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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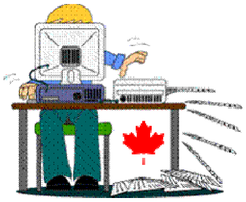

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Compiled & Annotated by Barry R. Ashpole

Effecting change in the illness experience: Scroll down to Specialist Publications and 'Expert discussion on taking a spiritual history' (p.11), in *Journal of Palliative Care*.

Canada

Legally speaking, an "emergency contact" doesn't cut it in Ontario

ONTARIO | TVO Ontario (Toronto) – 28 June 2017 – For reasons that can range from estrangement to embarrassment, some people don't want family involved in their health care. Perhaps they regularly list a non-relative as their emergency contact on medical forms, employee files, or waivers. But under Ontario's health and privacy laws, that's not enough. "'Emergency contact' is not a legally defined entity," explains Nadia Incardona, an emergency physician … and a clinical adviser with Hospice Palliative Care Ontario. "It's the nomenclature that's been passed down historically, but it has zero founding in the [province's] Health Care Consent Act." That act … protects the rights of capable people to make their own health-care decisions; when they are incapable of doing so, the act also sets out a hierarchy of "substitute decision-makers" (SDMs), which doctors must then consult. "By law," says Incardona, "everyone in Ontario automatically has an SDM – even if you dislike or disagree with them." The hierarchy consists of nine potential SDMs. Although it's easy for Ontarians to register themselves online as organ donors with the Ministry of Health, where any doctor can find that information, no similar registry exists for SDMs. That means there's no sure fire way to get this information from patient to doctor at urgent times. A March 2017 report from the Law Commission of Ontario concluded that the current SDM system is confusing, lacks coordination, and should be regulated.[1] https://goo.gl/KgyG42

Specialist Publications

'Choosing wisely for frail residents of long-term care homes: Six recommendations' (p.7), in *BC Medical Journal.*

'The home care conversation we're not having' (p.7), in *Canadian Medical Association Journal.*

'The care experiences of patients who die in residential hospice: A qualitative analysis of the last three months of life from the views of bereaved caregivers' (p.13), in *Palliative & Supportive Care.*

'Case review of medically assisted deaths on Vancouver Island' (p.16), in *BC Medical Journal.*

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1. 'Final Report on Legal Capacity, Decision-making and Guardianship,' The Law Commission of Ontario, March 2017. https://goo.gl/DfFShu

More than 11,000 Quebecers register directives for end-of-life care

QUEBEC | CBC News (Quebec City) – 26 June 2017 – More than 11,000 Quebecers have notified the province of the treatments they are willing and unwilling to receive in the event they can't consent to medical care... They are doing so by filing what are called advance medical directives (AMD) with a provincial registry. The process was created under Quebec's 2014 Act respecting end-of-life care and has been in place for a year.[1] According to the province, AMDs apply in specific clinical situations that are not necessarily emergency situations, including: 1) End-of-life situations; 2) Situation of severe, and irreversible loss of cognitive functions; and, 3) Another situation of severe, irreversible loss of cognitive functions. In total, 11,386 Quebecers have filed AMD forms with the province. Of that number, 6,767 are over the age of 65 and 2,806 are between the ages of 55 and 64. The remaining 1,813 people were between the ages of 18 and 54. https://goo.gl/KWWps4

1. 'Act respecting end-of-life care (Bill 52),' Minister of Health & Social Services, Government of Quebec, 2014. https://goo.gl/stvfTA

U.S.A.

End-of-life decisions for incapacitated adults: Caught between a conflict of laws

NEW YORK LAW JOURNAL | Online – 3 July 2017 – The common law principle is well-settled that every individual of sound mind and adult years has a right to determine what should be done with his or her own body. The right to accept or reject medical treatment has long been recognized for competent adults. However, for individuals who lack capacity, this right was not always recognized, often times forcing individuals to be subjected to treatments that went against their beliefs and desires. Unfortunately, the imposition of unwanted medical treatment still happens today in the context of incapacitated patients who reside in hospitals and nursing homes due to an apparent conflict between limitations placed on the powers of a guardian in some court jurisdictions versus the standards set forth under the Family Health Care Decisions Act. Signed into law in 2010, the Act ... reflected a major departure regarding the standard under which life sustaining treatment may be terminated for a mentally incompetent person. It flipped the switch from the prior "presumption of life" to a "presumption of termination" (absent indication from the principal to the contrary), and did so especially in the context of artificial nutrition and hydration. Intending to fill a gap in New York law by establishing a decision-making process applicable for patients lacking decision-making capacity in hospitals and nursing homes who do not have advance directives, the Family Health Care Decisions Act allows surrogate decisions regarding the withdrawal or withholding of life-sustaining treatment based on a best interests standard, subject to the medical standards set forth in the statute. https://goo.gl/R1Ty31

Specialist Publications

'How often is end-of-life care in the U.S. inconsistent with patients' goals of care?' (p.9), in *Journal of Palliative Medicine.*

'New study uncovers low rates of palliative care referral in patients with end-stage liver disease' (p.12), in *News Medical.*

'Poor caregiver mental health predicts mortality of patients with neurodegenerative disease' (p.7), in *Proceedings of the National Academy of Sciences of the United States of America*.

Cont. next page.

Noted in Media Watch 19 June 2017, #517 (p.10):

- *JOURNAL OF CLINICAL ETHICS*, 2017;28(2):117-121. **'A patient (not) alone.'** This case analysis examines questions that arise when an ethically appropriate recommendation initially appears to be in conflict with the legally appropriate recommendation. The case involves a dying, incapacitated octogenarian who had friends who were willing to share her values, but not to make decisions on her behalf. These circumstances put the patient in the unique position of being legally considered a "patient alone," but who was ethically like a patient with surrogates – distinctions that are crucial when making end-of-life decisions under the New York Family Health Care Decisions Act. https://goo.gl/7NdEr1

I learned how to break bad news to patients and loved ones more from business school than medical school

THE LOS ANGELES TIMES | Online – 27 June 2017 – A recent study of medical curricula[1] ... found the average time dedicated to end-of-life care is 13 hours spread across multiple courses over four years. In a recent survey of graduating medical students,[2] 42% reported that they were never taught how to talk to patients about dying, and 48% reported that they never received feedback on how they deliver bad news. No doubt this is one reason why so many people have personal stories of the "I can't believe my doctor said that to me" variety. Just the other day, I listened as one of my patients described the anger she felt when, days before her husband died of cancer, a doctor checked his phone while they were discussing her husband's treatment. By contrast, many business leaders direct much of their energy toward mastering the art of difficult conversations. As one of my business school professors liked to say, leadership is all about getting the details right in critical conversations. Why do medical schools devote so little time to cultivating these communication skills in their students? Few conversations are of greater consequence than those in which a doctor must tell someone their loved one is dying. Our conversational shortcomings in these moments prevent patients from understanding difficult diagnoses, leading some to pursue futile end-of-life treatments that do not increase the quality or duration of their lives. There isn't one way to teach these skills, but a handful of medical schools are pointing the way forward. https://goo.gl/GceX5t

1. 'A 40-year history of end-of-life offerings in U.S. medical schools: 1975-2015,' *American Journal of Hospice & Palliative Medicine*, published online 10 March 2016. [Noted in Media Watch 14 March 2016, #453 (p.8)] http://goo.gl/pa3cCV

2. 'Determinants of medical students' perceived preparation to perform end-of-life care, quality of end-of-life care education, and attitudes toward end-of-life care,' *Journal of Palliative Medicine*, 2010;13(3): 319-326. https://goo.gl/dVH9VH

Emergency rooms adding palliative care to treat seniors' chronic conditions

OHIO | *The Columbus Dispatch* – 26 June 2017 – Although palliative care has been around for decades, hospitals in central Ohio and across the country have only recently started offering the service in their often-hectic emergency departments (ERs). Historically, ERs have treated victims of gunshots, crashes and other traumatic injuries, plus people who have heart attacks, strokes and other medical emergencies. But as the nation's elderly population has swelled, ERs have been flooded by seniors and others with chronic and, sometimes, fatal illnesses who often need more or different things than just the traditional "life-extending" care provided there. Those 65 or older made nearly 25 million ER visits in 2014, up from 22 million in 2010, according to the Agency for Healthcare Research & Quality, a division of the U.S. Department of Health & Human Services. Those numbers will only surge as the nation's senior population almost doubles by 2050, reaching 83.7 million, according to Census Bureau projections. About half of older Americans went to an ER in the last month of their life, according to a study in the journal *Health Affairs*.[1] Of those seen in the ER, 77% were admitted to the hospital, and more than two-thirds of those admitted died there, even though most Americans say they want to die at home. https://goo.gl/iKb8zB

1. 'Half of older Americans seen in emergency department in last month of life; most admitted to hospital, and many die there,' *Health Affairs*, 2012;31(6):1277-1285. [Noted in Media Watch 11 June 2012, #257 (p.4)] https://goo.gl/96R6GW

Cont.

Noted in Media Watch 29 May 2017, #514 (p.2):

- NATIONAL PUBLIC RADIO | Online – 26 May 2017 – **'Can comfort care at the emergency room help older people live longer and suffer less?'** Adults 65 and older made 20.8 million emergency room (ER) visits in 2013, up from 16.2 million in 2000, according to the most recent hospital survey by the Centers for Disease Control & Prevention.[1] The survey found 1 in 6 visits to the ER were made by an older patient, a proportion that's expected to rise. Half of adults in this age group visit the ER in their last month of life, according to a 2012 study [cited above]. https://goo.gl/0A1PL3

  1. 'Health, United States, 2015 (With special features on racial and ethnic health disparities),' Centers for Disease Control & Prevention, April 2017. https://goo.gl/DWqWTW

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | *The Mercury News* (San Jose) – 28 June 2017 – **'Over 100 Californians took their lives under new assisted suicide law.'** One hundred and eleven. That's the number of California residents who committed suicide in 2016 with the help of doctor-prescribed drugs under the state's new aid-in-dying law, according to a first-of-its-kind report.[1] Nearly 200 received the drugs under the law... Nearly 60% of those who asked their doctor for the end-of-life remedy were suffering from cancer. Eighteen percent had been diagnosed with a neuromuscular disorder like ALS or Parkinson's disease, while many suffered from heart and respiratory diseases. The median age of people who used the new law was 73. Forty-two percent of those who used it were age 80 and over. Most of the people who used a prescription – 102 out of the 111 – were white, while Asians made up six of the total; the number included three blacks and three Hispanics https://goo.gl/oU7rVF

  1. 'California End Of Life Option Act 2016 Data Report,' California Department of Public Health, June 2017. https://goo.gl/h2ojaJ

- ALABAMA | *The Anniston Star* – 27 June 2017 – **'Assisted Suicide Ban Act passed with mixed reactions.'** Alabama's new Assisted Suicide Ban Act will make assisting in the death of others illegal in the state starting in August. https://goo.gl/a2MYn3

International

End-of-life care in Taiwan

Doctors still adjusting to concept of palliative care

TAIWAN | *Taipei Times* – 29 June 2017 – The promotion of palliative care (PC) has met opposition from doctors who say it contravenes their duty to save lives, a physician from Taipei City Hospital said. Many doctors found it difficult to let go of patients when the hospital first began promoting PC, despite the doctors being fully trained for the procedure, Taipei City Hospital director Huang Sheng-chien said. "There might have been 100 patients we could have put in PC wards, but only 15 were placed in such wards," Huang said. This was caused by doctors lacking the training to accurately judge whether a patient had a terminal illness, Huang added. There were incidents in which doctors considered the patient to be in moderately good health and the patient would pass away within a few months, Huang said. "For many patients, it was too late to be moved to PC," Huang said, adding that this was due to the reluctance of family members to accept that their loved ones were reaching the end of their life. Since the hospital began promoting PC two years ago, 50% of those who accepted such care were cancer patients, while patients with other illnesses comprised a small number of PC patients. https://goo.gl/sPoEFk

Cont.

Related

- TAIWAN | *Taiwan News* (Taipei City) – 29 June 2017 – **'Experts encourage communicating end-of-life wishes with advance care planning and advance directives.'** Taiwan's Patient's Self-determination Right Act was promulgated in 2016 and will take effect in 2019. The new law in essence legalizes and promotes advance care planning, giving capable people the rights to know about their medical conditions and available medical choices firsthand and make advance decisions about the care they would want to receive if they become unable to speak for themselves, such as the decisions to whether receive life-sustaining treatment or artificial nutrition and hydration under certain clinical conditions. https://goo.gl/ZTp7DS

Noted in Media Watch 6 February 2017, #498 (p.9):

- *INQUIRY: THE JOURNAL OF HEALTH CARE ORGANIZATION, PROVISION & FINANCING* | Online – 24 January 2017 – **'Branding palliative care units by avoiding the terms "palliative" and "hospice": A nationwide study in Taiwan.'** At the time of this study (September, 2016), there were 55 palliative care (PC) units in Taiwan. Only 20% of the PC unit names included the term "palliative," while 25.2% included the term "hospice." Religiously affiliated hospitals were less likely to use the terms "palliative" and "hospice." https://goo.gl/9Z6xAu

N.B. Taiwan was ranked 6th of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://goo.gl/nuPWIl

Charlie Gard parents lose European court appeal

U.K. (England) | BBC News – 27 June 2017 – Judges at the European Court of Human Rights have rejected a plea from the parents of terminally-ill baby Charlie Gard to intervene in his case. Chris Gard and Connie Yates lost their final legal bid to take their son to the U.S' for treatment. Specialists at Great Ormond Street Hospital believe Charlie has no chance of survival. The court agreed, concluding that further treatment would "continue to cause Charlie significant harm." Charlie is thought to be one of 16 children in the world to have mitochondrial depletion syndrome, a condition which causes progressive muscle weakness and brain damage. His parents had previously seen a Supreme Court challenge to continue Charlie's life support fail. European Court judges have now concluded it was most likely Charlie was "being exposed to continued pain, suffering and distress" and undergoing experimental treatment with "no prospects of success... would offer no benefit." They said the application presented by the parents was "inadmissible" and said the court's decision was "final." https://goo.gl/7HDvY2

Specialist Publications

'A matter of life and death' (p.10), in *Journal of Medical Ethics.*

Noted in Media Watch 17 April 2017, #508 (p.5):

- U.K. (England) | BBC News – 11 April 2017 – **'Charlie Gard case: Doctors can withdraw baby's life support.'** Doctors can withdraw life support from a sick baby with a rare genetic condition against his parents' wishes, a High Court judge has ruled. Specialists at Great Ormond Street Hospital said eight-month-old Charlie Gard has irreversible brain damage and should be moved to palliative care. His parents Connie Yates and Chris Gard, from London, had wanted to take him to the U.S. for a treatment trial. https://goo.gl/nzOZCr

Scotland lagging behind in delivery of end-of-life care

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 26 June 2017 – Scotland is fairing worse than similar sized countries when it comes to delivering end-of-life care (EoLC) with around a third of people in hospital on any given day likely to die within one year. Experts from Denmark, New Zealand and Scotland met in Glasgow ... to discuss the correlation between hospital admissions and the likelihood of death. In all three countries studies have revealed that the number of people who would benefit from palliative and EoLC but do not necessarily receive it is higher than previously thought. Of the three countries with similar populations, wealth and healthcare systems, Scotland has the greatest chance of a person admitted to hospital dying within 12 months at 30%, compared to Denmark with 22% and New Zealand which has 14.5 of people dying within a year of being admitted. This highlights the role of hospitals in caring for those at the end of life and the need for improving identification of those who would benefit from specialist support. Compared to New Zealand, hospitals in Scotland have a higher number of older people receiving care. The proportion of those aged over 60 was 73% in this country and 42% for New Zealand. Just 17% were over 80 years in New Zealand compared to 32% in Scotland. https://goo.gl/Tt6oEC

Noted in Media Watch 5 June 2017, #515 (p.13):

- *ACTA ONCOLOGICA* | Online – 30 May 2017 – **'Admittance to specialized palliative care of patients with an assessed need: A study from the Danish palliative care database.'** The authors found that admittance to specialized palliative care (SPC) was higher for younger patients (e.g., 50-59 versus 80 + years). This first nationwide study of admittance to SPC among patients with a SPC need indicates that prioritization of the limited resources means that certain sub-groups with a documented need have reduced likelihood of admission to SPC. https://goo.gl/2AjSJk

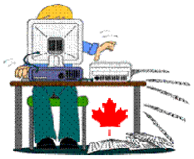
Noted in Media Watch 3 April 2017, #506 (p.6):

- NEW ZEALAND | News Talk ZB (Auckland) – 30 March 2017 – **'New Zealand government looks to prioritise palliative care.'** The Government's making assurances palliative care (PC) is one of its health priorities. It comes as a review of the sector recommends major changes and improvements because of a rising demand for PC from the country's aging population.[1] It's recommending greater emphasis be put on PC, its quality be improved, that the capability of informal carers be increased, and that response to those with PC needs be improved. https://goo.gl/Ql1Vr1

    1. 'The Adult Palliative Care Services in New Zealand: Review and Action Plan,' Ministry of Health, Government of New Zealand, March 2017. https://goo.gl/PT64BW

Noted in Media Watch 27 February 2017, #501 (p.3):

- U.K. (Scotland) | *The Scotsman* (Edinburgh) – 24 February 2017 – **'Thousands of Scots miss out on palliative care.'** Experts estimate about 11,000 people in Scotland could have benefited from palliative care (PC) at the end of their lives, but did not receive it. Charities Marie Curie, Sue Ryder and Hospice UK call for an anticipatory care plan which patients complete with their GP, recording their explicit wishes, to be added as a new indicator for reviewing end-of-life care. The government has committed to ensuring that by 2021 everyone who needs PC should be provided with it. https://goo.gl/5EEX2l



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

Specialist Publications

"This is what family does": The family experience of caring for serious illness

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 30 June 2017 – Seventy-three individuals participated in group interview sessions. While both families and individuals encountered caregiving challenges, the family unit experienced care in several unique ways. It accommodated differences in temperament and readiness, managed internal conflict, and strived to emerge as a cohesive unit. Individual struggles were often magnified or, more often, ameliorated by family context. Caregiving itself formed a legacy for future generations. Finally, care was seen as bidirectional, being tendered both by the family caregivers and in turn by the patient. When talking about care for serious illness, individuals report both rewards and challenges, often in a family context. The family enterprise manages a loved one's care, negotiates the health-care system, and adjusts its own internal dynamics. Integrating the family narrative provides a more balanced view of the family system that provides the day-to-day care for individuals with serious illness. https://goo.gl/hyJz3z

Related

- *PROCEEDINGS OF THE NATIONAL ACADEMY OF SCIENCES OF THE UNITED STATES OF AMERICA* | Online – 27 June 2017 – **'Poor caregiver mental health predicts mortality of patients with neurodegenerative disease.'** Although providing the best possible care for the large and growing number of individuals with neurodegenerative disease is an important public health priority, the authors' findings suggest that these efforts should also consider caregiver mental health as an important intervention target. These findings represent research at the intersection of psychology, neuroscience, and medical science, and highlight the importance of caring for caregivers as well as patients when attempting to improve patients' lives. https://goo.gl/gtvPoR

Elder care in Canada

The home care conversation we're not having

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2017;189(25):e875-e876. Despite major federal and provincial cash injections in recent years, seniors often receive home care too late and/or stay in it for too long – past the point when they would be better served in long-term care. There are also major problems with the quality and consistency of care, as well as limited data on the true costs for female family members who shoulder most of the care. Health officials are "deliberately deceiving the public with respect to living independently at home and they're deluding themselves that they're successfully offloading the costs onto people like me," said Kathy Bugeja, a healthcare consultant who has been an informal caregiver for family members. Most Canadians say they would prefer to age at home, but that assumes they would be healthy enough or have adequate supports to do so, she said. Many seniors only receive formal homecare support after major disability or deterioration, Bugeja explained. In reality, "the care is all incremental and reactive, so only when you get to the desperate stage, do you get the next crumb," said Bugeja. Home is not the best place for many seniors, she added, "but there's this dogma that we're keeping you at home at all costs, even when the client is well past that stage." https://goo.gl/mGsc9Y

Related

- *BC MEDICAL JOURNAL*, 2017;59(6):300-301. **'Choosing wisely for frail residents of long-term care homes: Six recommendations.'** Care for the frail elderly in care homes is an evidence-free zone. Following existing guidelines may be downright harmful and disturbing to the residents' comfort and peace. The Long Term Care Medical Directors Association of Canada was, therefore, approached by Choosing Wisely Canada to develop recommendations for the care of frail elderly residents for use by colleagues, caregivers, patients, and family members. https://goo.gl/NTeuZ7

Challenges to cancer pain management are multifactorial

CLINICAL ONCOLOGY NEWS | Online – 26 June 2017 – In the 1980s, up to 70% of cancer patients reported pain. Thirty years later, cancer pain prevalence has not changed noticeably [said Dr. Julie Waldfogel, a clinical pharmacy specialist in pain and palliative care at the Johns Hopkins Hospital in Baltimore]. The problem is there are many barriers to optimum treatment for cancer pain, including patient underreporting, age and cultural barriers and access issues, Dr. Waldfogel said. Patients underreport pain for all kinds of reasons, from not wanting to “bother” the oncologist to feeling they have no right to complain. “Some patients are fatalistic and feel pain is a part of life and a part of death and a part of cancer, so why do I need to spend time focusing your attention on that?” she said. “Others may feel that it is a sign of disease progression and fear the doctor will take them off their cancer medications.” There are also age, gender and cultural barriers to asking for or receiving pain medication, Dr. Waldfogel said, as well as misconceptions about the use of strong pain relievers, such as opioids. Some patients think they will become tolerant of the medications and they won’t be helpful in later, and probably more painful, cancer stages. Issues in access, adherence and cost, fear of addiction, and side effects also hinder a patient’s willingness to use pain medications. https://goo.gl/aHQiBG

End-of-life care and do not resuscitate orders: How much does age influence decision making? A systematic review and meta-analysis

GERONTOLOGY & GERIATRIC MEDICINE | Online – 12 June 2017 – With population aging, “do not resuscitate” (DNAR) decisions, pertaining to the appropriateness of attempting resuscitation following a cardiac arrest, are becoming commoner. It is unclear from the literature whether using age to make these decisions represents “ageism.” All studies fulfilling the authors’ inclusion criteria found that “do not attempt resuscitation” orders were more prevalent in older patients; eight demonstrated that this was independent of other mediating factors such as illness severity and likely outcome. In studies comparing age groups, the adjusted odds of having a DNAR order were greater in patients aged 75 to 84 and ≥85 years ... compared with those <65 years. In studies treating age as a continuous variable, there was no significant increase in the use of DNAR with age... In conclusion, age increases the use of “do not resuscitate” orders, but more research is needed to determine whether this represents “ageism.” https://goo.gl/Sdo1YV

Related

- *NURSING TIMES* | Online – 26 June 2017 – **‘The implications of an Nursing & Midwifery Council caution for nurse who did not perform CPR.’** In January 2017, the Nursing & Midwifery Council upheld charges that an experienced nurse had “failed to attempt cardiopulmonary resuscitation” (CPR) on a nursing home resident and “failed to contact or ensure that the emergency services were contacted.” The ruling prompted serious concerns about the implications for nursing practice, exercising professional judgement and withholding CPR when it is considered futile and not in the best interests of patients. https://goo.gl/XzCicx

- *TRENDS IN ANAESTHESIA & CRITICAL CARE* | Online – 23 June 2017 – **‘Family presence during resuscitation: A concise narrative review.’** Studies have shown that nursing staff are more supportive of FPDR than physicians are. Physicians, who do not often support FPDR, believe that FPDR may interfere with resuscitation, may induce psychological trauma, or be the object of legal repercussions. Currently, several international organizations have published statements and guidelines supporting FPDR. Studies investigating FPDR contain various methodological flaws meaning it is difficult to make any definite conclusions. https://goo.gl/mEzDkp

N.B. Additional articles on family presence during cardiopulmonary resuscitation are noted in the 1 May 2017 issue of Media Watch (#510, p.8).

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.18.

Barriers to goals of care discussions with patients who have advanced heart failure: Results of a multi-centre survey of hospital-based cardiology clinicians

JOURNAL OF CARDIAC FAILURE | Online – 22 June 2017 – The most important perceived barriers [identified by study recipients] were: family members' or patients' difficulty accepting a poor prognosis, family members' or patients' lack of understanding about the limitations and harms of life-sustaining treatments, and lack of agreement between family members about goals of care. Interprofessional team members were viewed as having different, but important roles in goals of care discussions. These findings can inform the design of future interventions to improve communication about goals of care in advanced heart failure. https://goo.gl/Ncc6uW

Noted in Media Watch 12 June 2017, #516 (p.11):

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 6 June 2017 – **'Implementation of advance care planning in oncology: A review of the literature.'** Although simple in concept, implementation [of advance care planning] in practice is challenging. A variety of patient education tools exist in several different forms, including pamphlets, guidebooks and question prompt lists, with the strongest data supporting use of video decision aids that depict cardiopulmonary resuscitation. https://goo.gl/VO1IJB

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 28 June 2017 – **'Factors associated with end-of-life planning in Huntington's disease.'** Being older, increased Huntington's disease stage, more years of education, lower anxiety, more swallowing symptoms, and higher meaning and purpose were associated with having advance directives (ADs). The prevalence of ADs in the sample is comparable to the general U.S. population, but surprisingly low. https://goo.gl/wZmm5W

  N.B. Additional articles on palliative care for patients and family living with Huntington's disease are noted in the 19 June 2017 issue of Media Watch (#517, p.6)]

- *HEALTH EXPECTATIONS* | Online – 22 June 2017 – **'A qualitative study exploring the difficulties influencing decision making at the end of life for people with dementia.'** Four key themes were identified: 1) Challenges of delivering coherent care in dynamic systems; 2) Uncertainty amongst decision makers; 3) Internal and external conflict amongst decision makers; and, 4) A lack of preparedness for the end of life. https://goo.gl/oJdYaR

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 June 2017 – **'How often is end-of-life care in the U.S. inconsistent with patients' goals of care?'** 13% [of the 1,212 family members interviewed] stated care was inconsistent with decedent's wishes. Death at home was more likely to represent consistent care, and death in the hospital or nursing home was more likely to represent inconsistent care. Respondents reporting inconsistent care were more likely to rate the quality of care as fair or poor, and reported more unmet needs for pain management, and concerns with communication. https://goo.gl/99FjSw

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 June 2017 – **'Goals of care ambulatory resident education: Training residents in advance care planning conversations in the outpatient setting.'** Advance care planning (ACP) discussions often occur in the inpatient setting when patients are too ill to participate in decision making. Although the outpatient setting is the preferred time to begin these discussions, few physicians do so in practice. https://goo.gl/FnekUB

- *MATURITAS* (European Menopause Journal**)** | Online – 24 June 2017 – **'Advance care planning within survivorship care plans for older cancer survivors: A systematic review.'** No papers were found that met the authors' inclusion criteria, with only one survivorship care plan including mention of an advance care directive. Despite increasing numbers of older and frail cancer survivors, there is little evidence for the use of advance care planning after cancer. https://goo.gl/M9xyTd

Towards accessible integrated palliative care: Perspectives of leaders from seven European countries on facilitators, barriers and recommendations for improvement

JOURNAL OF INTEGRATED CARE, 2017;25(3):222-232. Literature suggests that integrated palliative care (IPC) increases the quality of care for palliative patients at lower costs. However, knowledge on models encompassing all integration levels for successfully implementing IPC is scarce. Thirty-four IPC leaders in primary and secondary palliative care or public health in Belgium, Germany, Hungary, Ireland, The Netherlands, Spain and the U.K. were interviewed. IPC implementation efforts involved a multidisciplinary team approach and cross-sectional coordination. Informal professional relationships, basic medical education and general awareness were regarded as facilitators of IPC. Identified barriers included lack of knowledge about when to start palliative care, lack of collaboration and financial structures. Recommendations for improvement included access, patient-centeredness, coordination and cooperation, financing and ICT systems. Although IPC is becoming more common, action has been uneven at different levels. IPC implementation largely remains provisional and informal due to the lack of standardised treatment pathways, legal frameworks and financial incentives to support multilevel integration. In order to make IPC more accessible, palliative care education as well as legal and financial support within national healthcare systems needs to be enhanced. https://goo.gl/rnAvk7

Withdrawal or withholding of artificial nutrition and hydration

A matter of life and death

JOURNAL OF MEDICAL ETHICS | Online – 23 June 2017 – Cases concerning the withdrawal or withholding of artificial nutrition and hydration (ANH) from patients in a vegetative or minimally conscious state raise difficult medical, legal and ethical questions including the diagnosis and classification of disorders of consciousness, the legal processes to be followed, and the legal and ethical principles to be applied when making decisions. There is also an issue as to whether it is necessary or appropriate for such decisions to be taken by judges. This article, based on a lecture given in Oxford in October 2016,[1] considers a number of these issues and concludes that any consideration of the question from the patient's point of view must include an objective analysis of what is in his or her best interests, as well as subjective expressions of wishes and feelings. Whilst noting that it has been suggested that applications to the court should be confined to those cases where there is a dispute as to whether withdrawal of ANH would be in the patient's best interests, the author proposes that, until such time as we have greater clarity and understanding about the disorders of consciousness, and about the legal and ethical principles to be applied, there remains a need for independent oversight and that applications to the court should continue to be obligatory in all cases where the withdrawal of ANH is proposed, at least for the time being. https://goo.gl/S8stVP

Extract from the *Journal of Medical Ethics* article

Until such time as we have greater clarity and understanding about the disorders of consciousness, and about the legal and ethical principles to be applied, there remains a need for independent oversight and that applications to the court should continue to be obligatory in all cases where the withdrawal of ANH is proposed, at least for the time being.

1. 'A Matter of Life & Death,' Mr. Justice Baker, Oxford Shrieval Lecture 2016. https://goo.gl/PiWeCJ

Noted in Media Watch 10 April 2017, #507 (p.13):

- *MEDICO-LEGAL JOURNAL* | Online – 3 April 2017 – **'Judicial oversight of life-ending withdrawal of assisted nutrition and hydration in disorders of consciousness in the U.K.: A matter of life and death.'** The authors set out a rationale in support of court oversight of best interests decisions in assisted nutrition and hydration withdrawal intended to end life in any person with disorders of consciousness (who will lack relevant decision-making capacity). This ensures the safety of the general public and the protection of vulnerable disabled persons in society. https://goo.gl/46hm8u

Cont.

Noted in Media Watch 20 January 2014, #341 (p.13):

- *JOURNAL OF MEDICAL ETHICS* | Online – 14 January 2014 – **'Withdrawing artificial nutrition and hydration from minimally conscious and vegetative patients: Family perspectives.'** In *W v M*, family members made an application to the Court of Protection for withdrawal of artificial nutrition and hydration from a minimally conscious patient. Discussion has centred around the ethical adequacy of the judge's decision not to authorise withdrawal. This article draws on interviews with 51 individuals with a relative who is (or was) in a vegetative or minimally conscious state. https://goo.gl/k5n4Ct

Expert discussion on taking a spiritual history

JOURNAL OF PALLIATIVE CARE | Online – 29 June 2017 – This article elaborates on the hazards of spiritual history taking. It provides expert insights to consider before entering the field. Thematic analysis was applied to define the emerging themes. The results demonstrate that taking a spiritual history is a complex and challenging task, requiring a number of personal qualities of the interviewer, such as "being present," "not only hearing, but listening," "understanding the message beyond the words uttered," and "picking up the words to respond." To "establish a link of sharing," the interviewer is expected "to go beyond the ethical stance of neutrality." The latter may cause several dilemmas, such as "fear of causing more problems," "not daring to take it further," and above all, "being ambivalent about one's role." The interviewer has to be careful in terms of the "patient's vulnerability." To avoid causing harm, it is essential to propose "a follow-up contract" that allows responding to "patient's yearning for genuine care." These findings combined with available literature suggest that the quality of spiritual history taking will remain poor unless the health-care professionals revise the meaning of spirituality and the art of caring on individual level. https://goo.gl/yRdg8K

Noted in Media Watch 21 September 2015, #428 (p.13):

- *PALLIATIVE MEDICINE* | Online – 16 September 2015 – **'Spiritual history taking in palliative home care: A cluster randomized controlled trial.'** Many health-care providers experience barriers to addressing spiritual needs, such as not having the right vocabulary. Participants in this study indicated no demonstrable effect of spiritual history taking on patient scores for spiritual well-being, quality of life, health-care relationship trust or pain. https://goo.gl/FLQWNg

Hospital chaplains: Through the eyes of parents of hospitalized children

JOURNAL OF PALLIATIVE MEDICINE | Online – 26 June 2017 – Chaplain services are available in 68% of [U.S.] hospitals, but hospital chaplains are not yet incorporated into routine patient care. Seventy-four parents were interviewed; most were 25-50 years old, and 75% felt their child was very sick. Children ranged from newborn to adolescence. Forty-two percent of parents requested a chaplain visit; of the 58% with an unsolicited visit, 11% would have preferred giving prior approval. Parents felt chaplains provided religious and secular services, including family support and comfort, help with decision making, medical terminology, and advocacy. Chaplains helped most parents maintain hope and reduce stress. Seventy-five percent of parents viewed chaplains as a member of the healthcare team; 38% reported that chaplains helped medical personnel understand their preferences for care and communication. Most parents (66%) felt that hospital chaplaincy increased their satisfaction with hospital care. https://goo.gl/6haKJ8

Noted in Media Watch 29 May 2017, #514 (p.10):

- *JOURNAL OF HEALTH CARE CHAPLAINCY* | Online – 23 May 2017 – **'Evaluation of a chaplain residency program and its partnership with an in-patient palliative care team.'** Chaplain residents felt the program prepared them to provide care for those with serious illness. It also showed that chaplain residents and palliative care (PC) team members view spirituality as an integral part of PC and see the chaplain as the team member to lead that effort. Suggested program improvements include longer PC orientation period, more shadowing with PC team members, and improved communication between PC and chaplain residents. https://goo.gl/VVwQZc

Overthrowing barriers to empathy in healthcare: Empathy in the age of the Internet

JOURNAL OF THE ROYAL SOCIETY OF MEDICINE | Online – 27 June 2017 – Empathy-based medicine re-establishes relationship as the heart of healthcare. Practitioners often complain that their capacity to practise empathically is undermined by "tyrannical guidelines," insufficient time and an ever-increasing burden of paperwork. Clinicians often see this system as lacking empathy – uninterested in practitioners' perspectives, health or welfare. Within this context, it is unsurprising that National Health Service [in the U.K.] staff have significant work-related stress and ill health. As a result, patients suffer, claiming clinicians do not communicate adequately, often leaving their needs and concerns insufficiently addressed. The limitations of guideline- and evidence-driven care and healthcare's rising costs, together with the overwhelming evidence that empathic care can improve a wide range of outcomes in diverse patient populations, suggest a new paradigm for medicine necessary. Empathy-based medicine promises to improve patient outcomes, reduce practitioner burnout and save money. Empathy-based medicine uses skills we all have, and that most of us can enhance. https://goo.gl/2Yu4sB

Integrating palliative care into neurological practice

THE LANCET NEUROLOGY, 2017;16(7):489. When initiating end-of-life care (EoLC) discussions, both clinicians and patients often fail to distinguish palliative care (PC) from hospice care – palliative treatment which is delivered at the end of life. However, in recent years, PC specialists have begun to provide support more frequently in the early stages of disease, alongside disease-directed therapy. For patients with progressive neurological disease, discussing PC with their physician and family early in the course of their disease might be a crucial factor in their participation in treatment decisions and maintenance of their quality of life. Although PC has gained acceptance as an important part of comprehensive care in some fields such as oncology, early integration of PC in neurology is less common. Consistently good communication between clinicians and patients remains a barrier in planning EoLC https://goo.gl/TPXKh5

Noted in Media Watch 3 October 2016 #482 (p.9):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(5):232-235. **'Palliative care in chronic and progressive neurological disease: Summary of a consensus review.'** A taskforce of the European Association for Palliative Care makes recommendations on the early integration of palliative care, multidisciplinary team care, communication, symptom management, carer support, end-of-life care and training and education of professionals.

  N.B. Access to this article requires a subscription to the journal. Contents page: https://goo.gl/IUscng

Noted in Media Watch 20 June 2016, #467 (p.14):

- *NEUROLOGICAL SCIENCES* | Online – 14 June 2016 – **'Need for palliative care for neurological diseases.'** The realization of an effective palliative approach to neurological diseases requires specific skills and expertise to adapt the concept of palliation to the peculiarities of these diseases; this approach should be realized through the cooperation of different services and the action of a multidisciplinary team in which the neurologist should play a central role to identify and face the patient's needs. http://goo.gl/kOQ9z7

New study uncovers low rates of palliative care referral in patients with end-stage liver disease

NEWS MEDICAL | Online – 29 June 2017 – A new study has uncovered low rates of referral for palliative care (PC) in U.S. patients with end-stage liver disease, although rates have been slowly increasing over time.[1] The study also found that certain socioeconomic and ethnic barriers may hinder access to PC services. Historically, only a limited number of affected patients have used PC… Of 39,349 patients in this analysis, PC consultations were performed for 1789 (4.5%) of patients. The rate of PC referral increased

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from 0.97% in 2006 to 7.1% in 2012. Hispanic race and lower socio-economic status were linked with lower PC referrals. This study is one of the largest nationwide studies of PC referral in patients with end-stage liver disease. Although palliative care referrals in patients with end-stage liver disease is increasing, the rate of referrals is still very low. Researchers noted that there has traditionally been very little guidance for the use of PC in the setting of end-stage liver disease given the variable course of the disease, patients not appearing "sick," or a lack of recognition of symptoms; however, PC is of significant value as patients experience an improvement in quality of life and better alignment of goals with their medical care. https://goo.gl/iFcQTp

1. 'Palliative care access for hospitalized patients with end stage liver disease across the U.S.,' *Hepatology*, published online 29 June 2017. https://goo.gl/gKtDRR

Related

- *GASTROINTESTINAL NURSING* | Online – 20 June 2017 – **'Sooner rather than later: Early hospice intervention in advanced liver disease.'** Palliative care provision for these patients is often poor, with no clear national guidance for end-stage liver disease. This article describes a pilot project conducted to assess the impact of early hospice intervention on patients' wellbeing and experience. Patients remained under acute hospital management and were seen by the hospice's specialist nurse practitioner on a monthly basis and referred into hospice services as needed. https://goo.gl/U4CFvW

End-of-life care in Canada

The care experiences of patients who die in residential hospice: A qualitative analysis of the last three months of life from the views of bereaved caregivers

PALLIATIVE & SUPPORTIVE CARE | Online – 29 June 2017 – Despite the increasing prominence of residential hospices as a place of death and that, in many regards, this specialized care represents a gold standard, little is known about the care experience in this setting. A total of 550 caregivers completed the survey, 94% (517) of whom commented on either something good (84%) and/or bad (49%) about the care experience. In addition to residential hospice, the majority of patients represented also received palliative care (PC) in the home (69%) or hospital (59%). Overall, most positive statements were about care in hospice (71%), whereas the negative statements tended to refer to other settings (81%). The hospice experience was found to exemplify care that was compassionate and holistic, in a comforting environment, offered by providers who were personable, dedicated, and informative. These humanistic qualities of care and the extent of support were generally seen to be lacking from the other settings. The authors' examination of the good and bad aspects of PC received is unique in qualitatively exploring PC experiences across multiple settings, and specifically that in hospices. Investigation of these perspectives affirmed the elements of care that dying patients and their family caregivers most value and that the hospices were largely effective at addressing. https://goo.gl/zWjr1x

Noted in Media Watch 19 June 2017, #517 (p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 14 June 2017 – **'Palliative care experience in the last 3 months of life: A quantitative comparison of care provided in residential hospices, hospitals, and the home from the perspectives of bereaved caregivers.'** This is one of few quantitative examinations of the care experience of patients who accessed multiple care settings in the last months of life and died in a specialized setting such as residential hospice. The findings emphasize the importance of replicating the hospice approach in institutional and home settings, including greater attention to emotional and spiritual dimensions of care. https://goo.gl/kp6tGb

A scoping research literature review to assess the state of existing evidence on the "bad" death

PALLIATIVE & SUPPORTIVE CARE | Online – 28 June 2017 – A scoping research literature review on "bad death" was undertaken to assess the overall state of the science on this topic and to determine what evidence exists on how often bad deaths occur, what contributes to or causes a bad death, and what the outcomes and consequences of bad deaths are. This review identified a relatively small number of research articles that focused in whole or in part on bad deaths. Although the reasons why people consider a death to be bad may be highly individualized and yet also socio-culturally based, unrelieved pain is a commonly held reason for bad deaths. Although bad and good deaths may have some opposing causative factors, this literature review revealed some salient bad death attributes, ones that could be avoided to prevent bad deaths from occurring. A routine assessment to allow planning so as to avoid bad deaths and enhance the probability of good deaths is suggested. https://goo.gl/RHJxY8

Supporting in an existential crisis: A mixed-methods evaluation of a training model in palliative care

PALLIATIVE & SUPPORTIVE CARE | Online – 20 June 2017 – Palliative care (PC) staff often report they lack the skills and confidence to provide support during an existential crisis. In the quantitative part of the authors' study, participants showed significantly increased perceived knowledge, awareness, and preparedness... Focus group discussions revealed a process that made it possible to apply new knowledge and insight. The process began with theoretical knowledge and, through care-related reflection and self-reflection, the knowledge base gradually developed and provided useful skills and increased job satisfaction. The team-based model studied can be performed without excessive effort and contribute to improved competence in providing support during an existential crisis. It is particularly useful for staff working in clinical PC. https://goo.gl/8zxhpP

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 30 June 2017 – '**Suitable support for anxious hospice patients: what do nurses 'know', 'do' and 'need'? An explanatory mixed method study.**' This study highlights the struggles of nurses caring for anxious patients in hospice care. Anxiety management is dependent on the competencies and preferences of the individual nurse. One-third of the study participants required additional training. According to hospice care nurses, the intervention set should include guidelines for applying assessment tools, effective communication strategies and decision models as well as prediction models in order to select tailored interventions. https://goo.gl/tqF76L

- *JBI DATABASE OF SYSTEMATIC REVIEWS & IMPLEMENTATION REPORTS*, 2017;15(6):1711-1746. '**Experiences of non-specialist nurses caring for patients and their significant others undergoing transitions during palliative end-of-life cancer care: A systematic review.**' Non-specialist nurses providing palliative and end-of-life cancer care to patients and significant others undergoing psychosocial and existential transitions may experience dissatisfaction, frustration, and sorrow. They may also experience happiness, increased knowledge, and personal growth. The studies included provide useful and credible statements from non-specialist nurses... https://goo.gl/mT3ybs

- *JOURNAL OF NURSE PRACTITIONERS* | Online – 27 June 2017 – '**Integration of palliative care into a nurse practitioner.**' The purpose of this project was to integrate end-of-life and palliative care (PC) into a nurse practitioner-doctor of nursing practice course through didactic education and clinical immersion. The innovative and memorable clinical immersion in PC was highly rated by the majority of the students, with all students commenting on being positively impacted by observation of the family meeting. This project identifies methods for faculty to integrate end-of-life and PC into their curriculum to enhance students' ability to deliver evidence-based and compassionate care. https://goo.gl/StTQJr

Conscience clause in end-of-life care

RECENTI PROGRESSI IN MEDICINA, 2017;108(5):216-220. After a philosophical and normative analysis, this article is organized on the basis of two important documents for discussion: a position paper of Società Italiana di Anestesia Analgesia Rianimazione e Terapia Intensiva (SIAARTI) signed by several scientific societies 'Grandi insufficienze d'organo end stage: Cure intensive o cure palliative?' and the Design of Law currently being debated, 'Norme in materia di consenso informato e di disposizioni anticipate di trattamento.' In particular, the conscience clause has been discussed in the light of advance care planning, which represents the instrument to guarantee the shared planning of care and the shared-decision making. In this context, recourse to the clause of conscience brings out critical ethical and deontological issues that the article discusses, using the position paper SIAARTI and the text of law currently being debated, both built on the assumptions of a shared care relationship, where patient has a key-role in medical decisions. https://goo.gl/D5FPPj

N.B. Italian language article.

Noted in Media Watch 24 April 2017, #509 (p.8):

- *LIVERPOOL LAW REVIEW* | Online – 12 April 2017 – **'End-of-life decisions in Italy: An overview of the current situation.'** This article analyzes end-of-life (EoL) decisions in Italy. Its aim is to report the complex situation in EoL decisions. The scientific work applies an interdisciplinary approach by taking into consideration the position of the medical and biomedical communities. In addition, it examines the perspective of the jurisprudence and of the parliament. The investigation of all these parties is fundamental since Italy is one of the few Western European countries that does not have an *ad hoc* law ruling advance directives. https://goo.gl/L5bIY9

Noted in Media Watch 25 January 2016, #446 (p.16):

- *RECENTI PROGRESSI IN MEDICINA*, 2015;106(12):593-596. **'"Dignity" at the end of life: Ethical and deontologic reflections.'** In Article 32 of the Italian Constitution, the concept of dignity is taken into account when stating the autonomy of the individual decision-making about health treatment. This is confirmed by the Code of Medical Ethics (2014): the right to self-determination and the right of patients to decide for themselves in accordance with their own life plans, are at the core of the concept of "human dignity." http://goo.gl/CKwQqB

  N.B. Italian language article.

From will to live to will to die: Oncologists, nurses, and social workers identification of suicidality in cancer patients

SUPPORTIVE CARE IN CANCER | Online – 26 June 2017 – Suicidality in cancer patients exists on a wide spectrum that ranges from an active will to live to an active will to die. Four phases were identified that included: 1) A strong will to live expressed in themes of active treatments, seeking second opinions, overtreatment, and alternative treatments; 2) A decreasing will to live indicated in themes of mental health distress and physical pain and suffering; 3) A readiness to die expressed in themes of mental health distress, previous mental health diagnoses, physical pain, avoiding more suffering, preserving quality of life in old age, nearing end of life, lack of social support, and maintaining a sense of control; and, 4) A will to die indicated in themes of euthanasia and active suicidality. Suicidality in cancer patients exists on a continuum. Cancer patients fluctuate on this spectrum depending on circumstances such as degree of suffering, their personalities and life circumstances, and whether they are nearing the end of life. Results of the study emphasize the need to collect more context specific data on suicidality among cancer patients and the importance of early integration of psychosocial and palliative care in the cancer treatment trajectory. https://goo.gl/fp3H7c

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Noted in Media Watch 30 May 2016, #464 (p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 April 2016 – **'A survey of home hospice staff knowledge of suicide risk factors, evaluation, and management.'** Twenty-five percent of survey respondents had no mental health training. Thirty percent reported exposure to suspected suicides, and 20% were involved in confirmed cases. More than two-thirds of all staff were not able to identify four risk factors for suicide. http://goo.gl/QUQ8fv

Noted in Media Watch, 24 March 2014, #350 (p.13):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2014;10(1):95-105. **'Suicide prevention training program for gatekeepers working in community hospice settings.'** Gatekeepers in community hospice settings encounter patients and caregivers struggling with suicidal thoughts. This study evaluated one promising, evidence-based, suicide prevention program with a behavioral rehearsal practice session. http://goo.gl/xmLgx0

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BC MEDICAL JOURNAL*, 2017;59(6):305-309. **'Case review of medically assisted deaths on Vancouver Island.'** Medically assisted deaths (MAiD) on Vancouver Island during a 6-month period accounted for 2% of all deaths and this rate will probably increase. Patients ranged in age from 49 to 96 and included similar numbers of males and females. By the end of the study, patient assessments had been completed by 45 physicians and 1 nurse practitioner, and medical assistance in dying had been provided by 8 prescribers. It was not possible to determine the number of patients who made initial inquiries about MAiD, who made formal MAiD requests and did not meet criteria, who died without medical assistance, or who decided not to go ahead with medical assistance in dying. At present, access to MAiD is not uniform or sufficient to meet demand, and there is a need for coordination in all aspects of provision, data-gathering, and governance. https://goo.gl/yGuUgz

  Related

  - *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2017;189(25);e849-e850. **'Medical assistance in dying: Time for physicians to step up to protect themselves and patients.'** No abstract or summary available. https://goo.gl/jn9Zo5

- *BMC MEDICINE* | Online – 27 June 2017 – **'About the practice of psychiatric euthanasia: A commentary.'** Euthanasia motivated by mental disorders is legal in only a few countries and has a short history. In a recent report of all psychiatric euthanasia cases in Belgium between 2002 and 2013, Dierickx and colleagues suggest that the number of these cases is increasing, and provide a profile of the applicants.[1] To date, knowledge of the practice of psychiatric euthanasia is limited, but rising public awareness might increase the number of requests. The authors reveal several shortcomings in cases of psychiatric euthanasia and open avenues for future research. https://goo.gl/kRvHCV

  1. Euthanasia for people with psychiatric disorders or dementia in Belgium: Analysis of officially reported cases,' *BMC Psychiatry*, published online 23 June 2017. [Noted in Media Watch 26 June 2017, #518 (p.14)] https://goo.gl/37fVJF

- *HEALTH CARE ANALYSIS* | Online – 17 June 2017 – **'Are concerns about irremediableness, vulnerability, or competence sufficient to justify excluding all psychiatric patients from medical aid in dying?'** Some jurisdictions that have decriminalized assisted dying (like Canada) exclude psychiatric patients on the grounds that their condition cannot be determined to be irremediable, that they are vulnerable and in need of protection, or that they cannot be determined to be competent. The authors review each of these claims and find that none have been sufficiently well-supported to justify the differential treatment psychiatric patients experience with respect to assisted dying. They find bans on psychiatric patients' access to this service amount to arbitrary discrimination. Proponents of banning the practice ignore or overlook alternatives to their proposal, like an assisted dying regime with additional safeguards. Some authors have further criticized assisted dying for psychiatric patients by highlighting allegedly problematic practices in those countries which allow it. The authors address recent evidence from The Netherlands, showing that these problems are either misrepresented or have straightforward solutions. https://goo.gl/GHq9D4

Worth Repeating

Patient-satisfaction surveys on a scale of 0 to 10: Improving health care, or leading it astray?

THE HASTINGS REPORT | Online – 6 March 2015 – The current institutional focus on patient satisfaction and on surveys designed to assess this could eventually compromise the quality of health care while simultaneously raising its cost. The authors discuss the concept of patient satisfaction, which remains poorly and variously defined. Next, they trace the evolution of patient satisfaction surveys, including both their useful and problematic aspects. They then describe the effects of these surveys, the most troubling of which may be their influence on the behavior of health professionals. The pursuit of high patient satisfaction scores may actually lead health professionals and institutions to practice bad medicine by honoring patient requests for unnecessary and even harmful treatments. Patient satisfaction is important, especially when it is a response to being treated with dignity and respect, and patient satisfaction surveys have a valuable place in evaluating health care. Nonetheless, some uses and consequences of these surveys may actively mislead health care. The authors' critique of patient-satisfaction surveys takes into consideration three different ways patients may be "satisfied." First is the provision of medically necessary care that actually improves their outcomes. The second concerns interventions that patients or families want but that are medically unnecessary and may negatively affect health outcomes. The third category – comprising factors that are less likely to affect health outcomes but may certainly contribute to a sense of dignity and well-being – includes "humanistic" aspects of health care, such as good communication and treating patients with respect, as well as peripheral aspects, such as convenient parking and designer hospital gowns. These distinctions are important as we explore patient satisfaction and its implications. [Noted in Media Watch 9 March 2015, #400 (p.9)] https://goo.gl/kQFUZT

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.

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/UDj2IO

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: https://goo.gl/IXO4mD

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

Canada

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/lOSNC7

ONTARIO | Mississauga Halton Palliative care Network: https://goo.gl/ds5wYC

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

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

http://goo.gl/OTpc8I

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