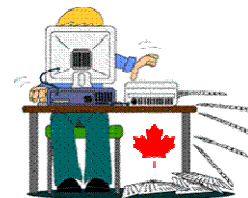


Media Watch...

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.

9 October 2017 Edition | Issue #533



Compilation of Media Watch 2008-2017 ©

Compiled & Annotated by Barry R. Ashpole

A marginal service within the palliative care landscape: Scroll down to [Specialist Publications](#) and 'The strengths and challenges of palliative day-care centers: Qualitative study with the professionals involved' (p.13), in *Journal of Palliative Care*.

[Canada](#)

Predatory publishing a growing problem, warn scientists

CTV NEWS | Online – 7 October 2017 – Predatory publishing is an increasing concern among scientists and the scientific community, as highlighted by three recent studies. There are now approximately 8,000 suspected predatory journals that publish more than 400,000 articles each year. The journals, which operate on a for-profit basis, are often publishing poorly researched and illegitimate science that could endanger scientific credibility and patients. One study, published in September in the journal *Nature*, looked at more than 1,900 studies published in suspected predatory journals and found the majority of them didn't meet the basic information requirements to be published by a legitimate journal. The Ottawa researchers found that more than 90% of studies claiming to be randomized controlled trials, a gold standard of scientific research, failed to describe how patients were assigned to different treatment groups. They also found that less than one-quarter noted whether patients and assessors were blind-controlled or not. While predatory publishing has often targeted researchers who are young and from developing nations, the study noted that more than half of the authors in the papers came from middle- or high-income countries, and well respected institutions like Harvard – many of whom were unaware they had contributed to a predatory journal. <https://goo.gl/GahLFy>



Ottawa Hospital
Research Institute
Institut de recherche
de l'Hôpital d'Ottawa

1. 'Stop this waste of people, animals and money,' *Nature*, published online 6 September 2017. **Full text:** <https://goo.gl/GahLFy>

N.B. The authors of a recent article in the *South African Journal of Science* (noted in the 14 August 2017 issue of Media Watch (#525, p.16)) commented: "In the final analysis, it is clear that predatory publishing poses a serious challenge to science in South Africa. If it continues to increase at the rate of growth seen in the past 5 years, predatory publishing may well become accepted practice in some disciplines and at some universities. Not only will it affect the very fabric of the science system (our confidence in the peer-review system), but it will also undermine the trust and confidence of the general public in science and its products." Additional articles on predatory journals are noted in the 19 June 2017 issue of Media Watch (#517, p.7).

Immigrants may get more intense care at end of life

ONTARIO | Reuters – 4 October 2017 – Recent immigrants may be more likely than other people to receive aggressive treatment in their last six months of life and die in intensive care, a Canadian study suggests.¹ Even after researchers accounted for other factors that can influence end-of-life (EoL) care such as income, age and cause of death, recent immigrants were 30% more likely to die in intensive care units (ICU), the study found. They were also more likely to be admitted to the hospital in their last six months of life, and more likely to have machines helping them eat and breathe... “The perception – I think often a mistaken perception – is that more procedures and machines represent better care, when in fact it doesn’t reflect care that would address patients’ and families’ fundamental needs at the EoL,” said senior study author Dr. Robert Fowler of the Dalla Lana School of Public Health at the University of Toronto. While the study didn’t assess why recent immigrants received different care than citizens or longtime

residents, a lack of awareness about care options outside the hospital and poor communication may both play a role, Fowler said. For the study, researchers examined data on 967,013 people who died in Ontario from 2004 to 2015. Out of this group, 47,515, or 5%, were classified as recent immigrants who arrived in the country in 1985 or later. Roughly 16% of recent immigrants died in intensive care, compared to 10% of longtime residents. In the last six months of life, 72% of immigrants were admitted to the hospital, compared to 68% of other people. Immigrants were also more likely to be admitted to ICU. <https://goo.gl/D4izf7>

Specialist Publications

‘End-of-life care among immigrants: Disparities or differences in preferences?’ (p.12), in *Journal of the American Medical Association*.

1. ‘Association between immigrant status and end-of-life care in Ontario, Canada,’ *Journal of the American Medical Association*, published online 2 October 2017. Full text: <https://goo.gl/GRkEsY>

Even behind bars, aging prisoners deserve proper health care

THE GLOBE & MAIL | Online – 2 October 2017 – According to the Office of The Correctional Investigator, which serves as an ombudsman for inmates, nearly 25% of people (3,500 prisoners) incarcerated in federal penitentiaries are 50 or older, a number that has doubled in the past decade.¹ More than one-third of them are serving long sentences – usually a minimum of 25 years – and rarely get parole. Most of them die of cancer, heart disease or liver failure, accounting for 366 of 542 prison deaths in the 10-year period between 2007 and 2017. There is a compassionate parole provision for terminally ill inmates, Section 121 of the Corrections & Conditional Release Act, but very few are granted – about four or five a year, according to the ombudsman’s office, with most prisoners dying before the parole board reaches a decision. Why should we care if an inmate old enough to be somebody’s grandparent dies in a cell without adequate medical treatment, access to appropriate palliative care or medical assistance in dying? I think there are three reasons: compas-

sion, equality and autonomy. In a [recent] panel discussion, Crystal Dieleman of Dalhousie’s School of Occupational Therapy pointed out that although prisoners are deprived of liberty while they are incarcerated, the rest of their human rights remain intact. Forget vengeance, they are entitled to the same access to health care as the rest of us, especially because our universal system is based on medical need, not social status. <https://goo.gl/LZB1WY>

Palliative Care Network Community

Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (updated 31 July 2017), can be downloaded/viewed at: <http://goo.gl/ZpEJyQ>

1. ‘Annual Report of the Office of the Correctional Investigator, 2015-2016,’ Office of the Correctional Investigator, June 2016. <https://goo.gl/tq32qo>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CTV NEWS | Online – 6 October 2017 – **‘Number of medically assisted deaths in first half of 2017 rise from 2016.’** Health Canada says there were 1,179 medically assisted deaths between 1 January and 30 June this year,¹ accounting for about 0.9% of all deaths nationally. In the previous six months, the first half-year in which medical assistance in dying was legal, there were 803 assisted deaths, or 0.6% of all deaths. The department says the overall numbers are consistent with international experience. Cancer was the most frequent underlying medical condition in assisted deaths, cited in 63% of cases. The Health Canada findings in its second interim report on medical assistance in dying say the average patient was 73 at death. While some patients were between 18 and 45 at the time of death, the vast majority of cases involved people aged 56 to 85. <https://goo.gl/c532f2>

1. ‘2nd Interim Report on Medical Assistance in Dying in Canada,’ Health Canada, October 2017. <https://goo.gl/gohAuW>

U.S.A.

Terminal illness bill passes in state house

PENNSYLVANIA | WTAJ News (Johnstown) – 6 October 2017 – Patients with terminal illnesses could soon have access to drugs not approved yet by the Federal Drug Administration. A house bill passed the last major hurdle and is on its way to the governor’s desk. The bill allows manufacturers to make the drugs available to eligible patients after successfully completing the first phase of clinical trials. Clinical trials normally take three phases. Under House Bill 45, physicians would not be held liable for recommending experimental products to their terminally ill patients. <https://goo.gl/yXzQ45>

N.B. Additional articles on “right-to-try” laws are noted in the 7 August 2017 issue of Media Watch (#524, p.2).

Specialist Publications

‘Quality hospice care in adult family homes: Barriers and facilitators’ (p.13), in *Journal of the American Medical Directors Association*.

‘Palliative and end of life care in solid organ transplantation’ (p.9), in *American Journal of Transplantation*.

‘Omitting DNR orders from risk-adjusted mortality measurements could skew rankings’ (p.11), in *Cardiovascular Business*.

‘Evaluating the economic impact of palliative and end-of-life care interventions on intensive care unit utilization and costs from the hospital and healthcare system perspective’ (p.14), in *Journal of Palliative Medicine*.

State program gives end-of-life patients right to choose care options

CONNECTICUT | *The Connecticut Post* (Bridgeport) – 4 October 2017 – The State Department of Public Health has launched a state-wide program called Medical Orders for Life Sustaining Treatment (MOLST), which gives patients approaching the end stage of a serious illness or who are in a condition of chronic progressive frailty the ability to choose the medical treatments for their end-of-life care (EoLC). “MOLST offers patients with life-limiting illnesses the opportunity to learn about the benefits and drawbacks of all treatment options and to make their wishes for EoLC known. It ensures that patient choices about life-sustaining interventions and EoLC options are documented as medical orders that are transferrable and respected across all health care settings,” said Commissioner Dr. Raul Pino. “The MOLST document applies equally to patients who choose to continue treatment and who choose to decline any or all life-sustaining interventions.” <https://goo.gl/Pq5vXU>

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Noted in Media Watch 19 October 2015 (#432, p.14):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 October 2015 – ‘**Toward evidence-based end-of-life care.**’ More than two thirds of U.S. states have implemented Physician (or Medical) Orders for Life-Sustaining Treatment programs despite the absence of compelling evidence that they improve patient outcomes.¹ Even less evidence is available to support such well-intentioned private initiatives as the Institute for Healthcare Improvement Conversation Project, the efforts of the Coalition to Transform Advanced Care, the Gundersen Health System’s Respecting Choices program, the widely used Five Wishes advance directive of the Aging with Dignity organization, and the services provided by for-profit companies such as Vital Decisions and Common Practice. **Full text:** <http://goo.gl/9gFs4X>

1. ‘Use of the Physician Orders for Life-Sustaining Treatment Program in the clinical setting: A systematic review of the literature,’ *Journal of the American Geriatrics Society*, published online 29 January 2015. [Noted in the 2 February 2015 issue of Media Watch (#395, p.9)] **Abstract:** <https://goo.gl/bDZqRF>

Hospice care in America

Hospice group’s point: People hurt themselves by delaying the service

AGING EDGE | Online – 3 October 2017 – The hospice community has long held that older, terminally ill adults and their families wait too long to take advantage of a Medicare-funded service that many appreciate once they have it, and the newest report on the topic continues to make that case.¹ About 28% of the people utilizing hospice in 2015 did so for seven days or less, and another 13% for just two weeks... The median length of hospice use – where equal numbers of people were above and below the time span – was 23 days. Advocates for hospice use in the past have said that people wait too long to tap the service because they cling to unrealistic notions of treatment and recovery, or they may simply be uneducated about what the benefit provides to a patient and family. Minorities, in particular, have resisted heavy use of hospice services ... for those expected to have no more than six months remaining. Among hospice patients in 2015, about 87% were Caucasian, 8% African-American, 2% Hispanic and 1% Asian. Among all patients using hospice, about 44% died at home; 32% in a nursing home or assisted living; 15% in a hospice residential unit; and, 8% in a hospital. 46% of Medicare beneficiaries who died made use of hospice for at least a day. Where the service was once primarily thought of for cancer patients, many people use it today while dying from other diseases. While cancer remains the most common disease responsible for the death of hospice patients, it is a diagnosis for only about 28% of them. <https://goo.gl/FRCxZt>



National Hospice and Palliative Care Organization

1. ‘Facts & Figures: Hospice Care in America,’ (2016 Edition), National Hospice & Palliative Care Organization, October 2017. <https://goo.gl/Z18Er7>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *U.S. NEWS & WORLD REPORT* | Online – 2 October 2017 – ‘**Deciding death: New York state is the latest train wreck for doctor-aided death.**’ The latest locomotive of so-called constitutional inevitability, physician-assisted suicide, has been derailed at least temporarily in the last two state supreme court decisions addressing that asserted “fundamental right.” This month, the New York Court of Appeals – New York’s high court – unanimously rejected an effort by activists to impose the practice there by judicial fiat. That decision from New York echoes a similar 2016 ruling by New Mexico’s Supreme Court that no “fundamental right to die” exists. The results in these two cases have certainly dealt a serious strategic setback to death-by-doctor efforts nationally, but the reasons the courts have given for refusing to accept doctor-aided death after having closely examined the arguments have been even more telling. <https://goo.gl/ekhAxU>

International

End-of-life care in Australia

Elderly people dying in emergency departments due to lack of palliative care

AUSTRALIA (Victoria) | *The Age* (Melbourne) – 6 October 2017 – Elderly people are being taken to emergency departments in their final hours of life and dying “under fluorescent lighting in a hospital cubical” because many aged-care homes are not equipped to provide palliative care (PC). It is common for ambulances to be called for people in their final stages of a terminal illness, with nursing home staff not experienced enough to recognise and treat a dying person, health professionals say. Australasian College for Emergency Medicine president-elect, Dr. Simon Judkins, said people who should be receiving PC are sometimes dying in an emergency department cubical before there was time or space to send them to another ward. <https://goo.gl/Kmt9pD>

Related

- AUSTRALIA (Australian Capital Territory) | *Australian Ageing Agenda* (Canberra) – 4 October 2017 – ‘**A new palliative approach for residential aged care.**’ The Palliative Care Needs Rounds Checklist is undergoing a second trial in 12 facilities after a pilot at four sites in 2014-2015 showed the benefits of taking a proactive integrated approach to providing specialist palliative care within aged care facilities. Benefits of the tool include improved skills and knowledge of the care team, cost-effectiveness for the acute sector, and an increased possibility for residents to die in their preferred place with pain and suffering well managed, according to the study.¹ <https://goo.gl/F75UPn>

1. ‘Improving specialist palliative care in residential care for older people: A checklist to guide practice,’ *BMJ Supportive & Palliative Care*, published online 2 August 2017. [Noted in the 7 August 2017 issue of *Media Watch* (#524, p.8)] **Abstract:** <https://goo.gl/vQ6PXV>

End-of-life care in Northern Ireland

Savings plans pose enormous questions over end-of-life care: Commentary

U.K. (Northern Ireland) | *The Belfast Telegraph* – 6 October 2017 – [The four adult hospice providers in Northern Ireland] Marie Curie, Foyle Hospice, Northern Ireland Hospice and Southern Area Hospice highlight very real concerns about the Health & Social Care Trusts’ saving plans. They envisage a huge inevitable impact on the horizon for the most vulnerable people in Northern Ireland. What is concerning, say the organisations, is that the proposals as currently presented will create stress for individuals and undue pressure on end of life (EoL) care services – with patients and their loved ones feeling the force of the impact. The focus of the concern is twofold. With proposals aimed at controlling costs in community care, there is considerable anxiety that the unintended consequences will mean people at this most difficult time in their lives will inevitably experience less than adequate support. The quality of care for people at EoL will be less than it should be, with people being discharged from hospital with inadequate care packages in place, or remaining in hospital because no packages are available. The risk is that hospice care providers may also be unable to discharge patients when they are ready to go home, preventing new patients from being admitted when they need care and support. <https://goo.gl/LYhbpg>

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

Why it really is better for the elderly to die at home: People aged over 79 are four times more likely to be comfortable than if they die in hospital

U.K. (England) | *The Daily Mail* (London) – 4 October 2017 – Older people are more likely to die comfortably if they spend their last hours at home rather than in hospital. A study has found the chances of a good death are four times higher for people in their own house or a care home than those in a hospital

Cont.

ward.¹ Researchers from Cambridge University looked at the “oldest old,” aged over 85, at the end of their lives. With life expectancy soaring, this age group now makes up almost half of people who die and many do so with multiple illnesses including dementia, heart disease and cancer. The study of 180 people found just one in 10 died without suffering symptoms including distress, pain, depression, delirium or confusion. However, interviews with their relatives and carers found their chances of a comfortable death were greatly increased if they were not taken to hospital. Most people express their desire to die at home if at all possible, and the findings have prompted criticism of the National Health Service. Lead author D. Jane Fleming, from the Department of Public Health & Primary Care at the University of Cambridge, said: “The U.K. is not the only country where an urgent review of the funding for older people’s long-term care is needed, along with commitments to staff training and development in this often undervalued sector. It’s heartening that the majority of very old people in our study, including those with dementia, appear to have been comfortable at the end-of-life, but we need to do more to ensure that everyone is able to die comfortably, wherever they are.” <https://goo.gl/LEi3gt>

1. ‘Dying comfortably in very old age with or without dementia in different care settings: A representative “older old” population study,’ *BMC Geriatrics*, published online 26 September 2017. **Abstract:** <https://goo.gl/a2T2Qq>

N.B. Additional information on this study is available at the Cambridge Institute of Public Health website: <https://goo.gl/d8xBFE>

Noted in Media Watch 12 October 2015 (#431, p.9):

- *BRITISH MEDICAL JOURNAL* | Online – 7 October 2015 – ‘**Is home always the best and preferred place of death?**’ Death at home is not necessarily good, and just because a patient did not die at home does not necessarily mean their death occurred in the wrong place. It is important to recognise and accommodate the diversity of patient preferences for place of death, especially in the context of a cultural heterogeneity that is rarely researched or recognised. When home death becomes normatively prescribed there is a risk that it becomes increasingly difficult for patients to express alternative preferences. **Abstract:** <https://goo.gl/e8Essi>

Children can decide their medical treatments under Victoria’s unique advance directive laws

AUSTRALIA (Victoria) | *The Conversation* – 3 October 2017 – All states and territories have varying laws enabling adults to make advance care plans or directives. In Victoria, new legislation will come into effect in March 2018, creating clear obligations for health practitioners to respect advance directives (ADs). A globally unique aspect of Victoria’s Medical Treatment Planning and Decisions Act 2016 is that it allows children to make ADs. In The Netherlands, children aged 12 and over can make advance decisions requesting euthanasia if their parents give consent. ADs in palliative care have also been used in the U.S., but these have no legal authority, merely the status of “moral persuasion.” In Victoria there will be no age limit, so anyone can set out a directive as long as they are competent to do so. This means a person can understand the nature of the treatment they are making decisions about and the potential outcomes if the AD is followed. At first glance, it may seem irre-

sponsible to give children the power over their future medical treatments, which in many cases are a matter of life and death. But respecting the autonomy of young people in their health-care choices is important. It encourages their engagement with treatment, gives voice to their values and provides a sense of empowerment at a time where illness can diminish their control of events. <https://goo.gl/URfQRH>

Specialist Publications

‘**Why are there so few ethics consults in children’s hospitals?**’ (p.11), in *HEC Forum*.

‘**Parenting in childhood life-threatening illness: A mixed-methods study**’ (p.14), in *Journal of Palliative Medicine*.

Cont.

Selected articles on involving children in their medical treatments

- *COCHRANE DATABASE OF SYSTEMATIC REVIEWS* | Online – 29 November 2016 – ‘**Interventions for promoting participation in shared decision-making for children with cancer.**’ There is considerable support for involving children in healthcare decision-making at a level commensurate with their experience, age and abilities. This review highlights the dearth of high-quality quantitative research on interventions to promote participation in shared decision-making for children with cancer. [Noted in the 5 December 2016 issue of Media Watch (#490, p.8)] **Abstract:** <https://goo.gl/YgAUW8>
- *HEALTH PSYCHOLOGY*, 2015;34(4):446-452. ‘**The parents’ ability to attend to the “voice of their child” with incurable cancer during the palliative phase.**’ Whether or not the voice of children approaching the end-of-life is heard often depends on their parents’ ability to give them a voice. Professional caregivers have a difficult task in supporting parents in giving their child his or her voice, while at the same time preserving their – and their parents’ – ability to cope. [Noted in the 27 April 2015 issue of Media Watch (#407, p.11)] **Abstract:** <http://goo.gl/fSgXw5>

N.B. Additional articles on the “child’s voice” in the context of end-of-life care are noted in the 26 September 2016 issue of Media Watch (#481, pp.3,7).

When life is coming to a close: Common myths about dying

NEW ZEALAND | *Stuff.com.nz* (Wellington) – 2 October 2017 – On average 85 New Zealanders die every day. Most will know that they are at the end of their lives. Hopefully, they had time to contemplate and achieve the “good death” we all seek. It’s possible to get a good death in New Zealand thanks to our excellent healthcare system – in 2015, our death-care was ranked third in the world.¹ We have an excellent but chaotic system. Knowing where to find help, what questions to ask, and deciding what you want to happen at the end of your life is important. But there are some myths about dying that perhaps unexpectedly harm the dying person and deserve scrutiny. [For example] the first myth is that positive thinking cures or delays death. It doesn’t. The cultivation of specific emotions does not change the fact that death is a biological process, brought about by an accident, or disease processes that have reached a point of no return. Fighting the good fight, remaining positive by not talking about end of life, or avoiding palliative care (PC), have not been shown to extend life. Instead, positive thinking may silence those who wish to talk about their death in a realistic way, to express negative emotions, realise their time is limited and plan effectively for a good death or access PC early, which has actually been shown to extend life. <https://goo.gl/hy2DPz>

1. New Zealand was ranked 3rd of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ The Economist Intelligence Unit (London, U.K.), October 2015. Commissioned by the Lien Foundation of Singapore [Noted in the 12 October 2015 issue of Media Watch (#431, p.6)] <https://goo.gl/zXrniA>

End-of-life care focuses on helping the dying achieve peace of mind

JAPAN | *Japan Today* (Tokyo) – 1 October 2017 – The End-of-Life Care Association of Japan, launched in 2015, is at the forefront of initiatives to help the elderly and those suffering from terminal illnesses come to terms with their approaching end. While family members and caregivers may have little to offer in the way of medical interventions, they will increasingly be called upon to play a significant role in addressing patients’ emotional and psychological needs in the last stages of their lives. The association has trained more than 2,000 people, including medical and nursing care staffers, through its two-day program. Through lectures and role-play activities, physician Taketoshi Ozawa helps participants understand how they can contribute, regardless of their profession. Among a number of techniques, Ozawa teaches seminar participants to properly “catch the messages” delivered by patients and articulate their suffering in words by repeating their comments, even if they could be construed as very negative.

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Done with the appropriate facial expressions, tone and style of speaking, patients may get a sense that their pain or distress has been understood, said Ozawa, adding, "People feel pleased when there is someone who can understand their suffering." Moments of silence may not necessarily be negative, either, he said, as they could indicate that patients are trying to reveal their true feelings or sort out their thoughts. If silences last too long, he recommends asking what patients are thinking about. Demand for such skills is expected to grow further as Japan's baby boomers will turn 75 or older in 2025 and annual deaths are projected to reach 1.5 million the same year... <https://goo.gl/A3vXwy>

Noted in Media Watch 17 July 2017 (#521, p.15):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 13 July 2017 – **'Meaningful communication prior to death, but not presence at the time of death itself, is associated with better outcomes on measures of depression and complicated grief among bereaved family members of cancer patients.'** Many survey respondents wished to be present at the moment of the patient's death; however, meaningful communication (saying "goodbye") between the patient and family members, and not their presence or absence itself, was associated with better outcomes on measures of depression or complicated grief. Healthcare professionals could consider promoting both mutual communication (relating to preparation for death) between family members and patients before imminent death, as well as the family's presence at the moment of death. **Abstract:** <https://goo.gl/uVQUjv>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (England) | *The Daily Telegraph* (London) – 5 October 2017 – **'Terminally-ill man loses High Court challenge against the law on assisted dying.'** A man who is terminally ill with motor neurone disease has lost his High Court challenge against the law on assisted dying. Retired college lecturer Noel Conway took his case to the Court of Appeal after he was refused permission to bring a judicial review over the blanket ban on providing a person with assistance to die. In March a panel of High Court judges rejected his bid to change the law, saying it would be "institutionally inappropriate" for the court to challenge the decision of Parliament. MPs debated changing the law in September 2015 but the proposals were voted down by a 212 majority. <https://goo.gl/jrTHzV>

Specialist Publications

Online public reactions to functional magnetic resonance imaging communication with patients with disorders of consciousness: Quality of life, end-of-life decision making, and concerns with misdiagnosis

AJOB EMPIRICAL BIOETHICS, 2017;8(1):40-51. Recently, the news media have reported on the discovery of covert awareness and the establishment of limited communication using a functional magnetic resonance imaging (fMRI) neuro-imaging technique with several brain-injured patients thought to have been in a vegetative state. This discovery has raised many ethical, legal, and social questions related to quality of life (QoL), end-of-life decision making, diagnostic and prognostic accuracy in disorders of consciousness, resource allocation, and other issues. Among the most frequent public reactions revealed in the online comments were discussions of the QoL of patients with disorders of consciousness, whether life-sustaining treatment should be withdrawn (and whether the fMRI communication technique should be used to ask patients about this), and misgivings about the accuracy of diagnosis in disorders of consciousness and brain death. These public perspectives are relevant to the obligations of clinicians, lawyers, and public policymakers to patients, families, and the public. Future work should consider how best to alleviate families' concerns as this type of research shakes their faith in diagnostic accuracy, to clarify the legal rules relating to advance directives in this context, and to address the manner in which public messaging might help to alleviate any indirect impact on confidence in the organ donation system. **Abstract:** <https://goo.gl/q8G7mU>

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Noted in Media Watch 13 March 2017 (#503, p.10):

- *JAMA NEUROLOGY* | Online – 6 March 2017 – ‘**The Catch-22 of neuro-imaging, disorders of consciousness, and end-of-life decisions.**’ The authors consider the case where the legitimacy of technology-assisted, medically assisted dying is tested and, however seemingly far-fetched, is already in the public eye. This specific context pertains to patients with brain injuries in whom functional magnetic resonance imaging that relies on blood oxygen levels in particular brain regions, or electrophysiological measurements from the scalp, have been used to reveal signals that are interpreted as consciousness. **Abstract:** <https://goo.gl/IRdrFu>

Noted in Media Watch 8 August 2016 (#474, p.5):

- *QUARTZ* | Online – 30 July 2016 – ‘**A deep flaw has been discovered in thousands of neuroscience studies.**’ Thousands of studies that use functional magnetic resonance imaging (fMRI) are published each year. When you see headlines such as ‘Vegetative state patients can respond to questions’ you can be sure fMRI was involved. A map of the brain based on fMRI scans was greeted as a scientific breakthrough. The latest in a series of papers shows a deep flaw in how researchers have been using fMRI.¹ **Abstract:** <http://goo.gl/0viqHl>

1. ‘Cluster failure: Why fMRI inferences for spatial extent have inflated false-positive rates,’ *Proceedings of the National Academy of Science*, 2016;113(28):7900. **Abstract:** <http://goo.gl/rD6Fh2>

Palliative and end-of-life care in solid organ transplantation

AMERICAN JOURNAL OF TRANSPLANTATION | Online – 4 October 2017 – Most transplant patients suffer from advanced chronic disease, significant symptom burden, and mortality awaiting transplant. Transplantation introduces new risks including perioperative death, organ rejection, infection, renal insufficiency, and malignancy. Numerous publications over the last decade identify that PC is well-suited to support these patients and their caregivers, yet access to palliative care (PC) and research within this population is lacking. This review describes PC and summarizes existing research supporting palliative intervention in advanced organ failure, and transplant populations. A proposed model to provide PC in parallel with disease directed therapy in a transplant program has potential to improve symptom burden, quality of life, and health care utilization. Further studies are needed to elucidate specific benefits of PC for this population. In addition, there is tremendous need for education, specifically for clinicians, patients, and families, to improve understanding of PC and its benefits for patients with advanced disease. **Abstract:** <https://goo.gl/gz1ZP6>

Related

- *LANCET ONCOLOGY* | Online – 28 September 2017 – ‘**Inpatient palliative care during transplantation.**’ It is well known that patients undergoing haemopoietic stem-cell transplantation have substantial physical and psychological morbidity; however, little is known about how to best ameliorate the latter in the long term. Newly published data¹ have shown a lasting benefit to self-reported psychological symptoms from contact with trained palliative care clinicians during the inpatient period. **Abstract:** <https://goo.gl/py98E5>

1. ‘Effect of inpatient palliative care during hematopoietic stem-cell transplant on psychological distress 6 months after transplant: Results of a randomized clinical trial,’ *Journal of Clinical Oncology*, published online 19 September 2017. **Abstract:** <https://goo.gl/r1uJGw>

N.B. Additional articles on organ transplantation in the context of end-of-life care are noted in the 15 May 2017 issue of Media Watch (#512, p.7).



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.20.

Understanding patients' experiences of the wish to hasten death: An updated and expanded systematic review and meta-ethnography

BMJ OPEN | Online – 29 September 2017 – Patients with advanced disease sometimes express a wish to hasten death (WTHD). In 2012, the authors published a systematic review and meta-ethnography of qualitative studies examining the experience and meaning of this phenomenon.¹ Since then, new studies eligible for inclusion have been reported, including in Europe, a region not previously featured, and specifically in countries with different legal frameworks for euthanasia and assisted suicide. The aim of the present study was to update the authors previous review by including new research and to conduct a new analysis of available data on this topic. Fourteen studies involving 255 participants with life-threatening illnesses were identified. Five themes emerged from the analysis: suffering (overarching theme), reasons for and meanings and functions of the WTHD and the experience of a timeline towards dying and death. In the context of advanced disease, the WTHD emerges as a reaction to physical, psychological, social and existential suffering, all of which impacts on the patient's sense of self, of dignity and meaning in life.

Full text: <https://goo.gl/qAAfo7>

1. 'What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients,' *Plos One*, published online 14 May 2012. [Noted in the 28 May 2012 issue of Media Watch (#255, p.8). **Full text:** <https://goo.gl/gBVHac>

Noted in Media Watch 10 July 2017 (#520, p.13):

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 1 July 2017 – '**Assumptions and moral understanding of the wish to hasten death: A philosophical review of qualitative studies.**' Qualitative studies of the wish to hasten death have found that such a wish may have different meanings, none of which can be understood outside of the patient's personal and socio-cultural background, or which necessarily imply taking concrete steps to ending one's life. **Abstract:** <https://goo.gl/cpiKba>

N.B. Additional articles on the desire to hasten death are noted in this issue of Media Watch.

Concerns about cost of future medical care as a factor in advance care planning: Review and agenda for future research

CANCER FORUM, 2017;41(2):42-48. This review explores the evidence for a relationship between healthcare related financial concerns and advance care planning (ACP). Large-scale surveys of public opinion in the U.S. have found that people perceive the financial domain to be an important aspect of quality of life and a major concern regarding end-of-life care, and qualitative research has found that financial worries have been found to be a distinct domain of patients' self-perceived burden on their family. Concerns about being a burden on others have some influence on treatment decisions and ACP. Healthcare related financial concerns have some basis in fact, as consumers' out-of-pocket costs continue to escalate in some countries. **Abstract:** <https://goo.gl/vgbFQV>

N.B. Articles on patients' and families' out-of-pocket expenses in the context of end-of-life care in the U.S. are noted in the 21 November 2016 issue of Media Watch (#488, pp.2-3).



[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>

U.S. hospital mortality metrics

Omitting DNR orders from risk-adjusted mortality measurements could skew rankings

CARDIOVASCULAR BUSINESS | Online – 3 October 2017 – A team of researchers who analyzed rates of do-not-resuscitate (DNR) orders in California are suggesting DNR mortality numbers should be taken into account when calculating hospital risk-adjusted heart failure mortality metrics. Current methods used to compare and assess hospitals don't take patients' DNR status into account, lead author Jeffrey Bruckel, and colleagues wrote in a recent study.¹ This isn't ideal, since DNR orders vary across hospitals and tend to predict higher in-hospital mortality. Higher mortality rates could mean lower national rankings for hospitals, resulting in funding cuts and other issues. The U.S. pours \$30.7 billion into medical care for heart failure annually, according to Bruckel's research, and heart failure hospitalizations are a focus of the Centers for Medicare & Medicaid. For many cardiovascular patients, though, that's not enough. Some individuals among the one million annually admitted heart patients suffer from advanced heart failure, which can come hand-in-hand with lower quality of life and additional co-morbidities. In these cases, patients might request a DNR order – called an “early DNR” if the request is submitted within 24 hours of hospital arrival. “Failure to account for patient DNR status when determining hospital mortality rates may strongly impact hospital mortality measurements and, thus, hospital rankings,” Bruckel and co-authors wrote. **Full text:** <https://goo.gl/FTVuNp>

1. 'Variation in do-not-resuscitate orders and implications for heart failure risk-adjusted hospital mortality metrics,' *Journal of the American College of Cardiology: Heart Failure*, 2017;5(10):743-752. **Abstract:** <https://goo.gl/uA6VMt>

Noted in Media Watch 8 November 2010 (#174, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 November 2010 – ‘**Hospital mortality rates: How is palliative care taken into account?**’ Using mortality rates to measure hospital quality presumes hospital deaths are medical failures. Palliative care and hospice leaders need to educate themselves and hospital administrators about the extent to which mortality rates take end-of-life care into account. **Abstract:** <https://goo.gl/ybqC4M>

Junior doctors and limitation-of-care orders: Perspectives, experiences and the challenge of dealing with persons with dementia

EUROPEAN JOURNAL FOR PERSON CENTERED HEALTHCARE, 2017;5(3):373-388. Globally, junior doctors play a central role in completing limitation of care orders (LCOs). This study aims to guide improvement of LCO utility by ascertaining junior doctor perspectives, LCO experiences and identifying challenges encountered in LCOs for patients with dementia, a particularly complex patient group. Participants [in this study] described inconsistent support, a lack of preparedness, a vague understanding of related hospital policies and inadequate knowledge and experience when it came to completing LCOs. Although participants acknowledged the additional nuances of capacity and prognosis assessment for patients with dementia, they did not feel that the processes for completing LCOs were significantly different for these persons. Many also recognised that decisions were often made without adequate consultation with the relevant stakeholders in this patient group. **Abstract:** <https://goo.gl/uvrWzP>

Why are there so few ethics consults in children's hospitals?

HEC FORUM | Online – 3 October 2017 – In most children's hospitals, there are very few ethics consultations, even though there are many ethically complex cases. The authors hypothesize that the reason for this may be that hospitals develop different mechanisms to address ethical issues and that many of these mechanisms are closer in spirit to the goals of the pioneers of clinical ethics than is the mechanism of a formal ethics consultation. To show how this is true, the authors review the history of collaboration between philosophers and physicians about clinical dilemmas. They describe the different venues that have developed at one children's hospital to address ethical issues. **Abstract:** <https://goo.gl/r6Un8Y>

Palliative care – carers and supportive networks

THE HIPPOCRATIC POST | Online – 5 October 2017 – Have you ever looked after someone who has died? And if so, what do you think was the most important thing to him or her? In the vast majority of cases, people will answer that question with “being with family members and loved ones.” The fact is that when we are dying, we want to be supported by a tight-knit group of 4-6 people usually in a familiar place. That is our inner network. And beyond that inner circle there can be up to 50 people who support the carers in the centre, without intruding on the privacy of the dying person. This is a natural pattern and it works very well. It means that the entire supportive network can become more resilient by everyone playing their part. The dying person benefits and the carers at the heart of the end-of-life drama benefit too. Carers have their own lives to get on with and this can continue if the burden is shared. Our job as clinicians is to make sure that this network is working and to offer support when needed to get the networks established and working properly. Of course, professional

care is essential, but it is not central when someone is dying. Network enhancement is of primary importance. We can have a tremendous impact on the last part of someone’s life, as well as helping the carers, by interacting positively with the network. **Full text:** <https://goo.gl/sd9gbX>

Social support following bereavement: The role of beliefs, expectations, and support intentions

DEATH STUDIES | Online – 6 October 2017 – Little is understood about the community’s recognition of grief and intentions to provide social support to grieving persons. Survey respondent gender, age, and bereavement status all had some association with expectations of grief, intentions to support, perceived helpfulness of support attempts, and opinions towards the diagnostic classification of grief. Given that most bereavement support is informal, this study informs the development of community capacity to provide constructive, timely bereavement support. **Abstract:** <https://goo.gl/hZ4h6F>

Noted in Media Watch 25 November 2013 (#333, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 19 November 2013 – ‘**Identifying changes in the support networks of end-of-life carers using social network analysis.**’ This paper analyses the caring networks of people with a terminal illness who are being cared for at home and identifies changes in these caring networks that occurred over the period of caring. The results showed an increase in the size of the networks and that ties between the original members of the network strengthened. **Full text:** <https://goo.gl/hTBVoB>

Noted in Media Watch 23 July 2012 (#263, p.9):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 16 July 2012 – ‘**A social capital framework for palliative care: Supporting health and well-being for people with life-limiting illness and their carers through social relations and networks.**’ Social relations and networks are vital for sustaining and enhancing end-of-life care. The social capital concept supports a framework to understand the association between social relations and well-being; yet, to date, there has been very limited investigation of social capital in the palliative care literature. **Abstract:** <https://goo.gl/nErW7k>

N.B. Articles on the concept of “compassion communities,” particularly in the context of end-of-life care, are noted in the 7 August 2017 issue of Media Watch (#524, p.6).

End-of-life care among immigrants: Disparities or differences in preferences?

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 2 October 2017 – Although describing a “good death” is an existentially challenging exercise, most people, if asked to do so, would note the importance of the presence of friends and family, relief from distressing symptoms, time at home, completing life goals, and other values. Although these goals are likely shared quite widely, how they are prioritized, and how they relate to other goals, may vary among individuals and across cultures.¹ Thus, in studies seeking to evaluate end-of-life care (EoLC), it is essential to differentiate observed variation that

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results from differences in quality of care from variation that is attributable to differences in the underlying preferences of patients or families. For example, hospital-based deaths are often viewed as a marker of low-quality care based on evidence that most individuals from Western cultures prefer to die at home.² However, some patients may prefer death in hospitals under certain circumstances, perhaps owing to greater abilities to receive palliation for severe symptoms, such as refractory dyspnea, or so as not to burden loved ones with caring for them at home. If such nuanced preferences vary among cultures, then comparing care quality across cultures by this metric might yield erroneous conclusions. These difficulties in evaluating the quality of EoLC challenge the interpretation of the elegant analyses of EoLC differences among immigrants to and native residents of Ontario, Canada, reported in this issue of the *Journal of the American Medical Association*.³ **Full text:** <https://goo.gl/unQG1K>

1. 'Common or multiple futures for end-of-life care around the world? Ideas from the "waiting room of history,"' *Social Science & Medicine*, published online 9 November 2016. [Noted in the 21 November 2016 issue of *Media Watch* (#488, p.6)] **Abstract:** <https://goo.gl/8wL1Jd>
2. 'Is home always the best and preferred place of death?' *British Medical Journal*, published online 7 October 2015. [Noted in the 12 October 2015 issue of *Media Watch* (#431, p.9)] **Abstract:** goo.gl/H2wZSz
3. 'Association between immigrant status and end-of-life care in Ontario, Canada,' *Journal of the American Medical Association*, published online 2 October 2017. **Full text:** <https://goo.gl/GRkEsY>

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

Quality hospice care in adult family homes: Barriers and facilitators

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 30 September 2017 – Study findings suggest that the adult family home (AFH) setting amplifies both the benefits and challenges associated with receipt of hospice. Homes that have effective working relationships with hospices enjoy an "extra set of hands," a "lifeline," and expertise regarding pain and symptom management. In these homes, the intimate environment provides a backdrop for rich connections, personalized care, and peace of mind for family members. In contrast, initiating hospice services for a resident in an AFH without a joint commitment to palliation or with a territorial versus collaborative approach to end-of-life care (EoLC) can increase stress for families and exacerbate misunderstandings or feelings of mistrust. Physicians and others providing services to older adults should remain mindful of the advice of experienced family members, who emphasized the importance of finding an AFH with a track record of positive collaborations with hospice agencies if the need for EoLC is anticipated. **Full text:** <https://goo.gl/UTgV4j>

The strengths and challenges of palliative day-care centers: Qualitative study with the professionals involved

JOURNAL OF PALLIATIVE CARE | Online – 3 October 2017 – Palliative day-care centers are a marginal service within the palliative care landscape. Relevant research on the potential and added value of this service model is lacking, and it may therefore be underappreciated. Participants [in this study] were professional representatives of all 5 Flemish palliative day-care centers: 7 participants for the individual interviews and 6 participants for the focus group. Five strengths were identified: 1) Unique care model; 2) Contact with peers in a non-clinical environment; 3) A reliable and competent multi-professional team; 4) Care tailored to the individual; and, 5) Respite for family caregivers. The most significant challenges were: 1) Optimizing government funding; and, 2) Achieving sufficiently high occupancy and referral. According to interviewees, this latter challenge was due to the low visibility of the service to professionals and the public, unclear referral criteria, and the psychological threshold for referral among patients and professionals. Palliative day-care centers strive to provide unique services for patients with advanced illness. However, negotiating adequate funding and raising referral by changing current perceptions are paramount to unlocking their potential. Scientific analysis of cost utility and patient outcomes associated with their use is necessary. **Abstract:** <https://goo.gl/xMPwCf>

Evaluating the economic impact of palliative and end-of-life care interventions on intensive care unit utilization and costs from the hospital and healthcare system perspective

JOURNAL OF PALLIATIVE MEDICINE | Online – 3 October 2017 – Understanding the impact of palliative care (PC) interventions on intensive care unit (ICU) costs and utilization is critical for demonstrating the value of PC. Performing these economic assessments, however, can be challenging. The purpose of this special report is to highlight and discuss important considerations when assessing ICU utilization and costs from the hospital perspective, with the goal of providing recommendations on methods to consider for future analyses. ICU length of stay (LoS) and associated costs of care are common and important outcome measures, but must be analyzed properly to yield valid conclusions. There is significant variation in costs by day of stay in the ICU with only modest differences between an ICU day at the end of a stay and the first day on the acute care floor; this variation must be appropriately accounted for analytically. Furthermore, reporting direct variable costs, in addition to total ICU costs, is needed to understand short-term and long-term impact of a reduction in LoS. Importantly, incentives for the hospital to realize savings vary depending on reimbursement policies. ICU utilization and costs are common outcomes in studies evaluating PC interventions. Accurate estimation and interpretation are key to understanding the economic implications of PC interventions. **Abstract:** <https://goo.gl/5wzs7C>

Parenting in childhood life-threatening illness: A mixed-methods study

JOURNAL OF PALLIATIVE MEDICINE | Online – 3 October 2017 – Participants (concurrent, cross-sectional mixed-methods study) included 31 parents of children with life-threatening illnesses who have healthy siblings and were admitted to a children's hospital. Qualitative interviews revealed how parents managed children's needs and their perceptions of the toll it takes. Quantitative data revealed that parents prioritized "making sure my child feels loved" highest for ill and healthy children. Other goals for healthy siblings focused on maintaining emotional connection and regularity within the family and for ill children focused on illness management. Mixed-methods analysis revealed that parents engaged in a process decision making and traded-off competing demands by considering needs which ultimately transformed the meaning of parenting. Future research can further examine trade-offs and associated effects, how to support parent problem-solving and decision-making around trade-offs, and how to best offer social services alongside illness-directed care. **Abstract:** <https://goo.gl/tEySF2>

Palliative care in neurology

MAYO CLINIC PROCEEDINGS, 2017;92(10):1592-1601. Neurologic conditions tend to have high symptom burdens, variable disease courses, and poor prognoses that affect not only patients but also their families and caregivers. Patients with a variety of neurologic conditions such as Parkinson disease, dementia, amyotrophic lateral sclerosis, brain tumors, stroke, and acute neurologic illnesses have substantial unmet needs that can be addressed through a combination of primary and specialty palliative care (PC). The complex needs of these patients are ideally managed with a comprehensive approach to care that addresses the physical, psychological, social, and spiritual aspects of care in an effort to reduce suffering. Early discussions about prognosis, goals of care, and advance care planning are critical as they can provide guidance for treatment decisions and allow patients to retain a sense of autonomy despite progressive cognitive or functional decline. With the rapid growth in PC across the U.S., there are opportunities to improve the PC knowledge of neurology trainees, the delivery of PC to patients with neurologic disease by both neurologists and non-neurologists, and the research agenda for neuro-PC. **Full text:** <https://goo.gl/Zk4adw>

Noted in Media Watch 7 August 2017 (#524, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 3 August 2017 – **'Integrating palliative care into neurology services: What do the professionals say?'** The authors present survey results describing the current levels of collaboration between neurology and palliative care (PC) services and exploring the views of professionals towards a new short-term integrated PC service. Collaborations between the two specialties were reported as being "good/excellent" by 36% of neurology and by 58% of PC professionals. However, nearly half (45%) of neurology compared with only 12% of PC professionals rated current levels as being "poor/none." **Abstract:** <https://goo.gl/UxpJfY>

Training otolaryngologists in palliative care delivery: An underutilized opportunity

OTOLARYNGOLOGY: HEAD & NECK SURGERY | Online – 3 October 2017 – Abundant evidence has demonstrated the beneficial effect for the early incorporation of palliative care (PC) in the treatment paradigm for patients with chronic diseases and malignancies, with findings supporting its positive effect on patients' quality of life as well their survival. Particularly for otolaryngologists, the unique morbidities of head and neck cancer make our patients especially vulnerable and even more in need of the support and benefits that can come from PC. While increased consultation with PC providers for patients with head and neck cancer is a good first step, training otolaryngologists to develop their own "primary PC competencies" is key for improving our patients' outcomes. **Abstract:** <https://goo.gl/9CDYLP>

N.B. Additional articles on palliative care for patients living with head and cancer noted in the 1 May 2017 issue of *Media Watch* (#510, p.15).

Cultural challenges in implementing palliative care services in Iraq

PALLIATIVE MEDICINE & HOSPICE CARE, 2017;SE(1):S19-S23. The concept of palliative care (PC) among Iraqi people and patients is primitive; the majority of them have no idea what PC is about. As long as there is no national PC program – most of the medical health care providers themselves are also not familiar with PC – it is not more than a terminology they had read about during under- and post-graduate course if this ever happened. The strength of the PC field in this country lies in the area of culture, religion and psychosocial entities. Yet, negative impacts also exist in the same culture. Health care in Iraq has witnessed remarkable regression in the last three decades parallel with political and economic troubles, struggling to provide basic diagnostic and therapeutic facilities. Hence, the idea of PC seems to be "luxurious" in these bad circumstances. Those in power and decision makers may think in this way: "budget from Ministry of Health or from non-government organizations is to be spent on buying essential medicine rather than improving the quality of life or decreasing the suffering of patients." Community awareness is very important and even within the medical community PC terminology is still embryonic and limited to part of the oncology medicine. **See sidebar (right).**

Palliative care in the Eastern Mediterranean Region



A recent issue of *Palliative Medicine & Hospice Care* focused on end-of-life care in the Eastern Mediterranean Region, specifically Iran, Iraq, Israel, Jordan, Lebanon, Morocco, Palestine, Turkey and the United Arab Emirates. Journal contents page (with links to the **full text** of each article): <https://goo.gl/7w5rWL>

N.B. See 'Atlas of Palliative Care in the Eastern Mediterranean Region,' a joint project of the Lebanese Center for Palliative Care and the Institute for Culture & Society, University of Navarra, Spain. [Noted in the 22 May 2017 issue of *Media Watch* (#513, p.14)] <https://goo.gl/i5Lc4e>

Noted in *Media Watch* 13 March 2017 (#503, p.14):

- *THE LANCET ONCOLOGY*, 2017;18(3):e176-e184. '**Barriers to, and opportunities for, palliative care development in the Eastern Mediterranean Region.**' Several barriers exist to the development and expansion of palliative care (PC) delivery in this region, including the absence of PC in national policies, little partnership working, insufficient PC education for health-care professionals and volunteers, poor public awareness, and gaps in access to essential pain-relief medicines. **Full text:** <https://goo.gl/apSSca>

What does the media say about palliative care? A descriptive study of news coverage in written media in Spain

PLOS ONE | Online – 2 October 2017 – A total of 627 articles were identified, of which 359 (57%) were published in printed newspapers ... and 268 (43%) in digital media sources. In general, they appeared mainly in sections concerning health (23%), culture and society (18%), and general/home news (15%). In printed editions, just 2% were found in the health section and nearly 70% in culture and society and general/home news. Most of the articles were informative in nature and contained socio-political messages (90%). Statements by palliative care (PC) professionals were found in 35% of the articles and by politicians in 32%. The most frequent content was related to facing end of life (74%) and patient quality of life (70%). The Spanish written media reflects the socio-political interest aroused by PC. Nevertheless, mes-

sages circulating about PC do not describe professional practice, or the contribution of the same for patients. Content more in line with the clinical practice might help contribute to the development of this new area of medicine. **Full text:** <https://goo.gl/RBBuuJ>

Oxford Textbook of

Palliative Medicine

'Communications with the Public, Politicians, and the News Media,' by Barry R. Ashpole. **Full text:** <https://goo.gl/F4TR4J>

Noted in Media Watch 8 February 2016 (#448, p.12):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(1):32-34. '**What message do Spanish media convey about palliative care?**' The presence of palliative care in the media does not guarantee the communication of positive messages related to its benefits for patients and families. Ideologically and politically charged messages linked to news stories and social debates can overshadow messages that reflect the reality of care or have an informative purpose.

N.B. Access requires a subscription. Contents page for the January/February issue: <http://goo.gl/qIWex7>

Commentary

Changing the conversation at the end of life: How the language we use impacts surrogates' decision-making burden

PROCEEDINGS, 2017;30(4):473-474. As a palliative care professional, I am frequently consulted when providers are struggling with how to care when cure is not possible. This is never an easy situation, but a few basic and universal principles can guide us through these conversations. First, we must understand both the biology and biography of our patient. Where is our patient in the trajectory of disease, but also who and where is our patient in the story of his or her life? Next, armed with that knowledge, we must utilize both the art and science of medicine to recommend interventions we believe are most appropriate – not for the disease, but for the patient who suffers with the disease. Finally, we must communicate our recommendation carefully, for language truly matters. **Full text:** <https://goo.gl/Ao42QL>



Related

- *CURRENT ONCOLOGY REPORTS* | Online – 2 October 2017 – '**Using geriatric assessment strategies to lead end-of-life care discussions.**' Developing a roadmap for these conversations can be challenging. Patients and caregivers may have expectations that are not concordant with what is reasonably achievable if the patient is frail. Measuring baseline cognition, nutritional status, and physical function and discussing goals of care are all essential pieces of information that can be obtained through a comprehensive geriatric assessment. **Abstract:** <https://goo.gl/7C7x1J>

Cont.

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 3 October 2017 – ‘**When a patient is reluctant to talk about it: A dual framework to focus on living well and the possibility of dying**’ The authors aim to help outpatient clinicians working with seriously ill patients ambivalent, uncomfortable, or fearful of further discussion about the future. They describe a dual framework that focuses on living well while acknowledging the possibility of dying and equips clinicians to help patients hold both possibilities. **Abstract:** <https://goo.gl/EW23zm>

Communicating bad news: An integrative review of the nursing literature

REVISTA BRASILEIRA DE ENFERMAGEM, 2017;70(5):1089-1095. This review enabled us to learn the reality of breaking bad news in the cultural and professional context, showing the strong cultural influence on the work process of nurses in developed countries; where they have greater autonomy in discussing news with patients. However, it is notable that the cultural issue influences nurses, making them a submissive and non-autonomous professional in the communication of news to patients and their families. Sometimes this behavior becomes comfortable for the nurse, when compared to other health professionals. Regarding the religious cultural aspect, the impact is characterized by the patient's desire to fully understand their diagnosis and/or prognosis and also to make decisions concerning their treatment. It has become clear that breaking bad news is prevalent and frequently approached in the areas of oncology and palliative care, due to the complexity of the treatment and the close relationship with the terminal phase of life. Nurses have an active role in the transmission of messages in this context; their behavior and how the information is disclosed is relevant because it will influence the thought processes and how the patient will receive and assimilate this information. Finally, despite the importance of communicating bad news, the subject is still little discussed in the literature. It is extremely relevant to encourage studies in the form of reports of experience, research and reviews so that scientific evidence can strengthen the practice of health professionals and promote quality care. **Full text:** <https://goo.gl/vMrkHF>

N.B. English language article.

Considerations on the role of palliative care in the mourning period

REVISTA DE CERCETARE SI INTERVENTIE SOCIALA, 2017;58(9):201-208. Death is a universal and inevitable phenomenon, with strong emotional loading for both the dying and those around them (family members or caregivers, of a medical or psychosocial, spiritual nature). The main response to the passing of someone dear is grief, which is usually reversible; however, in some cases, it may generate important general morbidity and mortality risks. Palliative care represents a complex approach meant to improve the quality of life of terminal patients and of their family members, by preventing and mitigating physical pain, as well as psychosocial and spiritual issues. In this field, responsibility toward the patient extends to his/her family after the patient's death. In this paper, the authors analyze the sources of mourning labour, as well as the intervention means suitable for the genuine existential crisis entailed by the passing of a

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Universal health coverage and palliative care – Don't leave those suffering behind

<https://goo.gl/diYn7i>

loved one. The importance of the theme resides in the fine line between physiological grief and depression (with all the risks it involves) and in the need of identifying ways to familiarize the family with the idea of death, both before the passing of the dying and afterwards (to facilitate the mourning labour of those left behind and to avoid its complications). **Abstract:** <https://goo.gl/iaCFmu>

N.B. English language article. To access the full text, click on “Download: Considerations on the Role of Palliative Care in the Mourning Period.’

Related

- *NORDIC PSYCHOLOGY* | Online – 25 September 2017 – ‘**Could grief be a mental disorder?**’ In the fifth edition of the diagnostic manual of the American Psychiatric Association (the DSM-5), published in 2013, a new diagnosis for complicated grief was included named “persistent complex bereavement disorder.” When the World Health Organization publish its next edition of its system, the International Classification of Diseases, in 2018, it is expected that a new diagnosis called “prolonged grief disorder” will also be included in this manual. In this article, the author presents the emerging diagnostic criteria for grief and situate the rise of the psychiatric grief diagnoses in the context of what has been called the “diagnostic culture” of contemporary society. **Abstract:** <https://goo.gl/X75KSk>

N.B. Additional articles on depressive episodes following the loss of a loved one and the debate surrounding the diagnostic manual of the American Psychiatric Association (DSM-5) are noted in the 19 June 2017 issue of *Media Watch* (#517, p.8).

- *PLOS ONE* | Online – 4 October 2017 – ‘**Bereavement support for family caregivers: The gap between guidelines and practice in palliative care.**’ Timeliness and consistency of relationship is crucial to building rapport and trust in the service’s ability to help at post-bereavement as well as a focus on the specific rather than the generic needs of the bereaved. In light of these limitations, palliative care (PC) services might do better investing their efforts principally in assessing and supporting family caregivers during the pre-bereavement period and developing community capacity and referral pathways for bereavement care. The authors findings suggest that bereavement support in Australian PC services has only a tenuous relationship with guidelines and assessment tools, a conclusion also drawn in studies from other countries, emphasizing the international implications of this study. **Full text:** <https://goo.gl/GcUqnn>
- *PRACTICAL NEUROLOGY* | Online – 28 September 2017 – ‘**Sudden unexpected death in epilepsy, the aftermath: Supporting the bereaved.**’ Sudden unexpected death in epilepsy is a recurring calamity, yet there is little evidence to guide standards of care for supporting the bereaved. Grief in bereavement includes loss, feelings of guilt, anger and blame. There is also the shock and trauma of the sudden event. How can this be alleviated? This paper focuses on guiding the physician to support the bereaved, while recognising the limited evidence and the varying circumstances that may not always facilitate this. The authors propose a pathway of care and mode of communication with the deceased’s family, with whom contact is currently limited.. **Abstract:** <https://goo.gl/GJRQbk>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BRITISH JOURNAL OF PSYCHIATRY*, 2017;211(4):238-245. ‘**When unbearable suffering incites psychiatric patients to request euthanasia: qualitative study.**’ The concept of “unbearable suffering” is central to legislation governing whether euthanasia requests may be granted, but remains insufficiently understood, especially in relation to psychiatric patients. The author identified five domains of suffering: medical, intrapersonal, interpersonal, societal and existential. Hopelessness was confirmed to be an important contributor. The lengthy process of applying for euthanasia was a cause of suffering and added to experienced hopelessness, whereas encountering physicians who took requests seriously could offer new perspectives on treatment. The development of measurement instruments to assess the nature and extent of suffering as experienced by psychiatric patients could help both patients and physicians to better navigate the complicated and sensitive process of evaluating requests in a humane and competent way. **Full text:** <https://goo.gl/GCFsZS>

Cont.

- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 5 October 2017 – ‘**Morally-relevant similarities and differences between assisted dying practices in paradigm and non-paradigm circumstances: Could they inform regulatory decisions?**’ There has been contentious debate over the years about whether there are morally relevant similarities and differences between the three practices of continuous deep sedation until death, physician-assisted suicide, and voluntary euthanasia. Surprisingly little academic attention has been paid to a comparison of the uses of these practices in the two types of circumstances in which they are typically performed. The author’s analysis suggests that a bright moral line cannot be demonstrated between any two of the practices in paradigm circumstances, and that there are significant, morally-relevant distinctions between their use in paradigm and non-paradigm circumstances. A thought experiment is employed to illustrate how these outcomes could possibly inform the decisions of hypothetical deliberators who are engaged in the collaborative development of assisted dying regulatory frameworks. **Abstract:** <https://goo.gl/7xq6o9>

- *MORTALITY* | Online – 3 October 2017 – ‘**Helping a loved one die: The act of assisted dying in New Zealand.**’ Assisted dying although illegal in New Zealand, is often in the spotlight and surrounded by much debate. Moreover, while sentencing may take into account the motivation (ending of suffering) of those who assist, this is done on a case-by-case basis, with the process and resulting punishment extremely taxing on the offender psychologically, physically and emotionally. The present study explored the personal experiences of family members who had assisted with the death of a loved one and resulting consequences (legal, emotional, psychological). Findings suggest that the act of assisted dying was motivated primarily by altruistic reasons, driven by empathy and compassion towards a suffering loved one. The act of assisted dying resulted in unforeseeable life-changing events such as imprisonment, activism for legalisation of euthanasia, and loss of significant relationships. The overall experience was characterised by coping strategies, predominantly negative emotional states, and a deliberate defiance of established legal and medical systems. Participants represented a sub-group of altruistic offenders. Findings draw attention to the four principles of medical ethics – autonomy, beneficence, non-maleficence and justice in relation to assisted dying. **Abstract:** <https://goo.gl/3Leq7g>

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[Something Missed or Overlooked?](#)

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

Media Watch: Online

Updated 10.09.2017

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/3oecYD>

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 'Media Watch by Barry Ashpole']

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/IXO4mD>

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

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLgxy2>
[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>
[Scroll down to 'Additional Resources']

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

ONTARIO | Mississauga Halton Palliative Care Network: <https://goo.gl/ds5wYC>
[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

Europe



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

HUNGARY | Magyar Hospice Alapítvány: <http://goo.gl/5d119K>

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

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

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