

## 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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## The troubled landscape of scientific publishing

### World's main list of “predatory” science publishers vanishes with no warning

*THE OTTAWA CITIZEN* (Ontario, Canada) | Online – 17 January 2017 – In 2012, a librarian from the University of Colorado presented research in a field so new that he had to name it himself: predatory publishing. Jeffrey Beall discovered thousands of online science journals that were either willing to publish fake research for cash, or just so inept that they couldn't tell the good from the bad and published it all. Beall, who became an assistant professor, drew up a list of the known and suspected bad apples, known simply as Beall's List. Since 2012, this list has been the world's main source of information on journals that publish conspiracy theories and incompetent research, making them appear real. But on Sunday, his website went blank. Only the headline, Scholarly Open Access, remains. <https://goo.gl/EJyNJJa>

#### Related postings on ‘The Conversation’ and ‘Retraction Watch’ worth noting

19 January 2017 – ‘Who will keep predatory science journals at bay now that Jeffrey Beall's blog is gone?’ <https://goo.gl/ixEI7A>

18 January 2017 – ‘Why did Beall's List of potential predatory publishers go dark?’ <https://goo.gl/9lymZh>

14 January 2017 – ‘Watch out for predatory journals, and consider retract/replace, suggests medical journal group.’<sup>1</sup> <https://goo.gl/lhnhZi>

1. ‘Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals,’ International Committee of Medical Journal Editors, December 2016. <https://goo.gl/uDQePz>

Noted in Media Watch 3 October 2016, #482 (p.1):

- CTV NEWS (Ontario, Canada) | Online – 29 September 2016 – ‘**Offshore firm accused of publishing junk science takes over Canadian journals.**’ An offshore publishing company accused of disseminating junk science and duping researchers has taken over the publishing of several respected Canadian medical journals, a CTV News/*Toronto Star* investigation has found. <https://goo.gl/yLi42q>

**N.B.** Additional articles on predatory journals are noted in past issues of Media Watch, e.g., 9 January 2017, #494 (p.7); 19 December 2016, #492 (p.6); 5 December 2016, #490 (p.2); 5 September 2016, #478 (p.14); 30 May 2016, #464 (p.11); and, 11 April 2016, #457 (p.7).

## Canada

### When men grieve

#### **Hospice program gets provincial recognition**

BRITISH COLUMBIA | *The Prince George Citizen* – 17 January 2017 – Realizing that very few men were attending the grief support programs provided by the Prince George Hospice Society for the last 30 years, a support team staff member decided to approach the grieving process from a different angle. There are two main kinds of grieving, intuitive and instrumental. An intuitive griever will talk, emote, and share to grieve, while an instrumental griever might not even be recognized as grieving as they act upon it, setting up a legacy fund, a scholarship, renovate their home, or go for walks – things not traditionally known as acts of grieving. “Just because they’re not crying, it doesn’t mean they’re not in pain, they’re just grieving in a different way,” said Denise Torgerson, support team member, who volunteered at Hospice House for 11 years before taking a paid position with the society three years ago. Everyone fits somewhere on the spectrum between intuitive and instrumental grieving and most men lean toward the instrumental. Torgerson created the Grief and Grub eight-week program more than a year ago where men 19-plus are invited to grieve in a way best suited for them. <https://goo.gl/3D7CvZ>

#### **Doctor hits the road to deliver palliative care to Toronto’s homeless**

ONTARIO | CBC News (Toronto) – 17 January 2017 – Dr. Naheed Dosani is a palliative care (PC) doctor in Toronto, but his patients are not in hospitals and clinics, they’re in homeless shelters, drop-in centres and sometimes even on the streets. His patients are the city’s homeless, an ebbing and flowing population that numbers approximately 5,000. “When you’re socially isolated on the streets, who’s advocating for you?” he asks rhetorically. Well, he is. Thanks to a program called Palliative Education & Care for the Homeless (PEACH), funded by Inner City Health Associates via the Ontario Ministry of Health & Long-Term Care. Right now, PEACH is Dosani, but ICHA hopes to be able to fund a second mobile unit soon. “PC is a human right for everybody in Canada,” says Dr. Simon Colgan, who set up a similar mobile medical service last October in Calgary, a city with about 900 people who are chronically homeless. CAMPP, Calgary’s Allied Mobile Palliative Program, is running with the help of a nurse and soon-to-run-out funding from the United Way. “If there are some sections of our society that have difficulty accessing that care,” Colgan says, “then I think we as leaders and as health care providers should find ways to navigate that system for them.” <https://goo.gl/xn8gzc>



Five principles of the PEACH program

Noted in Media Watch 11 August 2014, #370 (p.2):

- ONTARIO | CTV News (Toronto) – 3 August 2014 – **‘Mobile palliative programs give “end-of-life-care” to homeless.’** They’re too often the forgotten people – or the ones many of us turn a blind eye to as we pass a street corner where they might implore us for extra change: the homeless living rough outside through all kinds of weather or those precariously housed in a cot-for-the-night shelter or a decaying rooming house. But what happens when these people are dying? Where do they find care in their final days? <https://goo.gl/hdrull>

#### **Specialist Publications**

**‘Challenges and recommendations in increasing homeless persons’ access to palliative care: An international systematic review’** (p.7), in *Bulletin of European Health Psychology Society*.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | *The Calgary Herald* – 20 January 2017 – ‘**Pace of Alberta doc-assisted death increases, though fewer choose dying at home.**’ The rate of those choosing physician-assisted in death in Alberta continues to increase and more are opting out of dying at home, say Alberta Health Services officials (AHS). Since 6 February when the procedure was made possible, 76 people in the province have taken that route to end their lives which in Alberta has been through the intravenous delivery of drugs. In the week from 9-16 January, five more people died with the assistance of a physician, a process that became fully legal last June. That pace has been a surprise to medical practitioners, said Dr. James Silvius, the AHS’s lead for medical assistance in dying. “The numbers have continued to increase – we thought there’d be a significant number come through initially and it’d level off,” he said, adding the procedures have crept up to four or five a week. Just as surprising, he said, is the trend is going against Albertans choosing to die at home. <https://goo.gl/6B5Pvv>

## U.S.A.

### Who will care for the caregivers?

*THE NEW YORK TIMES* | Online – 19 January 2017 – According to the American association of Retired Persons and the National Alliance for Caregiving, the typical family caregiver is a 49-year-old woman caring for an older relative – but nearly a quarter of caregivers are now millennials and are equally likely to be male or female. About one-third of caregivers have a full-time job, and 25% work part time. A third provide more than 21 hours of care per week. Family caregivers are, of course, generally unpaid, but the economic value of their care is estimated at \$470 billion a year – roughly the annual American spending on Medicaid. A recent report from the National Academies of Sciences, Engineering & Medicine suggests that society’s reliance on this “work force” – largely taken for granted – is unsustainable.<sup>1</sup> While the demand for caregivers is growing because of longer life expectancies and more complex medical care, the supply is shrinking, a result of declining marriage rates, smaller family sizes and greater geographic separation. In 2015, there were seven potential family caregivers for every person over 80. By 2030, this ratio is expected to be four-to-one, and by 2050, there will be fewer than three potential caregivers for every older American. <https://goo.gl/leNlrx>

1. ‘Families Caring for an Aging America,’ National Academies of Sciences, Engineering & Medicine, September 2016. [Noted in Media Watch 19 September 2016, #480 (p.3)] <http://goo.gl/UllOd2>

### Is your digital life ready for your death?

*THE NEW YORK TIMES* | Online – 18 January 2017 – For the past two decades, most of us in the modern world have gradually shifted our central living space online. That’s 20-ish years of documenting our real-life experiences while also creating entirely new versions of ourselves in countless places online. These digital lives are basically immortal, so you may as well figure out while you’re still alive what will happen to them after you’re gone. There are two main things to consider: What will happen to your accounts and what will happen to the data contained therein. For example, you can give someone authority to delete your Google account and to download all your photos stored there after you die. Many online spaces offer some form of death planning. But this is still a relatively new concept, and some of the most popular destinations on the internet don’t give users a way to plan for their death. <https://goo.gl/iTni9B>

## **Nursing homes need improvement in end-of-life directives: Study**

MISSOURI | United Press International – 17 January 2017 – A study from the University of Missouri School of Social Work suggests nursing homes need to give more attention to how advanced directives (AD) are used.<sup>1</sup> “In a nursing home setting some providers use aggressive end-of-life care (EoLC), even if it is not in a person’s best interest or against a resident’s wishes,” says Colleen Galambos, professor in the University of Missouri School of Social Work. “Evidence suggests that AD improve the dying experience for nursing home residents and decrease the cost of EoLC while honoring residents’ expressed wishes about health care. However, at the national level only 65-70% of nursing home residents have AD; that number is significantly less here in Missouri.” The study examined more than 1,800 medical records from nursing homes in the St. Louis, Missouri, area. Roughly 50% of the records included AD, but researchers found that many were hard to find in the patients’ charts due to poor record keeping. Galambos suggests that healthcare providers include a section in medical records specifically for AD and reinforce the importance of checking for advance directives. <https://goo.gl/wJMjd1>

1. ‘Analysis of advance directive documentation to support palliative care activities in nursing homes,’ published online 13 September 2016. [Noted in Media Watch 26 September 2016, #481 (p.9)] <https://goo.gl/w6GYOz>

### **End-of-life care in Minnesota**

#### **Lawmakers should support improving palliative care access**

MINNESOTA | *The Mankato Free Press* – 15 January 2017 – Among the many issues the state Legislature is tackling this session, improving access to palliative care (PC) may not grab the big headlines other topics do. The issue, however, deserves close attention when it does arise. PC involves caring for the person as a whole rather than just the chronic disease or illness a patient is suffering from. Not only does PC address physical illness, but it includes the emotional, social and spiritual sides of dealing with sickness, using a team approach to help the patient. Hospice is the natural extension of that care when it comes to the end of life. The American Cancer Society Cancer Action Network in Minnesota is making PC a priority for good reason this legislative session. The network cites a number of barriers when it comes to this type of care, including limited provider and consumer understanding about PC; uneven access to PC in different hospital and community-based care settings; and ,a shortage in doctors, nurses and other staff trained to provide PC. As a result, the group is working on legislation to establish a state advisory committee to identify barriers preventing access to PC. The panel’s mission would be to help lawmakers identify gaps in health systems, consumer education, workforce development and promote solutions that will bring PC to more Minnesotans. <https://goo.gl/8z3Ztu>

#### **Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- COLORADO | Stat News (Boston, Massachusetts) – 19 January 2017 – ‘**Colorado’s aid-in-dying law in disarray as big Catholic health systems opt out.**’ Nearly one-third of Colorado’s hospitals are refusing to offer terminally ill patients the option of physician-assisted suicide – even though voters last fall overwhelmingly approved a ballot initiative legalizing the practice. And two of the state’s biggest health care systems, both faith-based, appear poised to bar their doctors from providing such services to patients at any of their facilities, under any circumstances – potentially running afoul of the new aid-in-dying law. <https://goo.gl/MqlgrV>
- *THE NEW YORK TIMES* | Online – 16 January 2017 – ‘**Physician aid in dying gains acceptance in the U.S.**’ In recent months, this option has become available to a growing number of Americans. Last June, aid-in-dying legislation took effect in California, the most populous state. In November, Colorado voters approved a ballot measure by nearly a two-thirds majority. The District of Columbia Council has passed a similar law, and the mayor quietly signed it last month. Aid in dying was already legal in Washington, Vermont, Montana and Oregon. So even if the District of Columbia’s law is blocked, as a

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prominent Republican representative has threatened to do, the country has arrived at a remarkable moment: Close to 20% of Americans live in jurisdictions where adults can legally end their lives if they are terminally ill and meet eligibility requirements. The laws, all based on the Death With Dignity Act Oregon adopted in 1997, allow physicians to write prescriptions for lethal drugs when patients qualify. The somewhat complicated procedure involves two oral requests and a written one, extensive discussions, and approval by two physicians. Patients must have the mental capacity to make medical decisions. <https://goo.gl/6ona2x>

## International

### End-of-life care on Scotland

#### **Patients at Clydebank hospice could be asked to pay for care**

U.K. (Scotland) | *The Evening Times* (Glasgow) – 19 January 2017 – Councillors have urged government leaders to exempt Scotland's oldest hospice from a policy which could threaten free nursing care for elderly people with long-term conditions. St. Margaret's of Scotland Hospice in Clydebank provides 28 beds for elderly patients who require continuing care – fully funded by National Health Service Greater Glasgow & Clyde (NHSGGC) – as well as a separate ward for palliative care financed by the board and charitable donations. However, from February, responsibility for funding the long-term care beds will shift from NHSGGC to the newly created Integrated Joint Board – made up of West Dunbartonshire Council and the health board – and future elderly patients will be means tested. It means that patients could be asked to make a contribution towards their care at St. Margaret's for the first time in its 66-year-history. Councillors say the hospice will effectively be treated like a care home and the policy will undermine its charitable status. St. Margaret's is thought to be the only facility in Scotland which will be impacted in this way by the legislation. <https://goo.gl/udDf3H>

### Specialist Publications

**'The experience of hospital death: Assessing the quality of care at an academic medical center'** (p.7), in *American Journal of Hospice & Palliative Medicine*.

**'How well do we currently care for our dying patients in acute hospitals: The views of the bereaved relatives?'** (p.7), in *BMJ Supportive & Palliative Care*.

## Specialist Publications

### End-of-life care in Canada

#### **Evolving ethical and legal implications for feeding at the end of life**

*ANNALS OF PALLIATIVE MEDICINE* | Online – Accessed 19 January 2017 – This paper examines the unique issues raised at the interface between law and ethics as it relates specifically to the controversial issue of alimentation (providing food and nourishment) at the end of life. This analysis will be based, in part, on a historical case involving Margot Bentley (MB), an 82-year-old Canadian residing in a long term care facility in British Columbia. MB is living with and dying from the end stages of Alzheimer's disease and in 2013 Margot, her family and the care facility she resides in were at the centre of a legal battle over the circumstances necessary to constitute an imposed duty on caregivers to provide the basic necessity of life (food). This case exposed a number of concerns: the questionable utility and limits of living wills, surrogacy decision making, the actual meaning of implied consent, and what exactly constitutes medical treatment versus basic care. What is unique about this case is that it does show gaps in both ethical and judicial analysis which has resulted in a legal decision to provide a level of care the family believes would be untenable and lacking in dignity for MB. <https://goo.gl/gEqYtf>

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Noted in Media Watch 22 June 2015, #415 (p.3):

- CANADA (British Columbia) | CBC News (Vancouver) – 14 June 2015 – ‘**How Margot Bentley is complicating the right-to-die debate.**’ Margot Bentley, 83, a retired nurse who looked after patients with dementia, wrote what she called her “statement of wishes” in 1991. That statement appeared clear to her and her family, but a judge did not see it that way. Bentley’s case demonstrates just how complicated advance-care directives are. <https://goo.gl/RtnM88>

Noted in Media Watch 9 March 2015, #400 (p.2):

- CANADA (British Columbia) | *The Province* (Vancouver) – 3 March 2015 – ‘**Family of Alzheimer’s patient loses right-to-die case despite living will.**’ The province’s Court of Appeal dismissed a bid from the family of an Alzheimer’s patient who argued she is being kept alive in a care home against her will. Justice Mary Newbury said in a ruling 83-year-old Margaret Bentley is exercising her consent when she opens her mouth to accept food and water. <https://goo.gl/fEhOOr>

### The Claeys-Leonetti law

#### **Opinions about the new law on end-of-life issues in a sample of French patients receiving palliative care**

*BMC PALLIATIVE CARE* | Online – 21 January 2017 – In February 2016, the French government enacted the Claeys-Leonetti law that forbade euthanasia and established the right to deep and continuous sedation for end-of-life patients. Moreover, the law also obliges clinicians to abide by any advance directives (ADs) regarding treatment and investigation, except in cases where they are “obviously inappropriate” in a given medical situation, or in cases of emergency, in order to allow medical staff to take time to assess the patient’s situation. Artificial feeding and hydration are considered as treatment. The aim of this report is to investigate individuals receiving palliative care about their opinion about euthanasia, about ADs, about the right to deep and continuous sedation, and the right to stopping artificial feeding and hydration. Forty patients were interviewed. The mean age was 59.8 years (standard deviation 12). Fifty three percent reported opposition to legalized euthanasia. Eighty three percent were in favour of the right to deep and continuous sedation in patients with refractory pain, 75% when it concerns a patient unable to express their wishes, and 68% when the patient decides to stop vital treatment. Fifty eight percent reported that artificial nutrition and hydration should be considered as care. Fifty eight percent of the patients interviewed would like to see doctors follow the express wishes contained in ADs and 53% that advance directives should be subject to a validity period. <https://goo.gl/u8J853>

Noted in Media Watch 31 October 2016, #485 (p.6):

- *CASE REPORTS IN ONCOLOGY*, 2016;9(3):650-654. ‘**End-of-life practices in France under the Claeys-Leonetti Law: Report of three cases in the oncology unit.**’ On 2 February 2016, the French government enacted the Claeys-Leonetti law introducing the right to deep and continuous sedation and forbade euthanasia for end-of-life patients. This article reports the first descriptions of this kind of intervention at the final stage of life of three patients and highlights the need of patient-centered goals and the importance of close collaboration between the patient, family, and medical and paramedical team to achieve a higher quality of final palliative care. <https://goo.gl/PWRDzs>

Noted in Media Watch 11 January 2016, #444 (p.14):

- *SOINS: LA REVUE DE RÉFÉRENCE INFIRMIÈRE*, 2015;60(801):49-51. ‘**The decision to withhold and withdraw active treatments: An ethical approach.**’ Intensive care medicine is confronted with situations of suffering and dependence experienced as the appropriation of the body or medical futility. In this context, withholding and withdrawing active intensive care must be given a framework. The ethical challenge is to decide to continue or not with care considered vain or futile. The ‘Leonetti Law,’ in particular, helps to clarify the situation for professionals and families. <http://goo.gl/mWYjJi>

**N.B.** French language article.

## End-of-life care in England

### **How well do we currently care for our dying patients in acute hospitals: The views of the bereaved relatives?**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 17 January 2017 – The National Care of the Dying Audit (Hospitals) was used as a method to evaluate care for dying patients in England. An additional component to the 2013/2014 audit was the Local Survey of Bereaved Relatives Views using the ‘Care Of the Dying Evaluation’ (CODE) questionnaire. From 3,414 eligible next-of-kin, 95 (2.8%) were excluded due to being involved in a complaint procedure and 1,006 (29.5%) due to insufficient next-of-kin details. From the remaining 2,313 potential [survey] participants, 858 returned a completed CODE questionnaire (37.1% response rate). Generally, symptoms were perceived to be well controlled with 769 (91%) participants reporting that either no pain was present or only there “some of the time.” Unmet information needs, however, was a recognised area for improvement, for example, 230 (29%) reporting having a discussion about hydration would have been beneficial. <https://goo.gl/SFeUSG>

#### **Related**

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 20 January 2017 – ‘**The experience of hospital death: Assessing the quality of care at an academic medical center.**’ Despite high satisfaction overall, the authors identified important unmet needs. Addressing these gaps will improve the care of dying patients. Opportunities for improvement included management of decedents’ anxiety or sadness, and personal care, emotional support of the family, communication regarding decedents’ illness, and receiving contradictory or confusing information. <https://goo.gl/902372>

### **Dying at home of cancer: Whose needs are being met? The experience of family carers and healthcare professionals (a multi-perspective qualitative study)**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 16 January 2017 – [In this study] the authors found that the home environment enabled normality, a sense of control and individualised care which family carers often perceived as contributing towards a good death. However, the home environment created challenges for both family carers and health care professionals due to the differing and at times conflicting needs of the dying person and their family carers. The authors shed light on the complexity of balancing the demands and the satisfaction of caring for someone dying at home. The ability to manage these conflicting needs influenced whether carers perceived the home setting as the best place for the person to have received care in their last days of life. <https://goo.gl/WOHCpy>

### **Challenges and recommendations in increasing homeless persons’ access to palliative care: An international systematic review**

*BULLETIN OF EUROPEAN HEALTH PSYCHOLOGY SOCIETY*, 2016;Suppl. The U.K. Department of Health strives to provide palliative care (PC) at the time of need for everyone, regardless of “wherever the person may be,” “irrespective of social economic deprivation.” This goal has not been reached for homeless people who face numerous multifaceted challenges, including accessing health care. Given the complexities of this population, qualitative research exploring perspectives of homeless people and care providers is key to understanding the difficulties in provision of PC to this vulnerable group. This review of qualitative literature identifies challenges to and recommendations for the provision of PC for homeless people. Twelve articles were eligible for review. Challenges and recommendations for the provision of PC for homeless people encompassed three core themes: 1) The unique circumstances of homeless people; 2) The structure of health care systems; and, 3) Limitations of temporary accommodation systems. The importance of the development of trusting relationships and flexible, joined-up services were highlighted. <https://goo.gl/9ecWXy>

**N.B.** Additional articles on end-of-life care for the homeless are noted in past issues of Media Watch, e.g., 17 December 2017, #495 (p.1); 5 December 2016, #490 (p.6); 8 August 2016, #474 (p.12); and, 14 March 2016, #453 (pp.14-15).

## Wisdom at the end of life: Hospice patients' reflections on the meaning of life and death

*COUNSELLING PSYCHOLOGY QUARTERLY* | Online – 9 January 2017 – This qualitative study explored 15 terminally ill hospice patients' perspectives on wisdom, the dying process, and the meaning of life using consensual qualitative research methods. Most participants cited humility as a key component of wisdom, emphasizing that "Wisdom is when we realize 'I don't really know much.'" Other components included self-knowledge, rationality, experiential learning, listening to and learning from others, and sharing knowledge with others. Participants also suggested that the process of facing illness and death presents opportunities for positive growth, including changing priorities and learning to appreciate life more fully in the present moment. In considering the sources of meaning in their lives, participants emphasized relational connections, personal growth, spirituality, vocational fulfilment, and living a full life. Participants also shared their reflections on important past experiences and regrets. Lastly, participants offered advice to others based on their experiences facing illness and mortality. <https://goo.gl/YHxv6N>

Noted in Media Watch 12 October 2015, #431 (p.12):

- *JOURNALS OF GERONTOLOGY* | Online – 5 October 2015 – '**Wisdom at the end of life: An analysis of mediating and moderating relations between wisdom and subjective well-being.**' Wisdom was positively related to subjective well-being in the later years [in this study], even after controlling for physical health, socioeconomic status, financial situation, social involvement, age, gender, race, and marital status. The association between wisdom and well-being was significantly stronger in the nursing home and hospice sample than the community sample. <https://goo.gl/Olr2yR>

## End-of-life decisions in heart failure: To turn off the intracardiac device or not?

*CURRENT OPINION IN CARDIOLOGY* | Online – 11 January 2017 – Studies suggest that up to one-third of patients with an implantable cardioverter defibrillator receive painful shocks in the last 24 hours of life. Disabling pacing or resynchronization devices may further weaken the heart function and expedite death, particularly if the patient has no underlying ventricular rhythm. Is it ethical or legal to discontinue functions of the implantable device? The discussion and the decision to be made are whether to continue both pacing and tachyarrhythmia therapies, disable tachyarrhythmia therapies while maintaining pacing, or discontinue both. The decision to disable all or parts of the device function is ultimately up to the patient. To avoid painful shocks near the end of life, it is recommended that tachyarrhythmia therapies be turned off when the patient is being treated palliatively. After informed discussion, withdrawing the resynchronization or pacing device option is also acceptable if requested by the patient regardless of the potential outcomes. <https://goo.gl/W9GQyg>

Noted in Media Watch 12 December 2016, #491 (p.9):

- *EUROPACE* | Online – 2 December 2016 – '**The ethics of unilateral implantable cardioverter defibrillators and cardiac resynchronization therapy with defibrillator deactivation: Patient perspectives.**' Decisions about deactivation of implantable cardioverter defibrillators are complicated. Unilateral do-not-resuscitate (DNR) orders (against patient/family wishes) have been ethically justified in cases of medical futility ... [and] ... may be seen as a logical extension of a unilateral DNR order. However, the ethical implications ... have not been explored. <https://goo.gl/5d4cVs>

**N.B.** Additional articles on implantable cardioverter-defibrillators in the context of end-of-life care are noted in past issues of Media Watch, e.g., 12 December 2016, #491 (p.9); and, 1 February 2016, #447 (p.11).

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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.15.



## Related

- *HEART FAILURE REVIEWS* | Online – 20 January 2017 – ‘**Hospice in heart failure: why, when, and what then?**’ Hospice is a model of care for patients nearing the end of their lives that emphasizes symptom management, quality of life, and support of the patient and caregiving family through the death of the patient and the family’s bereavement. It is associated with high patient and caregiver satisfaction and appears to not shorten lifespan for appropriately referred patients. Patients with advanced heart failure are being referred to hospice care more often than in the past, but the majority of deaths occur without this benefit. <https://goo.gl/Bvm8K5>

## Literature review

### Neonatal palliative care

*CURRENT OPINION IN PEDIATRICS* | Online – 13 January 2017 – A significant number of newborns are affected by life-limiting or life-threatening conditions. When prolongation of survival is no longer a goal, or prognosis is uncertain, a plan of care focused on the infant’s comfort is essential. The aim of this article is to review the most recent and relevant literature regarding neonatal palliative care (NPC). A variety of perinatal and NPC programs are described, but most programs focus exclusively on end-of-life care. Moreover, there is a great need to standardize practices and obtain follow-up quality measures. Guidelines to address infants’ basic needs, to achieve a state of comfort, are proposed. A multidisciplinary team addressing the infants’ medical and non-medical needs, parental grieving process, and providers’ distress is recommended. Further studies are warranted to assess whether NPC effectively promotes newborns’ comfort and parents and providers’ satisfaction. <https://goo.gl/iJmS19>

Noted in Media Watch 19 December 2016, #492 (p.9):

- *JBI DATABASE OF SYSTEMATIC REVIEWS & IMPLEMENTATION REPORTS*, 2016;14(11):99-105. ‘**Parents’ and families’ experiences of palliative and end-of-life neonatal care in neonatal settings: A systematic review protocol.**’ The overall objective of this systematic review is to identify, critically appraise, and synthesize the parents’ and families’ experiences of palliative and end-of-life neonatal care at facilities/services globally. <https://goo.gl/jzHQLW>

## Elderly care in the U.S.

### A focus on the Program of All-Inclusive Care for the Elderly (PACE)

*JOURNAL OF AGING & SOCIAL POLICY* | Online – 13 January 2017 – For over four decades, the Program of All-Inclusive Care for the Elderly (PACE) has been operated by non-profit organizations. Research has demonstrated that non-profit PACE provides quality, cost-effective community-based care to older adults who would otherwise require a nursing home-level of care. Recently, the U.S. Secretary of the Department of Health & Human Services has authorized for-profit entities to operate PACE, contingent on their ability to demonstrate that they can provide care that is similar to non-profit PACE with regard to access to care, quality of care and cost-effectiveness. In 2013, a study was conducted to evaluate how PACE operates under for-profit versus non-profit status. The results were presented to Congress which, in turn, authorized for-profit PACE providers. This paper critiques the 2013 study, offers a comparison to for-profit hospice, and argues that at best, there is not enough evidence to conclude that for-profit PACE provides the same quality of care as existing non-profit operators. <https://goo.gl/8XPSND>



## Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials.  
<http://goo.gl/OTpc8l>

## End of life in prison: Talking across disciplines and across countries

*JOURNAL OF CORRECTIONAL HEALTH CARE*, 2017;23(1):11-19. What a good end of life (EoL) means is a particularly relevant question in the context of confinement and prison. Most of the questions and issues raised by EoL for those living in liberty also apply to the correctional setting. However, the institutional particularities and logics of the prison create unique barriers and make it difficult in practice to reconcile concerns in regard to EoL – like care and comfort – with the mandate of corrections – confinement and punishment. The literature on EoL in prison is dominated by U.S. contributions. The authors ... invited researchers from various disciplines in various countries to analyze the topic from their disciplinary perspectives and within the respective institutional frames of their national contexts. <https://goo.gl/wf5lbu>



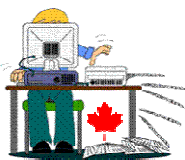
### Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of articles, reports, etc., noted in past issues of the weekly report can be downloaded at: <http://goo.gl/ZpEJyQ>

**N.B.** This issue of the *Journal of Correctional Health Care* includes several articles on end-of-life in the prison system. Journal contents page: <https://goo.gl/5jBKZk>

## Death notification: Someone needs to call the family

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 18 January 2017 – The death notification process can affect family grief and bereavement. It can also affect the well-being of involved physicians. There is no standardized process for making death notification phone calls. The authors assumed that residents are likely to be unprepared before and troubled after. Sixty-seven of 93 internal medicine residents ... responded to the survey. Eighty-seven percent of responders reported involvement in a death that required notification by phone. Eighty percent of residents felt inadequately trained for this task. Over 25% reported that calls went poorly. Attendings were involved in 17% of cases. Primary care physicians were not involved. Nurses and chaplains were not involved. Respondents never delayed notification of death until family arrived at the hospital. There was no consistent approach to rehearsing or making the call, advising families about safe travel to the hospital, greeting families upon arrival, or following up with expressions of condolence. <https://goo.gl/eDYkDg>



### [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://goo.gl/5CHoAG>

## **Palliative care involvement is associated with less intensive end-of-life care in adolescent and young adult oncology patients**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 18 January 2017 – Adolescent and young adult oncology patients who died in the hospital [i.e., study participants] required considerable medical and psychosocial care and experienced numerous symptoms during the last month of life (LMoL). Compared to those patients who received no formal palliative care (PC) services, patients followed by the PC team were less likely to die in the intensive care unit (ICU) ... and less likely to have been on a ventilator ... during the LMoL. They also received fewer invasive medical procedures during the LMoL ... and had a do not resuscitate order in place for a longer time before death... Involvement of the PC team was associated with the receipt of less intensive treatments and fewer deaths in the ICU. <https://goo.gl/vtld4y>

## **Self-care in palliative care nursing and medical professionals: A cross-sectional survey**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 January 2017 – Self-care is an important consideration for palliative care (PC) professionals. To date, few details have been recorded about the nature or uptake of self-care practices in the PC workforce. As part of a broader mixed methods study, this article reports findings from a national survey of nurses and doctors. Three hundred seventy-two PC nursing and medical professionals practicing in Australia [took part in this survey]. Most respondents regarded self-care as very important (86%). Some rarely practised self-care and less than half (39%) had received training in self-care. Physical self-care strategies were most commonly reported, followed closely by social self-care and inner self-care. Self-care plans had been used by a small proportion of respondents (6%) and over two-thirds (70%) would consider using self-care plans if training could be provided. These findings carry implications for professional practice and future research. <https://goo.gl/i78qjY>

Noted in Media Watch 16 May 2016, #462 (p.13):

- *MEDITERRANEAN JOURNAL OF CLINICAL PSYCHOLOGY*, 2016;4(1):1-12. **‘The burnout syndrome in palliative home care workers: The role of coping strategies and meta-cognitive beliefs.’** Recent studies have shown healthcare worker coping strategies may function either as a risk or a protective factor for the development of distress and emotional problems. The results show the presence of a statistically significant correlation between the variables investigated. <http://goo.gl/SKF4Pd>

Noted in Media Watch 24 August 2015, #424 (p.14):

- *PALLIATIVE MEDICINE* | Online – 17 August 2015 – **‘The transformation process for palliative care professionals: The metamorphosis, a qualitative research study.’** During their professional activity, palliative care professionals go through a series of phases, depending on the relationship between the cost of caring and the satisfaction of caring, which can influence both the care provided to patients and families and their own personal circumstances. Implementing self-care strategies, can protect professionals and enable them to conduct their work. <https://goo.gl/lwLK8u>

## **Physician power to declare death by neurologic criteria threatened**

*NEUROCRITICAL CARE* | Online – 11 January 2017 – Three recent lawsuits [in the U.S.] that address declaration of brain death (BD) garnered significant media attention and threaten to limit physician power to declare BD. The authors discuss these cases and their consequences including: 1) The right to refuse an apnea test; 2) Accepted medical standards for declaration of BD; and, 3) The irreversibility of BD. These cases warrant discussion because they threaten to: limit physicians' power to determine death; incite families to seek injunctions to continue organ support after BD; and force hospitals to disperse valuable resources to dead patients in lieu of patients with reparable illnesses or injuries. Physicians, philosophers, religious officials, ethicists, and lawyers must work together to address these issues and educate both the public and medical community about BD. <https://goo.gl/G1OutD>

## **Rural end-of-life care from the experiences and perspectives of patients and family caregivers: A systematic literature review**

*PALLIATIVE MEDICINE* | Online – 20 January 2017 – End-of-life care (EoLC) must be relevant to the dying person and their family caregiver regardless of where they live. Rural areas are distinct and need special consideration. Gaining EoLC) experiences and perspectives of rural patients and their family caregivers is needed to ensure optimal rural care. A total of 27 articles (22 rural/remote studies) from developed and developing countries were included, reporting rural EoLC experiences and perspectives of patients and family caregivers. Greatest needs were informational (developed countries) and medications (developing countries). Influence of rural location included distances, inaccessibility to EoLC services, strong community support and importance of home and “country.” Articulation of the rural voice is increasing; however, there still remain limited published rural studies reporting on patient and family caregivers’ experiences and perspectives on rural. Further research is encouraged, especially through national and international collaborative work. <https://goo.gl/jiAPA0>



End-of-life Care in Rural Communities:  
<http://goo.gl/WPJvBI>

Survey: Urban vs. Rural Palliative Medicine:  
<http://goo.gl/GEJL4u>

Noted in Media Watch 26 September 2016, #481 (p.8):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 19 September 2016 – ‘**Rural residents’ perspectives on the rural “good death”: A scoping review.**’ Twenty articles (for 17 studies and one systematic review) were identified. These papers revealed data collected from rural patients with a life-limiting illness and family caregivers, rural healthcare providers, the wider rural community, rural community leaders and rural health administrators and policy makers. Rural locations were heterogeneous. Residents from developed and developing countries believe a “good death” is one that is peaceful, free of pain and without suffering; however, this is subjective and priorities are based on personal, cultural, social and religious perspectives. <https://goo.gl/37rXhq>

**N.B.** Additional articles on end-of-life care in rural communities and remote regions noted in Media Watch 22 August 2016, #476 (p.11), 16 May 2016, #462 (p.18), and 18 April 2016, #459 (p.4).

### **End-of-life care in Ireland**

#### **Costs of formal and informal care in the last year of life for patients in receipt of specialist palliative care**

*PALLIATIVE MEDICINE* | Online – 17 January 2017 – Economic evaluation of palliative care (PC) has been slow to develop and the evidence base remains small. This article estimates formal and informal care costs in the last year of life for a sample of patients who received specialist PC in three different areas in Ireland. Formal care costs are calculated for community, specialist PC, acute hospital and other services. Where possible, a bottom-up approach is used, multiplying service utilisation by unit cost. Informal care is valued at the replacement cost of care. Mean total formal and informal costs in the last year of life do not vary significantly across the three areas. The components of formal costs, however, do vary across areas, particularly for hospital and specialist PC in the last 3 months of life. Costs in the last year of life for patients in receipt of specialist PC are considerable. Where inpatient hospice care is available, there are potential savings in hospital costs to offset specialist PC inpatient costs. Informal care accounts for a high proportion of costs during the last year of life in each area, underlining the important role of informal caregivers in PC. <https://goo.gl/xUFRho>

## A systematic review of religious beliefs about major end-of-life issues in the five major world religions

*PALLIATIVE & SUPPORTIVE CARE* | Online – 19 January 2017 – The authors' search strategy generated 968 references, 40 of which were included for this review... Whenever possible, they organized the results into five categories that would be clinically meaningful for palliative care practices at the end-of-life (EoL): 1) Advanced directives; 2) Euthanasia and physician-assisted suicide; 3) Physical requirements (artificial nutrition, hydration, and pain management); 4) Autopsy practices; and, 5) Other EoL religious considerations. A wide degree of heterogeneity was observed within religions, depending on the country of origin, level of education, and degree of intrinsic religiosity. This review describes the religious practices pertaining to major EoL issues and explains the variations in EoL decision making by clinicians and patients based on their religious teachings and beliefs. <https://goo.gl/OLh72z>

Noted in Media Watch 23 March 2015, #402 (p.10):

- *PHILOSOPHY, ETHICS & HUMANITIES IN MEDICINE* | Online – 11 March 2015 – ‘**An explanation and analysis of how world religions formulate their ethical decisions on withdrawing treatment and determining death.**’ This paper explores definitions of death from the perspectives of several world and indigenous religions [i.e. Buddhism, Christianity, Hinduism, Islam, Judaism] with practical application for health care providers in relation to end-of-life (EoL) decisions and organ and tissue donation after death. It provides background material on several traditions and explains how different religions derive their conclusions for EoL decisions from the ethical guidelines they proffer. <https://goo.gl/PNuAd7>

### From the archives

## THE LANCET

Culture and religious belief make end-of-life (EoL) experiences effect the dying, their carers, and health care professionals in different ways. A series of Viewpoints, first published in *The Lancet* in 2005, explores many contrasting EoL perspectives, e.g., Hindu, Islamic, Jewish, Buddhist, Christian, Catholic and Humanist: <https://goo.gl/6W2UkZ>

### Related

- *JOURNAL OF RELIGION & HEALTH* | Online – 19 January 2017 – ‘**The care of the Ultra-Orthodox Jewish patient.**’ The authors describe some of the unique challenges that stem from the encounter between modern medical practice and the Ultra-Orthodox world. Through examples of clinical and ethical scenarios ranging from prenatal care to end-of-life decisions, they illustrate problems related to observance of age-old practices in a modern hospital setting... <https://goo.gl/cgsJPY>

## Palliative care and Parkinson's disease: Meeting summary and recommendations for clinical research

*PARKINSONISM & RELATED DISORDERS* | Online – 13 January 2017 – An International Working Group Meeting on Parkinson's Disease & Palliative Care supported by the Parkinson's Disease Foundation was held in October 2015 to review the current state of the evidence and to make recommendations for clinical research and practice. Topics included: 1) Defining palliative care (PC) for Parkinson's disease (PD); 2) Lessons from PC for heart failure and other chronic illnesses; 3) Patient and caregiver needs; 4) Needs assessment tools; 5) Intervention strategies; 6) Predicting prognosis and hospice referrals; 7) Choice of appropriate outcome measures; 8) Implementation, dissemination and education research; and, 9) Need for research collaborations. The authors provide an overview of these discussions, summarize current evidence and practices, highlight gaps in knowledge and make recommendations for future research. <https://goo.gl/j9gZf1>

**N.B.** Additional articles on palliative care for people living with Parkinson's disease are noted in past issues of Media Watch, e.g., 28 November 2016, #489 (p.6); and, 11 April 2016, #457 (p.12).

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CRITICAL CARE MEDICINE*, 2017;45(2):149-155. ‘**Physician-assisted suicide and euthanasia in the ICU: A dialogue on core ethical issues.**’ Many patients are admitted to the ICU at or near the end of their lives. Consequently, the increasingly common debate regarding physician-assisted suicide and euthanasia holds implications for the practice of critical care medicine. The authors identified four issues highlighting the key areas of ethical tension central to evaluating physician-assisted suicide and euthanasia in medical practice: 1) The benefit or harm of death itself; 2) The relationship between physician-assisted suicide and euthanasia and withholding or withdrawing life support; 3) The morality of a physician deliberately causing death; and, 4) The management of conscientious objection related to physician-assisted suicide and euthanasia in the critical care setting. They reached differing positions on the first three core ethical questions and achieved unanimity on how critical care clinicians should manage conscientious objections related to physician-assisted suicide and euthanasia. The alternative positions presented in this article may serve to promote open and informed dialogue within the critical care community. <https://goo.gl/KuoKCy>

## Worth Repeating

### “Curative” treatments and palliative care: The lack of consensus

*CURRENT OPINION IN ONCOLOGY* | Online – 19 May 2014 – A survey was performed to assess whether authors who report about palliative treatments or palliative care share a common understanding of “curative” treatments. In the care for cancer patients, unambiguous terminology is essential for the participatory and interdisciplinary decision-making process. Clinicians, researchers and policy makers should be aware of the difference between curative and disease-modifying therapies. Otherwise, this may be a major source of misunderstandings as disease-modifying therapy may be indicated in the incurable stages of the disease as well. In these palliative situations, it is essential to identify the realistic aim(s) of the therapy: prolongation of life, alleviation of suffering or both. Of 107 authors from publications about cancer who used both “palliative” and “curative” in the same abstract, 42 (39%) responded. The majority [of survey respondents] understood “curative” treatments as “aimed at complete absence of disease for the rest of life,” but 43% did not share this view. For example, 19% stated that the term describes cancer-directed therapy for prolongation of life or even regardless of the aspired goal. [Noted in Media Watch 26 May 2014, #359 (p.8)] <https://goo.gl/kmxo4S>

### 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, research and teaching tool.

### Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Cont.

### [Links to Sources](#)

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### [Something Missed or Overlooked?](#)

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

### [Media Watch: Online](#)

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/7jyMed>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://goo.gl/frPgZ5>

PALLIATIVE CARE NETWORK COMMUNITY: <http://goo.gl/8JyLmE>

PALLIMED: <http://goo.gl/7mrgMQ> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

#### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <https://goo.gl/JL3j3C>

#### **Canada**

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <https://goo.gl/IOSNC7>

#### **Europe**

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1l9K>

U.K. | Omega, the National Association for End-of-Life Care: <http://goo.gl/UfSZtu>

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