=health&_r=0

1. 'Features and outcomes of patients who underwent cardiac device deactivation,' *JAMA Internal Medicine*, 2014;174(1):80-85. <https://archinte.jamanetwork.com/article.aspx?articleid=1783304>
2. 'The antidote for unprepared patients: A caring clinician,' *JAMA Internal Medicine*, 2014;174(1):86-87. <https://archinte.jamanetwork.com/article.aspx?articleid=1783299>

Noted in Media Watch, 27 February 2012, #242 (p.13):

- *THEORETICAL MEDICINE & BIOETHICS*, 2012;33(6):421-433. '**Pacemaker deactivation: Withdrawal of support or active ending of life?**' The authors argue that clinicians uncomfortable with pacemaker deactivation are nevertheless correct to see it as incompatible with the traditional medical ethics of withdrawal of support. Traditional medical ethics is presently taken by many to sanction pacemaker deactivation when such deactivation honors the patient's right to refuse treatment. <http://link.springer.com/article/10.1007/s11017-012-9213-5>

N.B. Footnoted in this issue of Media Watch is additional articles on ethical issues on defibrillator deactivation in end-of-life care noted in past issues of the weekly report.

Specialist Publications

'Why oncologists lag on palliative care' (p.11), in *Oncology Times*.

Media Watch Online

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

Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-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, exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

Embracing palliative care for the youngest patients

VERMONT PUBLIC RADIO | Online – 27 January 2014 – There is a national effort underway to get more health care providers to see the value of and recommend palliative care treatments for patients with serious illnesses, and that includes children.¹ Vermont Children's Hospital is among those embracing the campaign to introduce more palliative care options to children with chronic illnesses. "It is an important part of the care of pediatric patients, and an important component of support for their families. The purpose of palliative care is to improve quality of life for patients and families," explained Dr. Patricia Grady, Director of the National Institute of Nursing Research, part of the National Institutes of Health. "This particular campaign is directed at children who are not always thought of as recipients for palliative care. Most of the serious or life threatening illnesses that affect children ... can be helped by palliative care." Health care providers can be hesitant to discuss palliative care with parents because it can introduce a level of seriousness to the discussion that might be interpreted by parents to mean that their child's illness is more serious than it is. <http://digital.vpr.net/post/embracing-palliative-care-youngest-patients>

N.B. 'Palliative Care, Conversations Matter,' National Institute of Nursing Research:
<http://www.ninr.nih.gov/newsandinformation/conversationsmatter#.UufSNdlo40N>

Brain-dead Texas woman off life support

TEXAS | *The Boston Globe* (Massachusetts) – 26 January 2014 – A brain-dead, pregnant Texas woman's body has been removed from life support as the hospital keeping her on machines against her family's wishes acceded to a judge's ruling that it was misapplying state law. The hospital's decision brings an end to a case that became a touchstone for national debates about the beginning and end of life... [Marlise Muñoz was buried by her husband and parents; the fetus she was carrying was not born.] <http://www.bostonglobe.com/news/nation/2014/01/26/texas-hospital-end-care-for-brain-dead-woman/kWeC6X3f69gjMRaAPbInGI/story.html>

Noted in Media Watch, 30 December 2013, #338 (p.3):

- TEXAS | United Press International – 23 December 2013 – **'Texas man wants to end pregnant wife's life support.'** A Texas man [a paramedic] said he wants to end life support for his pregnant wife, but state law puts the rights of their 18-week-old fetus above the desires of the mother [also a paramedic]. http://www.upi.com/Top_News/US/2013/12/23/Texas-man-wants-to-end-pregnant-wifes-life-support/UPI-59541387805756/?spt=rln&or=1

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- OREGON | State Public Health Division – Accessed 29 January 2014 – **'Death with Dignity Act (DWDA) Statistics.'** As of 22 January 2014, prescriptions for lethal medications were written for 122 people during 2013, compared to 116 during 2012. There were 71 known DWDA deaths during 2013. Since the law was passed in 1997, a total of 1,173 people have had DWDA prescriptions written and 752 patients have died from ingesting medications prescribed under the DWDA. Of the 122 patients for whom DWDA prescriptions were written during 2013, 63 (51.6%) ingested and died from the medication. Eight patients with prescriptions written during the previous years (2011 & 2012) died after ingesting the medication during 2013, for a total of 71 DWDA deaths. Twenty-eight of the 122 patients who received DWDA prescriptions during 2013 did not take the medications and subsequently died of other causes. <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf>

International

Need for end of life care for older homeless, report finds

IRELAND | *The Irish Times* (Dublin) – 30 January 2014 – Provision should be made within the health service for end-of-life care for older homeless people, a new Irish study has recommended. 'Homelessness, Ageing & Dying,' commissioned by the Simon Communities of Ireland, found many older homeless people had a fear of dying on the streets or of dying alone and their body not being found for weeks. The study was carried out for the Simon Communities by independent researcher Dr. Kathy Walsh... The average life expectancy of homeless people is 47 years for men and 43 years for women. Dr. Walsh found many, particularly those drinking heavily, just lived on a day-to-day basis. But some were kept awake at night by the thought of dying. "Interviewees generally wanted to die in their sleep, they did not want to die alone. For those who were estranged from their family, they wondered who would be there when they were dying," said Dr. Walsh. "Most interviewees in this situation hoped they would 'go to sleep and not wake up.' A particular concern for the interviewees who lived alone was that they would die alone and their body not be found for weeks." <http://www.irishtimes.com/news/ireland/irish-news/need-for-end-of-life-care-for-older-homeless-report-finds-1.1673728>

Representative sample of articles on end-of-life care for the homeless noted in past issues of Media Watch:

- U.K. | *Inside Housing* – 10 May 2013 – **'Homeless charity publishes end of life care guide.'** A homelessness charity, in partnership with the end of life care charity Marie Curie Cancer Care, has produced a new guide to help improve end of life care for homeless people.¹ [Noted in Media Watch, 20 May 2013, #306 (p.7)] <http://www.insidehousing.co.uk/care/homeless-charity-publishes-end-of-life-care-guide/6526912.article>
 1. 'Homelessness and End of Life Care,' St Mungo's, 2013. <http://www.mariecurie.org.uk/Documents/Commissioners-and-referrers/HomelessReport.pdf>
- *BMC PALLIATIVE CARE* | Online – 15 September 2012 – **'Recommendations for improving the end-of-life care system for homeless populations: A qualitative study of the views of Canadian health and social services professionals.'** Changes in the rules and regulations that reflect the health needs and circumstances of homeless persons and measures to improve continuity of care have the potential to increase equity in the end-of-life care system for this underserved population. [Noted in Media Watch, 17 September 2012, #271 (p.7)] <http://www.biomedcentral.com/content/pdf/1472-684X-11-14.pdf>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 June 2012 – **'A qualitative study of homelessness and palliative care in a major urban center,'** In order to increase access and to serve the city's terminally ill homeless, the following areas must be addressed: 1) increasing positive interaction between the health care system and the homeless; 2) training staff to deal with the unique issues confronting the homeless; 3) providing patient-centered care; and, 4) diversifying methods of delivery. [Noted in Media Watch, 11 June 2012, #257 (p.8)] <http://ajh.sagepub.com/content/early/2012/06/03/1049909112448925.abstract>
- U.K. (ENGLAND) | National End of Life Care Programme – 8 December 2010 – **'End of life care – achieving quality in hostels and for homeless people.'** *End of life care – achieving quality in hostels and for homeless people – a route to success* is a guide to support hostel staff in ensuring people nearing end of their life receive quality end-of-life care. It is estimated that in England around 40,500 people are in the hostel system at any one time and that over the course of a year approximately 100,000 individuals move in and out of it. For some the lack of a settled home may be temporary and quickly resolved. Others may be homeless or living in insecure circumstances for longer periods and either sleep rough, in squats or on friends' floors when not in the hostel system. [Noted in Media Watch, 13 December 2010, #179 (p.6)] <http://www.qni.org.uk/docs/NHS%20End%20of%20life%20care%20for%20homeless%20people%20report.pdf>

Palliative care unavailable for majority of patients in developing countries

U.K. | *The Guardian* – 28 January 2014 – Nine out of 10 people in need of palliative care to relieve the pain and symptoms of a life-threatening illness – the majority of whom live in poor countries – are not receiving it, according to a new report. The Global Atlas of Palliative Care at the End of Life, published by the World Health Organisation and the Worldwide Palliative Care Alliance, found that only 20 countries have palliative care firmly integrated into their healthcare systems. According to the report, most palliative care is provided in high-income countries, but almost 80% of the global need for services is in low- and middle-income countries. The report is understood to be the first to map the need for, and availability of, palliative care globally. It calls on all countries to include palliative care as an essential component to all healthcare systems. It also

urges governments to introduce policies recognising the need for care at the end of life and spend more money on services, including access to pain relief. Health professionals should be educated about the importance of palliative care and the benefits outlined to the public, it adds. <http://www.theguardian.com/global-development/2014/jan/28/palliative-care-patients-developing-countries>

Specialist Publications

'The Global Opioid Policy Initiative: A wealth of information, but what is next?' (p.10), in *Journal of Pain & Palliative Care Pharmacotherapy*.

1. 'Global Atlas of Palliative Care at the End of Life,' World Health Organisation and the Worldwide Palliative Care Alliance, January 2014. <http://www.thewpca.org/resources/global-atlas-of-palliative-care/>

Noted in Media Watch, 27 January 2014, #342 (p.6):

- HUMAN RIGHTS WATCH | Online – 24 January 2014 – **'WHO boosts hope on pain relief, palliative care.'** World Health Organization has adopted a groundbreaking resolution urging countries to ensure access to pain medicines and palliative care for people with life-threatening illnesses. <http://www.hrw.org/news/2014/01/24/un-who-boosts-hope-pain-relief-palliative-care>

Dying in the U.K.

Church offers cut-price funerals ... if you opt for cremation

U.K. (England) | *The Daily Telegraph* – 27 January 2014 – The Church of England is to offer cut-price funerals to those who choose cremation instead of traditional burial, amid a national shortage of grave space. Plans expected to be approved by the Church's General Synod will ensure that bereaved families who wish to have the ashes of a loved-one interred in a church yard pay less than half the fee charged to those who choose the burial of a body. The proposal requires a change in ecclesiastical law... It follows warnings that Britain could run out of burial space by the end of this decade. <http://www.telegraph.co.uk/news/religion/10597791/Church-offers-cut-price-funerals-...-if-you-opt-for-cremation.html>

Noted in Media Watch, 27 January 2014, #342 (p.7):

- U.K. (England & Wales) | *Russia Today* (London Bureau) – 21 January 2014 – **""Can't afford to die": British families on low incomes struggle with "funeral poverty.""** Over 100,000 people in the U.K. will hardly manage to pay for a funeral this year. With the average cost of dying having risen by 7.1%, the poor simply cannot afford to pay the costs of funerals, a survey has found.¹ <http://rt.com/news/funeral-poverty-afford-die-958/>

1. 'Funeral poverty in the UK: Issues for policy,' University of Bath's Institute for Policy Research, January 2014. <http://www.bath.ac.uk/ipr/pdf/policy-briefs/affording-a-funeral.pdf>

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

Court of Appeal to hear case of terminally ill Ware woman Janet Tracey

U.K. (England) | *The Hertfordshire Mercury* (Hertford) – 27 January 2014 – The case of a Ware woman, Janet Tracey, who was not consulted before a "do not resuscitate" notice was placed on her medical file, is to be heard by the Court of Appeal. Three senior judges overturned an earlier ruling and agreed legal action into DNR orders at Cambridge University Hospitals (CUH), where Tracey was treated, and across the National Health Service, should continue. In 2012, High Court judge Mrs. Justice Nicola Davies said the failure to inform Mrs. Tracey had "minimal causative effect" as the notice was cancelled five days later when her family objected. She also found that a second notice, which followed three days afterwards and two days before Tracey's death at Addenbrooke's in March 2011, was in agreement with her family, who were unwilling to speak to her about it. The judge said that there should be no further hearing of husband David Tracey's application for a judicial review against CUH and the Health Secretary, but the Court of Appeal disagreed. <http://www.hertfordshiremercury.co.uk/News/Court-of-Appeal-to-hear-case-of-terminally-ill-Ware-woman-Janet-Tracey-20140127105459.htm>

Noted in Media Watch, 4 February 2013, #291 (p.10):

- **LEXOLOGY** | Online – 31 January 2013 – '**Do not resuscitate: The court's policy role in life and death.**' The High Court stopped the judicial review proceedings in the case of *R(Tracey) v Cambridge University Hospitals National Health Service Trust & Secretary of State for Health*. The Claimant also claimed against the Secretary of State for Health [for failure to have in place adequate national guidelines]. <http://www.lexology.com/library/detail.aspx?q=78fd7451-b7ed-463c-b1f8-4773a161b6d1>

Families believe terminal sedation is a humane way to die: New research reveals concerns over how vegetative patients are treated

U.K. (England) | *The Daily Mail* – 25 January 2014 – The sisters of a woman left severely brain damaged after she was injured in a car crash have published a study highlighting family concerns about how permanent vegetative patients are treated.¹ Some families [i.e., study participants] feel relatives are being kept alive in a "fate worse than death," but are horrified by the option of withdrawing artificial nutrition and hydration to allow them to die. The paper, by university professors Celia and Jenny Kitinger, calls for family perspectives to be taken in to account. The research was inspired by the professors' own experience; they were devastated when their sister Polly was involved in the crash in March 2009. Now they have pub-

lished research showing that other families of severely brain damaged patients believe that when all other avenues have been exhausted, terminal sedation is a humane option. <http://www.dailymail.co.uk/news/article-2540661/Families-believe-terminal-sedation-humane-way-die.html>

Specialist Publications

'Could meeting familial, psychosocial and cultural expectations under the aegis of palliative care result in a slippery slope to hastening of death?' (p.14), in *Palliative Medicine & Care*.

1. 'Withdrawing artificial nutrition and hydration from minimally conscious and vegetative patients: family perspectives,' *Journal of Medical Ethics*, 14 January 2014. Most medical ethicists have treated the issue as one of life versus death; by contrast, families [i.e., study participants] – including those who believed that their relative would not have wanted to be kept alive – focused on the manner of the proposed death and were often horrified at the idea of causing death by "starvation and dehydration." <http://jme.bmj.com/content/early/2014/01/03/medethics-2013-101799.abstract?sid=e163ee08-9328-48f7-ae13-eca744f64b71>

Cont.

Noted in Media Watch, 3 December 2012, #282 (p.13):

- *QUALITY HEALTH RESEARCH* | Online – 27 November 2012 – **'From hope to despair, and back: Being the wife of a patient in a persistent vegetative state.'** The authors examined the meaning of being the wife of a vegetative patient over time ... based on interviews with 12 wives of husbands diagnosed with persistent vegetative state between 1 year 2 months and 10 years prior to the interview. They found contradicting forces common to all of the wives across time. <http://qhr.sagepub.com/content/early/2012/11/22/1049732312467537.abstract>

"Palliative" or "end of life"? Why it is important to say the right words

U.K. | *The Guardian* – 24 January 2014 – Recently, as part of a film project, we posed the question to the general public: "What do you think and feel when you hear the terms 'palliative' and 'end of life' care?" The responses included: "Palliative care means you're not getting better, doesn't it?"; "End of life care sounds a bit frightening"; "Palliative is gentler but more confusing," and "I've got no idea." These responses will be fed into our new project on terms used by professionals. We will be working in partnership with the National Council of Palliative Care who lead the Dying Matters Coalition.¹ The evidence we collect will be used to consider whether there might be other, more readily understood terms or phrases that could be used instead of "palliative" and "end of life care." And if we can't find more acceptable words, we will disseminate our findings so that those working in health and social services are aware of the confusion, bafflement and misunderstanding that these terms can create for people. <http://www.theguardian.com/social-care-network/2014/jan/24/palliative-end-of-life-care-right-words>

1. 'Understanding the words we use,' National Council for Palliative Care, January 2014. <http://www.ncpc.org.uk/terminology>

Representative sample of articles on defining end-of-life care noted in past issues of Media Watch:

- *PLOS ONE* | Online – 3 July 2013 – **'Diversity in defining end-of-life care: An obstacle or the way forward?'** Two approaches were identified [in this study] to arrive at an understanding of EoL [end of life] care: exclusively by drawing boundaries through setting time frames, and inclusively by approaching its scope in an integrative way. This led to reflections about terminology and whether defining EoL care is desirable. The global expansion of EoL care contributes to the variety of interpretations of what it means. [Noted in Media Watch, 15 July 2013, #314 (p.13)] <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0068002>
- *THE ONCOLOGY REPORT* | Online – 10 April 2013 – **'Is the moniker "palliative care" too loaded?'** A survey of 169 patients with advanced cancer found those randomized to hear the term "supportive care" instead of "palliative care" rated their understanding, overall impressions and future perceived need for those services significantly higher. [Noted in Media Watch, 15 April 2013, #301 (pp.14-15)] <http://www.oncologypractice.com/oncologyreport/news/top-news/single-view/what-s-in-a-name-is-the-moniker-palliative-care-too-loaded/15b05715fc83fdc88503a88bc9cbfc0e.html>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 11 January 2013 – **'Medical oncologists' perception of palliative care programs and the impact of name change to supportive care on communication with patients during the referral process. A qualitative study.'** Although most [study participants] claimed that early referrals to the service are preferable, oncologists identified several challenges, related to the timing and communication with patients regarding the referral... [Noted in Media Watch, 14 January 2013, #288 (p.7)] <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8814761&fulltextType=RA&fileId=S1478951512000685>
- *SUPPORTIVE CARE IN CANCER* | Online – 31 August 2012 – **'Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks.'** Commonly used terms such as "supportive care," "best supportive care," "palliative care," and "hospice care" were rarely and inconsistently defined in the palliative oncology literature. [Noted in Media Watch, 3 September 2012, #269 (p.7)] <http://link.springer.com/article/10.1007/s00520-012-1564-y>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

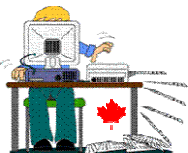
- U.K. (Scotland) | *The Daily Express* (London) – 29 January 2014 – '**Two-thirds of Scots want law to allow assisted suicide.**' A total of 69% of those questioned in a recent survey said they would like to see euthanasia laws passed by Holyrood [i.e., Scottish parliament]. It comes as independent MSP [Member of the Scottish Parliament] Margo MacDonald makes a new attempt to pass her Assisted Suicide (Scotland) Bill... The poll, which also showed that 13% are against the bill and 18% are unsure, was conducted by new campaign group My Life, My Death, My Choice. <http://www.express.co.uk/news/uk/456903/Two-thirds-of-Scots-want-law-to-allow-assisted-suicide>

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

Texas forced life-support case could happen in Canada

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 27 January 2014 - A controversial case in which a Texas hospital kept a brain-dead, pregnant woman's body on life-support against her family's wishes could be repeated in Canada, say ethicists. The case has attracted international attention and become a lightning rod for debate about patient, family and fetal rights at end-of-life – a legal and ethical grey zone that remains contentious, even in Canada, which according to experts is less politically polarized. Canadian consent statutes don't speak to "whether or not it is acceptable to keep the body of a deceased person functioning to ensure that a pregnancy can be carried to term," says Udo Schüklenk, Ontario Research Chair in Bioethics at Queen's University in Kingston. "The odds are that life support would be switched off, but nothing could stop either party from going to court over such a matter." Both the Supreme Court of Canada and provincial legislatures have confirmed the fundamental right of individuals to refuse medical intervention, including by advance directive or a substitute decision-maker. But determining how far such protection might extend after death, particularly when a living fetus is involved, is "very messy, both ethically and legally," says Kerry Bowman, a bioethicist at the University of Toronto in Ontario. "The person is now technically dead, so you no longer need consent of any form ... although what typically happens is you respectfully make plans as to what point you will stop the life-support." Although a neurologically compromised, pregnant woman is "legally one patient, ethically it's an open question and many people feel we essentially have two," Bowman adds. According to Dr. Eugene Bereza, director of the Biomedical Ethics Unit at McGill University in Montréal, Quebec, the issue becomes more complicated as a pregnancy progresses. He cites the example of a living, competent woman refusing a caesarean section, although it's clear her otherwise healthy, full-term baby will die. <http://www.cmaj.ca/site/earlyreleases/27jan14/Texas-forced-life-support-case-could-happen-in-Canada.xhtml>

Cont. next page



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.ipcr.net/barry-r-ashpole.php>

Noted in Media Watch, 30 December 2013, #338 (p.3):

- TEXAS | United Press International – 23 December 2013 – **'Texas man wants to end pregnant wife's life support.'** A Texas man [a paramedic] said he wants to end life support for his pregnant wife, but state law puts the rights of their 18-week-old fetus above the desires of the mother [also a paramedic]. http://www.upi.com/Top_News/US/2013/12/23/Texas-man-wants-to-end-pregnant-wifes-life-support/UPI-59541387805756/?spt=rln&or=1

Languages of Grief: A model for understanding the expressions of the bereaved

HEALTH PSYCHOLOGY & BEHAVIORAL MEDICINE, 2014;2(1):132-143. Grief is a response to loss or anticipated loss. Although universal, its oral and non-verbal expression varies across cultures and individuals. The languages used by the bereaved to express grief differ from the language used by professionals. To bridge the gap between professional language and that used by the bereaved, a Languages of Grief model was developed consisting of four Modes of Expression, four Types of Language, plus three Contingent Factors. The Languages of Grief provides a framework for comprehending the grief of the individual, contributing to clinical understanding, and fruitful exploration by professionals in better understanding the use of languages by the bereaved. <http://www.tandfonline.com/doi/full/10.1080/21642850.2013.879041#UuifTlo40M>

Of related interest:

- *DEATH STUDIES* | Online – 23 January 2014 – **'Planting hope in loss and grief: Self-care applications of horticultural therapy for grief caregivers in Taiwan.'** The Taiwan Association for Care & Counseling for Loss organized a workshop about horticultural therapy. Results demonstrated most participants displayed an increased awareness of personal loss and meaning in grief, indicating horticulture and nature appreciation might relieve individual grief and stress. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2013.820231#UufKTdlo40M>

Attitudes toward death, dying, end-of-life palliative care, and interdisciplinary practice in long term care workers

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 24 January 2014 – Healthcare workers [i.e., study participants] had a relatively positive attitude toward more than one-half of the selected aspects of interdisciplinary practice and end-of-life palliative care for long-term residents. However, attitudes were more mixed about 10 other aspects and a higher percentage of respondents indicated negative attitudes toward them. Overall, there are significant differences between upper-level professionals and managers (registered nurses, physicians, rehabilitation staff, and clinical managers) versus the hands-on caregivers (nursing assistants, patient assistants, and volunteers) with regard to some aspects of the care of the dying. [http://www.jamda.com/article/S1525-8610\(13\)00659-2/abstract](http://www.jamda.com/article/S1525-8610(13)00659-2/abstract)

Do not resuscitate

Should you pay attention to or obey a patient's medical tattoo?

JOURNAL OF EMERGENCY MEDICAL SERVICES | Online – 28 January 2014 – What about a so-called "medical tattoo" that says "do not resuscitate" (DNR)... Can that be honored as a valid instruction not to begin CPR if the patient is in cardiac arrest? The law generally doesn't recognize a statement on a tattoo as a lawful "advance directive." DNR laws typically require the patient to be in a "terminal" condition as certified by a physician, which is another reason a DNR tattoo wouldn't be an appropriate notification to healthcare providers. Unless tattoos are specifically enumerated by your state law as an acceptable form of a DNR ... then EMS providers would have no right or obligation to honor them. <http://www.jems.com/article/administration-and-leadership/pro-bono-should-you-pay-attention-or-obe>

Cont.

Noted in Media Watch, 1 October 2012, #273 (p.9):

- *JOURNAL OF GENERAL INTERNAL MEDICINE*, 2012;27(10):1383. **'DNR tattoos: A cautionary tale.'** By imprinting the letters DNR on their body, a person obtaining a tattoo may wish to increase the certainty that their decision will be respected. Paradoxically, however, such a tattoo may exacerbate the uncertainty of emergency responders at a critical time. Legally sanctioned forms, e.g., Physician Orders for Life-Sustaining Treatment, exist for a reason: they provide certainty for emergency responders who must be decisive about attempting or forgoing attempted resuscitation. A DNR tattoo, however, may cause confusion at the very moment when certainty is needed. <http://www.springerlink.com/content/5j87325767302ht1/fulltext.pdf>

The sentinel hospitalization and the role of palliative care

JOURNAL OF HOSPITAL MEDICINE | Online – 29 January 2014 – With current healthcare reform and calls for improving care quality and safety, there is renewed emphasis on high-value care. Moreover, given the significant healthcare resource utilization for patients with chronically progressive illnesses or for patients at the end of life, innovative and efficient care delivery models are urgently needed. The authors propose the concept of a sentinel hospitalization, defined as a transitional point in the patient's disease course that heralds a need to reassess prognosis, patient understanding, treatment options and intensities, and goals of care. Hospitalists are well positioned to recognize a patient's sentinel hospitalization and use it as an opportunity for active integration of palliative care that provides high-quality and cost-saving care through its patient- and family-oriented approach, its interdisciplinary nature, and its focus on symptom control and care coordination. <http://onlinelibrary.wiley.com/doi/10.1002/jhm.2160/abstract>

Integrating professional apprentices into an end-of-life course

JOURNAL OF NURSING EDUCATION, 2014;1(4). Nursing education faces several challenges in providing quality and meaningful education. Providing such an education is most important in teaching end-of-life care, as nurses are pivotal in helping patients to achieve a good death. Many obstacles hinder a patient's wishes about dying, including how nurses perceive their role in end-of-life care situations and knowing how to intervene on behalf of the patient. Therefore, nursing education needs to create meaningful and relevant learning experiences to enable future nurses to effectively care for the dying patient. To this endeavor, the palliative and end-of-life care course described in this article integrated knowledge through the use of three professional apprenticeships: a) acquiring and using knowledge and science (cognitive); b) using clinical reasoning and skilled know-how (practice); and, c) ethical comportment and formation (moral reasoning). <http://europepmc.org/abstract/MED/24444009>

The Global Opioid Policy Initiative: A wealth of information, but what is next?

JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY | Online – 28 January 2014 – Recently, the outcomes were published of the Global Opioid Policy Initiative, evaluating the availability, cost of opioid medicines and the regulatory barriers that are possibly impeding access for the management of cancer pain in developing countries. Other studies have shown that the vast majority of the world population has no access to opioid analgesics. This study shows by country which opioid medicines are available, what they cost to the patient, and investigates the presence of barriers for access to these medicines. Data from the project will be an important resource for those who advocate for improved access to opioid analgesics. Yet, like so often, many more aspects of inadequate opioid analgesic consumption require exploration and reporting, including legislative barriers. The last publication on the project is a "What's next?" that is over focusing on palliative care, forgetting that outside palliative care is also a huge need for opioid analgesics in moderate and severe pain. <http://informahealthcare.com/doi/abs/10.3109/15360288.2013.873513>

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Noted in Media Watch, 2 December 2013, #334 (p.9):

- *ANNALS OF ONCOLOGY*, 2013;24(suppl11):xi7-xi13. **'The Global Opioid Policy Initiative project to evaluate the availability and accessibility of opioids for the management of cancer pain in Africa, Asia, Latin America and the Caribbean, and the Middle East: Introduction and methodology.'** As the follow-up to a successful project to evaluate the availability and accessibility of opioids and regulatory barriers in Europe, the European Society for Medical Oncology and the European Association for Palliative Care undertook to expand their research to those parts of the world where data were lacking regarding these aspects of care, in particular Africa, Asia, the Middle East, Latin America and the Caribbean, and the states of India. This project has been undertaken in collaboration with the Union for International Cancer Control, the Pain and Policy Studies Group of the University of Wisconsin, and the World Health Organization, together with a consortium of 17 international oncology and palliative care societies. http://annonc.oxfordjournals.org/content/24/suppl_11/xi7.abstract

Why oncologists lag on palliative care

ONCOLOGY TIMES | Online – 25 January 2014 – It has been more than two years since the American Society of Clinical Oncology [ASCO] published its provisional clinical opinion (PCO) on early palliative care, which says that "combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden."¹ But oncologists are not all on board. As shown ... research conducted at three cancer centers that have well-established outpatient palliative care clinics found that 22 of the 74 medical oncologists interviewed believe that palliative care is an alternative to chemotherapy, rather than complementary care.² The interviews were conducted in 2012; the ASCO Board of Directors approved the PCO in November 2011 and published it in February 2012. "There is a significant minority of oncologists who feel that palliative care is incompatible with chemotherapy even though that is no longer supported by guidelines," said ... Yael Schenker, MD, MS, a palliative care specialist at the University of Pittsburgh Cancer Institute (UPCI) in Pennsylvania. <http://journals.lww.com/oncology-times/blog/PracticeMatters/pages/post.aspx?PostID=288>

1. 'American Society of Clinical Oncology Provisional Clinical Opinion: The integration of palliative care into standard oncology care,' *Journal of Oncology Practice*, 6 February 2012. [Noted in Media Watch, 13 February 2012, #240 (p.10)] <http://jco.ascopubs.org/content/early/2012/02/06/JCO.2011.38.5161.abstract>
2. 'Oncologist factors that influence referrals to subspecialty palliative care clinics,' *Journal of Oncology Practice*, 3 December 2013. The authors [of this study] identified three main oncologist barriers to subspecialty palliative care referrals... 1) persistent conceptions of palliative care as an alternative philosophy of care incompatible with cancer therapy; 2) a predominant belief that providing palliative care is an integral part of the oncologist's role; and, 3) a lack of knowledge about locally available services. [Noted in Media Watch, 9 December 2013, #335 (p.11)] <http://jop.ascopubs.org/content/early/2013/12/02/JOP.2013.001130.abstract>

Noted in Media Watch, 29 July 2013, #316 (p.10):

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 22 July 2013 – **'Time to define high-quality palliative care in oncology.'** The time has come to enhance how the field of oncology assesses and manages patient and family distress, and then to integrate those efforts with ... palliative care. Although ... research continues to build the evidence base, oncology providers will need to simultaneously prioritize both aspects of palliative care that fall within the scope of oncology practice and those best suited for the expertise of specialty palliative care. <http://jco.ascopubs.org/content/early/2013/07/22/JCO.2013.50.2484.full.pdf+html>

The troubles of telling: Managing communication about the end of life

QUALITATIVE HEALTH RESEARCH | Online – 27 January 2014 – Communication about palliative care represents one of the most difficult interpersonal aspects of medicine. Delivering the "terminal" diagnosis has traditionally been the focus of research, yet transitions to specialist palliative care are equally critical clinical moments. The authors focus on twenty medical specialists' strategies for engaging patients around referral to specialist palliative care. Their aim was to develop an understanding of the logics that underpin their communication strategies when negotiating this transition. The authors draw on qualitative interviews to explore their accounts of deciding whether and when to engage in referral discussions; the role of uncertainty and the need for hope in shaping communication; and, their perceptions of how patient biographies might shape their approaches to, and communication about, the end of life. They argue that communication is embedded in social relations of hope, justice, and uncertainty, as well as being shaped by patient biographies. <http://qhr.sagepub.com/content/early/2014/01/27/1049732313519709.abstract>

Noted in Media Watch, 19 November 2012, #280 (p.11):

- *SOCIAL SCIENCE & MEDICINE* | Online – 15 November 2012 – '**The art of letting go: Referral to palliative care and its discontents.**' While medical specialists are expected to ease their patients transitions to specialist palliative care if required, few have received formal training in such interpersonal complexities. The results [of this study] illustrate how this transitional realm can be embedded in emotions, relationships and the allure of potentially life-prolonging intervention. <http://www.sciencedirect.com/science/article/pii/S0277953612007575?v=s5>

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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.

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 January 2014 – **'How to estimate understanding: Professionals' assessment of loved ones' insight into a patient's fatal disease.'** Ways to communicate with loved ones are crucial when making an assessment. The different ways loved ones use hope and other strategies made it problematic for the professionals to use these as indicators of state of mind in this matter. Training in conversation skills could be one way to support professionals when discussing and managing these difficult situations. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0507>

Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology

SEMINARS IN PERINATOLOGY, 2014;38(1):38-46. The nature and content of the conversations between the healthcare team and the parents concerning withholding or withdrawing of life-sustaining interventions for neonates vary greatly. These depend upon the status of the infant; for some neonates, death may be imminent, while other infants may be relatively stable, yet with a potential risk for surviving with severe disability. Healthcare providers also need to communicate with prospective parents before the birth of premature infants or neonates with uncertain outcomes. Many authors recommend that parents of fragile neonates receive detailed information about the potential outcomes of their children and the choices they have provided in an unbiased and empathetic manner. However, the exact manner this is to be achieved in clinical practice remains unclear. Parents and healthcare providers may have different values regarding the provision of life-sustaining interventions. However, parents base their decisions on many factors, not just probabilities. The role of emotions, regret, hope, quality of life, resilience, and relationships is rarely discussed. End-of-life discussions with parents should be individualized and personalized. [http://www.seminperinat.com/article/S0146-0005\(13\)00106-7/abstract](http://www.seminperinat.com/article/S0146-0005(13)00106-7/abstract)

Of related interest:

- *AMERICAN JOURNAL OF MATERNAL CHILD NURSING* | Online – 17 January 2014 – **'Leaning in and holding on: Team support with unexpected death.'** As healthcare professionals journey with a dying child, they experience an ongoing dual nature of their own grief, shifting between focusing on the loss at hand or avoiding the loss and refocusing their attention elsewhere. This internal conflict may be potentiated with the sudden, unexpected death of a patient, which affords little time for caregivers to process their own experience of the loss. http://journals.lww.com/mcnjournal/Abstract/publishahead/Leaning_In_and_Holding_On_Team_Support_With.99942.aspx

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *EUROPEAN JOURNAL OF HEALTH LAW*, 2013;20(5):451-469. **'The Dutch Euthanasia Act: Recent legal developments.'** The Dutch Termination of Life on Request & Assisted Suicide Act ... came into force in 2002. Its aim is to increase the degree of due care exercised by physicians when terminating a patient's life and to provide a legal framework within which physicians account for their actions in such cases. This article provides an overview of the most recent legal developments regarding the Act. Special attention [in this article] is given to patients with dementia, psychiatric patients and patient who are "weary of life." <http://europepmc.org/abstract/MED/24437331/reload=0;jsessionid=e8jd8O0mrdILM9fWmtai.0>

Of related interest:

- *NEDERLANDS TIJDSCHRIFT VOOR GENEESKUNDE*, 2014;158(4):A7213. **'General practitioner and palliative sedation.'** Recent publications in Dutch national newspapers on palliative sedation have raised concerns about its use in general practice. There is now evidence that there is no significant increase in the incidence of palliative sedation. <http://europepmc.org/abstract/MED/24447672>

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- *JOURNAL OF LAW, MEDICINE & ETHICS* | Online – 21 January 2014 – '**Adherence to the request criterion in jurisdictions where assisted dying is lawful? A review of the criteria and evidence in The Netherlands, Belgium, Oregon, and Switzerland.**' The authors review the criteria and evidence in respect of requests for assisted dying ... with the aim of establishing whether individuals who receive assisted dying do so on the basis of valid requests. The evidence suggests individuals who receive assisted dying in the four jurisdictions examined do so on the basis of valid requests and third parties who assist death do not act unlawfully. <http://onlinelibrary.wiley.com/doi/10.1111/jlme.12098/abstract;jsessionid=8E72B749742F99ACCA5C5370049F611D.f03t01?deniedAccessCustomisedMessage=&userIsAuthenticated=false>
- *PALLIATIVE MEDICINE & CARE*, 2014;1(1):11. '**Could meeting familial, psychosocial and cultural expectations under the aegis of palliative care result in a slippery slope to hastening of death?**' Palliative care utilises inclusive and reflexive practices in order to meet its pivotal goal of holistic care provision. This practice has been seized upon by detractors who posit that such working practices in attempting to accommodate and respond appropriately to the demands and considerations of cultural, religious, psychosocial and local beliefs will succumb to increasingly aberrant practices. These repeated and increasing overt breaches are thought to represent a slippery slope to unacceptable practices. Using the example of continuous deep sedation within the context of end of life care, this paper investigates the possibility of prevailing flexible care ethics being manipulated to result in a slippery slope to euthanasia. <http://symbiosisonlinepublishing.com/palliative-medicine-care/palliative-medicine-care04.php>

Worth Repeating

Dire deadlines: Coping with dysfunctional family dynamics in an end-of-life care setting

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2009;15(1):34-41. Working in a hospice and being able to focus on individualized, specialized end-of-life care is a privilege for the hospice staff member. However, it also presents the hospice staff with unique challenges. This descriptive study is based upon two cases from an end-of-life care setting in Denmark, where dysfunctional family dynamics presented added challenges to the staff members in their efforts to provide optimal palliative care. The hospice triad – the patient, the staff member, and the family member – forms the basis for communication and intervention in a hospice. Higher expectations and demands of younger, more well-informed patients and family members challenge hospice staff in terms of information and communication when planning for care. The inherent risk factors of working with patients in the terminal phase of life become a focal point in the prevention of the development of compassion fatigue among staff members. A series of coping strategies to more optimally manage dysfunctional families in a setting where time is of the essence are then presented in an effort to empower the hospice team, to prevent splitting among staff members, and to improve quality of care. <http://www.internurse.com/cgi-bin/go.pl/library/article.cgi?uid=37951>

Noted in Media Watch, 2 July 2012, #260 (p.9):

- *SOCIOLOGY OF HEALTH & ILLNESS* | Online article – 28 June 2012 – '**The end of life and the family: Hospice patients' views on dying as relational.**' The authors argue family dynamics strongly influence individual experiences near death and the focus on individual preferences and the management of disease in palliative care contexts must be augmented with sophisticated and nuanced understandings of the family context. They suggest sociological conceptual explanations of shifts in social and family life, such as individualisation and ontological security, may also help us better understand the ways families approach and respond to the dying process. <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-9566.2012.01497.x/abstract>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/1/media-watch/>

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

PALLIATIVE CARE NETWORK COMMUNITY: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

PALLIMED (Hospice & Palliative Medicine Blog): <http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/updates/international-palliative-care-resource-center-media-watch/>

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> [Scroll down to 'International Websites' and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report]

Canada

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

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

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> [Click on 'Current Issue' under 'Media Watch']

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

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

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

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/news-events> [Scroll down to 'Media Watch']

Europe

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

HUNGARY | Hungarian Hospice Foundation: <http://www.hospicehaz.hu/en/training/> [Scroll down to 'Media Watch']

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

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