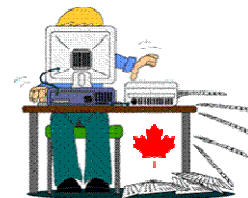


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

The illness experience from the perspective of the health professional: Scroll down to [Specialist Publications](#) and 'Direct care workers' experiences of grief and needs for support' in (p.12), in *Journal of Applied Research in Intellectual Disabilities*.

Canada

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *The Windsor Star* – 28 February 2017 – '**Local Health Integration Network looks to improve how physician-assisted death handled locally.**' The Erie St. Clair Local Health Integration Network (LHIN) wants to improve how physician-assisted dying is handled in the region, following a recently revealed dispute that happened last fall when [Catholic-based] Hotel-Dieu Grace Healthcare refused a patient's request and Windsor Regional Hospital refused to accept the patient transfer. "Our attempt is to do what we can to improve the situation," LHIN board chairman Martin Girash... He said his motion requests a medically assistance in death (MAiD) committee – recently created by the Erie St. Clair Community Care Access Centre – iron out a protocol with local organizations that deal with requests from patients. Girash wants all these hospitals, hospices and long-term care homes to agree to this new protocol in written agreements. The board approved his motion, with some members suggesting that organizations that are publicly funded shouldn't refuse patient requests for a procedure that was made legal last year under certain conditions. But Girash said Ministry of Health guidelines allow organizations to exempt themselves if they have religious or moral objections, though they can't just abandon the patient. They're required to take action to ensure the patient is connected with a professional who agrees to honour the request. <https://goo.gl/3lmwLU>

[Specialist Publications](#)

'Conscientious objection and medical assistance in dying (MAiD) in Canada: Difficult questions – insufficient answers' (p.15), in *Canadian Journal of General Internal Medicine*.

'Survey evaluations of University of British Columbia residents' education and attitudes regarding palliative care and physician assisted death' (p.16), in *Canadian Medical Education Journal*.

U.S.A.

Patients demand the “right to try” experimental drugs, but costs can be steep

NATIONAL PUBLIC RADIO | Online – 3 March 2017 – In the last three years, 33 U.S. states have passed laws aimed at helping dying people get easier access to experimental treatments that are still in the early stages of human testing. Supporters say these patients are just looking for the right to try these treatments. Such laws sound compassionate, but medical ethicists warn they pose worrisome risks to the health and finances of vulnerable patients. California’s “right to try” law went into effect in January. It protects California doctors and hospitals who want to prescribe any medicine that has successfully made it through a Phase 1 drug trial. That’s the first stage of human testing required by the Food & Drug Administration (FDA) – usually, all the study participants are healthy in the small Phase 1 trial, and it focuses merely on a drug’s general safety and questions about dosage, not its effectiveness. Phase 2 and Phase 3 drug trials watch for toxic side effects of the experimental medicine among a group of people who have the disease or condition. About 20% of all drugs tested in Phase 2 are found to have too many serious side effects to move on to

Phase 3, the FDA says. And only between 25 and 30% of drugs that pass the larger Phase 3 tests for effectiveness and side-effects move on. Only after passing that several-year – and several-stage – gauntlet is a drug finally approved for market. <https://goo.gl/Stsw7W>

Specialist Publications

‘To understand and be understood: The ethics of language, literacy, and hierarchy in medicine’ (p.7), in *American Medical Association Journal of Ethics*.

‘Impact of a new palliative care program on health system finances: An analysis of the palliative care program inpatient unit and consultations at Johns Hopkins Medical Institutions’ (p.12), in *Journal of Oncology Practice*.

‘Communication challenges and strategies of U.S. health professionals caring for seriously ill South Asian patients and their families’ (p.12), in *Journal of Palliative Medicine*.

Selected articles on “right-to-try” laws

- *BMC MEDICAL ETHICS* | Online – 18 October 2016 – **‘An analysis of common ethical justifications for compassionate use programs for experimental drugs.’** In this paper the arguments given in favour of compassionate use or expanded access programs have been put into three broad categories. [Noted in Media Watch 24 October 2016, #484 (p.6)] <https://goo.gl/jHLAey>
- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 11 February 2016 – **‘The ethical challenges of compassionate use.’** Granting access to drugs, vaccines, biologics, and devices not yet approved by governmental regulatory authorities is a growing challenge for physicians, public officials, patient advocacy groups, institutional review boards, and patients. [Noted in Media Watch 22 February 2016, #450 (p.12)] <http://goo.gl/Llu1iO>
- *ANNALS OF INTERNAL MEDICINE* | Online – 29 September 2015 – **‘Right-to-try laws: Hope, hype, and unintended consequences.’** Most “right-to-try” laws do not set qualifications for either the health care provider making attestation of terminal illness or the physician recommending experimental treatment. [Noted in Media Watch 5 October 2015, #430 (p.7)] <http://goo.gl/JWjfyu>



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.17.

How to find meaning in the face of death

THE ATLANTIC | Online – 2 March 2017 – The psychiatrist William Breitbart lives at the edge of life and death. As chairman of the Department of Psychiatry & Behavioral Sciences at Memorial Sloan Kettering Cancer Center in New York, Breitbart specializes in end-of-life care for terminally ill cancer patients. For many of his patients, the most pressing question isn't when they'll die or how painful death will be. Rather, it's what makes life meaningful. They are in search of a meaning that cannot be destroyed by death. Is there one? Breitbart has spent the better part of his career trying to answer that question. His groundbreaking research shows that while the specter of death often leads people to conclude that their lives are meaningless, it can also be a catalyst for them to work out, as they never have before, the meaning of their lives. When people believe their lives are meaningful, according to psychologists,¹ it's because three conditions have been satisfied: they feel their existence is valued by others; they are driven by a sense of purpose, or important life goals; and, they understand their lives as coherent and integrated. Psychologists and philosophers say that the path to meaning lies in connecting and contributing to something that is bigger than the self, like family, country, or God. Meaning and death, Breitbart believes, are the two sides of the same coin – the fundamental problems of the human condition. How should a human being live a finite life? How can we face death with dignity and not despair? What redeems the fact that we will die? <https://goo.gl/tO1nRT>

1. 'Meaning in life as comprehension, purpose, and mattering: Toward integration and new research questions,' *Review of General Psychology* (American Psychological Association), 2016;20(3):205-220. <https://goo.gl/C8QKku>

Noted in Media Watch 20 February 2017, #500 (p.16):

- *PALLIATIVE MEDICINE* | Online – 13 February 2017 – '**Understanding meaning in life interventions in patients with advanced disease: A systematic review and realist synthesis.**' This review offers an exhaustive analysis of all the published meaning in life (MiL) interventions that have been implemented to date in patients with advanced disease. Despite increasing interest over the last decade, the number of interventions designed specifically to enhance MiL among end-of-life (EoL) patients remains small. <https://goo.gl/V95A1J>

For some hospice patients, a 911 call saves a trip to the ER

TEXAS | *Kaiser Health News* – 28 February 2017 – On average, 18% of hospice patients go to the emergency room at least once before their death, according to an analysis of Medicare data...¹ Melissa Aldridge, an associate professor at New York City's Icahn School of Medicine at Mount Sinai, describes paramedic-hospice partnerships such as in Fort Worth as "forward-thinking" in promoting better patient care. These emerging programs rely upon a new type of emergency responder. Dubbed community paramedics, they can offer a range of in-home care and support for home health patients, frequent 911 callers and others to reduce unnecessary ambulance trips. <https://goo.gl/uUdszk>

1. 'The impact of reported hospice preferred practices on hospital utilization at the end of life,' *Medical Care*, 2016;54(7): 657-663. <http://goo.gl/prUukM>

International

Madrid region approves new dignified death measures

SPAIN | *El País* (Madrid) – 3 March 2017 – The Madrid regional assembly ... unanimously approved the final draft of a law regulating palliative care (PC) in the last stages of life. The new legislation stipulates that terminally ill and agonizing individuals may receive comprehensive PC in a hospital (either public or private), or in their own home, if they so wish. The law also sets out the duties of health professionals and

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provides for their legal security. Madrid thus becomes the ninth Spanish region to pass this kind of legislation, following the example of Andalusia in 2010. The others are Galicia, Asturias, Catalonia, Basque Country, Navarre, the Balearic Islands and the Canary Islands. However, none of these laws contemplates either euthanasia or physician-assisted suicide. <https://goo.gl/3xtlrm>

Noted in Media Watch 5 December 2016, #490 (p.4):

- SPAIN | Agencia Efe (Madrid) – 28 November 2016 – ‘Spain’s low palliative care ranking in European Union due to lack of speciality.’ The lack of recognition of palliative care (PC) as a medical specialty explains in part why Spain has fallen during the last decade in its ranking in Europe, according to Dr. Carlos Centeno, a member of the European Association of Palliative Care (EAPC) and a co-author of the EAPC’s 2013 ‘Atlas on Palliative Care in Europe.’¹ <https://goo.gl/cQRpD3>

1. Full edition: <https://goo.gl/XEltbc>

Don’t be afraid to talk to dying patients about God, National Health Service tells doctors and care workers

U.K. (England) | *The Daily Mail* – 2 March 2017 – Health and care workers looking after dying people in their final days must do more to ask about spiritual beliefs, experts have said. Spiritual wishes were only documented for one in seven people who died in hospitals in England who were able to communicate in their final days, a 2016 report found.¹ Now the National Institute for Health & Care Excellence (NICE) has urged health and care workers to do more to ensure they take into account cultural, religious or social preferences of adults in their final days. A new quality standard from the health watchdog sets out standards of care for those aged 18 or over in their last two to three days of life.² NICE said that of the half a million deaths each year in England, three-quarters of these deaths were anticipated by medical staff <https://goo.gl/jsvTFS>

1. ‘End of Life Care Audit – Dying in Hospital National report for England 2016,’ Royal College of Physicians, May 2016. [Noted in Media Watch 9 May 2016, #461 (p.6)] <https://goo.gl/x2qSih>
2. ‘Care of dying adults in the last days of life,’ National Institute for Health & Care Excellence, March 2017. <https://goo.gl/x28lv>

National Health Service “standing on burning platform” of outdated acute care model

U.K. (England) | *The Guardian* – 2 March 2017 – The health service “stands on a burning platform” of an outdated model of acute care that is no longer able to deliver the services needed for modern patients, according to England’s top hospital inspector. Sir Mike Richards, the Care Quality Commission’s chief inspector of hospitals, said safety remains a “real concern” in the National Health Service, with wide variations of quality between hospitals and even between services within the same hospitals. Remarking on the first round of inspections of England’s 136 acute non-specialist trusts and 18 specialist trusts, carried out between 2014-2016,¹ he said inspectors had uncovered pockets of “very poor care” in otherwise good hospitals. The scale of the challenge that hospitals are now facing is unprecedented. <https://goo.gl/kwr0SG>

End-of-life care: Key points made in Care Quality Commission report

End-of-life care (EoLC) is a hospital-wide concern and leadership must be provided at board level and across directorates to achieve high standards.

However, some hospitals still regard EoLC as a peripheral activity solely managed by specialist teams.

We have found some excellent palliative care services, but in some cases the majority of patients are not being referred to them.

We have also found issues with “do not attempt cardiopulmonary resuscitation forms” not being completed properly.

1. ‘State of care in National Health Service acute hospitals: 2014 to 2016,’ Care Quality Commission, March 2017. <https://goo.gl/kEq4zM>

Cost of dying in the U.K.

Number of paupers' funerals on the rise

U.K. | *The Irish World* – 2 March 2017 – The cost of dying continues to rise, placing more pressure on councils that have to pay for “paupers’ funerals.” At the end of 2015, it was revealed that local authorities had shelled out £1.7 million across the previous four years to cover public health funerals. These are carried out when someone dies alone or with relatives who are unable to fund the costs. Research suggests that the increase in overall spend can be attributed to the fact that people are living longer and therefore more people are dying alone. A study carried out by BBC Local Radio showed that costs for public health funerals had risen by 30%, while the number of these services had jumped by 11%. While the largest number of public health funerals were carried out in the North West of England, London has seen the cost of such funerals double over the past three years. There were almost 2,153 public health funerals carried out in the capital – almost two a day – between 2013 and 2016, compared to just 1,000 across the three years prior. Analysis published in *The Evening Standard* showed that the average bill paid by councils to cover funeral costs now stood at £1,230. In 2013, this figure was just £673. <https://goo.gl/o6ReKL>

Noted in Media Watch 7 December 2015, #439 (p.7):

- U.K. | BBC News – 30 November 2015 – **“Paupers’ funerals” cost councils £1.7 million.** The cost to local councils of so-called “paupers’ funerals” has risen almost 30% to £1.7 million in the past four years. The number of these funerals has risen by 11%, a Freedom of Information request by BBC Local Radio revealed. <http://goo.gl/hYWfll>

End-of-life care in England

Researchers warn of postcode lottery in care for the dying

U.K. (England) | BT.com – 1 March 2017 – Dying people are being left with inadequate round-the-clock pain relief and poor access to specialist help, according to new research (see ‘Specialist Publications’ box, right below). They are caught in a postcode lottery which affects whether their families are able to secure proper National Health Service (NHS) end-of-life care on weekends and during the night, it suggests. In some parts of England, NHS bosses only provide a telephone advice line to cater for people in their last days of life. Meanwhile, others have full palliative care (PC) teams with expertise in areas such as controlling cancer pain or lessening distress. The research is based on Freedom of Information requests made to clinical commissioning groups (CCGs), which control millions of pounds of NHS money and are responsible for arranging care for patients. The study, led by Baroness Iora Finlay, an independent cross-bench member of the House of Lords and world expert on PC, found the “provision of round-the-clock access to specialist palliative care and pain control is inconsistent.” Some regions only

offered “basic” services such as a phone line with no access to consultant advice, while others ran dedicated night-time services, including access to consultants and nursing teams. Just under a third of CCGs had specialist pain control teams, but most of these operated only in normal working hours, with no cover overnight. The report found there was a heavy reliance on hospices to plug gaps, even though many of these had too few beds to cater for people in need. <https://goo.gl/0x1Ptz>

Specialist Publications

‘Commissioning of specialist palliative care services in England’ (p.8), in *BMJ Supportive & Palliative Care*.

‘How continuity of care is experienced within the context of integrated palliative care: A qualitative study with patients and family caregivers in five European countries’ (p.13), in *Palliative Medicine*.

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Selected articles on “postcode lottery” access to end-of-life care in the U.K.

- U.K. (England, Northern Ireland, Scotland, Wales) | *The Daily Mirror* – 14 January 2016 – ‘**Patients at end of life face a postcode lottery doctors warn.**’ Patients face a postcode lottery on end-of-life care, doctors warn. The British Medical Association said it has to be made a top priority after a review found services varied according to geography and the illnesses people were suffering.¹ [Noted in Media Watch 18 January 2016, #445 (p.4)] <http://goo.gl/Sdc8rH>
 1. ‘End-of-life care and physician-assisted dying,’ British Medical Association, January 2016. <http://goo.gl/IR5KmY>
- U.K. (England, Northern Ireland, Wales) | *The Daily Telegraph* – 19 June 2013 – ‘**Call to stop “lottery” of end-of-life care.**’ Terminally ill patients are suffering wildly varying standards of end-of-life care depending on their disease, postcode and ethnicity, a new report has found.¹ [Noted in Media Watch 24 June 2013, #311 (p.6)] <http://goo.gl/Ttt2WJ>
 1. ‘People’s final journey must be one of their choosing ... Ways and Means,’ Demos, U.K., June 2013. <http://goo.gl/DroC3v>
- U.K. (England) | *The Daily Telegraph* – 28 November 2012 – ‘**Terminally ill face postcode lottery in end-of-life care.**’ Terminally ill people in London can expect a worse death than almost anywhere in the country, a study by the Office for National Statistics suggests.¹ Analysis of a data from almost 50,000 bereaved people found wide variations in the standards of dignity, respect and basic care provided to their loved ones in different areas. [Noted in Media Watch 3 December 2012, #282 (p.6)] <http://goo.gl/ZvESkL>
 1. ‘Quality of care at the end of life varies with cause and place of death,’ Office for National Statistics, 2012. <https://goo.gl/nWDZ7O>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- FINLAND | Expatica (Amsterdam, The Netherlands) – 2 March 2017 – ‘**Finnish parliament debates legalising euthanasia.**’ Finland’s parliament ... debated a citizens’ initiative to make euthanasia legal, a widely supported cause in the Nordic country. “A law on euthanasia is needed to add an alternative at life’s end for those who cannot get sufficient relief to their unbearable agonies even from the finest of palliative treatment,” the initiative read. In Finland, citizens can require parliament to debate an issue by gathering a minimum of 50,000 signatures. The debate was just the first step in the parliamentary process. A special committee will draft a more detailed memorandum for lawmakers to consider at a later, undisclosed date. It is not yet known how much support the idea has in parliament. But a poll conducted by public broadcaster YLE (i.e., The Finnish Broadcasting Company) in 2015 suggests that nearly 60% of the current lawmakers are favourable to the possibility of an assisted death for a terminally ill patient. And several polls in recent years have shown Finns to be largely supportive of the idea. <https://goo.gl/vTQo2a>
- U.K. | *The Guardian* – 1 March 2017 – ‘**The euthanasia debate is polarised, yet shared concerns unite all sides.**’ A [recent] study sought the views of people with strongly opposed opinions on the matter [of euthanasia]. Participants in both groups included people with palliative care (PC) backgrounds, older and disabled people, those from organisations concerned with care and support and individuals from academic, social work and policy backgrounds. What emerged is a surprising amount of common ground. People with apparently polarised views on legalising the right to die often shared areas of interest and concern. It is these areas that should form the basis for further public discussion, argues the report. Shared concerns included clear agreement that PC for terminally ill people is inadequate. Whether for or against assisted dying, participants showed a willingness to discuss quality of life for terminally ill people, the value placed on good-quality care, and how to invest in and provide access to this care in the face of economic inequality. <https://goo.gl/E1TIHh>
 1. ‘Assisted Dying: Developing the Debate,’ Joseph Rowntree Foundation. Published by the Shaping our Lives network, March 2017. <https://goo.gl/voVbUe>

Specialist Publications

To understand and be understood: The ethics of language, literacy, and hierarchy in medicine

AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS, 2017;19(3):234-237. Clear communication and understanding between patients and physicians is essential to the practice of medicine. And yet approximately 80 million Americans have limited health literacy – the ability to process and understand medical information in order to make decisions about health care. Low health literacy can be the by-product of differences in spoken language, underlying knowledge about medical conditions, and cultural beliefs about health and sickness. Demographically, low health literacy is associated with educational level, ethnicity, socioeconomic status, and age. The tragedy of linguistic failures with respect to health outcomes is well known: low health literacy among patients is consistently associated with more hospitalizations, greater use of emergency care, lower receipt of critical preventative interventions such as mammography screening and influenza vaccination, poorer ability to take medications properly, and, among seniors, poorer overall health status and higher mortality rates. In fact, poor health literacy par-

tially explains the existence of racial disparities in some health outcomes. The prevalence of low health literacy and its association with poor health outcomes create ethical challenges for medical practitioners. <https://goo.gl/5cbNAT>



The current issue focuses on language and hierarchy in medicine. Articles include: 'Clinicians' obligations to use qualified medical interpreters when caring for patients with limited English proficiency,' 'Strategies for acing the fundamentals and mitigating legal and ethical consequences of poor physician-patient communication,' and 'The role of universal health literacy precautions in minimizing "medspeak" and promoting shared decision making.' Journal contents page: <https://goo.gl/D5jrUL>

Related

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2016;18(6):544-549. '**The impact of health literacy on palliative care outcomes.**' Limited health literacy is a recognized health problem often leading to poorer health outcomes. Health care professionals, including nurses, are responsible for delivering health information in a clear and understandable way. Yet nurses may overestimate patients' health literacy and miss opportunities to help patients understand and then incorporate medical information. Health outcomes may improve when nurses recognize potential barriers to health literacy and use evidence-based interventions. <https://goo.gl/Yt7BHN>

Patient values informing medical treatment: A pilot community and advance care planning survey

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 2 March 2017 – Medicine regards the prevention of death as an important priority. Yet patients may have a range of priorities of equal or greater importance. These other priorities are often not discussed or appreciated by treating doctors. The authors used a locally developed survey tool 'What Matters Most' to identify values. Choices presented were: maintaining dignity, avoiding pain and suffering, living as long as possible, and remaining independent. Participants rated the importance of each and then selected a main priority for their doctor. "Living as long as possible" was not the most important value for advance care planning patients, or for a younger general population. Prioritisation of other goals appeared to be independent of extreme age or illness. When end-of-life treatment is being discussed with patients, priorities other than merely prolonging life should be considered. <https://goo.gl/m3y3KA>



Media Watch: Behind the Scenes
<http://goo.gl/XDjHxz>

Commissioning of specialist palliative care services in England

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 28 February 2017 – This study goes some way to provide evidence that while there is excellent specialist palliative care (PC) provision in parts of England, there is a vast degree of variation across the country and across different services. Most strikingly, there is little uniformity in the data Clinical Commissioning Groups (CCGs) are required to hold, and disparity in the responsibility of service provision between CCGs, Trusts and local hospices. As a result, a paucity of services means that patient choice at the end of life cannot always be honoured and unless national guidelines are put in place to support CCGs in commissioning care, the deficits described in the Parliamentary & Health Service Ombudsman's report will not be addressed. PC needs to be available at all times because crises often occur out of hours.¹ In Wales, specialist staffing levels have been determined within the available funding, and a dedicated number of PC beds ensures fair access to specialist PC across 7 days [see sidebar, 'The Welsh experience'].² This model provides a starting point for CCGs to benchmark and improve provision for their population. The authors' data reveal that the devolution of decision-making down to CCGs suggests that PC

provision is not being considered as a core service in some parts of England. Despite much evidence of its cost efficacy, the provision of specialist PC is in need of a national framework to ensure that patients achieve good end-of-life care everywhere. <https://goo.gl/SnmBW0>

The Welsh experience

A formula has been developed to meet the specialist palliative care (PC) needs across Wales, appropriate to both urban and rural settings, for populations of all ages and to take into account the requirements for hospital support teams and those working in cancer centers. In addition, where hospice inpatient beds exist, a funding formula has been developed to guide reimbursement for basic care costs. Where there are no beds, hospice-at-home provision provides an alternative model of care, with funding adjusted pro rata. The formula aims to ensure fairness of specialist PC provision, available out of hours as well as during the working day, providing patient-focused evidence-based care. This means that the specialist team must meet specialist education standards, act as a resource to generalist teams and use a core clinical data set to allow comparable audits against agreed all-Wales standards.²

1. 'Dying without dignity,' Parliamentary and Health Service Ombudsman, 2015. [Noted in Media Watch 25 May 2015, #411(p.6)]. <https://goo.gl/aUEApU>
2. 'Developing a template to plan palliative care services: The Welsh experience,' *Journal of Pain & Symptom Management*, 2009;38(1):81-86. <https://goo.gl/ilwHk9>

Related

- *BRITISH MEDICAL JOURNAL* | Online – 27 February 2017 – '**Palliative care from diagnosis to death.**' Many people still associate palliative care (PC) with care in the terminal stage of cancer, and patients with cancer remain more likely to receive it than those with other illnesses. It is often delayed until the last weeks or days of life once the illness is advanced and disease focused treatments are no longer effective. However, late PC is a missed opportunity to do better for patients, families, and health services. In high income countries, up to 80% of people who die could benefit from PC much earlier in their illness. The World Health Organization adopted a resolution on early PC in 2014.¹ It states that PC should be considered from diagnosis onwards and integrated into care for people with any condition that means they may die in the foreseeable future. <https://goo.gl/GFlusO>

1. 'Strengthening of palliative care as a component of integrated treatment within the continuum of care,' Sixty-seventh World Health Assembly, World Health Organization, January 2014. <https://goo.gl/fqSHlb>

Survivorship of severe medically unexplained symptoms in palliative care

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 28 February 2017 – Patients who articulate their psychological distress primarily through physical symptoms – medically unexplained symptoms (MUS) – pose a challenge to the skills of most clinicians, including palliative care (PC) physicians. The philosophical underpinnings of PC with a stated focus on symptom management and care of the person in their psycho-socio-spiritual context lend itself to the care of these patients. This case series highlights the complexities and challenges inherent in providing assessment and care for patients with MUS that present to PC. Characteristics that were identified included the clustering of “trigger” symptoms, backgrounds of multiple chronic illnesses and relationship dysfunction. Patient outcomes in this group were universally poor, including the death of two patients. Knowledge of this patient group is vital given the likely increase in prevalence of MUS as PC broadens its focus earlier in the trajectory of illness. The strengths of PC, including psycho-socio-spiritual assessment, multidisciplinary input and communication skills holds the potential to accurately identify patients with MUS and allow the opportunity for specialist psychiatric input with the hope of improving outcomes for patients and their families. <https://goo.gl/82WzQ1>

New approaches to resuscitation decisions

Resuscitation policy should focus on the patient, not the decision

BRITISH MEDICAL JOURNAL | Online – 28 February 2017 – Do not attempt cardiopulmonary resuscitation (DNACPR) decisions are made commonly in healthcare, but can be a source of ethical concern and legal challenge. They differ from other healthcare decisions because they are made in anticipation of a future event and concern withholding, rather than giving, a treatment. DNACPR decisions were introduced to protect patients from invasive treatments that had little or no chance of success. However, inconsistencies in decision making, communication, and documentation have led to misunderstandings about what DNACPR means and to delivery of poorer care to some patients. The authors discuss the problems with current practice and outline newer approaches that place the patient, and their family, at the centre of the discussions. They focus on overall treatment plans and supporting clinicians and patients to make shared decisions about emergency treatments. Given the weight of evidence against DNACPR decisions being made in isolation, how much (and what kind of) evidence is needed before a new approach is adopted? Some of the principles underpinning the new approaches to resuscitation decisions are already widely accepted – clinicians need to understand what is important to each individual patient and to advise their patients which outcomes are clinically possible or likely. Others are drawn from the research literature – conversations should be undertaken proactively before a crisis occurs; the option of attempting CPR should be discussed with more people, not just those needing DNACPR decisions or approaching the end of life; resuscitation decisions should be contextualised within overall goals of care. The aim of ensuring that recommendations are documented in such a way that patients receive the right treatments at the right time is one which is universally accepted. <https://goo.gl/e88gY1>

Selected articles on resuscitation policies and practices

- *RESUSCITATION* | Online – 11 March 2016 – ‘**Themes and variations: An exploratory international investigation into resuscitation decision-making.**’ Eighty-eight percent of survey respondents reported a method for implementing do not attempt cardiopulmonary resuscitation (DNACPR) decisions, 90% of which discussed resuscitation wishes with patient at least half of the time; 94% of respondents thought that national guidance for DNACPR order implementation should exist, with 53% of countries surveyed reporting existence of such guidance. [Noted in Media Watch 21 March 2016, #454 (p.13)] <http://goo.gl/sNCM0G>
- *RESUSCITATION* | Online – 14 January 2016 – ‘**A survey of key opinion leaders on ethical resuscitation practices in 31 European Countries.**’ The authors report the responses to a survey covering four domains of resuscitation: 1) Approaches to end-of-life care and family presence during CPR; 2) Determinants of access to best resuscitation and post-resuscitation care; 3) Diagnosis of death and organ donation; and, 4) Emergency care organisation. [Noted in Media Watch 25 January 2016, #446 (p.16)] <http://goo.gl/me0mUy>

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- *BMJ OPEN* | Online – 13 January 2015 – ‘**Variation in local trust do not attempt cardiopulmonary resuscitation (DNACPR) policies: A review of 48 English healthcare trusts.**’ There was variation in terminology (85% described documents as policies, 6% procedures, and 8% guidelines). Only one quarter of National Health Service Trusts used the recommended Resuscitation Council record form (or a modification of the form). There was variation in the terminology used, which included DNAR (Do Not Attempt Resuscitation), DNACPR (Do Not Attempt CPR), CPR, and AND (Allow Natural Death). [Noted in Media Watch 19 January 2015, #393 (p.9)] <http://goo.gl/cxZMNM>

Acceptable regret model in the end-of-life setting: Patients require high level of certainty before forgoing management recommendations

EUROPEAN JOURNAL OF CANCER, 2017;75(3):159-166. End-of-life decisions involve substantial uncertainty. Every patient could face the consequences of a wrong decision. The acceptable regret model postulates that under some circumstances patients may tolerate wrong decisions. The authors used acceptable regret to investigate when patients are willing to forgo life-prolonging treatment versus hospice care. They showed that there is a requirement for high level of certainty before accepting recommended management in end-of-life care. <https://goo.gl/78wjYN>

Noted in Media Watch 12 December 2016, #491 (p.8):

- *BLOOD* | Online – Accessed 6 December 2016 – ‘**Improving hospice referral: Application of regret-based decision modeling at end-of-life care.**’ The authors report the application of a regret-based model built to facilitate referral to hospice while helping patients clarify their preferences related to how they wish to spend the remaining days of their lives. <https://goo.gl/s18aEM>

Noted in Media Watch 21 March 2016, #454 (p.12):

- *MEDICAL DECISION MAKING* | Online – 14 March 2016 – ‘**Extent and predictors of decision regret about health care decisions: A systematic review.**’ People often face difficult decisions about their health and may later regret the choice that they made. However, little is known about the extent of decision regret in health care or its predictors. <http://goo.gl/GpZL4w>

Thanatophobia (death anxiety) in the elderly: The problem of the child’s inability to assess their own parent’s death anxiety state

FRONTIERS IN MEDICINE | Online – 27 February 2017 – Death anxiety of death is usually absent in the elderly, but rather they fear the dying process. On the other hand, their children do fear death, which they extrapolate onto their parents. This causes conflicts since the children prevent disclosure of relevant medical information to their parents. This has to be addressed by the staff when dealing with family members, to allow open and honest communication with their patients. The staff need to explain to the family that the elderly are not afraid of death but of the suffering from the dying process. <https://goo.gl/KNH22Z>

Involving healthcare professionals and family carers in setting research priorities for end-of-life care

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING | Online – 28 February 2017 – It is important to ensure regional variances are considered when setting future end-of-life (EoL) research priorities, given the differing demographics and service provision. This project sought to identify EoL research priorities within Greater Manchester (U.K.). Following an initial scoping exercise, six topics within the 10 national priorities outlined by The Palliative & End-of-Life Care Priority Setting Partnership were selected for exploration. A workshop involving 32 healthcare professionals and a consultation process with 26 family carers was conducted. Healthcare professionals and carers selected and discussed the topics important to them. The topics selected most frequently by both healthcare professionals and carers were: 1) Access to 24 hour care; 2) Planning end-of-life care in advance. And, 3) Staff and carer education. Healthcare professionals also developed research questions for their topics of choice which were refined to incorporate carers views. <https://goo.gl/j7HU5w>

Cont.

Noted in Media Watch 5 December 2016, /490 (p.8):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(6):290-293. **‘Does current U.K. research address priorities in palliative and end-of-life care?’** Published in 2015, the Palliative and end-of-life care (EOLC) Priority Setting Partnership (PeolcPSP) report is being used to guide palliative and EOLC research funding. This project highlights that research spending in palliative and EOLC remains low, with pockets of good news. It also highlights the need for more research proposals and testing interventions to tackle the problems encountered in palliative and EOLC. The number one PeolcPSP priority – how to provide palliative care out of hours – is one of the questions most in need of further research investment. Of the 83 questions, 19 are not addressed by any directly related research funding active in 2014.

N.B. Access to the journal requires a subscription. Contents page for the November/December issue: <https://goo.gl/qGVJCP>

Related

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 28 February 2017 – **‘Prioritisation of future research topics in paediatric palliative care in Ireland: A Delphi study.’** There is a notable overlap between the needs of children requiring palliative care (PC) and those with disabilities and other complex care needs, resulting in care being provided by a range of voluntary and statutory agencies. As a new specialty, there is a need to develop an evidence-based approach to providing children's PC. In order to do this in a systematic way, identification of the research priorities in children's PC within Ireland is required. <https://goo.gl/HP7mQY>

End-of-life care: Challenges faced in the field of nutrition

An ethical perspective on palliative care

JOURNAL OF THE ACADEMY OF NUTRITION AND DIETETICS | Online – 24 February 2017 – A multi-dimensional paradigm shift in health care continues to spread as palliative care (PC) grows into an overarching concept integrated throughout the field. Once thought of in terms of hospice and long-term care units, research indicates that the concept can improve not only quality of life and patient satisfaction, but perhaps extend life as well in patients who might otherwise suffer less-desirable outcomes. These quantitative results, added to strong anecdotal support, help build a compelling case for the shift, particularly as it appeals to a heightened sense of ethics in terms of beneficence, non-maleficence, and justice. This brings a multi-dimensional dynamic to the discussion of wellness and improved outcomes, and registered dietitian nutritionists accustomed to the concept report it's completely in line with the profession's traditional model of optimizing patient health through nutrition. The objective of the present article is to first explain the concept of PC, consider it from the perspective of ethics, and offer examples of challenges faced in the field of nutrition, as well as resources for the practitioner's benefit. <https://goo.gl/rq8DmN>

Related

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 28 February 2017 – **‘Declining oral intake towards the end of life: How to talk about it? A qualitative study.’** Decreasing oral intake is common towards the end of life (EoL) and a potential source of distress and concern for patients, relatives, whānau and clinicians. This paper provides insight to inform practice regarding clinicians' perceptions, practices, responses and communication with patients and their companions regarding declining oral intake towards the EoL. <https://goo.gl/JLYbu1>

Noted in Media Watch 23 January 2017, #496 (p.5):

- *ANNALS OF PALLIATIVE MEDICINE* | Online – Accessed 19 January 2017 – **‘Evolving ethical and legal implications for feeding at the end of life.’** 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. <https://goo.gl/gEqYtf>

Direct care workers' experiences of grief and needs for support

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Online – 1 March 2017 – A paucity of information is available on direct care workers' (DCWs') experiences with loss when their clients (people with intellectual and developmental disabilities [I/DD]) die. This study explored DCWs' grief experiences, their coping methods, and their needs for support. Three themes (factors affecting DCW loss, ways that DCWs cope with loss, and organizational issues affecting the bereavement experience) and associated sub-themes emerged from the data. This highlighted not only DCW professional grief experiences, but how organizational communication and policy affected their grief experience. DCWs experience grief in the workplace but may receive insufficient organizational bereavement supports. Recommendations are made for organizational policies and resources to improve organizational communication and assist DCWs in coping with their grief. <https://goo.gl/pVDnuk>

Noted in Media Watch 7 December 2015, #439 (p.14):

- *INTELLECTUAL & DEVELOPMENTAL DISABILITIES*, 2015;53(6):394-405. '**A Delphi study on staff bereavement training in the intellectual and developmental disabilities field.**' Results showed that training should help staff identify and support service users experiencing grief. Importantly, staff also needs help in managing their own grief. Organizational policies and resources should be instituted to support the grief processes of both service users and staff. <http://goo.gl/YZx0ar>

Impact of a new palliative care program on health system finances: An analysis of the palliative care program inpatient unit and consultations at Johns Hopkins Medical Institutions

JOURNAL OF ONCOLOGY PRACTICE | Online – 28 February 2017 – This study considered three components of the program: palliative care unit (PCU), palliative care consultations, and professional fees. Using 13 months of admissions data, the team calculated the per-day variable cost pre-PCU (i.e., in another hospital unit) and after transfer to the PCU. These fees were multiplied by the number of patients transferred to the PCU and by the average length of stay in the PCU. Consultation savings were estimated using established methods. Professional fees assumed a collection rate of 50%. The total positive financial impact of the program was \$3,488,863.17. There were 153 transfers to the PCU, 60% with cancer, and an average length of stay of 5.11 days. The daily loss pre-transfer to the PCU of \$1,797.67 was reduced to \$1,345.34 in the PCU (-25%). The PCU saved Johns Hopkins Medical Institutions \$353,645.17 in variable costs, or \$452.33 per transfer. Cost savings for PC consultations in the hospital, 60% with cancer, were estimated at \$2,765,218. \$370,000 was collected in professional fees savings. <https://goo.gl/spqF0Y>

Communication challenges and strategies of U.S. health professionals caring for seriously ill South Asian patients and their families

JOURNAL OF PALLIATIVE MEDICINE | Online – 2 March 2017 – While effective communication is important in the care of seriously ill patients, little is known about communication challenges faced by healthcare providers serving U.S. patients of South Asian origin, one of the fastest growing demographic groups in the U.S. Researchers conducted a thematic analysis of qualitative data obtained through focus groups and individual interviews with 57 healthcare providers, including physicians, social workers, nurses, chaplains, and others drawn from different healthcare settings in one Midwestern city. While acknowledging the considerable diversity within the U.S. South Asian community, participants discussed three types of communication challenges they often encounter when serving this population: 1) Ensuring effective interpretation; 2) Identifying a spokesperson; and, 3) Challenges posed by different cultural norms. Participants shared strategies to address these challenges such as proactively inquiring about patients' and families' preferences and encouraging early appointment of a spokesperson. While providers should avoid stereotyping patients, an awareness of common challenges and adoption of recommended strategies to address these challenges may enhance the provision of culturally responsive person-centered services... <https://goo.gl/MaUPJ1>

Cont.

Noted in Media Watch 6 July 2015, #416 (p.7):

- American Journal of Hospice & Palliative Medicine | Online – 29 June 2015 – ‘**Perspectives of health care providers on U.S. South Asians’ attitudes toward pain management at end of life.**’ A lack of research on pain management among seriously ill South Asians reveals a critical gap in the knowledge base regarding culturally responsive end-of-life care. <https://goo.gl/8LZLBd>

Repatriation of human remains following death in international travellers

JOURNAL OF TRAVEL MEDICINE, 2017;24(2). Repatriation of human remains is a difficult task which is emotionally challenging for the bereaving family and friends. As a travel medicine practitioner, it is prudent to discuss all eventualities, including the risk of death, during the pre-travel consultation. Awareness of the procedures involved in this process may ease the burden on the grieving family at a difficult time. The local national embassy, travel insurance broker and tour operator are important sources of information to facilitate the repatriation of the deceased traveller. Formal identification of the deceased’s remains is required and a funeral director must be appointed. Following this, the coroner in the country or jurisdiction receiving the repatriated remains will require a number of documents prior to providing clearance for burial. Costs involved in repatriating remains must be borne by the family of the deceased although travel insurance may help defray some of the costs. If the death is secondary to an infectious disease, cremation at the site of death is preferred. No standardized procedure is in place to deal with the remains of a migrant’s body at present and these remains are often not repatriated to their country of origin. <https://goo.gl/ZxfGlc>

N.B. Related articles on repatriation to their homeland of patients living with a terminal illness are noted in Media Watch 28 November 2016, #489 (pp.15-16).

Differences in place of death between lung cancer and chronic obstructive pulmonary disease patients: A 14-country study using death certificate data

NATURE PARTNER JOURNALS: PRIMARY CARE RESPIRATORY MEDICINE | Online – 3 March 2017 – Cross-national comparisons of place of death, as an important outcome of terminal care, between people dying from chronic obstructive pulmonary disease (COPD) and lung cancer have not been studied before. The authors collected population death certificate data from 14 countries (year: 2008), covering place of death, underlying cause of death, and demographic information. Of 5,568,827 deaths, 5.8% were from lung cancer and 4.4% from COPD. Among lung cancer decedents, home deaths ranged from 12.5% in South Korea to 57.1% in Mexico, while hospital deaths ranged from 27.5% in New Zealand to 77.4% in France. In COPD patients, the proportion dying at home ranged from 10.4% in Canada to 55.4% in Mexico, while hospital deaths ranged from 41.8% in Mexico to 78.9% in South Korea. Controlling for age, sex, and marital status, patients with COPD were significantly less likely die at home rather than in hospital in nine countries. This study found in almost all countries that those dying from COPD as compared with those from lung cancer are less likely to die at home and at a palliative care institution and more likely to die in a hospital or a nursing home. <https://goo.gl/twrLrw>

How continuity of care is experienced within the context of integrated palliative care: A qualitative study with patients and family caregivers in five European countries

PALLIATIVE MEDICINE | Online – 2 March 2017 – This international qualitative study showed that patients and family caregivers (FCGs) are most likely to experience continuity of care by having a small number of health care professionals who are available, who provide multidisciplinary care, and who regularly transfer information to all health care professionals involved. Collaborative integrated palliative care (PC) initiatives could optimize continuity of care experiences and thus improve quality of PC in Europe. However, further integration of these initiatives with other health care professionals involved in the care networks of patients with advanced diseases and their FCGs is needed. Researchers, clinicians and policy makers could use these insights in order to enhance integrated PC and improve experiences of patients with life-threatening diseases and FCGs. <https://goo.gl/mc5gcn>

Cont.

Related

- *BMC FAMILY PRACTICE* | Online – 23 February 2017 – ‘**Patient-centeredness to anticipate and organize an end-of-life project for patients receiving at-home palliative care: A phenomenological study.**’ This study showed that, despite a relative lack of specialized, specific end-of-life training, the GPs in the study sample devised a patient-centred approach to palliative care (PC) based on their professional values. This process allowed them to anticipate all potential events and discuss them with patients and families. These discussions generated opportunities for GPs to design personalized PC projects for the remaining time left to live hand-in-hand with their patients. <https://goo.gl/ibGp1y>

End-of-life care in Australia

The nature of conflict in palliative care: A qualitative exploration of the experiences of staff and family members

PATIENT EDUCATION & COUNSELING | Online – 24 February 2017 – This study aimed to understand staff and relatives’ perspectives on the characteristics of conflict and serious disagreement in adult palliative care (PC), including triggers, risk factors and the impact on themselves and clinical care. Participants in this qualitative study included 25 staff and seven bereaved relatives, recruited from a multidisciplinary specialist PC setting in Australia. Communication was frequently cited as a cause of conflict. Further, different understandings regarding disease process, syringe drivers and providing nutrition/hydration caused conflict. Staff applied empathy to moderate their responses to conflict. Relatives’ reactions to conflict followed a trend of anger/frustration followed by explanations or justifications of the conflict. Relatives identified systemic rather than interpersonal issues as triggering conflict. Family meetings may fruitfully be applied to prevent and de-escalate conflict. Clinical audits may be useful to identify and provide support to families where there may be unresolved conflict impacting grief process. <https://goo.gl/pPFVoX>

Noted in Media Watch 23 May 2016, #463 (p.12):

- *HEALTH COMMUNICATION* | Online – 13 May 2016 – ‘**Reframing, refocusing, referring, reconciling, and reflecting: Exploring conflict resolution strategies in end-of-life situations.**’ This article explores the strategies used by those individuals to resolve conflict. Using grounded practical theory as a theoretical and method-ological framework, qualitative interviews revealed how they manage family conflict at the end of life. The management styles include reframing, refocusing, referring, reconciling, and reflecting (the “5 Rs”). <http://goo.gl/svw3Cj>



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>



Closing the Gap Between Knowledge & Technology

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

Canadian perspective

Children's end-of-life health care use and cost

PEDIATRICS | Online – 2 March 2017 – Health care use and cost for children at the end of life is not well documented across the multiple sectors where children receive care. The study objective was to examine demographics, location, cause of death, and health care use and costs over the last year of life for children aged 1 month to 19 years who died in Ontario, Canada. In a cohort of 1,620 children, 41.6% died of a chronic disease with wide variation across age groups. The mean health care cost over the last year of life was \$78,332 (Canadian) with a median of \$18,450, reflecting the impact of high-cost decedents. The mean costs for children with chronic or perinatal/congenital illnesses nearly tripled over the last 4 months of life. The majority of costs (67.0%) were incurred in acute care settings, with 88.0% of children with a perinatal/congenital illness and 79.7% with a chronic illness dying in acute care. Only 33.4% of children received home care in the last year of life. <https://goo.gl/hdB5X4>

Pediatric palliative care in Canada in 2012: A cross-sectional descriptive study

CANADIAN MEDICAL ASSOCIATION JOURNAL OPEN | Online – 11 October 2016 – All 13 programs identified participated. Of the 431 children who died in 2012, 105 (24.4%) died in a critical care setting. Programs with a hospice provided care to 517 children (36.9%). Children in this group tended to be older, more often had a neurologic illness and received care for a longer time than those who received care from programs without a hospice. Program growth and changes in patients' demographic and clinical characteristics indicate improved reach of programs. However, barriers remain that prevent most children with life-threatening conditions from receiving specialized pediatric PC services. [Noted in Media Watch 17 October 2016, #483 (p.10)] <https://goo.gl/HaZMWk>

U.S. perspective

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 24 May 2016 – '**Cost analysis and policy implications of a pediatric palliative care program.**' In 2010, California launched Partners for Children (PFC), a pediatric palliative care pilot program offering hospice-like services for children eligible for full-scope Medicaid delivered concurrently with curative care, regardless of the child's life expectancy. The average per enrollee per month (PEPM) health care costs of program enrollees decreased by \$3,331 from prior to their participation in PFC to the enrolled period, driven by a reduction in inpatient costs of \$4,897 PEPM. PFC enrollees experienced a nearly 50% reduction in the average number of inpatient days per month, from 4.2 to 2.3. Average length of stay per hospitalization dropped from an average of 16.7 days prior to enrollment to 6.5 days while in the program. [Noted in Media Watch 30 May 2016, #464 (p.11)] <http://goo.gl/83nGDu>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CANADIAN JOURNAL OF GENERAL INTERNAL MEDICINE* | Online – Accessed 28 February 2017 – '**Conscientious objection and medical assistance in dying (MAiD) in Canada: Difficult questions – insufficient answers.**' "Conscientious objection" typically implies refusal to participate in an action based on strongly held ethical beliefs. It is historically associated with refusing to fight on the grounds of personal conscience or religion. Like other military allusions such as collateral damage or life in the trenches, its usage has spread into wider societal use. Conscientious objection is now used in regards to opposing euthanasia in Canada. Euthanasia, in turn, is now referred to by the less emotive term, Medical Assistance in Dying (MAiD). Most medical practitioners and hospitals that object do so in part because of their disagreement or discomfort with the act of killing. As such, the analogy is not wholly unjustified. What is less clear is how this construct, and this terminology, will ultimately affect patients, practitioners, administrators and politicians. <https://goo.gl/UmXh1q>

Cont.

- *CANADIAN MEDICAL EDUCATION JOURNAL*, 2017;8(1):e6-e21. ‘**Survey evaluations of University of British Columbia residents’ education and attitudes regarding palliative care and physician assisted death.**’ Residents receive little education about palliative care (PC) and physician assisted death (PAD)... Residents have significant misunderstandings regarding the interactions between PC and the provision of PAD, and education in these areas should be provided in all residency training programs in order to meet the needs of future practicing physicians. Further research could explore what types and what quantity of educational opportunities are sufficient to meet resident needs. The regulation and practice of PAD is rapidly evolving, and future research should explore if opinions and experiences with respect to PAD change over time, and how the opinions of residents in different programs and levels of training compare on these important questions. <https://goo.gl/WmAeCU>

Worth Repeating

If I paint a rosy picture, will you promise not to cry?

JOURNAL OF CLINICAL ONCOLOGY, 2012;30(27):3421-3423. It can be a tough question. Many of our patients are not going to be okay, and most physicians have not received the kind of communication skills training that would make them feel as competent having difficult conversations as they do performing difficult medical procedures. Although patients want guidance and hope, they also want candor. The fear that candor is incompatible with hope is unfounded, but telling a patient the truth in a way that is caring and not brutal requires skill. Our gut instinct and our medical training often instruct us to fix whatever problems we encounter, and this gets us into trouble when the problem cannot be fixed. Sometimes we actively mislead the patient, and sometimes we mislead ourselves, giving third-, fourth-, and fifth-line chemotherapy rather than facing reality. Perhaps, if we had more candid conversations, we would not have so many patients receiving chemotherapy when they have only days or a few weeks to live, and we would not have so many hospice referrals delayed until a few days before death. [Noted in Media Watch 24 September 2012, #272 (p.8)] <https://goo.gl/NtGrnl>

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.

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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.

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International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/o9wzNe>

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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