

## 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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Compilation of Media Watch 2008-2018 ©

Compiled & Annotated by Barry R. Ashpole

**The illness experience: Scroll down to [Specialist Publications](#) and 'How family caregivers help older relatives navigate statutory services at the end of life: A descriptive qualitative study' (p.15), in *Palliative Medicine*.**

## Canada

### **New Brunswick announces palliative care strategy framework**

NEW BRUNSWICK | Global TV News (Fredericton) – 19 April 2018 – The Government of New Brunswick announced its framework for a palliative care (PC) strategy to help improve access to palliative and end-of-life (EoL) care services.<sup>1</sup> New Brunswick Seniors & Long-Term Care Minister Lisa Harris said an advisory committee will be set up to develop an action plan. The committee will be led by the New Brunswick Cancer Network, made up of representatives from PC, health care and community stakeholders. Harris said there will be \$2.5 million put into the framework and said there will be more money invested in the future. Harris added that there isn't a timeline yet, but said the committee will get to work as soon as possible. "What we know is that New Brunswickers are going to have better, easier access to PC and that there's going to be teams in place that are going to be able to go into people's homes and to really support them. Support

the person that's suffering from the illness, but as well to support their families as they go through the different stages of the EoL and that's what's extremely important today," Harris said. <https://goo.gl/M5w1d3>

### Specialist Publications

**'What really matters at the end: Perspectives from a patient, a family member and an oncologist'** (p.14), in *Canadian Medical Association Journal*.

**'Medical decision-making in paediatrics: Infancy to adolescence'** (p.9), in *Paediatrics & Child Health*.

**'Medical assistance in dying: A paediatric perspective'** (p.14), in *Paediatrics & Child Health*.

1. 'Palliative Care in New Brunswick: A person-centred care and integrated services framework,' Department of Health, Government of New Brunswick, April 2018. **Download/view at:** <https://goo.gl/WXWj5o>

**N.B.** Additional articles on the provision and delivery of palliative care in New Brunswick noted in the 9 November 2015 issue of Media Watch (#435, p.2).

## Poor communication is compromising care for the dying

*THE CONVERSATION* | Online – 18 April 2018 – Research shows that up to 70% of seriously ill, hospitalized elderly Canadians are receiving invasive end-of-life (EoL) treatments that they don't want.<sup>1</sup> This could be your mother or your grandfather. Maybe someday, it will be you. For more than 10 years, our team of health researchers ... has been working to understand and improve palliative and EoL care in Canada. Many older patients with serious illness want to maintain quality of life rather than prolong it. However, the use of aggressive life-sustaining technologies in this vulnerable population is common. Instead of a peaceful EoL experience, they are receiving invasive medical treatments during their last days. A national, multi-year study involving seriously ill older Canadians revealed that even though 28% of the participants stated a preference for "comfort care" (meaning no curative treatments), this was documented in only 4% of their charts.<sup>1</sup> This discrepancy can lead to a poor EoL experience and an increase in family distress. Why is this happening? Often, it comes down to a lack of communication. Even though studies have shown that seriously ill patients and families have identified EoL communication and decision-making as high priority targets for quality improvement, these conversations are typically "too little, too late and not great."<sup>2,3</sup> <https://goo.gl/7MSn7s>

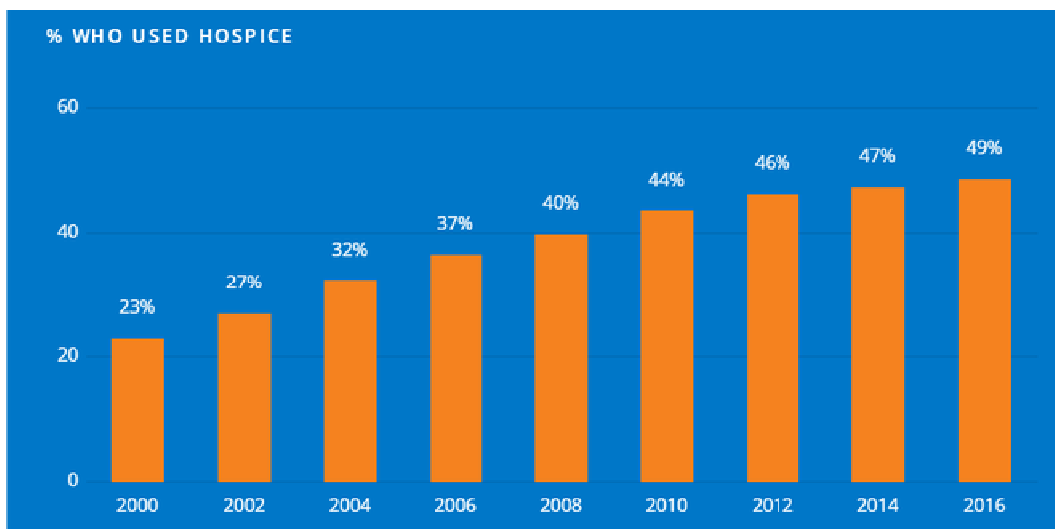
**CARENET**  
Canadian Researchers at  
the End of Life Network

1. 'Failure to engage hospitalized elderly patients and their families in advance care planning,' *JAMA Internal Medicine*, 2013;173(9):787-778. [Noted in the 8 April 2013 issue of Media Watch (#300, p.2)] **Full text:** <https://goo.gl/fokFZT>
2. 'Defining priorities for improving end-of-life care in Canada,' *Canadian Medical Association Journal*, 2010;182(16):e747-e752. [Noted in the 11 October 2010 issue of Media Watch (#170, p.2)] **Full text:** <https://goo.gl/T7g1jF>
3. 'What really matters in end-of-life discussions? Perspectives of patients in hospital with serious illness and their families,' *Canadian Medical Association Journal*, 2014;186(18):e679-e687. [Noted in the 10 November 2014 issue of Media Watch (#383, pp.1-20)] **Full text:** <https://goo.gl/jESRBY>

## U.S.A.

### Hospice use among Medicare decedents has steadily increased over time

KAISER FAMILY FOUNDATION | Online – 19 April 2018 – The Foundation's analysis is of a 5% sample of Medicare claims from the Centers for Medicare & Medicaid Services Chronic Conditions Data Warehouse, 2000-2016. **Download/view at:** <https://goo.gl/XKxpGU>



## Bill aims to ensure disposal of hospice drugs

NEW HAMPSHIRE | Edge Radio (Concord) – 19 April 2018 – A bipartisan group of U.S. senators introduced a bill aimed at closing one more loophole contributing to the opioid crisis. The Safe Disposal of Unused Medication Act of 2018 is legislation intended to address the problem of unused prescription drugs when a patient is receiving hospice care at home. Under current federal regulations, hospice staff are not allowed to dispose of unused medications, even after the patient has died. As a result, dangerous medications with a high risk of diversion, theft and abuse are frequently left in the deceased person's home. The Act would permit hospice staff (physicians and registered nurses) or emergency medical services professionals to dispose of controlled substances when a patient dies, or a medication expires... <https://goo.gl/WDrhMv>

Noted in Media Watch 9 April 2018 (#558, p.3):

- TEXAS | *The Tyler Morning Telegraph* – 2 April 2018 – **'Hospice and substance abuse prevention coalitions partner to safely dispose of leftover prescriptions.'** Hospice of East Texas and Next Step Community Solutions are partnering in an effort to keep unused prescription drugs away from people who could abuse them. The hospice serves about 2,000 patients per year in the East Texas area. Much of the coverage area overlaps with Next Step's coverage area under its substance abuse coalition program. <https://goo.gl/xPBrDc>

## The problem with miracle cancer cures

*THE NEW YORK TIMES* | Online – 19 April 2018 – Over the past 20 years, evidence has demonstrated palliative care decreases pain, improves comfort, and even, in some cases, prolongs life by a few months. In my experience, conversations about turning to it often begin with patients recognizing that curing their cancer is impossible. Patients sometimes ask for my opinion on this. While the conversation is often heartbreaking, it has rarely been a hard call. But now it is. And that has thrown a wrench into the way we treat patients with advanced cancer. The reason is a new generation of cancer treatments that have become available in the last few years. Some, called immunotherapy, harness the patient's own immune system to battle the tumor. Others, known as targeted therapies, block certain molecules that cancers depend on to grow and spread. The medical literature – usually circumspect when it comes to cancer, in light of many overhyped treatments in the past – now fairly gushes with terms like “revolutionary” and “cure.” In this case, the hype feels mostly justified. Much has been written about the promise of these treatments, as well as their staggering costs – many cost several hundred thousand dollars a year. But what strikes me most about them is that, by blurring the line between cure

and comfort – and between hope and hopelessness – they have disrupted the fragile equilibrium that we doctors have long taken for granted. <https://goo.gl/Km7QLv>

### Specialist Publications

**'Next-of-kin's notification of patient's death: A qualitative and quantitative preliminary analysis'** (p.7), in *American Journal of Hospice & Palliative Medicine*.

**'Interprofessional rounds improve timing of appropriate palliative care consultation on a hospitalist service'** (p.7), in *American Journal of Medical Quality*.

**'Rural-urban differences in costs of end-of-life care for the last six months of life among patients with breast, lung, or colorectal cancer'** (p.12), in *Journal of Rural Health*.

**'Access to aid-in-dying in the U.S.: Shifting the debate from rights to justice'** (p.17), in *American Journal of Public Health*.

## Release programs for sick and elderly prisoners could save millions. But states rarely use them

WISCONSIN | *The Milwaukee Journal Sentinel* – 18 April 2018 – Around the country, early release provisions for elderly and infirm prisoners are billed as a way to address problems such as prison overcrowding, skyrocketing budgets and civil rights lawsuits alleging inadequate medical care. But throughout the U.S., they are used so infrequently that they aren't having much impact. Of the 47 states with processes to free such prisoners early or court rulings requiring them to do so, just three ... released more than a dozen people in 2015, according to a *Journal Sentinel* survey. The reasons for the low numbers, according to experts, are usually found in the statutes that created the programs, known as compassionate release, geriatric release and medical parole, among other things. <https://goo.gl/T1v3xt>

Noted in Media Watch 2 April 2018 (#557, p.10):

- *EPIDEMIOLOGIC REVIEWS* | Online – 23 March 2018 – ‘**The health of America’s aging prison population.**’ In this systematic review, the authors summarize the epidemiologic evidence of the health challenges facing the aging U.S. prison population. The findings of this review reveal few empirical data in this area and highlight the need for new data to drive policy and practice patterns that address critical health issues related to the aging prison population. **Full text:** <https://goo.gl/TmdFXK>

**N.B.** End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 February 2018) can be downloaded/view at Palliative Care Network-e: <https://goo.gl/YLckx6>

## How to talk with your dying loved one

*THE WALL STREET JOURNAL* | Online – 16 April 2018 – The conversations we have with a loved one who is dying are among the most important, and difficult, we may ever have. Research shows that when family members have these talks – and when they are open and honest – they become closer to each other and more hopeful of the future. Yet too often we dodge any mention of death. Survivors worry that bringing it up will hurt or scare their dying family member. And the person who is dying tries to prevent their loved ones from thinking about the impending loss. Each wants to protect the other. Yet, many times, people are trying to protect themselves, as well – and living alone in their sadness. Part of the challenge is intellectual, says Brian Carpenter, professor of psychological and brain sciences at Washington University in St. Louis, who studies the psychology of aging and family relationships in late life. “No matter how hard we try, it is difficult to genuinely understand that the dying person will be gone,” he says, and it’s hard to talk about death if you can’t grasp or accept it. Denial is easier. Even when family members do want to talk, they sometimes aren’t sure what to say. Survivors worry it’s wrong to show sadness in front of the dying person, so they chat about superficial topics they think are less distressing. This only adds

to the pain. “The more authentic approach is to say what’s on your mind – and to say that it’s important to you,” says Dr. Carpenter. “You might not get another chance if you wait.” But it’s important to always be compassionate, he says. <https://goo.gl/td44Xa>

### Barbara Bush’s end-of-life decision stirs debate over “comfort care”

*KAISER HEALTH NEWS* | Online – 16 April 2018 – As she nears death at age 92, former first lady Barbara Bush’s announcement that she is seeking “comfort care” is shining a light – and stirring debate – on what it means to stop trying to fight terminal illness. Bush, the wife of former President George H.W. Bush, has been suffering from congestive heart failure and chronic obstructive pulmonary disease. In a public statement, the family announced she has decided “not to seek additional medical treatment and will focus on comfort care.” The announcement comes amid a national effort to define and document patients’ wishes, and consider alternatives, before they are placed on what has been described as a “conveyor belt” of costly medical interventions aimed at prolonging life. <https://goo.gl/n2Uphn>

**N.B.** Barbara Bush died the evening of the 17 April at her home in Houston, Texas. She was 92.

## International

### End-of-life care in Scotland

#### **Sturgeon defends changes to terminal illness support plans**

U.K. (Scotland) | BBC News (Glasgow) – 19 April 2018 – [First Minister of Scotland] Nicola Sturgeon has defended changes to plans to speed up access to assistance for the terminally ill. People with terminal conditions are currently “fast-tracked” by the welfare system to receive financial support. The forthcoming Social Security (Scotland) Bill included plans to extend the definition of a terminal illness from six months to two years. However, ministers now want to change this, saying they want doctors to judge when claimants are eligible. The reversal has been criticised by some doctors and health charities who argue it could leave people with

fatal conditions waiting longer and facing more assessments. Ms. Sturgeon said it was difficult to accurately diagnose such illnesses over a longer time period, and that ministers wanted to rely on clinical judgement instead of “arbitrary” time limits. <https://goo.gl/DLbgYW>

#### **Specialist Publications**

**‘Scotland’s public health palliative care alliance’** (p.8), in *Annals of Palliative Medicine*.

#### **Personal experiences of care highlight need for further evidence to reduce harm and distress at end of life**

U.K. (Wales) | Wales 24/7 (Cardiff) – 18 April 2018 – A study looking at the personal perceptions and experiences of patients, families and healthcare professionals, has highlighted the need for improvement in symptom management in end-of-life care.<sup>1</sup> Analysis ... has identified several areas of treatment which were often perceived as sub-optimally managed by healthcare professionals, including; pain, breathing difficulties, nutrition, and hydration. Nutrition and hydration were specifically recognised as being “of significant concern,” particularly for carers. Pain was identified as the area of symptom management most discussed by respondents with many bereaved carers sharing upsetting or traumatic experiences of their relatives uncontrolled pain. Several questioned the competence and confidence of healthcare professionals in effectively managing pain, while others highlighted reluctance to prescribe or administer adequate analgesia as a barrier to controlling their relative’s pain. Based on their analysis, the researchers say there is a need for further research to test interventions in these areas, and ultimately, inform an evidence-based approach to clinical care. For example, the researchers point to carers’ concerns around under-recognised pain in patients who are unable to communicate verbally, such as those with dementia, noting that there is currently limited evidence around the validity of pain assessment tools. **Abstract:** <https://goo.gl/jRmQmy>

Marie Curie  
Palliative Care Research Centre  
CARDIFF

1. ‘Symptom management, nutrition and hydration at end-of-life: A qualitative exploration of patients’, carers’ and health professionals’ experiences and further research questions, *BMC Palliative Care*, published online 16 April 2018. **Full text:** <https://goo.gl/JwxdZP>



#### **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>

## Palliative care in Australia

### Palliative care budget needs to be better spent

AUSTRALIA | *The Financial Review* (Melbourne, Victoria) – 16 April 2018 – It is rare that a group of economic hardheads recommends expansion of services, but the Productivity Commission recently did just that. In a report with a somewhat obscure and threatening title, the commission calls for a big increase in palliative care (PC) investment.<sup>1</sup> It recommends that state and territory governments increase the availability of community-based PC so that more people who want to die at home can get support to do so, and, end-of-life care (EoLC) should be core business for aged-care facilities, and the quality of EoLC in residential aged care should be no lower than the quality of EoLC available to other Australians. The Commission's recommendations are unequivocally good. The only problem is they don't go far enough. PC services don't just need expansion, they need a revolution. Expenditure on people in the last year of their life consumes about 10% of public hospital budgets in Australia... <https://goo.gl/ZmWEvP>

1. 'Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services' (See 'Caring for people at the end of life,' pp.8-13), Productivity Commission, Australian Government, October 2017. [Noted in the 2 April 2018 issue of Media Watch (#557, p.7)] **Download/view at:** <https://goo.gl/Rq12qb>

## Specialist Publications

### End-of-life care in Italy

#### **The palliative care in dementia context: Health professionals point of view about advantages and resistances**

*ACTA BIO MEDICA ATENEI PARMENSIS*, 2018;89(4-S):45-54. This study investigates the point of view of healthcare professionals, working in the context of dementia, regarding the knowledge and application of palliative care (PC) in the field of dementia. The focus is on the analysis of the resistance that may prevent the spread of PC, slowing the application of such care in different settings of terminality. Thirty-three health workers who work in health centres or in the Alzheimer Nucleus of Northern Italy. Most interviewees think they understand PC, they believe it to be useful and necessary, but often only connect it with terminal illness. Others have a broader vision based on a more abstract and theoretical level than on real practical knowledge. A majority think that the spread of PC is slow and difficult because of the prevalence of the biomedical model that holistically and prejudicially hinders the introduction of new models. Appropriate training is the fundamental key to overcoming resistance. The professionals interviewed showed that they were aware of their lack of knowledge and declared that they had little competence in managing the complexity of long-term pathologies. **Full text:** <https://goo.gl/2bZrv9>

**N.B.** English language article. Additional articles on palliative care for people living with Alzheimer's and other forms of dementia noted in the 9 April and 26 March 2018 issues of Media Watch (#558, pp.8-9 and #556, p.6, respectively).

### Specialist Publications

**'The palliative care in dementia context: Health professionals point of view about advantages and resistances'** (p.6), in *Acta Bio Medica Atenei Parmensis*.

**'Palliative home care teams in Germany'** (p.9), in *Deutsche Medizinische Wochenschrift*.

**'(Early) palliative care in emergency medicine'** (p.10), in *Deutsche Medizinische Wochenschrift*.

**'Spirituality in palliative care: Experiences of an interdisciplinary team'** (p.16), in *Revista da Escola de Enfermagem da Universidade de São Paulo*.

**'Early identification of patients in need of palliative care in Slovenian general practice'** (p.17), in *Slovenian Journal of Public Health*.

## Next-of-kin's notification of patient's death: A qualitative and quantitative preliminary analysis

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 16 April 2018 – Analysis of death notifications revealed two themes: direct and indirect death notifications. In direct notifications, death was portrayed by the notifier in direct and specific words such as death, the patient has died, or the patient is not alive. Indirect notifications included non-specific or general descriptions of death such as breath cessation, it ended, or it's over or finished. Direct notifications tended to include specific requests from the medical staff and expressed acceptance and closure, while indirect notifications tended to include more general requests and expressed more panic, distress, or doubt in death. Although spouses were more likely to serve as the primary caregiver, the children or other family members were more likely to notify the treating staff. In 30% of the notifications, there was an element of doubt or uncertainty. Emotions were expressed in 20% of the notifications. Cessation of breathing was the most common physical sign mentioned. **Abstract:** <https://goo.gl/a3rB8M>

Noted in Media Watch 23 January 2017 (#496, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 18 January 2017 – '**Death notification: Someone needs to call the family.**' The death notification process can affect family grief and bereavement. It can also affect the well-being of involved physicians. There is no standardized process for making death notification phone calls. Eighty-seven percent of survey responders reported involvement in a death that required notification by phone. Eighty percent felt inadequately trained for this task. Over 25% reported that calls went poorly. **Abstract:** <https://goo.gl/eDYkDg>

## Interprofessional rounds improve timing of appropriate palliative care consultation on a hospitalist service

*AMERICAN JOURNAL OF MEDICAL QUALITY* | Online – 12 April 2018 – Palliative care (PC) consultation for hospitalized patients remains underutilized. The objective of this study was to improve frequency and timeliness of appropriate inpatient PC consultation. On 2 of 11 hospitalist teams, a PC representative attended discharge rounds twice a week. Control teams' discharge rounds were unenhanced. Subjects were all patients admitted to a hospitalist service in a quaternary academic medical center. The primary outcome was change in provision of PC consultation over time; the secondary outcome was change in time-to-consult (days). The unadjusted proportion of patients receiving PC consultation increased from 2.7% to 5.2% on the intervention teams. Compared to control teams over time and adjusting for multiple covariates, the intervention increased PC consultation ... and decreased time to consult ... in patients admitted for non-cancer diagnoses. Hospitalists thought the intervention facilitated effective patient care without increased burden. **Abstract (inc. list of references):** <https://goo.gl/MQgYfL>

Noted in Media Watch 1 January 2018 (#544, p.17):

- *JOURNAL OF HOSPITAL MEDICINE* | Online – 20 December 2017 – '**Improving quality of care for seriously ill patients: Opportunities for hospitalists.**' Hospitalists are ideally positioned to identify patients who could most benefit from palliative care (PC) approaches and often refer the most complex cases to specialty PC teams. Though hospitalists are frequently called upon to provide PC, most lack formal training in these skills, which have not typically been included in medical education. **Full text:** <https://goo.gl/gJSU1s>

Noted in Media Watch 2 April 2017 (#557, p.14):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 4 April 2017 – '**Confidence with and barriers to serious illness communication: A national survey of hospitalists.**' On most or every shift, many respondents reported concerns about a patient's or family's understanding of prognosis (53%) or the patient's code status (63%). Most were confident discussing goals of care (93%) and prognosis (87%). Fewer were confident or very confident in responding to patients or families who had not accepted the seriousness of an illness (59%) or in managing conflict (50%). **Abstract:** <https://goo.gl/oflMKZ>

## Scotland's public health palliative care alliance

*ANNALS OF PALLIATIVE MEDICINE* | Online – Accessed 21 April 2018 – People's experiences of death, dying and bereavement are only partially determined by formal health and social care services. A broad-based alliance of organisations and individuals was established in Scotland in 2011 with the aim of influencing a wider range of social, cultural and other environmental factors which impact on people's experiences towards the end of life. This alliance has grown and developed over the past 6 years, with a current diverse membership of over 1,100. A small central resource hosted by the Scottish Partnership for Palliative Care provides infrastructure, resources, promotion, events and advocacy for the alliance. The alliance's approach is primarily to engage, support and enhance the assets of communities, organisations and individuals who have the potential to improve the experience of death, dying and bereavement in Scotland. In addition to having very limited financial and staff resources the alliance has faced and responded to some other major challenges; the breadth and diversity of areas needing action; a lack of evidence to inform prioritisation and advocacy; how to operationalise theory in specific contexts; risk aversion on the part of some institutions in relation to death, dying and bereavement; how to measure change and demonstrate impact. The alliance has developed or used different frameworks for conceptualising and organising its work, but always with an emphasis on practical and adaptable approaches to action.

**Abstract:** <https://goo.gl/7yJaod>

## Adding a second surprise question triggers general practitioners to increase the thoroughness of palliative care planning: Results of a pilot randomized clinical trial with cage vignettes

*BMC PALLIATIVE CARE* | Online – 19 April 2018 – Many general practitioners (GPs) say that one of their most significant challenges is to assess the right moment to start anticipatory palliative care (PC). The "Surprise Question" (SQ1: "Would I be surprised if this patient were to die in the next 12 months"?), if answered with "no," is an easy tool to apply in identifying patients in need of PC. However, this tool has a low specificity. Therefore, the aim of this pilot study was to determine if adding a second, more specific "Surprise Question" (SQ2: "Would I be surprised if this patient is still alive after 12 months"?), in case SQ1 is answered in the negative, prompts GPs to plan for anticipatory PC. Up to now, the classical SQ(1) alone was used and has proven to have low specificity as a tool to predict death, which may lead to a large and unselected group of patients for whom a GP should plan multidimensional, proactive, PC. Some participating GPs in this study underlined this shortcoming. Furthermore, its performance is insufficient in non-cancer patients. Adding SQ2 may improve specificity as prognostic tool, but more meaningfully, combining the two SQs will help a medical professional to select a smaller, more accessible group of patients in need of anticipatory PC. **Full text:** <https://goo.gl/UkG3Mq>

**N.B.** Additional articles on the "surprise question" noted in the 7 August 2017 and the 10 April 2017 issues of *Media Watch* (#524, p.4 and #507, pp.10-11, respectively).

## Pediatric palliative care

### Children's experience of symptoms: Narratives through words and images

*CHILDREN* | Online – 19 April 2018 – Symptoms may be either physical or psychological in nature (or a confluence of both) and their effective management has a direct impact on the child's quality of life. This article provides an integrative overview of children's experience of selected physical and psychological symptoms, as expressed through their words and images. Understanding their perspectives is an essential component in the design and provision of optimal symptom management. Included, as well, are examples from siblings – a reminder of the profound impact of illness on these children who also "live" the experience, albeit in a different way. The symptoms that are described are pain, nausea and vomiting, fatigue, weakness, seizures, hair loss, depression, and anxiety. Although psychological symptoms are often inextricable from the physical, they may also present independently as part of the overall illness experience. **Full text:** <https://goo.gl/TYvNfZ>



## Charlie Gard: How did things go wrong?

*CURRENT PEDIATRIC REPORTS* | Online – 16 April 2016 – The authors examine the discussions generated to date by the Charlie Gard case, as well as the events of the case itself, in order to examine lessons for providers dealing with similar situations in the future. Publications regarding the Gard case are relatively few and focus primarily on the ethical and legal issues that arise when involving the court system in complex medical decision-making and potential limits to parental authority. Some publications have addressed the subject of experimental therapies, especially from the perspective of potential harms, suffering, and cost. The authors suggest early introduction of palliative care and careful attention to communication might reduce conflict and improve satisfaction for all involved parties. Likewise, they suggest limiting court system to truly extraordinary circumstances; all efforts should be made to avoid legal action and to honor and respect parental authority. **Abstract (inc. list of references):** <https://goo.gl/MVGxSR>

**N.B.** Selected articles/reports on the Charlie Gard case noted in the 12 March 2018 issue of *Media Watch* (#554, p.12). The November 2017 issue of the *American Journal of Bioethics*, noted in the 13 November 2017 issue of *Media Watch* (#538, p.8), focuses on the medical decision-making process in pediatrics. **Journal contents page:** <https://goo.gl/yQE2Lk>

### Related

- *NURSING ETHICS* | Online – 15 April 2018 – ‘**The ethics of concurrent care for children: A social justice perspective.**’ The Concurrent Care Provision of the U.S.’s Affordable Care Act eliminated the need to forgo curative therapies in order to enroll in hospice for children in Medicaid or Children’s Health Insurance Program. Concurrent care for children can help mitigate the tension families experience in choosing between essential forms of care, as well as contribute to improved end-of-life outcomes for the child and possibly bereavement outcomes for the family. **Abstract (inc. list of references):** <https://goo.gl/RFw9WN>
- *PAEDIATRICS & CHILD HEALTH*, 2018;23(2):138-146. ‘**Medical decision-making in paediatrics: Infancy to adolescence.**’ Health care providers (HCPs), while not decision-makers *per se*, have a significant role in medical decision-making throughout childhood. This policy statement of the Canadian Paediatric Society outlines the ethical principles of medical decision-making for HCPs involved in caring for paediatric patients. **Full text:** <https://goo.gl/q2j9xi>

**N.B.** Download/view French language version of the Society’s position statement at: <https://goo.gl/cJAsde>

## Palliative home care teams in Germany

*DEUTSCHE MEDIZINISCHE WOCHENSCHRIFT*, 2018;143(8):558-565. Since 2007, patients with severe advanced life-limiting illnesses and high, complex symptom burdens have a right to receive specialized outpatient palliative care (SOPC). Multi-professional teams with heterogeneous organizational structures provide care in cooperation with primary care givers, not limited to cancer patients. The aim of SOPC is to foster patient’s autonomy and quality of life. SOPC can be provided as counseling of patient and care givers, coordination of care, additional supportive and full care provision. While the basis of SOPC provision is regulated by a SOPC directive, different contracts between care providers and health care insurances regulate organization, cooperation, definition of care levels, service provision and compensation. Some regions have model contracts that are binding for all SOPC teams in the area; in other regions teams negotiate e.g., compensation, individually with insurances. This article gives an overview of the regulations regarding SOPC. **Abstract:** <https://goo.gl/Ef8Ngu>

**N.B.** German language article.



### 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.19.

## **(Early) palliative care in emergency medicine**

*DEUTSCHE MEDIZINISCHE WOCHENSCHRIFT*, 2018;143(8):551-557. At the end of life (EoL) patients with a life-limiting disease are often admitted to emergency departments (ED). Mostly, in the setting of an ED there may not be enough time to meet the needs for palliative care (PC) of these patients. Therefore, integration of PC into the ED offers a solution to improve their treatment. In the outpatient setting a cooperation between pre-hospital emergency services, the patient's general practitioner and specialized outpatient PC teams may allow the patient to die at home – this is what most patients prefer at the EoL. Furthermore, due to the earlier integration of PC after admission the hospital stay is shortened. Also the number of PC consultations may increase. Additionally, a screening of PC needs among all patients visiting the ED may be beneficial: to avoid not meeting existing PC needs and to standardize the need of PC consultation. An example for such a screening tool is the Palliative Care & Rapid Emergency Screening (P-CaRES). **Abstract:** <https://goo.gl/g3nVuC>

**N.B.** German language article.

### **Related**

- *ACADEMIC EMERGENCY MEDICINE: TRAINING & EDUCATION* | Online – 6 February 2018 – ‘**Development of hospice and palliative medicine knowledge and skills for emergency medicine residents...**’ Unlike emergency medicine (EM) residency curricula in disciplines like trauma, there is no nationally defined hospice palliative medicine (HPM) curriculum for EM resident training. An expert consensus group has defined content areas and competencies for HPM primary-level practice in the emergency department setting. **Abstract:** <https://goo.gl/mgWDKk>
- *EMERGENCY MEDICINE AUSTRALASIA* | Online – 16 April 2018 – ‘**Testing a new form to document “goals-of-care” discussions regarding plans for end-of-life care for patients in an Australian emergency department.**’ There is limited literature to inform the content and format of goals-of-care forms for use by doctors when they are undertaking these important conversations. This study supports having a goals-of-care form in emergency medicine. The ideal contents of the form, however, was not determined. **Abstract:** <https://goo.gl/qnpX17>

## **A website supporting sensitive religious and cultural advance care planning (ACPTalk): Formative and summative evaluation**

*JMIR RESEARCH PROTOCOLS*, 2018;7(4):e78. This study demonstrates that all facets of the context, input, process, and product framework can be effectively applied for evaluation of eHealth technologies, specifically advance planning (ACP) websites, with assessment of ACPTalk. Results show that most users viewed the website positively in terms of design, content, and functionality and found it useful to increase knowledge and preparation for ACP with people of different religious and cultural backgrounds. Further ACP website development should consider the recommendations derived from this study, including multilingual translations and the development of comparable culturally sensitive websites tailored for patients and families, which may assist in strengthening understanding and cognizance of ACP among these populations. **Full text:** <https://goo.gl/UdsWYh>

### **Related**

- *JOURNAL OF PHILOSOPHICAL CRITICISM*, 2018;1(1):89-106. ‘**Advance directives: Regarding the recovery of subjectivity between independence and self-narration.**’ After 41 years from the approval of the first living will law in 1976 in California, on 22 December 2017 the bill on rules on informed consent and advance directives has been approved in Italy. The applicability of the law highlights a lack of a methodology regarding the recovery process of the patient's subjective dimension under a testamentary will... Is the individual who freely drafts an advance directive, choosing to decide now for the future, the same person for which the provisions were outlined? **Abstract:** <https://goo.gl/DrKfri>

Cont.

- *NURSING OUTLOOK* | Online – 10 April 2018 – ‘**Achieving advance care planning in diverse, underserved populations.**’ There remains a gap in meeting the palliative and end-of-life care (P&EoLC) needs, including advance care planning, of ethnic minority, under resourced veterans, and lesbian, gay, bisexual, and transgender Americans, as well as persons with disabilities and residing in geographically isolated regions. These persistent gaps pose a serious barrier to achieving high-quality care, including P&EoLC, across the lifespan of members of these growing populations. **Summary (w. link to references):** <https://goo.gl/GiqnYQ>
- *QUALITY HEALTH RESEARCH* | Online – 20 April 2018 – ‘**Care planning: What works, for whom, and in what circumstances? A rapid realist review.**’ Each person with long-term conditions faces individual challenges and each health care setting is fundamentally different, so there is a need for empirical testing of the specific mechanisms through which care planning may lead to health improvements. A rapid realist review was conducted to unearth underpinning mechanisms leading to outcomes in particular contexts. These are expressed in the form of realist theories, which are developed and refined through the review process. **Abstract:** <https://goo.gl/7ipVoy>

### **Ethical and legal concerns with Nevada’s brain death amendments**

*JOURNAL OF BIOETHICAL INQUIRY* | Online – 17 April 2018 – In early 2017, Nevada amended its Uniform Determination of Death Act (UDDA), in order to clarify the neurologic criteria for the determination of death. The amendments stipulate that a determination of death is a clinical decision that does not require familial consent and that the appropriate standard for determining neurologic death is the American Academy of Neurology’s (AAN) guidelines. Once a physician makes such a determination of death, the Nevada amendments require the withdrawal of life-sustaining treatment within twenty-four hours with limited exceptions. Neurologists have generally supported Nevada’s amendments for clarifying the diagnostic standard and limiting the ability of family members to challenge it. However, it is more appropriate to view the Nevada amendments with concern. Even though the primary purpose of the UDDA is to ensure that all functions of a person’s entire brain have ceased, the AAN guidelines do not accurately assess this. In addition, by characterizing the determination of death as solely a clinical decision, the Nevada legislature has improperly ignored the doctrine of informed consent, as well as the beliefs of particular faiths and cultures that reject brain death. Rather than resolving controversies regarding brain death determinations, the Nevada amendments may instead instigate numerous constitutional challenges. **Abstract (inc. list of references):** <https://goo.gl/TrN7Gc>

**N.B.** Additional articles on defining “brain dead” noted in the 16 April 2018 issue of Media Watch (#559, p.9).

### **Increasing information dissemination in cancer communication: Effects of using “palliative,” “supportive,” or “hospice” care terminology**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 20 April 2018 – When attempting to share information about comfort-oriented care, many use “palliative,” “supportive,” and “hospice” care terminology interchangeably, but we lack evidence about the effects of using these different terms. This experimental study was conducted at a major U.S. hospital serving a diverse population. Patients visiting a cancer clinic encountered opportunities to learn more about cancer care. They were offered health materials that were described as reporting on “palliative,” “supportive,” or “hospice” care and the primary outcome was whether a patient decided to select or reject each. As a secondary outcome, the study measured the patient’s level of interest in receiving each. In this study, the terminology used had a large effect and, compared with alternatives, the information labeled as being about “supportive” care was significantly more likely to be selected. If these effects are supported by additional research, there may be low-cost, highly feasible changes in language choice that increase the dissemination of relevant health information. **Abstract:** <https://goo.gl/1mWwno>

**N.B.** Additional articles on terminology in end-of-life care noted in the 25 April 2016 issue of Media Watch (#459, p.2).

## Palliative care experiences and needs of direct care workers

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 19 April 2018 – As people with intellectual and developmental disabilities (PWIDD) are living longer and experience chronic health conditions, there is greater likelihood that direct care workers (DCWs) will need to provide palliative care (PC) services. Fifty-four DCWs participated in nine focus groups at five non-profit community-based organizations that provided residential and day programming services for PWIDD. Challenges DCWs faced and strategies they employed to meet PWIDD's needs were described using two main themes: “challenges” and “meeting PWIDD's needs.” The first encompassed difficulties in communicating with clients, anxiety of anticipating death, and limited organizational resources or support. Empathy, extra attention, adaptation in care, and peer support comprised the second theme. The results of this

study indicate some intellectual and developmental disability service agencies and DCWs are not equipped to care for PWIDD with PC needs, and DCWs try to meet PWIDD PC needs through individual efforts and peer support. **Abstract:** <https://goo.gl/sFPpss>



The focus of the April 2018 issue of *Médecine Palliative* is palliative and end-of-life care for people living with intellectual and developmental disabilities. **Journal contents page:** <https://goo.gl/996v17>

**N.B.** Additional articles on palliative and end-of-life care for people living with intellectual and developmental disabilities noted in the 9 April 2018 issue of Media Watch (#558, p.2)..

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

#### **Rural-urban differences in costs of end-of-life care for the last six months of life among patients with breast, lung, or colorectal cancer**

*JOURNAL OF RURAL HEALTH* | Online – 15 April 2018 – For each type of cancer, total Medicare expenditures in the last 6 months of life were lower for rural decedents compared to their urban counterparts. During the last 6 months of life, median Medicare expenditures were lower for rural decedents for breast cancer (\$21,839 vs \$25,698), lung cancer (\$22,814 vs \$27,635), and colorectal cancer (\$24,156 vs \$28,035... The authors' findings indicate that Medicare expenditures are lower for rural beneficiaries with each type of cancer than urban beneficiaries, even after adjusting for age, gender, race, dual eligibility, region, chronic conditions, and type of service utilization. **Abstract:** <https://goo.gl/mYSCJ9>

Noted in Media Watch 2 October 2017 (#532, p.3):

- U.S. (South Carolina) | *The Daily Yonder* (Knoxville, Tennessee) – 26 September 2017 – **'Hospice services in rural areas can reduce need for more expensive services.'** Expanding the use of hospice services among rural residents in the last six months of their lives could reduce patients' need for more expensive and inconvenient medical treatments, a new report suggests.<sup>1</sup> <https://goo.gl/yJJ9JV>

1. 'Rural-Urban Differences in Medicare Service Use in the Last Six Months of Life,' South Carolina Rural Health Research Center, University of South Carolina, Columbia, South Carolina, August 2017. **Download/view at:** <https://goo.gl/mqT5Po>

**N.B.** Only 32% of those eligible in rural areas utilize hospice compared to 48% in urban areas, according to Medicare Payment Advisory Commission statistics. In April 2016 bipartisan legislation to improve access to hospice care in rural America has been tabled in the Senate.



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

## **A survey of mobile phone use in the provision of palliative care services in the African region and priorities for future development**

*JOURNAL OF TELEMEDICINE & TELE CARE* | Online – 11 April 2018 – Palliative care (PC) services in the African region need to adapt to manage rising numbers of patients with cancer or other life-limiting conditions. Mobile phone use in healthcare delivery (mHealth) is at an early stage of development for PC, but may provide new approaches to supporting patients regionally, particularly those with non-communicable diseases. The authors conducted an online survey of 51 PC providers across 21 countries ... mHealth approaches were reported across 71.4% of services in which respondents were based. Barriers to mHealth research include patients not having access to phones, mobile network access, and limited access to expertise and hardware required for mHealth. Research priorities were identified, which included exploring ways of incorporating mHealth into patient care and ensuring access and relevance of mHealth for patients and health professionals. Further work is required to explore how existing mHealth activities might be further developed and aligned with priority areas for PC development. Crucially, user engagement that seeks to understand the preferences and priorities of patients with PC needs, their caregivers, and those involved in the provision of PC should remain central to these efforts. **Abstract (inc. list of references):** <https://goo.gl/cKkLFD>

## **Deactivating implantable cardioverter-defibrillators near the end of life**

*MEDSCAPE* | Online – 19 April 2018 – Advanced technologies – such as implantable cardioverter-defibrillators (ICDs) – have extended life yet have also created clinical challenges, including decisions about when and how to deactivate these devices to prevent inappropriate electrical shocks in patients nearing the end of life (EoL). Researchers recently presented a systematic review of the deactivation of ICDs in patients with end-stage heart failure.<sup>1</sup> The investigators screened 211 articles, but only nine studies met their criteria of involving patients with heart failure and ICDs, and focusing on issues related to deactivation of the devices and EoL care. The nine studies included a total of 24,770 patients and 362 physicians. This review revealed discussions with patients about deactivating their ICDs were uncommon. Many patients did not fully understand how an ICD works or the impact that ICDs can have on their lives. Typically, patients with heart failure had not considered deactivating their ICDs; indeed, many were not aware that deactivating these devices at some point was even an option, and consent forms for ICD placement rarely addressed the need to eventually discontinue them or how this might occur. In reality, ICDs were often not deactivated until the patient's condition took a marked turn for the worse, and the patient was nearing death. **Full text:** <https://goo.gl/QebJjc>

### **Palliative care in heart failure**

*CURRENT TREATMENT OPTIONS IN CARDIOVASCULAR MEDICINE* | Online – 19 April 2018 – This review illustrates the dynamic role of palliative care (PC) in heart failure management and encapsulates the commonly utilized pharmacologic and non-pharmacologic therapeutic strategies for symptom palliation in heart failure. In addition, the authors provide their experience regarding patient care issues common to the domain of heart failure and palliative medicine which are commonly encountered by heart failure teams. Addition of PC to conventional heart failure management plan results in improvement in quality of life, anxiety, depression, and spiritual well-being among patients. PC should not be confused with hospice care. PC teams should be involved early in the care of heart failure patients with the aims of improving symptom palliation, discussing goals of care and improving quality of life without compromising utilization of evidence-based heart failure therapies. A consensus on the appropriate timing of involvement and evidence for many symptom palliation therapies is still emerging. **Abstract (inc. list of references):** <https://goo.gl/sEUSyY>

1. 'Deactivation of implantable cardioverter-defibrillators in heart failure: A systematic review,' *Journal of Hospice & Palliative Nursing*, 2018;20(1):63-71. **Abstract:** <https://goo.gl/wwbfmx>

**N.B.** Additional articles on implantable cardioverter-defibrillators in the context of end-of-life care noted in the 23 January 2017 issue of *Media Watch* (#496, p.8).

## Effective palliative care: What is involved?

*ONCOLOGY* | Online – 15 April 2018 – This article reviews the ways in which palliative care (PC) and oncology teams can collaborate to provide high-quality care to patients and their families; it also provides practical tips for oncologists who wish to initiate primary PC for their patients. Prior to referral to a specialized interdisciplinary PC team, oncologists may start advance care planning discussions, provide basic pain and non-pain symptom relief, and utilize assessment tools. **Full text:** <https://goo.gl/ZwVL7y>

### Related

- *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2018;190(15);e473-e475. ‘**What really matters at the end: Perspectives from a patient, a family member and an oncologist.**’ The authors present the perspectives of a patient, the spouse of another patient, and the oncologist who cared for both patients. They share their thoughts on terminal cancer, doctor-patient communication, and what changes when you know the end is near. **Summary:** <https://goo.gl/GrWtfY>

**N.B.** See ‘Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline update,’ *Journal of Clinical Oncology*, 2017;35(1):96-112. [Noted in the 31 October 2016 issue of *Media Watch* (#486, p.7)] **Full text:** <https://goo.gl/RGjFMP>

### Canadian Paediatric Society

#### Medical assistance in dying: A paediatric perspective

*PAEDIATRICS & CHILD HEALTH*, 2018;23(2): 125-130. In June 2016, [Canada’s] Bill C-14 was enacted, allowing medical assistance in dying (MAiD) for an eligible adult whose death is “reasonably foreseeable.” An independent report on the status of “mature minors” (who are currently excluded under federal legislation), with focus on their potential eligibility for MAiD, was required by the 2016 Act and is expected to be presented to Parliament by December 2018. Ensuring that newborns, children and youth receive the highest possible standard of care as they are dying is a privilege and a responsibility for physicians and allied professionals. Bringing a thoughtful, respectful and personal approach to every end-of-life situation is an essential and evolving duty of care, and the process should meet each patient’s (and family’s) unique social, cultural and spiritual needs. This statement describes the current Canadian legal and medical context of MAiD and articulates a paediatric perspective that has emerged from – and been informed by – the broad, structured consultation process unfolding in Canada and elsewhere. Although “mature minors” are the only youth currently mandated for further legislative consideration in Canada, the need to examine requests for and attitudes around MAiD for minors of all ages remains compelling for two main reasons: Canadian health care professionals are increasingly being approached by the parents of “never-competent” infants and children, including those too young to make a reasoned decision, and by

youth themselves, to discuss MAiD-related issues; and, the discussion of MAiD policy in Canada has been framed as much by the issue and context of suffering as by considerations of autonomy. While current legislation clearly prohibits MAiD for incapable persons at the request of any other person, it is possible that parents may request MAiD on behalf of their dying child. **Full text:** <https://goo.gl/FPQSTb>

#### The role of palliative care

Palliative care (PC) and medical assistance in dying (MAiD) provide philosophically and clinically distinct – though interconnected – medical services. Some parents and clinicians fear PC as being focused on death rather than on life, and education around PC often involves explaining its essential role in optimizing quality of life for as long as possible. If PC physicians were also to engage in the MAiD process, some practitioners believe that fear and apprehension might intensify. At the same time, however, PC practitioners have acquired invaluable wisdom and experience caring for individuals and families living with advanced illness. Requests for MAiD may still arise in the context of excellent PC, and the expertise and experience of PC specialists must remain available to families considering MAiD. Furthermore, paediatric PC physicians may also wish to participate in MAiD, if and when legislative changes extend MAiD to some paediatric patients. Irrespective of personal beliefs, access to high quality PC must be seamless for those in need, whatever end-of-life options are being contemplated.

## End-of-life care in New Zealand

### **How family caregivers help older relatives navigate statutory services at the end of life: A descriptive qualitative study**

*PALLIATIVE MEDICINE* | Online – 18 April 2018 – A key challenge in meeting the palliative care needs of people in advanced age is the multiple healthcare and social service agencies typically involved in their care. The “patient navigator” model, originally developed in cancer care, is the professional solution most often recommended to address this challenge. However, little attention has been paid, or is known, about the role that family carers play in enabling their dying relatives to negotiate service gaps. In this study, fragmentation of services was the key concern, causing distress both for the older person and their family caregivers. Carers identified and engaged with appropriate services in order to facilitate care and treatment. Their involvement was not always met by healthcare professionals with respect or regard to their knowledge of the older person’s needs. Family caregivers are trying to help their older relatives overcome the limitations of fragmented health systems at the end of life. They are doing so at times by stepping in to perform patient navigator tasks usually conceptualised as a role for statutory services to carry out. Programmes and services need to be implemented that will better support family carers who are acting as care navigators. **Abstract:** <https://goo.gl/2h5ueJ>

### **The involvement of cancer patients in the four stages of decision-making preceding continuous sedation until death: A qualitative study**

*PALLIATIVE MEDICINE* | Online – 18 April 2018 – Professional guidelines emphasize that the decision to initiate continuous sedation should be made in accordance with the wishes of the dying person and be preceded by their consent. Interviews were conducted with 26 physicians, 30 nurses and 24 relatives caring for 24 patients with cancer who received continuous sedation until death in Belgium, the U.K. and The Netherlands. The authors distinguished four stages of decision-making: initiation, information exchange, deliberation and the decision to start continuous sedation until death. There was wide variation in the role the patient had in the decision-making process. At one end of the spectrum (mostly in the U.K.), the physician discussed the possible use of sedation with the patient, but took the decision themselves. At the other end (mostly in Belgium and The Netherlands), the patient initiated the conversation and the physician’s role was largely limited to evaluating if and when the medical criteria were met. The authors recommend building into clinical practice regular opportunities to discuss the goals and preferences of the person who is dying for their future medical treatment and care. **Abstract:** <https://goo.gl/ar4THo>

#### **Related**

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 21 April 2018 – “**“Suffering” in palliative sedation: Conceptual analysis and implications for decision-making in clinical practice.**” Palliative sedation (PS) is an increasingly used and, simultaneously, challenging practice at the end of life. Many controversies associated with this therapy are rooted in implicit differences regarding the understanding of “suffering” as prerequisite for PS. The aim of this paper is to inform the current debates by a conceptual analysis of two different philosophical accounts of suffering: 1) The subjective and holistic concept; and, 2) The objective and gradual concept and by a clinical-ethical analysis of the implications of each account for decisions about PS. **Abstract:** <https://goo.gl/7oiBXG>

**N.B.** Additional articles on palliative sedation noted in the 26 March 2018 issue of Media Watch (#556, p.15).

**Palliative Care Network**

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

## Neonatal palliative care

### **Between birth and death: Palliative care in the experience of health professionals**

*REVISTA BRASILEIRA EM PROMOÇÃO DA SAÚDE*, 2018;31(1):1-10. It was possible to identify, in the statements of the participants in this study, practices consistent with the palliative proposal in some cases. It can be seen that, despite lacking the palliative care (PC) program in the institution, there is an initiative to carry out a practice that approaches such care, mainly when seeking comfort for the baby and greater inclusion of the family, which already shows awareness of this perspective. The challenges were described as difficulty in admitting the death of the baby. The experiences of health professionals at the Neonatal Intensive Care Unit (NICU) appeared with their multiplicity of differences, based on the life history of each one. As a similarity, the reports on how moving it is to care for the baby at the NICU, because of the fear of impending death so close to birth. The feelings of attachment and sadness, emerging during the care; the perception of the baby as a subject and belonging to a family; and, the mechanism of denial of the child's condition appeared. The professionals expounded on their relations with relatives. For some, the involvement with the family demonstrates an interest in learning of the history and, for others, the detachment, which has been understood as a measure to avoid suffering. The establishment of bonds and the validation of the professionals' expression were pointed as important in PC, which should be discussed since the academic training levels, having professionals provided with support for recognition of such needs in this implication. Through the expression of their experiences, the participants thought death as a difficult event to be experienced, with a sense of sadness and loss, and the need for self-care in order to face this moment, in addition to professional training for it. **Full text:** <https://goo.gl/9DGk22>

**N.B.** English language article.

Noted in Media Watch 12 February 2018 (#550, p.9):

- *CHILDREN* | Online – 7 February 2018 – ‘**Pediatric palliative care in infants and neonates.**’ This article addresses the history, current considerations, and anticipated future needs for palliative and hospice care in the neonatal intensive care unit, and is based on recent literature review. Neonatologists have long managed the entirety of many newborns' short lives, given the relatively high mortality rates associated with prematurity and birth defects, but their ability or willingness to comprehensively address of the continuum of interdisciplinary palliative, end of life, and bereavement care has varied widely. **Full text:** <https://goo.gl/GPkMRU>

Noted in Media Watch 1 January 2018 (#544, p.11):

- *CLINICAL PRACTICE IN PEDIATRIC PSYCHOLOGY*, 2017;5(4):392-403. ‘**Perspectives from bereaved parents on improving end-of-life care in the neonatal intensive care unit.**’ Four themes emerged in this retrospective study, including parents as partners in care, communication with the health-care team, relationships with staff, and bereavement support. Both mothers and fathers generally felt positive about their role in treatment decisions, relationships with staff, and memory-making activities. Parents noted areas for improvement, including team communication, anticipatory guidance, family inclusion at bedside, and bereavement care. **Abstract:** <https://goo.gl/VzxWe1>

**N.B.** The November 2017 issue of the Children's Project on Palliative/Hospice Services (ChiPPS) e-journal focuses on perinatal and neonatal palliative and hospice care. **Download/view at:** <https://goo.gl/GPH48x>

## Palliative care in Brazil

### **Spirituality in palliative care: Experiences of an interdisciplinary team**

*REVISTA DA ESCOLA DE ENFERMAGEM DA UNIVERSIDADE DE SÃO PAULO*, 2018;52. The spirituality exercised by health professionals [i.e., study participants] in their care of patients was beneficial in coping with cancer and dealing with the conflict between life and death, in addition to facilitating the creation of bonds with palliative care (PC) patients and their families. Through the findings of this study, it was

Cont.



possible to affirm that spirituality-related actions, such as prayer and the provision of comprehensive care, impart meaning to the work of PC professionals, since they involve the end-of-life process of individuals and seek to humanize death, i.e., provide a dignified death. The professionals also pointed out that patients serve as a mirror for their own mortality and, if health workers are open to listening and sharing distress, they will be able to understand the process that patients are undergoing and facilitate the search for meaning in the suffering arising from illness. However, professionals who are unable to deal with their own issues regarding death will have greater difficulty dealing with the death of another person and will seek to somehow distance themselves from it. This will be manifested by fragmenting patients into organs or referring to them by their disease or physical symptoms. **Full text:** <https://goo.gl/QjrCLd>

**N.B.** Click on pdf icon to access Portuguese, Spanish, Italian or English language versions of this article

Noted in Media Watch 2 April 2018 (#557, p.14):

- *NEUROPSYCHIATRY*, 2018;8(2):484-494. **'The psychological and spiritual dimensions of palliative care: A descriptive systematic review.'** Lack of definitional consensus of spirituality is still evident. Nevertheless, spiritual well-being was considered an important component of quality of life, closely related to physical and psychological distress symptoms, therefore highlighting the importance of psychological and psychiatric care in enhancing the wellbeing of palliative care patients. **Full text:** <https://goo.gl/NkUGwA>

**N.B.** Additional articles on spirituality in the context of end-of-life care noted in the 12 February 2018 issue of Media Watch (#550, pp.12-13).

### **Early identification of patients in need of palliative care in Slovenian general practice**

*SLOVENIAN JOURNAL OF PUBLIC HEALTH*, 2018;57(2):55-64. During advanced stages of chronic life-limiting diseases, patients might benefit from palliative care (PC). Many in the Western world wish to remain at home during this palliative phase and to die there. Therefore, general practitioners (GPs) should play an important role in PC provision. In Slovenia, this is challenging since the average consultation time per patient is 7 minutes, and GPs do not receive extra payment for home visits. Other barriers in PC provision are the lack of knowledge, PC skills and experience, sub-optimal communication with patients and with other healthcare professionals, and the uncertainty and unpredictability of illness trajectories, especially in non-cancer illnesses. Therefore, PC is often restricted to physical symptom relief in the terminal phase, including emergency visits by the GP, transfers and unplanned hospital admissions. Moreover, 4% of the elderly Slovenian population have severe limitations, for which they do not receive any care. Without a universally accepted definition of "early" PC, the dilemma arises of marking the right moment to start anticipatory PC alongside or instead of disease-oriented care in the advanced stages of chronic diseases. Physicians can approach this dilemma by (silently) asking themselves the surprise question: "Would I be surprised if this patient died within the next 12 months?" PC, including anticipating future problems, needs and wishes, would be indicated if the answer to this question was "no." The usefulness of this question has been validated in different populations. However, two recent reviews conclude that there is a wide range in accuracy and that further research is needed to develop more accurate tools. Therefore, the second question was formulated: "Would I be surprised if this patient was still alive in 12 months?" **Full text:** <https://goo.gl/PWJoU9>

**N.B.** English language article.

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

- *AMERICAN JOURNAL OF PUBLIC HEALTH* | Online – 19 April 2018 – **'Access to aid-in-dying in the U.S.: Shifting the debate from rights to justice.'** Much of the literature on aid-in-dying (AiD) has drawn heavily on rights-based ethical and legal frameworks that emphasize patients' rights of self-determination in end-of-life (EoL) decision-making. Less attention has focused on how terminally ill people actually experience such putative rights once they are legally authorized. This essay draws on

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findings from the Vermont study on AiD, an ethnographic study of the implementation of AiD in Vermont (2015-2017). First, the author shows that terminally ill people can face a range of barriers to accessing AiD in permissive jurisdictions, and that access to AiD is mediated by various inequalities endemic to U.S. health care, as well as some that are unique to AiD. She then builds on these findings to examine the utility of the concept of justice for public health scholarship on AiD. By integrating empirical, ethical, and policy analysis, the author reframes rights-based frameworks that emphasize the role of individual choice and decision-making at the EoL. In doing so, she draw attention to health care justice as a neglected issue in public health perspectives on AiD. **Abstract:** <https://goo.gl/8f6NRG>

## Worth Repeating

### **“Why are we doing this”: Clinician helplessness in the face of suffering**

*JOURNAL OF PALLIATIVE MEDICINE*, 2015; 18(1):26-30. When the brutality of illness outstrips the powers of medical technology, part of the fallout lands squarely on front-line clinicians. In the authors’ experience, this kind of helplessness has cognitive, emotional, and somatic components. They draw on social psychology and neuroscience to define a new approach. First, they show how clinicians can re-frame helplessness as a self-barometer indicating their level of engagement with a patient. Second, they discuss how to shift deliberately from hyper- or hypo-engagement toward a constructive zone of clinical work, using an approach summarized as “RENEW” – recognizing, embracing, nourishing, embodying, and weaving – to enable clinicians

from all professional disciplines to sustain their service to patients and families. [Noted in the 19 January 2015 issue of *Media Watch* (#393, p.13)] **Abstract:** <https://goo.gl/aXad3Q>

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

The feeling of helplessness in the face of suffering is an unavoidable experience for clinicians who work with serious illness. Yet “human beings are not only passive perceivers in the context of social interactions but also active creators of shared emotional experiences.” How we respond to our own helplessness likely shapes the suffering of our patients.

## Journal Watch

### **Predatory publishing: What are the alternatives to Beall’s List?**

*AMERICAN JOURNAL OF MEDICINE*, 2018;131(4):333-334. After Beall’s List was removed from the Internet owing to (as Beall puts it himself) “legal reasons,” there has been a vacuum on the publishing market, and many questions have been left unanswered. For instance, there is no clear recommendation regarding what to do about the journals that were suspected of predatory practices by Beall and that are also indexed in reputable citation databases, such as Scopus or the Web of Science. Should the researchers publish in them anyway, or should they search for some other blacklists and publishing ethics committees’ guidelines? If so, who will appoint these committees, or who will decide which journals are good and which are bad? *Quis custodiet ipsos custodes* (“Who will guard the guardians”)? The question is troubling, and the decision is uneasy. For instance, there is the well-known case of Multidisciplinary Digital Publishing Institute (MDPI), an open access publishing house from Switzerland. In 2014 MDPI was added to Beall’s list. However, an Open Access Scholarly Publishers Association (OASPA) investigation concluded that MDPI met the OASPA membership criteria, and MDPI was subsequently removed from Beall’s List on the 28 October 2015. Several of MDPI’s journals currently appear in the prestigious ABS Academic Journal Guide, and in 2017 MDPI partnered with Wiley, Sage, Springer Nature, and Cambridge University Press to work on Publons, the new initiative intended to encourage reviewers to peer-review academic papers and earn “publons.” **Full text:** <https://goo.gl/QggCyV>

**N.B.** Publons website: <https://goo.gl/iaCRhA>

## Media Watch: Access on Online

### International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/T2tCWF>

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 'Media Watch by Barry Ashpole'; 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']

### Australia

PALLIATIVE CARE WESTERN AUSTRALIA: <https://goo.gl/fCzNTL>

[Scroll down to 'International Websites']

### Canada

BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION: <https://goo.gl/gw5ti8>

[Click on 'National Resources,' scroll down to 'Palliative Care Network Community']



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']

SASKATCHEWAN | Saskatchewan Medical Association: <https://goo.gl/5cftPV>

[Scroll down to 'Palliative Care Network Community']

### Europe



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

[January/February 2018 issue (Scroll down to 'Paediatric palliative care; the patient's voice')]

HUNGARY | Magyar Hospice Alapítvány: <https://goo.gl/3jnH7K>

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

### South America



Academia Nacional de Cuidados Paliativos (Brazil): <https://goo.gl/b5CV31>

## 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

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## 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.

[Search Back Issues of Media Watch @ http://goo.gl/frPgZ5](http://goo.gl/frPgZ5)

### Media Watch Archives

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