

## 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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Lived experiences: Scroll down to [Specialist Publications](#) and 'Ways of knowing and caring used by nurses in community hospice agencies' (p.11), in *Journal of Hospice & Palliative Nursing*.

## Canada

### Medical Assistance in Dying (MAiD)

#### Should Catholic hospitals have to provide access to medically assisted dying?

CBC ('The Current') | Online – 11 January 2018 – Religious institutions have been deeply involved in Canada's healthcare system since it began, running the system until public funding took over in the middle of the 20th century, points out Andre Picard, a health reporter and columnist at *The Globe & Mail*. Questions around their right to refuse procedures that go against their values have come up before, but have never been fully resolved. Picard wants to see these issues dealt with reasonably and with as little conflict as possible. "We don't want to throw out the good things that these institutions have brought into our healthcare system," Picard tells [The Current's Anna Maria] Tremonti. "To this day, I'd say Catholic institutions are among the most progressive... They do really great social work in addition to medicine, so we can't forget that aspect." But he doesn't see politicians jumping in to resolve the situation. "No politician wants to touch this with a ten-foot pole," he says. Daphne Gilbert, an Associate Professor, Faculty of Law at University of Ottawa and a Member of its Centre for Health Law, Policy & Ethics, says ... she believes the question will likely end up in court instead, through a patient who is denied MAiD at a religious facility. <https://goo.gl/VsvKpB>

#### Related

- BRITISH COLUMBIA | *The Globe & Mail* – 8 January 2018 – '**Patient's botched transfer renews calls for assisted dying in all publicly funded health-care facilities.**' A publicly funded Catholic healthcare network in British Columbia apologized last spring to a secular hospital after it mismanaged part of the transfer of a patient seeking a physician-assisted death, documents obtained through a freedom-of-information request show. <https://goo.gl/iAswni>

Noted in Media Watch 8 January 2018 (#545, p.1):

- *THE GLOBE & MAIL* | Online – 5 January 2018 – '**Assisted dying in religious facilities means tough choices for families.**' It is not clear if these institutions enjoy the same Charter-protected religious freedoms as individuals when it comes to refusing assisted deaths because the issue has not yet been tested in court. In the vast majority of cases, such patients are transferred to another facility to die. Sometimes the only hospital or nursing home in town is faith-based. <https://goo.gl/P7FXnu>

Cont.

Noted in Media Watch 11 December 2017 (#542, p.2):

- BRITISH COLUMBIA | *Policy Options* (Institute for Research on Public Policy) – 7 December 2017 – ‘**Faith-based care and medical assistance in dying.**’ Currently there are no federal or provincial laws mandating such procedures in faith-based facilities. More than half respondents [to a poll] said religiously affiliated nursing homes should be allowed to *not* provide medical aid in dying and to move patients wishing MAiD to another facility. <https://goo.gl/hQaTpy>

Noted in Media Watch 20 November 2017 (#539, p.2):

- SASKATCHEWAN | CBC News (Saskatoon) – 14 November 2017 – ‘**Faith-based health care should end with Saskatchewan’s health region amalgamation.**’ There are at least five Catholic-run hospitals in Saskatchewan. They are refusing to provide medical assistance in dying. The only palliative care unit within the Saskatoon Health Region is located in St. Paul’s Hospital. <https://goo.gl/Es9cg3>

**N.B.** Additional articles on medical aid in dying *vis-à-vis* faith-based hospitals are noted in this issue of Media Watch.

## [U.S.A.](#)

### **Giving family caregivers a seat at the policy table**

*FORBES* | Online – 10 January 2018 – When Congress and the White House develop health or long-term care policy, they hear plenty from providers, drug or medical device makers, and scores of other lobbyists and advocates for various interests. But they rarely hear from family caregivers (FCGs) – those people in the trenches who struggle every day to assist their loved ones. Called the Recognize, Assist, Include, Support & Engage Family Caregivers Act, the bill would require the Secretary of the federal Department of Health & Human Services to develop a national strategy to recognize and support FCGs. To help design that plan, it also creates an advisory council that includes FCGs as well as representatives of government and business. Among the issues that the strategy would address are expanding person- and family-centered care, training and respite services for FCGs, policies to help support caregivers at

work, enhancing the financial security of caregivers, sharing information about innovative caregiving models, and assessing the effectiveness of federal family caregiving programs. <https://goo.gl/NEaota>

#### [Specialist Publications](#)

‘**Quality of end-of-life care is higher in the Veterans Affairs compared to care paid for by traditional Medicare**’ (p.10), in *Health Affairs*.

‘**Life of the second-order patient: Factors impacting the informal caregiver**’ (p.12), in *Journal of Loss & Trauma*.

‘**Federal right-to-try legislation – threatening the U.S. Food & Drug Administration’s public health mission**’ (p.14), in *New England Journal of Medicine*.

### **Missouri offenders help their peers come to terms with death**

MISSOURI | KBIA Radio (Columbia) – 10 January 2018 – Offenders in some Missouri prisons are breaking down walls – emotional walls. They’re demolishing the barriers they’ve spent years building while inside a prison cell. But it’s only at the end of their sentence, the end of their life, that those walls finally crumble. And they crumble with a fellow inmate by their side. It’s all part of the Missouri Department of Corrections (MODC) Hospice Program ... where offenders are trained to provide end-of-life care for their peers. Deloise Williams, assistant division director of medical services at MODC, said Missouri prisons have anywhere between eight to 10 hospice patients each month. But the fact that they’re prisoners doesn’t change the kind of care they’re getting. <https://goo.gl/gmZ5Bk>

**N.B.** End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. Available is a compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 November 2017). **Downloaded/viewed at:** <https://goo.gl/YLckx6>

## This was not the good death we were promised

*THE NEW YORK TIMES* | Online – 6 January 2018 – When a doctor said my father had about six months to live, I invited a hospice representative to my parents' kitchen table. She went over their Medicare-funded services, including weekly check-ins from a nurse and 24/7 emergency oversight by a doctor. Most comfortingly, she told us if a final "crisis" came, such as severe pain or agitation, a registered nurse would stay in his room around the clock to treat him. For several months, things went well. His primary nurse, who doubled as case worker, was kind and empathetic. But at the very end, confronted by a sudden deterioration in my father's condition, hospice did not fulfill its promise to my family – not for lack of good intentions, but for lack of staff and foresight. At the end of life, things can fall apart quickly, and neither medical specialist nor hospice worker can guarantee a painless exit. But we were told a palliative expert would be at my father's bedside if he needed it. We were not told this was conditional on staffing levels. I didn't realize how common our experience was until a few months after his death, when two reports on home hospice came out – one from *Politico* and one from *Kaiser Health News*.<sup>1,2</sup> According to their investigations, the

hospice system, which began idealistically in the 1970s, is stretched thin and falling short of its original mission. Many of the more than 4,000 Medicare-certified hospice agencies in the U.S.<sup>3</sup> exist within larger health care or corporate systems, which are often under pressure to keep profit margins up. <https://goo.gl/Rws6p2>

### Extract from *The New York Times* article

Granted, more than a million Medicare patients go into hospice care every year,<sup>4</sup> so the complaints are in the minority. Mr. Banach [president of the National Hospice & Palliative Care Organization] told me he's worried that drawing attention to what he called the "salacious" stories of failed hospice care means more families will turn to less holistic, less humane end-of-life care. That could be true. But then, should there be more transparency early on? Should the hospice reps explain that in most cases, someone will rush to your loved one's side in a crisis, but sometimes the agency just doesn't get the timing and the logistics right? As the number of for-profit hospice providers grows, does that model provide too great an incentive to under staff night-time and weekend shifts? The solution may have to come from consumer advocacy and better regulation from Medicare itself.

1. 'Hospice in crises,' *Politico*, 27 September 2017. [Noted in the 2 October 2017 issue of Media Watch (#532, p.3)] <https://goo.gl/JvXX22>
2. 'No one is coming': Hospice patients abandoned at death's door,' *Kaiser Health News*, 26 October 2017. [Noted in the 30 October 2017 issue of Media Watch (#536, p.4)] <https://goo.gl/3HWmxt>
3. 'Hospice care,' Centers for Disease Control & Prevention, National Center for Health Statistics, 6 July 2016. **Download/view at:** <https://goo.gl/RmEG7s>
4. 'Facts & Figures: Hospice Care in America,' (2016 Edition), National Hospice & Palliative Care Organization, October 2017. [Noted in the 9 October 2017 issue of Media Watch (#533, p.4)] **Download/view at:** <https://goo.gl/Z18Er7>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- VERMONT | Vermont Public Radio (Colchester) – 12 January 2018 – '**Vermont's end-of-life law, 4 years on.**' Twenty-nine Vermonters have used medical aid to hasten their own death since the passage of the law, according to the state Department of Health. In all, 52 cases met the legal criteria of the state's 'Patient Choice at End of Life' law, often referred to as Act 39. Forty-three of those were terminal cancer cases, and seven were advanced cases of ALS. <https://goo.gl/VF3C6B>

## International

### Home care in Scotland

#### **Majority of home care services “concerned about survival”**

U.K. (Scotland) | STV News (Glasgow) – 10 January 2018 – More than 80% of independent home care services are concerned about being able to survive this year, a new survey has found. Research by Scottish Care, which represents independent social care providers, found 86% were concerned about their sustainability and survival in 2018, with 24% saying they were “extremely concerned.” Half of home care services did not apply for local authority contracts in 2017 due to sustainability and capacity, while 40% handed work back to councils last year on these grounds. The online survey represents 5,893 home care staff across Scotland looking after more than 12,000 people per week. <https://goo.gl/j1fwT2>

Noted in Media Watch 24 April 2017 (#509, p.6):

- U.K. (Scotland) | *The Herald* (Glasgow) – 16 April 2017 – “**Crippling**” shortages of care workers in Scotland.’ New figures show independent care homes and services which care for elderly people in their own homes are facing an increasing struggle to attract workers.<sup>1</sup> A separate survey among care workers in the private sector by the GMB Scotland union also paints a picture of a workforce under increasing stress, with more than two-thirds considering leaving for another job. <https://goo.gl/4nd9RE>

1. ‘Survey of care staff in care home, care at home and housing support services for older people,’ Scottish Care, April 2017. **Download/view at:** <https://goo.gl/fGu4kY>

#### **“Not the way they wanted to die”: Final wishes of thousands of Australians going unmet**

AUSTRALIA | *The Sydney Morning Herald* – 9 January 2018 – The desire of thousands of gravely ill Australians to die without pain and surrounded by family is going unmet because palliative care (PC) services fall badly short, the national peak body has warned. Just one palliative medicine specialist is available for every 704 deaths each year, according to Palliative Care Australia. It has called on the Turnbull government to make PC a national health priority, appoint a “national palliative commissioner” and ensure health workers can better help grief-stricken families. The pleas come six months after a draft Productivity Commission report predicted that without a significant policy overhaul, “tens of thousands of Australians will die in a way and in a place that does not reflect their values or their choices.”<sup>1</sup> “Their end-of-life journey will likely be punctuated with avoidable, or unwanted, admissions to hospital with the confusion, loss of dignity and loss of control that comes with it. This is not acceptable,” it said, adding that reforms in this area “should be a high priority for governments.” <https://goo.gl/AW8Ex1>



1. ‘Reforms to Human Services,’ Productivity Commission, Australian Government, June 2017. [Noted in the 5 June 2017 issue of Media Watch (#515, p.4)] **Download/view at:** <https://goo.gl/VoBZBX>

**N.B.** Additional articles on palliative and end-of-life care in Australia are noted in the 18 December and 27 November 2017 issues of Media Watch (#543, p.9 and #540, p.7, respectively).



### Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.17.

### Specialist Publications

‘Hospice and palliative care in China: Development and challenges’ (p.7), in *Asia-Pacific Journal of Oncology Nursing*.

‘A philosophical critique of the U.K.’s National Institute for Health & Care Excellence guideline ‘Palliative care for adults: Strong opioids for pain relief’” (p.8), in *British Journal of Pain*.

## Ireland's Assisted Decision-Making (Capacity) Act

### 25,000 elderly and vulnerable people held illegally in care homes

IRELAND | *The Irish Examiner* (Blackpool, Cork) – 8 January 2018 – The anomaly – thought to involve 25,000 nursing home residents and thousands more in other residential settings – came to light during preparations for the implementation of new laws giving people with restricted decision-making capacity more say in their care. A new State agency, the Decision Support Service (DSS), is being set up to oversee the Assisted Decision-Making (Capacity) Act,<sup>1</sup> which appoints formal decision-makers or decision-making assistants to adults whose capacity to make decisions is diminished by mental or physical illness or disability. Under the act, 2,800 wards of court will have to have their cases reviewed, while people entering care for the first time will have a more robust examination of their own wishes. One of the issues the act has thrown up is the status of adults already in residential care who have not given express consent to be there. The act has implications far beyond nursing homes. When fully commenced, it will end the ad-hoc arrangements put in place by many families making decisions for loved ones and it will require healthcare, legal, financial, and other professionals to satisfy themselves that a client or customer has full capacity to make decisions and to call in the DSS where that capacity is in doubt. <https://goo.gl/Y982i8>

1. 'Assisted Decision-Making (Capacity) Act 2015,' Mental Health Commission, Ireland. **Download/view:** <https://goo.gl/as2UZs>

#### Related

- IRELAND | *The Irish Examiner* (Blackpool, Cork) – 8 January 2018 – '**It will always be a matter of life and death at pioneering Decision Support Service.**' The Decision Support Service will implement the Assisted Decision-making (Capacity) Act, enabling people who are physically or mentally diminished to have a say in how they live, but its terms will inevitably be set and reset by the messiness of human need. It's the new state agency that few will people have heard of, but which many will come to entrust with some of the most personal aspects of their life and death. <https://goo.gl/Higpw3>

## Palliative care in Australia

### Opioid errors add to suffering of ill patients: Study

AUSTRALIA (New South Wales) | *The Brisbane Times* – 7 January 2018 – A review of medication errors involving opioids in palliative care (PC) has found under-dosing may be contributing to the burden of the pain of terminally ill patients in the last weeks of their lives.<sup>1</sup> Researchers from New South Wales (NSW) and the University of South Australia found errors involving opioids are almost three times higher than previously reported in other healthcare settings. The most common types of errors were missed doses and wrong doses, with the study finding 57% of patients in PC received a lower dose of opioid than ordered. The study found the errors adversely impacted on pain and symptom management in 42% of patients, with more than half of them requiring additional treatment as a direct consequence of the opioid error. <https://goo.gl/2qGZ7p>

1. 'Opioid errors in inpatient palliative care services: A retrospective review,' *Supportive & Palliative Care*, published online 4 January 2018. **Abstract:** <https://goo.gl/pyCmYA>

Noted in Media Watch 16 November 2016 (#436, p.10):

- *PALLIATIVE MEDICINE* | Online – 4 November 2015 – '**Quantifying the burden of opioid medication errors in adult oncology and palliative care settings: A systematic review.**' This review highlights the paucity of the literature examining opioid error incidence, types and patient impact in adult oncology and palliative care (PC) settings. Defining, identifying and quantifying error reporting practices for these populations should be an essential component of future oncology and PC quality and safety initiatives. **Abstract (inc. a list of references):** <https://goo.gl/McZMaB>

## Specialist Publications

### **From “long shot” to “fantasy”: Obligations to pediatric patients and families when last-ditch medical efforts fail**

*AMERICAN JOURNAL OF BIOETHICS*, 2018; 18(1):3-11. Clinicians at quaternary centers see part of their mission as providing hope when others cannot. They tend to see sicker patients with more complex disease processes. Part of this mission is offering long shot treatment modalities that are unlikely to achieve their stated goal, but conceivably could. When patients embark on such a treatment plan, it may fail. Often treatment toward an initial goal continues beyond the point at which such a goal is feasible. The authors explore the progression of care from long shot to fantasy using two pediatric cases. This progression may be differentiated into four distinct stages of care related to the potential of achieving the initial goals-of-care. Physicians are often ill prepared for the progression of treatments from a long shot hope to an unfeasible and, therefore, typically unjustified intervention. The authors present a structured approach to guide clinicians at referral institutions where these situations may be common. The transition of care from “long shot” to “fantasy” is an inherent part of quaternary care for the sickest of patients that has been underexplored. Physicians are often poorly equipped to approach that transition. The authors advocate this approach to the shift from long shot to fantasy with the belief that such a structured method will have multiple benefits, including: reduced suffering for the patient; decreased emotional burden on patient and family; decreased provider moral distress; increased likelihood of seeking high quality palliative care earlier; and provision of honest and straightforward information to patients and their families. **Abstract:** <https://goo.gl/CWibZU>

#### **Commentary**

- *AMERICAN JOURNAL OF BIOETHICS*, 2018;18(1):1-2. **‘Managing expectations: Delivering the worst news in the best way?’** The authors advocate for expectation management at its finest: clear, highly specific communication that empowers parents to understand their child’s illness better and to come to terms with narrowing treatment options. They propose a four-step process in which clinicians may build a series of signposts for parents, connecting an already unlikely cure to an unrealistic one. As the clinical picture evolves, parents are aware that forks in the road lie ahead. Presumably, this helps parents and clinicians build a stronger relationship while working in tandem to manage expectations of success and failure. We have some concerns about whether this proposal would be workable or even desirable in practice. **Full text:** <https://goo.gl/vRu6HK>

### **High-risk communication at the time of hospice enrollment: Standardizing pediatric hospital to hospice sign out**

*PEDIATRIC BLOOD & CANCER* | Online – 9 January 2018 – Most hospice patients are adults with cancer who receive hospice services for a short time only after foregoing all cancer-related treatments. Children and families, however, generally wish to keep seeing their oncology team, so hospice is frequently added as a home-based team while families are still pursuing therapy, thereby lengthening the time a child receives hospice care. The oncology and hospice teams not only need to communicate effectively during hospice enrollment, but collaborate over many months as children often receive both disease-directed and hospice care through ‘Concurrent Care for Children,’ a requirement of the Affordable Care Act. While adding hospice services to the care team is in the best interests of the patients and their families, the time of hospice referral is often a high risk time for families. This period can be marred by provider confusion about overlapping roles of multiple specialists and home care agencies, shock if the oncology team has not prepared the family for the difficult hospice intake questions, frustration by a family who has already explained their values or expected care that is not available, and missed opportunities for excellent communication and care. Families often have a great relationship and trust in their cancer team who knows the patient, the family dynamic, the current regimen and medication history, and the current status of difficult conversations. They expect the oncology team to skillfully communicate these nuances to any new providers. **First page view:** <https://goo.gl/ir96yJ>

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## Related

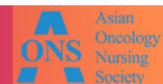
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 9 January 2018 – ‘**It’s all about communication: A mixed-methods approach to collaboration between volunteers and staff in pediatric palliative care.**’ Nine staff members and seven volunteers participated in this study. Their ideas of collaboration could be grouped into three categories: 1) Factual level of collaboration; 2) Relationship level of collaboration; and, 3) Overall appraisal of collaboration (suggestions for improvement). Because many patients in pediatric palliative care units are not able to communicate verbally, good information flow between volunteers and staff is crucial for ensuring quality patient care. Moreover, communication is the key to establishing a team philosophy by clarifying roles and building relationships between volunteers and staff. **Abstract:** <https://goo.gl/GDfqFk>
- *FRONTIERS IN PEDIATRICS* | Online – 8 January 2018 – ‘**A review of the integrated model of care: An opportunity to respond to extensive palliative care needs in pediatric intensive care units in under-resourced settings.**’ The integrated model of care appears to: 1) Improve the delivery of pediatric palliative care; 2) Allow clinicians to better respond to the care needs of patients and the epidemiological realities of their settings in ways that are consistent with evidence-based recommendations; 3) Facilitate the universal delivery of care to all patients with special care needs; 4) Maximize available resources; and, 5) Build local capacity. **Abstract:** <https://goo.gl/KVNdkP>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 10 January 2018 – ‘**The enactment stage of end-of-life decision-making for children.**’ Typically pediatric end-of-life decision-making studies have examined the decision-making process, factors, and doctors’ and parents’ roles. Less attention has focussed on what happens after an end-of-life decision is made; that is, decision enactment and its outcome. Findings [of this study] indicate that, despite differences in context, including the child’s condition and age, end-of-life decision-making did not end when an end-of-life decision was made. Enacting the decision was the next stage in a process. Time intervals between stages and enactment pathways varied, but the enactment was always distinguishable as a separate stage. **Abstract:** <https://goo.gl/8E7dLm>

## Hospice and palliative care in China: Development and challenges

*ASIA-PACIFIC JOURNAL OF ONCOLOGY NURSING*, 2018;5(1):26-32. Although death is believed to be a natural part of life, the Chinese find it hard to think and talk about death and dying, as it may create imbalance in the inner harmony. Further, in China, there is a misunderstanding about the role of palliative and hospice care (P&HC). Many people have a misconception that once they are offered P&HC, it means that the health-care providers are giving up on them and that they are just waiting for death. They do not want to be regarded as dying persons. As a result, many terminally ill patients refuse the service. Second, diseases and death are inevitable, and they are necessities of life, but most people are reluctant to face them. In some situations when cure is impossible, active treatments, including life-sustaining measures, are still given, which not only increases the patient’s suffering but also potentially leads to an undignified death. Further, in most instances, it is the family members, rather than patients, who usually make decisions; and often, the patients are not included in discussions related to their care. This practice creates patient confusion and

misunderstanding about their illness and prognosis. Many patients have no time to say goodbye, and leave the world with regrets, which does not serve the best interest of the patients or their families. Therefore, more education of the patients and the public needs to be done to make the end-of-life experience as peaceful as possible. On the one hand, it is important to improve the quality of P&HC service to show more positive outcomes to the public. On the other hand, it is needed to support patients to receive proper care at the right time, guide people to face death, and allow them to decide their care with all the information they need. **Full text:** <https://goo.gl/h1njbC>

Asia-Pacific Journal of  
Oncology Nursing



The current issue includes several articles on different aspects of palliative and end-of-life care. **Journal contents page:** <https://goo.gl/qtnsKN>

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Noted in Media Watch 27 November 2017 (#540, p.4):

- CHINA | China Internet Information Center (Beijing) – 22 November 2017 – **‘Barriers to China’s hospice care development.’** Statistics show there are a total of about 2,000 beds in Beijing’s 30-plus hospice inpatient facilities. According to an investigation starting from early October, no bed was accessible in a dozen hospices in Beijing and patients had to reserve them in advance. However, many patients died while waiting for admission. While most hospice inpatient facilities are crowded, some of the beds there are not being used by those who really need them. <https://goo.gl/dZ3USz>

Noted in Media Watch 31 July 2017 (#523, p.13):

- *THE ONCOLOGIST* | Online – 24 July 2017 – **‘Development of palliative care in China: A tale of three cities.’** With a population of 1.3 billion, China is the most populous country in the world and cancer is the leading cause of death. However, only 0.7% of hospitals offer palliative care (PC) services. The authors describe the program development and infrastructure of the PC programs at three Chinese institutions, using these as examples to discuss strategies to accelerate PC access for cancer patients in China. **Full text (to access click on pdf icon):** <https://goo.gl/ZwBaob>

### **A philosophical critique of the U.K.’s National Institute for Health & Care Excellence guideline ‘Palliative care for adults: Strong opioids for pain relief’**

*BRITISH JOURNAL OF PAIN* | Online – 10 January 2018 – The National Institute for Health & Care Excellence (NICE) promotes evidence-based medicine throughout contemporary health care. Its guidelines are employed in the U.K. and elsewhere, influencing the type and quality of health care provided. NICE considers a range of evidence in the process of creating guidelines; however, the research accepted as evidence greatly relies on positivist methodologies. At times, it is unnecessarily restricted to quantitative methods of data collection. Using the Clinical Guideline 140, opioids in palliative care, as an example, it is demonstrated that the research accepted as evidence is unable to provide answers to complex problems. In addition, several inherent biases are discussed, such as age inequality and pharmaceutical company influence. In order to provide coherent and useful guidelines relevant to complex problems in a real world setting, NICE must move away from focusing on data from randomised controlled trials. **Abstract (w. list of references):** <https://goo.gl/dM11oL>

### **Living with life-limiting illness: Exploring the narratives of patients with advanced lung cancer and identifying how social workers can address their psycho-social needs**

*BRITISH JOURNAL OF SOCIAL WORK* | Online – 8 January 2018 – The “pedagogy of suffering” contributes to the growing body of evidence available in relation to the lived experiences of patients with advanced lung cancer and highlights what we can learn from patient narratives. The findings emphasise the consequences of unnecessary delays and the preciousness of time for patients and professionals. Patients with life-limiting illness suffer a range of losses, which impact on different life domains and need to be skilfully explored. Opportunities to explore psycho-social needs and advance care planning should be facilitated and revisited by all health and social care professionals to capture changing values, preferences and priorities of patients and their family care-givers. Psychological and spiritual needs should also be explored, taking into consideration their religious beliefs, family support network and fears about dying alone or in pain. In keeping with the global definition of social work, structures and processes should be in place to support individuals with such devastating life challenges from the point of being diagnosed with a life-limiting illness. **Full text:** <https://goo.gl/59rFkY>

### **Error trawling and fringe decision competence: Ethical hazards in monitoring and address patient decision capacity in clinical practice**

*CLINICAL ETHICS* | Online – 10 January 2018 – This article addresses how health professionals should monitor and safeguard their patients’ ability to participate in making clinical decisions and making subsequent decisions regarding the implementation of their treatment plan. Patient participation in clinical

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decision-making is essential, e.g., in self-care, where patients are responsible for most ongoing care. The authors argue that one common, fact-oriented patient education strategy may in practice easily tend to take a destructive form that they call error trawling. They argue on independent grounds that this strategy not only risks to overlook significant weaknesses in patient decision competence, but also to undermine patient capacity for decision-making and implementing care. In effect, this strategy for clinically monitoring and addressing the problem of fragile decision-making capacity brings hazards in need of address. The authors close by suggesting complementary and alternative strategies, and comment on how these may call for broadened competency among clinical health professionals. **Abstract:** <https://goo.gl/guv53Q>

### Testing conscientious objection by the norm of medicine

*CLINICAL ETHICS* | Online – 8 January 2018 – Debate persists over the place of conscience in medicine. Some argue for the complete exclusion of conscientious objection, while others claim an absolute right of refusal. This paper proposes that claims of conscientious objection can and should be permitted if they concern kinds of actions which fall outside of the normative standard of medicine, which is the pursuit of health. Medical practice which meets this criterion we call *medicine qua* medicine. If conscientious refusal concerns something consonant with the health-restoring aims of medicine, it entails a desertion of professional duty. If, however, it relates to something other than *medicine qua* medicine, it can rightly be refused. It thus becomes possible to test instances of conscientious objection to determine their validity, and thereby conserve both the principle of conscientious objection and define its scope. This test of conscience prevents arbitrary discrimination, and preserves doctors' agency. It is a theoretical razor rooted in the practical reasoning of medicine whose operation will prompt, if nothing else, reflection on the goals of medicine. **Abstract:** <https://goo.gl/J9Gj8i>

Noted in Media Watch 19 December 2016 (#492, p.14):

- *CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS*, 2017;26(1):32-43. ‘**Conscientious objection and “effective referral.”**’ Physicians and others should not be coerced into involvement of any kind in what they regard as wrong. Such coercion goes against the very principles of liberal democracy. Conscience matters. Reasonable accommodation should be given to those whose moral judgment may be at variance with prevailing professional norms. Moral questions should still be given weight within medicine, and disagreements respected. Dedication to the promotion of human welfare should be paramount, but it should be recognized that there may be different visions of what such welfare consists of. **Abstract (inc. list of references):** <https://goo.gl/CSzHq7>

**N.B.** This issue of the *Cambridge Quarterly of Healthcare Ethics* includes several articles on conscientious objection. **Journal contents page:** <https://goo.gl/YRIVy>

### Pathfinders: Promoting healthy adjustment in bereaved children and families

*DEATH STUDIES* | Online – 9 January 2018 – Pathfinders is a 10-session program developed in a community setting to creatively address the diverse needs of bereaved children and families, prevent complications of grief and trauma, and promote healthy adaptation. It is an accessible, grief-focused and trauma-informed family systems model that is theory-driven, research-informed, and grounded in practice-based evidence. Pathfinders incorporates principles central to narrative approaches, with a focus on restorative processes for helping children and families stay on track developmentally. This article outlines the structure, process, and content of Pathfinders, including examples of creative interventions used within the program. **Full text:** <https://goo.gl/GYZGPK>

#### Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 9 January 2018 – ‘**Communication disparity between bereaved and others: What hurts them and what is unhelpful? A nationwide study of the cancer bereaved.**’ A number of the bereaved have experienced unhelpful communication regarding advice on dealing with bereavement and cancer. To prevent putting an unnecessary burden on the bereaved with such unhelpful communication, it is essential to understand problematic aspects. Even when people have no intention of hurting the bereaved, some communication may do so. Communication with the bereaved is also a core clinical skill required by health professionals, and further efforts are required to support the grieving process. **Full text:** <https://goo.gl/EAorGB>

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

### **Quality of end-of-life care is higher in the Veterans Affairs compared to care paid for by traditional Medicare**

*HEALTH AFFAIRS*, 2018;37(1):95-103. Congressional and Veterans Affairs (VA) leaders have recommended the VA become more of a purchaser than a provider of health care. Fee-for-service Medicare provides an example of how purchased care differs from the VA's directly provided care. Using established indicators of overly intensive end-of-life care (EoLC), the authors compared the quality of care provided through the two systems to veterans dying of cancer in fiscal years 2010-2014. The Medicare-reliant veterans were significantly more likely to receive high-intensity care, in the form of chemotherapy, hospital stays, admission to the intensive care unit, more days spent in the hospital, and death in the hospital. However, they were significantly less likely than VA-reliant patients to have multiple emergency department visits. Higher-intensity EoLC may be driven by financial incentives present in fee-for-service Medicare, but not in the VA's integrated system. To avoid putting VA-reliant veterans at risk of receiving lower-quality care, VA care-purchasing programs should develop coordination and quality monitoring programs to guard against overly intensive EoLC. **Abstract:** <https://goo.gl/T8YPqv>

#### **Related**

- *AMERICAN JOURNAL OF KIDNEY DISEASES* | Online – 10 January 2018 – ‘**End-of-life care for patients with advanced kidney disease in the U.S. Veterans Affairs health care system, 2000-2011.**’ Compared with decedents treated with dialysis, those for whom a decision not to pursue dialysis therapy had been made were less often hospitalized, less often the recipient of an intensive procedure, more often the recipient of a palliative care consultation, more often used hospice services, and died less frequently in a hospital. **Abstract:** <https://goo.gl/y5YptJ>

**N.B.** Additional articles on end-of-life care in a Veterans Affairs setting are noted in the 2 October 2017 issue of *Media Watch* (#532, p.10).

### **What is needed to prepare speech pathologists to work in adult palliative care?**

*INTERNATIONAL JOURNAL OF LANGUAGE & COMMUNICATION DISORDERS* | Online – 12 January 2018 – Speech pathologists have a pivotal role in palliative care (PC), assisting patients with swallowing and communication disorders, yet very little is known about the preparedness of speech pathologists to work in this field. Participants [i.e., respondents to an online survey] were Australian-trained speech pathologists who provided adult PC services. The majority (70%) indicated that their university training did not prepare them to practice in PC. Participants who received PC education at the tertiary level were significantly more prepared to work with palliative patients than those who had not; however, only a minority (27%) had received such training. Just over half (57%) reported having completed post-university professional development in PC. The speech pathologist's role in PC was also highlighted, with speech pathologists outlining their contribution to the assessment of patients' communication and swallowing abilities. In addition, recommendations for PC content to be incorporated into university curriculum were suggested. **Abstract:** <https://goo.gl/GxbYqw>

Noted in *Media Watch* 29 February 2016 (#451, p.12):

- *PROGRESS IN PALLIATIVE CARE* | Online – 19 February 2016 – ‘**The role of speech-language pathologists in palliative care: Where are we now? A review of the literature.**’ Potential challenges to providing services include the impact of working with people who are dying, limited professional preparation, ongoing education constraints, and legal and ethical considerations. Further research into speech-language pathology (SLP) activities with patients with life-limiting conditions is required to explore the valuable contributions already being made by SLPs to the care of patients with life-limiting illnesses and to identify opportunities to develop and improve evidence-based services in this area. **Abstract:** <http://goo.gl/XIC1ny>

## Ways of knowing and caring used by nurses in community hospice agencies

*JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2018;20(1):74-80. Hearing the narrative of nurses providing end-of-life care (EoLC) through phenomenological research can inform nursing education and institutions' methods to support the development of skills and characteristics to improve palliative and end-of-life nursing care. The purpose of this research was to question nurses who work in hospice agencies concerning their lived experiences related to knowing about and caring for individuals who were receiving hospice services. Four themes were identified related to the concepts of knowing and caring. These are difficult-to-measure concepts, but add value to the profession and document how nurses contribute to patient care. In addition, the concepts are meaningful to patients and families receiving hospice services. The research provided a method of making the work of these nurses visible and gave more knowledge about nurses who provide EoLC. **Abstract:** <https://goo.gl/nh7DxR>

## Components of the advance care planning process in the nursing home setting

*JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2018;20(1):95-102. Themes based on [study] participants' statements were used to generate an advance care planning (ACP) process framework, which has three primary phases: 1) Assess resident's status regarding end-of-life care, which includes establishing common language, identifying resident's unrealistic goals and wishes, and Identifying inconsistencies between resident's expressed wishes and the preferences documented in medical record; (2) Negotiate realistic plan of care, which includes addressing inconsistencies between resident's and family's goals, rephrasing goals and wishes in hypothetical scenarios, and clarifying goals; and, 3) Create action plan, which includes complete advance directives (ADs) and revisit/revise in the future as needed. Most of the consultations resulted in action plans to facilitate concordance between resident wishes and medical records. ACP with palliative care specialists provided a valuable opportunity for nursing home residents and families to discuss ADs and provided valuable clarification of their goals-of-care. **Abstract:** <https://goo.gl/mtfaZN>

### Staff experiences forming and sustaining palliative care teams in nursing homes

*THE GERONTOLOGIST* | Online – 3 January 2018 – Building palliative care (PC) capacity in nursing homes (NH) is a national priority and essential to providing high quality care for residents with advanced illness. The authors report on NH staff experiences in developing and sustaining PC teams as part of a randomized clinical trial to improve PC through teamwork. The authors found four key structural themes in their analysis: 1) Administrative support; 2) Financial considerations; 3) Turnover and staffing; and, 4) Competing priorities. The development and sustainability of the nascent PC teams were constantly threatened by competing priorities and the key factor in their success was consistent and tangible administrative support. **Abstract:** <https://goo.gl/9mE9r6>

**N.B.** Additional articles on palliative and end-of-life care in the nursing home setting are noted in the 8 January 2018 and 27 November 2017 issues of *Media Watch* (#545, p.10 and #540, p.3, respectively).

Noted in *Media Watch* 23 October 2017 (#535, p.9):

- *INTERNATIONAL PSYCHOGERIATRICS* | Online – 9 October 2017 – ‘**Discussing advance care planning: Insights from older people living in nursing homes and from family members.**’ Three main themes were identified [in this study]: 1) Life in the nursing home (NH), including thoughts about life in a nursing home, residents' concerns, wishes and fears, and communication barriers; 2) Future plans and attitudes toward advance care planning (ACP), including attitudes toward planning for the future and plans already made, and attitudes toward and barriers against ACP; and, 3) Contents and manner of ACP, including contents of ACP discussions, the right moment to introduce ACP, with whom it is better to discuss ACP, and attitudes toward advance directives. **Abstract (inc. list of references):** <https://goo.gl/Xg597i>

**N.B.** Additional articles on advance care planning in the nursing home setting are noted in this issue of *Media Watch*.

Cont.

## Related

- *BRITISH JOURNAL OF GENERAL PRACTICE*, 2018;68(666):e44-e53. ‘GPs’ perceptions of advance care planning with frail and older people: A qualitative study.’ Although some general practitioners (GPs) [i.e., study participants] were concerned it might cause distress, the majority felt that raising advance care planning (ACP) was important, especially as preparation for future emergencies. Several considered that service limitations made it difficult to fulfil patients’ wishes and risked raising unrealistic patient expectations. Other barriers identified included uncertainty over prognosis and difficulties ensuring that individuals’ wishes were respected. Most GPs viewed ACP as important. However, their enthusiasm was tempered by experience. **Full text:** <https://goo.gl/t8ahf7>
- *SEMINARS IN DIALYSIS* | Online – 3 January 2018 – ‘A practical guide for the care of patients with end-stage renal disease near the end of life.’ This review presents a framework for how to incorporate advance care planning (ACP) in the care of dialysis patients throughout the kidney disease course and at the end of life. Check-in conversations can be used to continue longitudinal discussions with patients and identify opportunities for symptom management and support. Triggered ACP is useful to clarify care preferences for patients with worsening clinical status. **Abstract:** <https://goo.gl/non258>

### Voluntarily stopping eating and drinking: A normative comparison with refusing lifesaving treatment and advance directives

*JOURNAL OF LAW, MEDICINE & ETHICS* | Online – 10 January 2018 – Refusal of lifesaving treatment, and such refusal by advance directive, are widely recognized as ethically and legally permissible. Voluntarily stopping eating and drinking (VSED) is not. Ethically and legally, how does VSED compare with these two more established ways for patients to control the end of life? Is it more questionable because with VSED the patient intends to cause her death, or because those who assist it with palliative care could be assisting a suicide? In fact the ethical and legal basis for VSED is virtually as strong as for refusing lifesaving treatment and less problematic than the basis for refusing treatment by advance directive. VSED should take its proper place among the accepted, permissible ways by which people can control the time and manner of death. **Abstract:** <https://goo.gl/xzMKiA>

**N.B.** Additional articles on voluntarily stopping eating and drinking are noted in the 1 January 2018 issue of *Media Watch* (#544, p.10).

### Life of the second-order patient: Factors impacting the informal caregiver

*JOURNAL OF LOSS & TRAUMA* | Online – 8 January 2018 – Informal caregivers (ICs) are forced to make adaptive lifestyle changes to meet the significant demand of caring for loved one who are terminally ill. Open-ended questions were administered with 26 ICs who cared for loved ones diagnosed with terminal illnesses whose prognosis was less than six months. The results add substantive information to parsimonious literature and demonstrate a correlation with existing studies that coincide with the debilitating effects that caregiving has on the informal carer. The study clarifies the complexities of the caregiving role characterized by the involvement that may adversely affect socialization, physical health conditions, and marital dynamics, among other areas of the IC’s personal life. **Abstract:** <https://goo.gl/abPBXR>

### Two ways to kill a patient

*JOURNAL OF MEDICINE & PHILOSOPHY*, 2018;43(1):44-63. According to the Standard View, a doctor who withdraws life-sustaining treatment does not kill the patient but rather allows the patient to die – an important distinction, according to some. The author argues that killing (and causing death) can be understood in either of two ways, and given the relevant understanding, the Standard View is insulated from typical criticisms. **Full text:** <https://goo.gl/wqsfYX>



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

## Milestones in palliative care's evolution

### World domination

*JOURNAL OF PALLIATIVE MEDICINE*, 2018; 21(1):2-3. We are just 50 years from the founding of St. Christopher's Hospice in London, England, by Dr. Cicely Saunders in 1967. In response to the deficiencies in care she observed as a nurse, social worker, and physician, she raised the money to build a building in which to demonstrate a new model of interdisciplinary care. In short, it was the world's first academic hospice. We are now 45 years from the founding of the palliative care service at the Royal Victoria Hospital in Montreal, Canada, in 1974 where Dr. Balfour Mount showed that the model worked in the major teaching hospital of a leading medical school – the place where the future of medicine is discovered. We are now 35 years from the demonstration that a government funding model, the Medicare Hospice Benefit, can ensure broad distribution of the model to people and their families at home with more quality and less cost than other approaches. Each of these developments has been scientifically proven to improve the quality of medical care. The official recognition of the specialty of palliative medicine 30 years ago in the U.K. is an evolutionary mark of the acceptance of that science and the impor-

tance of those three evolutionary milestones. The observation that new developments in the care of the dying works as well, or better, in those who are not dying does not diminish the importance of the evolution. Put in the experimental terms of oncology, where we test new treatments for cure in the dying before using them in patients who are not dying, we should have expected this path of evolution. The most recent evidence that this model not only improves quality of life but also length of life should not be a surprise – its better care, not an alternative to standard care. **Access options to article:** <https://goo.gl/YfFRdD>

#### **Extract from the *Journal of Palliative Medicine* article**

In short, world domination (from a palliative care perspective) is in sight. A future wherein palliative medicine is the leading, most important aspect of a health system when it is focusing on serious medical illness is plainly on the horizon. Paint that picture when you are recruiting new staff!

### Top 10 tips palliative care clinicians should know when caring for patients with ovarian cancer

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 January 2018 – The vast majority of women diagnosed with ovarian cancer present with advanced-stage disease with a five-year survival rate less than 50%. Studies have shown that in the past, gynecologic oncologists were not routinely collaborating with palliative care (PC) physicians resulting in goals-of-care planning often not occurring until the last 30 days before death. In recent years, professional societies have been increasingly more vocal about the importance of incorporating PC early in a patient's disease course. As these calls increase, PC clinicians will be likely to co-manage patients with ovarian cancer and may benefit from additional targeted education on this unique population. The authors brought together a team of gynecologic oncology and PC experts to collate practical pearls for the care of women with epithelial ovarian cancer. In this article, they use a "Top 10" format to highlight issues that may help PC physicians understand a patient's prognosis, address common misconceptions about ovarian cancer, and improve the quality of shared decision making and goals-of-care discussions. **Abstract:** <https://goo.gl/MpRAuT>

#### **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>



## The term “supportive care” is preferable to “palliative care” for consults in the cardiothoracic ICU

*JOURNAL OF THORACIC & CARDIOVASCULAR SURGERY* | Online – 6 January 2018 – As part of the response to the challenges of caring for severely ill patients who are close to death or on maximal mechanical support, medical centers have created support teams. These “supportive” care teams address the complex psychological, ethical and financial issues that patients and families are experiencing. The teams may include psychologists, social workers, and religious leaders, as well as physicians trained in providing communication support during end-of-life care. The teams have unfortunately been termed “palliative care” teams by some centers. This term conflicts with the basic goal of the cardiothoracic surgery, which is to restore the patient to a meaningful life outside the hospital. The patient has been offered the surgery with the potential for recovery from the clinical condition which led to the patient’s hospital admission. The term “palliative” sends a negative message. However, the surgeon’s perspective may be too optimistic and unrealistic. Members of the “supportive care” team can provide a balanced perspective to a patient’s family and health care providers, and provide support if “end-of-life care” is instituted. This latter role is the same as

that of “palliative care” teams in hospitals when cancer and stroke patients have a dismal prognosis with no chance for recovery. **Full text (click on pdf icon):** <https://goo.gl/1kjXJZ>

### ‘Who is not comfortable with the term “palliative care” – patient, family or surgeon?’

*JOURNAL OF THORACIC & CARDIOVASCULAR SURGERY* | Online – 11 January 2018 – Importantly, those who feel uncomfortable with the term “palliative care” may be cardiothoracic surgeons rather than patients or families. A study in pediatrics showed while parents initially responded more favorably to the term “supportive care” than “palliative care,” the difference disappeared after they received proper explanation. The current challenge in cardiothoracic surgery appears similar to that in oncology 10 years ago, when many oncologists felt uncomfortable making a referral to palliative care (PC). Now, after multiple studies have showed the benefit of PC, including improved survival, recent clinical guidelines from the American Society of Clinical Oncology recommend early incorporation of “palliative care” with active treatment as the standard of care. **Full text (click on pdf icon):** <https://goo.gl/G7tJo4>

Noted in Media Watch 9 May 2016 (#461, p.8):

- *ANNALS OF THE AMERICAN THORACIC SOCIETY*, 2016;13(5):595-597. ‘**Integrating palliative care in the intensive care unit. Evidence gaps and quality gaps.**’ As clinicians, administrators and patients place greater value on care processes to support quality of life, there is a corresponding need to ensure those processes to support quality of life are delivered in expected ways. **Abstract:** <http://goo.gl/bC2IFs>

## Federal right-to-try legislation – threatening the U.S. Food & Drug Administration’s public health mission

*NEW ENGLAND JOURNAL OF MEDICINE* | Online – 10 January 2018 – The Food & Drug Administration (FDA) is the gatekeeper of the country’s drugs and medical devices. Originally created to prevent the misleading of patients, it was later tasked with ensuring the safety of medical products. In 1962, Congress expanded the FDA’s mandate again, requiring it to determine that medical products are effective for their intended use and that their benefits outweigh their risks. Access to products that are not yet FDA-approved is typically restricted to participants in clinical trials. Consequently, some patients who might benefit from investigational drugs cannot obtain them. Recognizing this problem, the FDA created “expanded access” pathways to give desperate patients without other options access to promising products before approval, while still providing oversight. The agency received more than 5,000 requests under those pathways between 2010 and 2014. But in August 2017, the Senate passed the ... Right to Try Act, which would sharply curtail the FDA’s oversight of access to investigational drugs for patients with life-threatening illnesses. Though popular with the public and supported by politicians from both parties, the legislation has been widely criticized by policy experts. **Full text:** <https://goo.gl/47Fgn4>

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

## **Patients' and carers' perspectives of palliative care in general practice: A systematic review with narrative synthesis**

*PALLIATIVE MEDICINE* | Inprint – Accessed 13 January 2018 – General practitioners (GPs) have overall responsibility for community care, including towards end-of-life. Current policy places generalists at the centre of palliative care (PC) provision. However, little is known about how patients and carers understand the GP's role. 25 studies were included: 14 employed qualitative methods, eight quantitative survey methods and three mixed-methods. Five key themes were identified: 1) Continuity of care; 2) Communication between primary and secondary care; 3) Contact and accessibility; 4) Communication between GP and patient; and, 5) Knowledge and competence. Though the terminology and context of general practice vary internationally, themes relating to the perceived role of GPs were consistent. GPs are considered well placed to provide PC due to their breadth of clinical responsibility, on-going relationships with patients and families, and duty to visit patients at home and coordinate healthcare resources. These factors, valued by service users, should influence future practice and policy development. **Abstract:** <https://goo.gl/CoHX77>

## **Patients' and oncologists' views on family involvement in goals-of-care conversations**

*PSYCHO-ONCOLOGY* | Online – 5 January 2018 – Research on patient and physician perspectives about family involvement and influence on goals-of-care conversations is limited. The authors conducted semi-structured interviews at academic, community and municipal hospitals with patients with advanced cancer and their oncologists. They identified four themes: 1) Presence and duration of family involvement; 2) Family expectations; 3) Protecting patients'/family members' feelings; and, 4) Patient-family disagreement. For patients, the authors identified two additional themes: 1) Family and oncologist relationship; and, 2) Effects of cancer on family. Both patients and oncologists emphasized the importance of family support for the patient's understanding of their illness and on patients' emotions. The authors also identified ways in which family involvement may benefit or prove challenging to goals-of-care conversations. **Abstract:** <https://goo.gl/u3tnM7>

Noted in Media Watch 4 December 2017 (#541, p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 November 2017 – '**Sharing end-of-life care preferences with family members: Who has the discussion and who does not.**' Four themes emerged in this study: 1) Being proactive or passive/reactive; 2) Perceiving discussion of death as normal or abnormal; 3) Response to family resistance/disconnection; and, 4) Knowledge acquired. A fifth theme, the role of healthcare providers in family end-of-life care (EoLC) discussions, resulted from facilitators' questions. **Abstract:** <https://goo.gl/eHJsiw>

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

Representative sample of recent journal articles:

- *LUSO-BRAZILIAN REVIEW*, 2017;54(2):129-151. '**Bioethical issues in contemporary Brazilian culture: Euthanasia and literature.**' This article focuses on the way in which contemporary Brazilian literature participates in the international debate regarding bioethical issues, with a particular focus on the representation and discussion of euthanasia and assisted suicide. The author demonstrates how Brazilian literature today is engaged in such problematic discussions as: patients' rights, disability, and "good death," presenting unusual points of view (*a morte e a vida*) and offering nuanced approaches that do not necessarily fit into binary simplifications for or against euthanasia (*uma duas*). **Abstract:** <https://goo.gl/DfEoUb>
- *PEDIATRICS* | Online – 9 January 2018 – '**Should pediatric euthanasia be legalized?**' Voluntary active euthanasia for adults at their explicit request has been legal in Belgium and The Netherlands since 2002. In those countries, acceptance of the practice for adults has been followed by acceptance of the practice for children. Opponents of euthanasia see this as a dangerous slippery slope. Proponents argue that euthanasia is sometimes ethically appropriate for minors and that, with proper safeguards, it should be legally available in appropriate circumstances for patients at any age. The authors asked philosophers from the U.S. and The Netherlands, and a Dutch pediatrician, to discuss the ethics of legalizing euthanasia for children. **Abstract:** <https://goo.gl/QbS1Vc>

## Journal Watch

### **Predatory publishing: How to safely navigate the waters of open access**

*CANADIAN JOURNAL OF NURSING RESEARCH* | Online – 5 January 2018 – Open access publishing enables scholarship to be openly accessible to everyone, which has countless benefits. However, the open access movement has opened the door for “predatory publishers” to take advantage of researchers surviving in this publish or perish academic landscape. Predatory journals are becoming increasingly common. Nursing researchers, instructors, and students need to be made aware of the dangers of predatory journals, and they need to know how to identify them. While there are blacklists and whitelists that can be used to aid in decision-making, it is critical to note that these lists can never be entirely up to date. This article incorporates a literature review which provides insights into newer trends in predatory and unethical publishing, including “journal hijacking” and “bogus impact factors.” Extensive criteria for assessing emerging or unknown journals is compiled to aid researchers, students, educators, and the public in evaluating open access publications. Abstract: <https://goo.gl/FR8zdd>

### **Predatory journal has firm grip on universities in Ottawa and Canada**

CANADA | *The Ottawa Citizen* – 5 January 2018 – Scientists from the University of Ottawa, The Ottawa Hospital and other top-tier institutions across Canada keep publishing their results in fake science journals, tainting the work despite years of warnings. One veteran science publisher warns all the work that produced these studies “is just thrown away.” Until recently, the scope of the problem of “predatory” journals has been hard to measure. Now, one giant in the fake publishing field, OMICS International of India, has improved the search engine for 700 journals. As a result, we found hundreds of Canadian scientists publishing recently with the

Indian firm – the same company that accepted this newspaper’s analysis of how pigs fly.<sup>1</sup> Although [recent Ottawa papers published by OMICS] may be fine, they have not been independently reviewed – a crucial step that real journals provide but OMICS ignores. The result is like a financial report that has not been audited. People won’t trust it. The improved ability to search puts a Canadian face on the problem. Recent surveys, including one from the Ottawa Hospital Research Institute, have said fake journals still prey on Canadians. But now, there are visible examples. <https://goo.gl/vt697s>

1. ‘When pigs fly: Fake science conferences abound for fraud and profit,’ *The Ottawa Citizen*, 10 March 2017. <https://goo.gl/AaKhCW>

Noted in Media Watch 5 December 2016 (#490, p.2):

- CANADA | *The Ottawa Citizen* – 28 November 2016 – ‘**Shadowy publisher of Canadian medical journals retracts “steaming pile of dung”**’ The *Citizen* exposed scientific fraud by the new owners of two Canadian medical publishing firms – printing fake research for cash. Now, after the news got international publicity, the company that published our trashy little fake study is retracting it. OMICS International bought Pulsus Group and Andrew John Publishing. Both were reputable medical journal publishers, but under OMICS they have been used as fronts for “predatory” publishing. <https://goo.gl/9n3CoI>

**N.B.** In November 2017, a U.S. federal court granted a preliminary injunction against OMICS requested by the Federal Trade Commission “temporarily halting the deceptive practices” of the publisher. [Noted in the 27 November 2017 issue of Media Watch (#540, p.18)] See Retraction Watch: <https://goo.gl/XrocPi>

## **Palliative Care Network**

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>



## Worth Repeating

### Patient choice and informed consent

#### Reining in patient and individual choice

*JOURNAL OF MEDICAL ETHICS*, 2014;40(5):291-292. Patient choice, we might think, is the popular version of the ideas of informed consent and the principle of respect for autonomy and intimately connected to the politics of liberal individualism. There are various accounts to be given for why patient choice, in all its forms, has dominated thinking in bioethics and popular culture. All of them [the author suggests] will make reference to the decline of paternalism. The bad old days of “doctor knows best” are gone and were replaced by the primacy of patient choice and informed consent. The response to the dominance of the principle of patient choice has been slow in building but it has come in a number of ways. Two sets of papers in this issue of the *Journal of Medical Ethics* show just how far this response has come and the degree to which the pendulum is swinging back in the other direction.<sup>1,2</sup> [Noted in the 5 May 2014 issue of Media Watch (#356, p.8)] **Full text:** <https://goo.gl/uvDqB6>

1. ‘Forced to be free? Increasing patient autonomy by constraining it.’ **Full text:** <https://goo.gl/S8wfgq>
2. ‘Against autonomy: Justifying coercive paternalism.’ **Abstract:** <https://goo.gl/eVcXYh>

### Media Watch: Online

Updated 01.12.2018

#### International



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

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

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

PALLIMED: <http://goo.gl/7mrgMQ>

[Scroll down to ‘Aggregators’ and ‘Media Watch by Barry Ashpole’; see also ‘Media Watch: Behind the Scenes’ at <https://goo.gl/6vdk9v>]

#### Asia

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

[Scroll down to ‘Resource Collection’ and ‘Media Watch Barry Ashpole’]

#### Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLgxy2>

[Scroll down to ‘Are you aware of Media Watch?’]

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>

[Scroll down to ‘Additional Resources’]

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

ONTARIO | Mississauga Halton Palliative Care Network: <https://goo.gl/ds5wYC>

[Scroll down to ‘International Palliative Care Resource Center hosts Media Watch’]

#### Europe



EUROPEAN JOURNAL OF PALLIATIVE CARE: <https://goo.gl/sBTcJS>

[November/December 2017 issue (Scroll down to ‘Vulnerable populations: From the homeless to the unbefriended’)]

HUNGARY | Magyar Hospice Alapítvány: <http://goo.gl/5d1l9K>

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

### 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.

### Links to Sources

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

### Something Missed or Overlooked?

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

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