

Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

The disconnect between names and expected outcomes with chemotherapy: Scroll down to [Specialist Publications](#) and 'Curative, life-extending, and palliative chemotherapy: New outcomes need new name' (p.15), in *The Oncologist*.

Canada

How a 1980 letter on drug addiction fuelled the opioid epidemic

THE TORONTO STAR | Online – 1 June 2017 – Nearly 40 years ago, a respected doctor wrote a letter to the *New England Journal of Medicine* with some very good news: Out of nearly 40,000 patients given powerful pain drugs in a Boston hospital, only four addictions were documented.¹ Doctors had been wary of opioids, fearing patients would get hooked. Reassured by the letter, which called this “rare” in those with no history of addiction, they pulled out their prescription pads and spread the good news in their own published reports. And that is how a one-paragraph letter with no supporting information helped seed a nationwide epidemic of misuse of drugs such as Vicodin and OxyContin by convincing doctors that opioids were safer than we now know them to be. The journal published an editor’s note about the 1980 letter and an analysis from Canadian researchers of how often it has been cited – more than 600 times, often inaccurately. Most used it as evidence that addiction was rare and most did not say it only concerned hospitalized patients, not outpatient or chronic pain situations such as bad backs and severe arthritis that opioids came to be used for. “It’s difficult to overstate the role of this letter,” said Dr. David Juurlink of the University of Toronto, who led the analysis. “It was the key bit of literature that helped the opiate manufacturers convince front-line doctors that addiction is not a concern.” <https://goo.gl/u1ccqk>

[Specialist Publications](#)

‘Critical care at the end of life: A population-level cohort study of cost and outcomes’ (p.8), in *BMC Critical Care*.

‘A home care palliative sedation simulation program’ (p.9), in *Canadian Nurse*.

“‘I’m only dealing with the acute issues’: How medical ward “busyness” constrains care of the dying’ (p.11), in *Health*.

‘A national survey of Canadian psychiatrists’ attitudes toward medical assistance in death’ (p.17), in *Canadian Journal of Psychiatry*.

1. ‘A 1980 letter on the risk of opioid addiction,’ *New England Journal of Medicine*, 2017;376(22):2194-2195. <https://goo.gl/p9oIC7>

Cont.

Selected articles on opioid use in the context of end-of-life care

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(3):256-260. **‘Hospice-appropriate universal precautions for opioid safety.’** Universal precautions for opioid safety... is one approach to managing the epidemic of prescription pain medication misuse that has been used in pain clinics, primary care practices, and in some hospices. In this project, a set of hospice-appropriate universal precautions was designed, drawing on hospice nursing strengths, and implemented in a mid-size hospice agency. [Noted in Media Watch 29 May 2017, #514 (p.11)] <https://goo.gl/7Wg1TE>
- *REHABILITATION ONCOLOGY* | Online – 27 February 2017 – **‘Opioid campaigns’ impact on advanced cancer and hospice and palliative care.’** Recent national opioid campaigns may have significant, unintentional, and adverse consequences on the medical management of patients with advanced cancers or those receiving hospice and palliative care. New guidelines are likely to impose even tighter controls on opioids, further reducing accessibility to these drugs. [Noted in Media Watch 20 March 2017, #504 (p.14)] <https://goo.gl/Qw3dYU>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 23 February 2016 – **‘The pendulum swings for opioid prescribing.’** Although we learned pain is complex and multifactorial, and that opioids are good for some kinds of pain ... there are other kinds of pain ... where it doesn’t work at all. But nuance doesn’t make for good marketing and opioids as all-around safe analgesics ... made for promiscuous prescribing. [Noted in Media Watch 29 February 2016, #451 (p.10)] <http://goo.gl/rDY6wn>

Framework on Palliative Care in Canada Act

Gladu’s palliative care bill passes third reading

ONTARIO | *Lambton Shield* – 31 May 2017 – Sarnia-Lambton MP Marilyn Gladu’s private member’s bill, which was introduced in the House of Commons in May 2016, has passed third reading with unanimous [i.e., all-party] support and is on its way to the Senate. Bill C-277 – also known as an Act providing for the development of a ‘Framework on Palliative Care in Canada’ – would require the Minister of Health to develop and implement a framework designed to give all Canadians access to palliative care provided through hospitals, home care, long-term care facilities, and residential hospices... [Conservative] Gladu’s bill is the first opposition private member’s bill to pass third reading [in the House]... The bill must now go through three readings in the Senate... <https://goo.gl/cZvLDH>

U.S.A.

Dying people are surprisingly happy about it, study finds

NORTH CAROLINA | *The Independent* (U.K.) – 6 June 2017 – People who are dying are far more positive about it than people expect, according to new research.¹ Many expect that death will be an anxious, unhappy process. But the new study sheds light on people’s feelings as they approach the end of their life – and they are surprisingly happy. The research ... compared the way that people imagine they will feel when they’re dying with the way that people who actually are dying feel. It did so by looking at the writing of people who had terminal illnesses or were on death row. The research should encourage people to look differently at death, and to the way that we care for people who are dying, the scientists said. It found that the people who imagined their own death tended to think it would be a negative, worrying. But the people who were actually dying tended to be more positive than expected. <https://goo.gl/0T7A4H>

Specialist Publications

‘The Affordable Care Act and end-of-life care for patients with cancer’ (p.10), in *The Cancer Journal*.

‘End-of-life care planning in Accountable Care Organizations: Associations with organizational characteristics and capabilities’ (p.10), in *Health Services Research*.

1. ‘Dying is unexpectedly positive,’ *Psychological Science* (Association for Psychological Science), published online 1 June 2017. <https://goo.gl/uekQfg>

What the future of caregiving looks like

FORBES | Online – 30 May 2017 – Expect a caregiving environment rich in technology in the not-so-distant future. But along with that, there'll be an emphasis on human connection to counter the devastating health effects of social isolation on older people. Demographically, we'll be facing hard realities in the next 5-10 years, says Ken Dychtwald, founder and CEO of the research and consulting firm AgeWave... "There'll be a handful of profound demographic shifts" – among them, a boomer generation with fewer children than their parents – "that will alter our capacity for caregiving," Dychtwald says. "The hope with the experimentation that's going on [now], is that we'll come up with better models that don't involve residential care for the disabled elderly" in nursing homes, says John Haaga, director of the Division of Social & Behavior Research at the National Institute on Aging. Technology will play a big role in helping people stay in their homes, says Laura Sands, professor at the Center for Gerontology at Virginia Tech... <https://goo.gl/oo4aMw>

Extract from *Forbes* article

The social, emotional and financial costs of a stretched caregiving system will prompt us to look hard at our health care system's bias toward prolonging life – even when prolonging it isn't what the dying person wants. But many people will welcome a conversation "about 'good death' ... the idea of dying in a natural way without a lot of technology hooked up to you, in a comfortable setting, perhaps at home and not having it stretched out longer than nature would have it."

Related

- ILLINOIS | *Kaiser Health News* – 1 June 2017 – '**Putting in place an A-Team of allies.**' Earlier this year, 30 senior citizens convened in a living room to talk about growing older and needing more help. Who will be my allies as I go through this process, they asked. Many were unmarried, without children, living alone. Some had adult children living elsewhere, with demanding jobs and busy lives. Others had spouses who were ill or temperamentally unsuited to the task. None of the seniors had talked about this issue in a public forum before the gathering here. Most weren't sure what to do. Millions of older adults are in a similar situation, peering into an uncertain future without knowing whom they can count on to be at their side. <https://goo.gl/xRT555>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | The Associated Press – 1 June 2017 – '**More than 500 Californians requested life-ending prescriptions under law inspired by Brittany Maynard.**' At least 504 terminally ill Californians have requested a prescription for life-ending drugs since a state law allowing physician-assisted deaths went into effect in June 2016, marking the first publicly released data on how the practice is playing out in the nation's most populous state. The number represents only those who have contacted Compassion & Choices, an advocacy group that provides information on the process. State officials have not released figures yet. <https://goo.gl/fydf2>

[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>



International

End-of-life care in Australia

Where do you want to die? Most Australians say at home, but end life in hospital

AUSTRALIA | ABC News – 2 June 2017 – While the majority of Australians say they would prefer to die at home, they are instead dying in hospital – and often at great expense, a new report shows.¹ The Productivity Commission, which was asked to look at a range of human services, has released the first of several reports on how best to manage end-of-life (EoL) care at home, and the services that should be made available to support those who choose to die that way. “Many of us have parents that are aging, and if we have the conversation with them about what they would like in the last phase of their life, most would say: ‘I want to be at home, surrounded by family and friends,’” Productivity Commission social policy commissioner Richard Spencer said. “But that doesn’t happen in Australia, it happens very rarely. Over 70% would like that at the EoL, [but] less than 10% experi-

ence that possibility.” There are many issues surrounding the subject of where a person should die – including what the patient wants, what their family wants, and what doctors recommend. <https://goo.gl/G0giaE>

Specialist Publications

‘Exploring the knowledge, attitudes and needs of advance care planning in older Chinese-Australians’ (p.12), in *Journal of Clinical Nursing*.

“‘Unexpected and distressing’”: Understanding and improving the experience of transferring palliative care inpatients to residential care’ (p.14), in *Journal of Social Work in End-of-Life & Palliative Care*.

1. ‘Reforms to Human Services’ (draft report), Productivity Commission, Australian Government, June 2017. <https://goo.gl/VoBZBX>

Noted in Media Watch 22 May 2017, #513 (p.5):

- AUSTRALIA | ABC News – 20 May 2017 – **‘Older Australians opting for in-home care over nursing homes.’** While consumers are demanding more flexible services, structural reforms are forcing aged care providers to change the way they operate. In February, the Federal Government restructured aged care funding, allocating home care packages to individuals rather than aged care providers. A recent study by the national Cognitive Decline Partnership Centre ... assessed health as well as financial outcomes, including staffing, catering, laundry and corporate costs. Preliminary results showed residents in group homes had fewer hospital admissions and scored higher on quality of life measures, with overall costs 20% lower than for traditional care. <https://goo.gl/TwnlVI>

Related

- AUSTRALIA | *The Record* (Perth, Western Australia) – 1 June 2017 – **‘Respecting and meeting end-of-life care needs in residential aged care.’** Consumer peak bodies said ... that access to high quality palliative and end-of-life (EoL) care in aged care facilities will enable more Australians to have a good death, aged care, and palliative care. Palliative Care Australia, COTA (Councils on the Ageing) Australia, Alzheimer’s Australia, Aged & Community Services Australia, Leading Age Services Australia, Aged Care Guild and Catholic Health Australia have released a set of agreed principles to guide the delivery of palliative and EoL care services in residential aged care.¹ <https://goo.gl/Yyxbvl>

Specialist Publications

‘International survey of end-of-life care in nursing homes’ (p.13), in *Journal of Post Acute & Long-Term Care Medicine*.

1. ‘Principles for Palliative & End-of-Life Care in Residential Aged Care,’ 2017. <https://goo.gl/kEm2Ox>

Research must be shared to promote debate and shape policy

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 31 May 2017 – Research is vital in supporting improvement and practice, yet, far too often, good research is restricted to academic journals without cutting through to the people that could ultimately benefit. In fact, we know that it takes, on average, 17 years for health research to become practice. Research can play a much bigger role than the one it currently does in supporting decisions around public policy and ways of working. For many researchers, seeing their work published in the most relevant journal and receiving a high number of citations is enough. While it's important to secure academic recognition there are many equally important audiences such as the government, public bodies, third sector organisations and the public. We do see some research hitting the headlines, but this is nearly always framed within the context of the latest “medical breakthrough,” which barely scratches the surface of what compelling research stories are out there. We need to see research discussed much more frequently within the Scottish Government and Scottish Parliament to help inform legislation and public policy. This does happen, but often only representing a small sample of the research that exists on the

given subject being deliberated. It's also sometimes limited to research which is being championed by a cause, politician or organisation. <https://goo.gl/EZNwr4>

Extract from *The Scotsman* article

In the palliative and end-of-life care research community in Scotland, there has been an acceptance that more needs to be done to reach out beyond the usual academic journals and conferences. There has been a spate of activity, which has seen researchers work in partnership with many key stakeholders including the Scottish Government, the third sector, National Health Service and other statutory organisations. One of the commitments of the Scottish Government's 'Strategic Framework for Action on Palliative & End-of-Life Care'¹ was the establishment of a research forum to bring together academics, policy-makers, practitioners and service managers to discuss and share research findings.

1. 'Strategic Framework for Action on Palliative & End-of-Life Care,' Scottish Government, December 2015. [Noted in Media Watch 21 December 2015, #441 (p.8)] <http://goo.gl/CKePjU>

Free GP care for all proposed in €5.8 billion healthcare plan

IRELAND | *The Irish Times* (Dublin) – 30 May 2017 – An additional €5.8 billion should be spent on the health service over the next decade in order to provide equal access to universal healthcare, a new report recommends.¹ The report ... calls for free GP care and free hospital care for all, as well as cuts to or abolition of health charges. The report, drawn up by a cross-party Oireachtas committee, agreed a vision of a universal single-tier health and social care system to replace the current mix of public and private. Its recommendations include guaranteed maximum waiting times for appointments and procedures, a massive shift in services from hospitals to primary care delivered in the community, and the phased elimination of private care in public hospitals. Every Irish citizen would be provided with a Carta Slainte, or health care card, which would entitle them to access to a wide range of services based on need rather than ability to pay. <https://goo.gl/dj0zF1>

1. 'Future of Healthcare,' Oireachtas Committee on the Future of Healthcare (Sláintecare Report), 30 May 2017. <https://goo.gl/bUeCVa>

Extract from the Oireachtas Committee on the Future of Healthcare report

The current specialist palliative care (PC) budget is €76 million. Estimates submitted to the Department of Health indicate that with an additional €50 million, universal PC can be provided. The Committee recommends that this be introduced in the first five years of the plan. This figure includes funding for Laura Lynn Hospice, child respite and PC as well as specialist PC services for adults with a €10 million allocation each year.

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Selected reports on end-of-life care in Ireland

- 'Finite lives: Dying, death and bereavement.' An independent report examining State services in Ireland by Oireachtas Senator Marie-Louise O'Donnell, May 2017. [Noted in Media Watch 22 May 2017, #513 (p.6)] <https://goo.gl/UA4q9r>
- 'Economic Evaluation of Palliative Care in Ireland.' Commissioned by The Atlantic Philanthropies, August 2015. [Noted in Media Watch 17 August 2015, #423 (pp.7-8)] <https://goo.gl/HxXS6h>
- 'Access to Specialist Palliative Care Services and Place of Death in Ireland: What the data tells us.' Irish Hospice Foundation, May 2013. [Noted in Media Watch 28 October 2013, #329 (p.5)] <https://goo.gl/Omx9gS>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- LUXEMBOURG | *Luxemburger Wort* (Luxembourg City) – 29 May 2017 – '**Slight rise in euthanasia cases for Luxembourg.**' A total of 18 people ... were euthanised between 2015 and 2016, explains a report issued by the Commission for Control & Evaluation... The statistics show that a total of 12 men and six women were euthanised during this period, a slight increase of the previous two years where 15 people were recorded. Since the euthanasia law came into force in 2009, 52 patients in Luxembourg received assisted suicide treatment. <https://goo.gl/f8jLKo>

Specialist Publications

Strategies to improve quality of life at the end of life: Interdisciplinary team perspectives

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 2 June 2017 – The authors surveyed 133 staff and volunteers (physicians, physician assistants, nurse practitioners, registered nurses, social workers, chaplains, administrators, and volunteers) who provide end-of-life (EoL) care to patients in both home and institutional settings for four organizations in two counties in Upstate New York. The results identified numerous strategies to enhance and safeguard quality of life for patients and their family members. These can be categorized into six domains: 1) Organization philosophy and mission; 2) Organizational policies; 3) Caregivers' behaviors and practices; 4) Symptom management; 5) Facility design, operation and management; and, 6) Patient, family member, and caregiver experience. The diverse list of identified strategies indicates that improving care to address the unique, complex, multilayered dimensions of quality of life at the EoL requires a multidisciplinary approach and consistency among care providers, including administration, clinical management, front-line caregivers, and support staff. <https://goo.gl/MGBMu4>

How big a problem are articles that should be open access but end up behind paywalls



THE SCHOLARLY KITCHEN | Online – 25 May 2017 – Over the past several years, some online commenters have uncovered examples of publishers failing to make freely available articles for which an article processing charge had been paid for that very purpose. <https://goo.gl/tPTGBO>

How upset should we get when articles are paywalled by mistake?

Interview on Retraction Watch with the author of The Scholarly Kitchen posting. <https://goo.gl/fq0V3R>

IPCRC.NET International Palliative Care Resource Center

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<http://goo.gl/frPgZ5>

A review of prognostic tools in heart failure

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 30 May 2017 – A minority of patients with end-stage disease are referred to palliative medicine for consultation in advanced heart failure. Educating stakeholders, including primary care, cardiology, and critical care of the benefits of hospice and palliative medicine for patients with poor prognosis, may increase appropriately timed referrals and improve quality of life for these patients. This article reviews multiple tools useful in prognostication in the setting of advanced heart failure. <https://goo.gl/bEIG4V>

Noted in Media Watch 15 May 2017, #512 (p.11):

- *PROGRESS IN CARDIOVASCULAR DISEASES* | Online – 5 May 2017 – ‘**Palliative care in heart failure: What triggers specialist consultation?**’ Unfortunately, despite recommendations to routinely include palliative care (PC) techniques and providers in the care of heart failure (HF) patients, the use of general PC strategies, as well as expert PC consultation, is limited by a dearth of evidence-based interventions in the HF population and the knowledge as to when to initiate these interventions, uncertainty regarding patient desires, prognosis and the respective roles of each member of the care team, and a general shortage of specialist PC providers. <https://goo.gl/l0d2Jn>

N.B. Additional articles on end-of-life care for heart failure patients are noted in this issue of Media Watch.

Strategies for promoting high-quality care and personal resilience in palliative care

AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS, 2017;19(6):601-607. Palliative care (PC) clinicians are faced with ever-expanding pressures, which can make it difficult to fulfill their duties to self and others and lead to moral distress. Understanding the pressures that PC clinicians face and the resources that could be employed to ease their moral distress is crucial to maintaining a healthy PC workforce and to providing necessary PC services to patients. The authors discuss recommendations related to two promising pathways for supporting PC clinicians in providing high-quality PC: 1) Improving systemic PC delivery; and, 2) Strategies to promote ethical practice environments and individual resilience. Enacting these recommendations holds promise for sustaining higher-quality and accessible PC and a more engaged PC workforce. <https://goo.gl/WAKNHv>

Related

- *AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS*, 2017;19(6):585-594. ‘**Initiatives for responding to medical trainees’ moral distress about end-of-life cases.**’ Moral distress frequently arises for medical trainees exposed to end-of-life (EoL) cases. The authors review the small literature on best practices for reducing moral distress in such cases and propose two areas to target for moral distress reduction: medical education and organizational ethics programs. Students require training in EoL dialogues and truthful prognostication, which are not generally available without skilled mentors. But physician-mentors and teachers can suffer from lingering moral residue themselves, which can affect the teaching culture and student expectations. <https://goo.gl/loQ2wP>

What should physicians do when they disagree, clinically and ethically, with a surrogate’s wishes?

AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS, 2017;19(6):558-563. When patients’ surrogates and physicians disagree about the appropriateness of aggressive treatment in intensive care units, physicians can experience surrogates’ demands as sources of moral distress. This article addresses the virtues and communication strategies needed to respond appropriately in such situations. Specifically, the authors offer a framework and language that rely on moral community to facilitate common ground and alleviate moral distress. <https://goo.gl/vULkwl>

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Noted in Media Watch 15 May 2017, #512 (p.7):

- *INTERNATIONAL PSYCHOGERIATRICS* | Online – 5 May 2017 – ‘**Surrogate prediction of quality-of-life and desire for treatment: A guess of a guess.**’ Surrogates predict patient preferences with only 68% accuracy. Bravo *et al* explore differences in quality-of-life assessments between patients and surrogates as a potential explanation for surrogate inaccuracy.¹ <https://goo.gl/wbQV4Z>

1. ‘Surrogate inaccuracy in predicting older adults’ desire for life-sustaining interventions in the event of decisional incapacity: Is it due in part to erroneous quality-of-life assessments?’ *International Psychogeriatrics*, published online 16 March 2017. <https://goo.gl/RQ1ziC>

N.B. Additional articles on surrogate decision makers in the context of end-of-life care are noted in the 27 March 2017 issue of Media Watch (#505, pp.3-4).

Critical care at the end of life: A population-level cohort study of cost and outcomes

BMC CRITICAL CARE | Online – 31 May 2017 – Despite the high cost associated with ICU use at the end of life (EoL), very little is known at a population level about the characteristics of users and their EoL experience. The authors’ findings indicate that the majority of individuals admitted to ICU at the EoL are elderly and burdened by chronic illness. The existing medical literature indicates that this is the exact type of population that would be expected to do worse in the ICU. Moreover, EoL care costs are much more expensive when patients have a greater burden of disease and when they are admitted to the ICU. In addition, a large percentage of the population admitted to critical care at the EoL die in hospital with aggressive care measures taken. When put in the context of rising healthcare costs and a movement towards aging in place (in the community), this represents an area where more work is needed to ensure that only patients who can clearly benefit from critical care receive it at the EoL. <https://goo.gl/Y61yWc>

Related

- *DIMENSIONS OF CRITICAL CARE NURSING*, 2017;36(4):264-270. ‘**Critical care nurses suggestions to improve end-of-life care obstacles: Minimal change over 17 years.**’ Major themes identified [in this study] were ensuring characteristics of a good death, improving physician communication with patients and families, adjusting nurse-to-patient ratios to 1:1, recognizing and avoiding futile care, increasing end-of-life education, physicians who are present and “on the same page,” not allowing families to override patients’ wishes, and the need for more support staff. When compared with data gathered 17 years previously, major themes remained the same but in a few cases changed in order and possible causation. <https://goo.gl/knbjku>

End-of-life care in France

Integration and activity of hospital-based palliative care consultation teams: The INSIGHT multi-centric cohort study

BMC PALLIATIVE CARE | Online – 30 May 2017 – In France, the first Palliative Care Consultation Team (PCCT) was created in 1989, shortly after the opening of the first inpatient Palliative Care Unit (PCU). Since then, the number of hospital-based teams has continuously increased. In 2013, the National End of Life Observatory counted 430 PCCT and 127 PCU all around the country. This high number of PCCTs is the result of the national policy for palliative care (PC) development whose main objective has been to disseminate palliative culture in hospital services concerned with end-of-life (EoL) care. However, several studies have been published since 2008 showing the poor results of this policy. In a large population of patients who died in 200 acute care hospitals, only 20% of those whose death was deemed predictable received PC by a PCCT. Death is still perceived by health professionals as an incongruity, a failure, and, as such, is largely hidden. A national survey of doctors who signed death certificates also confirmed the delay in the appropriation of good decision-making practices at the EoL: 30% of decisions taken for discontinuation or intensification of treatments before death were not discussed with patients themselves although they would have been capable for it. The more recent report, delivered to the French President for revision of the law on EoL pointed the poor integration of PC in curative medicine with elusion of death by patients and professionals. <https://goo.gl/5MBchv>

Cardiopulmonary resuscitation and advanced cardiac life support

When teachable moments become ethically problematic

CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS, 2017;26(3):491-494. There is frequently tension in medical education between teaching moments that provide skills and knowledge for medical trainees, and instrumentalizing patients for the purpose of teaching. The author questions the ethical acceptability of the practice of providing cardiopulmonary resuscitation and advanced cardiac life support to dying patients who would be unlikely to survive resuscitation, as a teaching opportunity for medical trainees. This practice violates the principle of informed consent, as the patient agreed to resuscitation for the purpose of potentially prolonging life rather than to futile resuscitation as a teaching opportunity. Justifying futile resuscitation in order to practice normalizes deceptive and non-consensual teaching cases in medical training. Condoning these behaviors as ethically acceptable trains physicians to believe that core ethical principles are relative and fluid to suit one's purpose. The author argues these practices are antithetical to the principles espoused by both medical ethics and physician professionalism. <https://goo.gl/k6cu5Z>

Related

- *CLINICAL ETHICS* | Online – 29 May 2017 – ‘**The ethical basis for performing cardiopulmonary resuscitation only after informed consent in selected patient groups admitted to hospital.**’ This article reviews the nature of potential harms caused by futile cardiopulmonary resuscitation (CPR), the reasons why de-prescription may be delayed, recent legal judgements relevant to timely do-not-attempt CPR decision making, and the possible detrimental effects of do not attempt CPR on end-of-life care. The moral and operational feasibility of a model in which informed consent must be obtained before CPR is attempted in some patient groups is then explored. <https://goo.gl/UqiORs>
- *HEALTH LAW JOURNAL* 2017;22(1):37-41. ‘**A proposal to restore medical futility as a clinical basis for a DNR order under New York law.**’ Under New York’s former Do-Not-Resuscitate (DNR) Law ... a physician could write a DNR order for a patient who lacked capacity if he or she determined, among other circumstances, that resuscitation would be “medically futile,” another physician concurred, and a surrogate decision-maker consented to the DNR order. In 2010, with the enactment of the Family Health Care Decisions Act (FHCDA), the medical futility standard for a DNR orders was superseded by more general criteria for decisions about the withdrawal or withholding of life-sustaining treatment. Overall, the FHCDA has greatly improved care toward the end of life (EoL) by empowering family decision-makers and establishing clear principles and procedures. But by attempting to create clinical criteria that could apply to all EoL decisions, the FHCDA forfeited the helpful specificity of the medical futility standard for DNR decisions, and thereby created problems in clinical practice. <https://goo.gl/SiIXii>

N.B. *Health Law Journal* is published by the New York State Bar Association.

End-of-life care in Canada

A home care palliative sedation simulation program

CANADIAN NURSE | Online – Accessed 1 June 2017 – The Edmonton Zone of Alberta Health Services covers a large geographic area of 11,800 km and has 1.3 million residents... Palliative and end-of-life (EoL) care is provided in private residences, long-term care and supportive living sites, hospice and acute care. Clients living at home at the EoL are supported by the Edmonton Zone home care program. Palliative sedation (PS) in the home is an infrequent occurrence. However, although the circumstances surrounding it are somewhat difficult to predict, an order for PS requires swift and confident coordination. This includes confirming and clarifying the orders, calling the pharmacy to confirm delivery of the medication, obtaining the infusion pump, gathering supplies, faxing documents to the call centre for independent double check and confirming that the patient and family are ready for the sedation. With a large staff complement spread over an extensive geographic area, home care nursing staff, educators and managers were finding it challenging to establish or sustain the complex, specialized skills required: communicating with prescribers, starting the infusion, assessing the level of sedation, providing caregiver support,

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troubleshooting and documenting. Some of the registered nurses and other health-care practitioners involved in providing PS reported finding the process anxiety producing. They were requesting support through more information and training. Providing simulation to practise skills used during highly stressful health-care situations is more common than ever as a way to connect theoretical learning with practical application. <https://goo.gl/SgQdfX>

Noted in Media Watch 27 June 2016, #468 (p.11):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 21 June 2016 – ‘**Ethical dilemmas faced by hospice nurses when administering palliative sedation to patients with terminal cancer.**’ Hospice nurses in the U.K. frequently encounter ethical and emotional dilemmas when administering palliative sedation (PS). Making such decisions about using PS causes general discomfort for them. Undertaking this aspect of care requires confidence and competence on the part of nurses. <http://goo.gl/cKbRXp>

Noted in Media Watch 7 March 2016, #452 (p.9):

- *END OF LIFE JOURNAL* | Online – 3 March 2016 – ‘**Experiences of palliative care nurses in the utilisation of palliative sedation in a hospice setting.**’ The results of this study indicate that the participants were generally satisfied with the processes that underpinned decisions to introduce palliative sedation. They saw it as a highly complex intervention, in part because it involved individuals with very complex conditions and symptoms. <http://goo.gl/YZBmfk>

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

The Affordable Care Act and end-of-life care for patients with cancer

THE CANCER JOURNAL, 2017;23(3):190-193. The Affordable Care Act (ACA) expanded access to high-quality end-of-life care (EoLC) for Americans with serious illness, including cancer. Before the ACA was enacted in 2010, nearly 715,000 patients died in hospitals annually, despite evidence that most Americans prefer to die at home. Moreover, fewer than half of Medicare beneficiaries used hospice before death, despite evidence that hospice services improve cancer patients’ quality of life near death and caregivers’ bereavement outcomes. The ACA-stipulated programs and subsequent efforts were designed to address these deficiencies in access to high-quality EoLC. However, important gaps in coverage persist. <https://goo.gl/AwmKuh>

Related

- *HEALTH SERVICES RESEARCH* | Online – 30 May 2017 – ‘**End-of-life care planning in Accountable Care Organizations: Associations with organizational characteristics and capabilities.**’ In this is a cross-sectional survey study, 21% Accountable Care Organizations (ACOs) had few or no end of life (EoL) care planning processes, 60% had some processes, and 19.6% had advanced processes. ACOs with a hospital in their system, and ACOs with advanced care management, utilization management and shared decision-making capabilities were more likely to have EoL care planning processes than those with no hospital or few to no capabilities. <https://goo.gl/8W2uB6>

Palliative care: How GPs can handle conversations about end-of-life care

GP | Online – 30 May 2017 – Speaking honestly about death with someone who will soon face it themselves can be daunting, but can also be extremely rewarding. A new report¹ ... explores the taboo around death, and included the worrying revelation that while 76% of people with cancer have thought about their own death, just 8% of these have shared their feelings with a healthcare professional. This is concerning for a few reasons. GPs and their teams have the potential to play a significant role in helping people work through an advance care plan. When healthcare professionals have a record of where someone would like to die, they are nearly twice as likely to die in the place of their choosing. <https://goo.gl/g5e2jr>

1. ‘No Regrets,’ Macmillan Cancer Support, April 2017. [Noted in Media Watch 1 May 2017, #510 (p.6)] <https://goo.gl/lnd9sq>

“I’m only dealing with the acute issues”: How medical ward “busyness” constrains care of the dying

HEALTH | Online – 29 May 2017 – Acute hospital units are a common location of death. Curative characteristics of the acute medical setting make it difficult to provide adequate palliative care (PC); these characteristics include an orientation to life-prolonging treatment, an emphasis on routine or task-oriented care, and a lack of priority on emotional engagement with patients. Indeed, research shows that dying patients in acute medical units often experience unmet needs at the end of life (EoL), including uncontrolled symptoms (e.g., pain, breathlessness), inadequate emotional support and poor communication. A focused ethnography was conducted on an acute medical ward in Canada to better understand how this curative/life-prolonging care environment shapes the care of dying patients. On the acute medical ward, a “logic of care,” driven by discourses of limited resources and the demanding medical unit, created a context of busyness. Staff experienced an overwhelming workload and felt compelled to create priorities, which reflected taken-for-granted values regarding the importance of curative/life-prolonging care over PC. This could be seen through the way staff prioritized life-prolonging practices and rationalized inconsistent and less attentive care for dying patients. These values influenced care of the dying through delaying a palliative approach to care, limiting PC to those with cancer and providing highly interventive EoL care. Awareness of these taken-for-granted values compels a reflective and critical approach to current practice and how to stimulate change. <https://goo.gl/3a3lnq>

Palliative care professionals’ care and compassion for self and others: A narrative review

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2017;23(5):219-229. Compassion is arguably central to palliative care (PC). However, calls for the restoring of compassionate care suggest a need for greater understanding and promotion of compassion in practice. This review explored the literature relating to PC professionals’ self-care, self-compassion, and compassion for others. This review highlights both the importance and multi-faceted nature of PC professionals’ self-care, in relation to self-compassion and compassion for others. Despite widespread discussion, empirical knowledge of these variables is limited. Future research could usefully explore health promotion interventions in self-care practice, or a positive psychology paradigm that encompasses compassion and self-compassion as positive emotions associated with wellbeing. <https://goo.gl/kwL3WC>

Related

- *JOURNAL OF HEALTH ORGANIZATION & MANAGEMENT*, 2017;31(3). **‘Rethinking compassion fatigue.’** In contrast to the assumption that compassion fatigue arises from too much compassion, historical use of the term suggests just the opposite: compassion fatigue is the result of too little compassion. Healthcare literature on compassion fatigue has not only failed to account for this opposing view, but also the underlying psychodynamics at play. By attending to these neglected dimensions, healthcare scholars and practitioners can gain new insights into compassion fatigue and devise more sustainable interventions. <https://goo.gl/iqlkNJ>

Noted in Media Watch 23 January 2017, #496 (p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 January 2017 – **‘Self-care in palliative care nursing and medical professionals: A cross-sectional survey.’** This article reports findings from a national survey of nurses and doctors. Most survey respondents regarded self-care as very important (86%). Some rarely practised self-care and less than half (39%) had received training in self-care. Self-care plans had been used by a small proportion of respondents (6%) and over two-thirds (70%) would consider using self-care plans if training could be provided. <https://goo.gl/j78qjY>



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 beginning on p.17.

Exploring the knowledge, attitudes and needs of advance care planning in older Chinese-Australians

JOURNAL OF CLINICAL NURSING | Online – 23 May 2017 – The participants of this study were open to conversations regarding future medical planning and end-of-life care, suggesting the low uptake of advance care planning (ACP) amongst Chinese-Australians is not culturally motivated, but may be due a lack of knowledge relating to ACP. Three key themes were identified: knowledge of, attitudes towards and needs for undertaking ACP... There was a low awareness of ACP amongst the participants and some confusion regarding the concept. Most reported positive attitudes towards ACP but acknowledged that others may be uncomfortable discussing death-related topics. Participants would want to know the true status of their health and plan ahead in consultation with family members to reduce the burden on the family and suffering for themselves. Language was identified as the largest barrier to overcome in order to increase ACP awareness. <https://goo.gl/EFBtOB>

Related

- *NEW ENGLAND JOURNAL OF MEDICINE*, 2017;376(22):2105-2107. **'Delegalizing advance directives – facilitating advance care planning.'** Legal formalities impose barriers to creating advance directives. Eliminating legal requirements would allow such documents to be more easily integrated into health care systems and would increase the likelihood of their being used to achieve their intended goals. <https://goo.gl/zEytYr>

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

Aggressive end-of-life care for metastatic cancer patients younger than age 65 years

JOURNAL OF THE NATIONAL CANCER INSTITUTE | Online – 25 May 2017 – Using the HealthCore Integrated Research Database, the authors analyzed patients who died between 2007 and 2014 with metastatic lung, colorectal, breast, pancreatic, or prostate cancer. Based on published quality measures, they assessed uses of chemotherapy, intensive care, emergency room visits, and hospice care at the end of life (EoL). They examined additional items including radiotherapy, invasive procedures, hospitalization, and in-hospital deaths. Across the five cancers, 10.1% to 14.1% of patients received chemotherapy within the last 14 days of life, 15.9% to 20.6% received intensive care in last 30 days, and 1.5% to 2.5% went to the emergency room two or more times in last 30 days. Hospice enrollment at least three days before death was 54.4% to 59.6%. However, 55.3% to 59.3% of patients had a hospital admission in the last 30 days, and one-third died (30.3% to 35.4%) in the hospital. There was low use of cancer-directed treatment at the EoL for younger cancer patients, and hospice use was higher than 50%. However, there was a relatively high utilization of hospital-based care. These results demonstrate an opportunity for continued improvements in the provision of high-value, patient-centered care at the EoL. <https://goo.gl/b2XH11>

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 2 June 2017 – **'Occupational variation in end-of-life care intensity.'** The authors identified 660,599, non-health maintenance organization Medicare beneficiaries aged ≥66 years who died between 2004-2011. Linking death certificates, they identified beneficiaries with pre-specified occupations: nurses, farmers, clergy, mortuary workers, homemakers, first-responders, veterinary workers, teachers, accountants, and the general population. Occupations with likely exposure to child development, death/bereavement, and naturalistic influences demonstrated lower end of life (EoL) care intensity. <https://goo.gl/xij50l>

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

End-of-life care in Denmark

Preferred place of care and death in terminally ill patients with lung and heart disease compared to cancer patients

JOURNAL OF PALLIATIVE MEDICINE | Online – 2 June 2017 – Previous research on end-of-life preferences focuses on cancer patients, most of whom identify home as their preferred place of care (PPOC) and preferred place of death (PPOD). These preferences may, however, not mirror those of patients suffering from non-malignant fatal diseases. Of the 354 eligible patients, 167 patients agreed to participate in this study. Regardless of their diagnosis, most patients wished to be cared for and to die at home. Patients with cancer and heart diseases chose hospice as their second most common preference for both PPOC and PPOD, whereas patients with lung diseases chose nursing home and hospice equally frequent as their second most common preference. Regardless of their diagnosis, all patients had a higher level of anxiety than the average Danish population; patients with heart diseases had a much higher level of anxiety than patients with lung diseases and cancer. <https://goo.gl/F1SxXD>

Related

- *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.**’ Admittance to specialized palliative care (SPC) has been discussed in the literature, but previous studies examined exclusively those admitted, not those with an assessed need for SPC, but not admitted. The authors found that admittance 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>

Qualitative study of patients’ and caregivers’ perceptions and information preferences about hospice

JOURNAL OF PALLIATIVE MEDICINE | Online – 30 May 2017 – Participants showed variable gaps in understanding about hospice, including who would benefit from hospice care and the extent of services provided. They all perceived that hospice involves a psychological transition to accepting imminent death and often referred to hospice from a relatively cognitive distance, using hypothetical scenarios of others for whom hospice would be more relevant. Participants’ attitudes about hospice reflected their concerns about suffering, loss of dignity, and death, as well as their perceived understanding of hospice services. These attitudes along with the psychological barriers to projecting a need for hospice and lack of knowledge were all perceived as important barriers to hospice utilization. All participants felt they needed more information about hospice, yet they were mixed regarding the optimal timing of this information. <https://goo.gl/86i1HI>

International survey of end-of-life care in nursing homes

JOURNAL OF POST ACUTE & LONG-TERM CARE MEDICINE, 2017;18(6):465-469. This article reports the findings of a survey on end-of-life (EoL) care in nursing homes of 18 long-term care (LTC) experts across 15 countries. The experts were chosen as a convenience-based sample of known experts in each country. The survey was administered in 2016 and included both open-ended responses for defining hospice care, palliative care (PC) and EoL, and a series of questions related to the following areas: attitudes toward EoL care, current practice and EoL interventions, structure of care, and routine barriers. Overall experts strongly agreed that hospice and PC should be available in LTC facilities and that both are defined by holistic, interdisciplinary approaches using measures of comfort across domains. However, it appears the experts felt that in most countries the reality fell short of what they believed would be ideal care. As a result, experts call for increased training, communication, and access to specialized EoL services within the nursing home. <https://goo.gl/U3c3Xy>



Cont.

Noted in Media Watch 24 April 2017, #509 (p.12):

- *JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 13 April 2017 – ‘**Palliative care development in European care homes and nursing homes: Application of a typology of implementation.**’ The authors identified three levels of palliative care (PC) implementation: 1) Macro (national/regional policy, legislation, financial and regulatory drivers); 2) Meso (implementation activities, such as education, tools/frameworks, service models, and research); and, 3) Micro (PC service delivery). This typology was applied to data collected from 29 European countries and demonstrates the diversity of PC implementation activity across Europe with respect to the scope, type of development, and means of provision. <https://goo.gl/h35EXR>

N.B. Additional articles on palliative and end-of-life care in care homes and nursing homes are noted in this issue of Media Watch.

End-of-life care in Australia

“Unexpected and distressing”: Understanding and improving the experience of transferring palliative care inpatients to residential care

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 1 June 2017 – A core component of the role of palliative care (PC) social workers involves working with patients and their families/carers when the care pathway shifts and the option of residential aged care facility (RACF) needs to be considered. This research explored several issues, including the impact of this transition on the patient and their families and on the interdisciplinary health care team treating the patient. An investigation was undertaken to identify concerns and barriers regarding the transition from hospice care to RACF and opportunities were highlighted to improve clinical practice in this area. The research highlights the difficulties that patients/families encounter in this transition, as well as the emphases of protecting the integrity of the patient and family. This is achieved by holding open and ongoing dialogue, particularly through family meetings and working in collaboration with the patient, the family, and the team. Understanding the experience and impact of this transition on key stakeholders is helpful in building up a knowledge base and to ensure a more effective relationship occurs. <https://goo.gl/ySYVPO>

Korea’s “death culture” less than 60 points out of 100

KOREA BIOMEDICAL REVIEW | Online – 30 May 2017 – Koreans do not have positive views of the situation concerning their final moments, a recent survey has shown. Notably, doctors who treat patients expressed most negative views about the nation’s “deathbed culture.” Seoul National University College of Medicine conducted a survey on 1,241 healthy people, 1,001 patients, 1,008 family members, and 928 medical workers, about hospice, palliative care, and death culture... According to the opinion poll, most Koreans do not have positive views of deathbed situations. The survey assumed a situation in which everyone leads a happy and meaningful life and dies a comfortable and beautiful death as 100 points, and a situation in which everyone lives unhappily and without meaning and dies a painful and miserable death, as 0 point. The respondents’ evaluation stood at 58.3 points on average. By group, ordinary people and patients gave above-average marks of 65 and 59.9 points, but their family members and doctors gave below-average marks of 58.1 and 47.7 points, respectively. <https://goo.gl/Q6rE0D>

Noted in Media Watch 20 June 2016, #467 (p.13):

- *KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE*, 2016;19(2):99-108. ‘**Hospice palliative care in South Korea: Past, present, and future.**’ Hospice and palliative care in Korea has developed steadily since its introduction in 1965. Currently, it is targeted only towards terminal cancer patients and their families, and the national health insurance scheme covers only inpatient hospice care for said patients. <http://goo.gl/Aa6FL3>

Haematologists' perceptions about end-of-life discussion: A qualitative study

MÉDECINE PALLIATIVE | Online – 31 May 2017 – Haematological patients have half as much access to palliative care (PC) than their counterparts with solid malignancies. The main objective of the study was to understand what makes an end-of-life (EoL) discussion easy or difficult at the time of relapse of an aggressive haematologic malignancy, according to oncohaematologists. The side issue was to explore the consequences of such discussions on integration of PC in haematology. At the time of relapse, the possibility of an EoL discussion was subordinated to the fear of loss of therapeutic alliance. Haematologists had a lot of difficulty opening up to the patients' subjectivity and to take one stand facing their progress in a therapeutic context. The anticipation of bad prognosis was not exploited in a doubtful situation. Communication centered on hope has been preferred to approach the question of death, seen as a threat. The consideration of clinicians' subjectivity in the complexity of EoL discussions brings up the question of advanced care, narrative medicine and the third parties in order to integrate the early PC in haematology model. <https://goo.gl/7eAWso>

N.B. French language article.

Curative, life-extending, and palliative chemotherapy: New outcomes need new name

THE ONCOLOGIST | Online – 26 May 2017 – Given the growing disconnect between names and expected outcomes with chemotherapy, the authors' recommend a re-naming such that the terms curative, life-extending, and palliative chemotherapy correspond to the current outcomes expected to result from the administration of chemotherapy... In their redefined nomenclature, curative chemotherapy retains its meaning as chemotherapy given with a high likelihood of improving a patient's probability of non-recurrence. Life-extending chemotherapy then refers to chemotherapy whose primary intent is to extend a patient's life for a meaningful length of time. The real challenge will then be to determine in each case what constitutes "meaningfully" enhanced survival. The authors recognize that every administration of chemotherapy may have this as its goal, but this would require evidence that the chemotherapy prescribed would provide the expected outcome in terms of "extra" life worth living. Finally, palliative chemotherapy could resume its meaning as it had when it began – the use of chemotherapy for the primary purpose of palliating symptoms. Whether there are many circumstances where this can be justified anymore is a matter of debate and further discussion. The American Society of Clinical Oncology has issued guidelines discouraging such usage. <https://goo.gl/IEHQ4j>

N.B. To access full text click on [Show PDF in full window](#)

Developing a "toolkit" to measure implementation of concurrent palliative care in rural community cancer centers

PALLIATIVE & SUPPORTIVE CARE | Online – 1 June 2017 – Despite national guidelines recommending early concurrent palliative care (PC) for individuals newly diagnosed with metastatic cancer, few community cancer centers, especially those in underserved rural areas do so. The authors are implementing an early concurrent PC model, ENABLE (Educate, Nurture, Advise, Before Life Ends) in four, rural-serving community cancer centers [in Vermont]. They developed four instruments to measure ENABLE implementation: 1) The ENABLE RE-AIM Self-Assessment Tool to assess reach, adoption, implementation, and maintenance; 2) The ENABLE General Organizational Index to assess institutional implementation; 3) An Implementation Costs Tool; and, 4) An Oncology Clinicians' Perceptions of Early Concurrent Oncology Palliative Care survey. The authors developed four measures to determine early PC implementation. These measures have been pilot-tested, and will be integrated into a comprehensive "toolkit" to assist community cancer centers to measure implementation outcomes. They describe the lessons learned and recommend strategies for promoting long-term program sustainability. <https://goo.gl/wPFCHD>

Cont.

Noted in Media Watch 23 January 2017, #496 (p.12):

- *PALLIATIVE MEDICINE* | Online – 20 January 2017 – ‘**Rural end-of-life care from the experiences and perspectives of patients and family caregivers: A systematic literature review.**’ The greatest needs were informational (developed countries) and medications (developing countries). Influence of rural location included distances, inaccessibility to EoLC services, strong community support and importance of home and “country.” Articulation of the rural voice is increasing; however, there still remain limited published rural studies reporting on patient and family caregivers’ experiences and perspectives on rural. <https://goo.gl/jiAPAO>

N.B. Additional articles on end-of-life care in rural communities and remote regions are noted in the 26 September 2016 (#481, p.8), 22 August 2016 (#476, p.11), 16 May 2016 (#462, p.18), and 18 April 2016 (#459, p.4) issues of Media Watch.

Disenfranchised grief in the PICU: Crying for attention

PEDIATRIC CRITICAL CARE MEDICINE | Online – 29 May 2017 – The death of any child is distressing to parents, family, friends, and healthcare staff alike. However, the close family circle is accorded the right to grieve by society, as the nature of the relationship with the child is acknowledged and socially validated. The relationship between the child and the staff caring for the child is not acknowledged to the same extent, and this may cause difficulties for staff who grieve following the death of the child. This experience is repeated many times when working in the PICU. <https://goo.gl/quMdRz>

Noted in Media Watch 4 April 2016, #456 (p.10):

- *LEARNING DISABILITY PRACTICE*, 2016;19(3):16-22. ‘**How nurses grieve for children who die in their care.**’ This study suggests disenfranchised grief may be experienced by nurses who have cared for children with an intellectual disability who have died. Nurses may feel helpless because of their limited experience and knowledge... <http://goo.gl/l6kYLB>

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of “current thinking” on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

Distribution

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

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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.

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CANADIAN JOURNAL OF PSYCHIATRY* | Online – 26 May 2017 – ‘**A National survey of Canadian psychiatrists’ attitudes toward medical assistance in death.**’ Bill C-14 allows for medical assistance in dying (MAiD) for patients who have intolerable physical or psychological suffering that occurs in the context of a reasonably foreseeable death. In Canada, psychiatrist support for MAiD on the basis of mental illness and beliefs influencing level of support are unknown. The response rate [to and online survey of 528 psychiatrists] was 20.9%... This study found that most psychiatrists do not support the legalisation of MAiD for mental illness, despite being quite supportive of MAiD in general. Objections seemed to be based upon concern for vulnerable patients, personal moral objections, and concern for the effect it would have on the therapeutic alliance. <https://goo.gl/TMeZTI>

Worth Repeating

The compensatory nature of personhood

ASIAN BIOETHICS REVIEW, 2014;6(4):332-342. At the crux of modern end-of-life (EoL) care is a patient-centred approach focused upon maintaining the personhood of each individual patient. All too often, determinations of personhood are led by clinical considerations – such as their conscious and functional levels and/or by their relational ties – and have served to inform critical ethical debate on EoL care, such as terminal sedation and euthanasia... Recent clinical studies ... suggest that these prevailing concepts that underpin the definitions of the poorly delineated terms – “person” and “personhood” – are inadequate and serve to highlight “the complexities and contradictions underlying their apparent simplicity” ... While some look to neuroscience for an objective basis of a criterion for “personhood,” others rely on philosophical and theological sources for clarity... As a result, there are contrasting views on the concept of personhood... Efforts to appropriately contextualise the concept of personhood within the EoL setting appear to have come to a head with suggestions that unconscious terminally ill patients ought to be considered devoid of personhood – “socially dead” – and thus ought to be considered to be in a state indistinguishable from biological death as a result of their potentially irreversible loss of consciousness till their biological demise... The impact of such a suggestion has significant repercussions on the practice of palliative care at the EoL where sedation and unconsciousness are not uncommon either by virtue of ongoing disease processes or as a result of treatment of their symptoms... [Noted in Media Watch 22 December 2017, #389 (p.11)] <https://goo.gl/f8uZJy>

Media Watch: Online

Updated 06.01.2017

International

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

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/XO4mD>

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

Cont.

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/IOSNC7>

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>

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