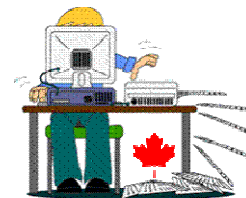


## Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Living with loss and separation: Scroll down to [Specialist Publications](#) and 'Understanding how bereaved parents cope with their grief to inform the services provided to them' (p.16), in *Qualitative Health Research*.

## Canada

### House of Commons-Senate Committee on Physician-Assisted Dying

#### Dealing with life and death at breakneck speed

ONTARIO | *The Toronto Star* – 12 February 2016 – Meet the most important Member of Parliament you may not have heard of, co-chair of the most important Parliamentary committee no one seems to be noticing. Don Valley West [Ontario] Liberal Rob Oliphant, a soft spoken United Church minister, has 13 days to present to Parliament and Justice Minister Jody Wilson-Raybould a framework for a federal law governing physician-assisted suicide, a process now routinely bathed in the softer, more euphemistic name of physician-assisted dying. The Commons-Senate committee, the first joint committee in two decades, heard from 62 witnesses, expects to receive up to 120 briefs, and has done four months of committee work in three

weeks... Oliphant, his co-chair, Conservative Senator Kelvin Ogilvie, and 13 other MPs and senators have absorbed the findings of a federal panel and provincial-territorial task force as they race toward a Supreme Court-imposed deadline that will mean a law enshrined by June. <http://goo.gl/qAgDfc>

### [Specialist Publications](#)

'People with disabilities and the Charter: Disability rights at the Supreme Court of Canada under the Charter of Rights & Freedoms' (p.10), in *Canadian Journal of Disability Studies*.

#### Related

- ONTARIO | *The London Free Press* – 12 February 2016 – 'Hospice shortage fuels fear.' The London region so desperately lacks hospice beds and supports for people to die at home, about 2,000 people a year instead must spend their final weeks in hospital, *The Free Press* has learned. The region has just 26 hospice beds when as many as three times that many are needed in an area with a population of nearly one million and that stretches from Georgian Bay to Lake Erie, and from west of Waterloo to much of the Lake Huron shore, according to a critical report by the key players who provide palliative care in the region, the South West Hospice Palliative Care Network. <http://goo.gl/k6XL5y>

Cont.

- *THE GLOBE & MAIL* | Online – 11 February 2016 – **‘Liberals to whip the vote in favour of assisted-dying law.’** Liberal MPs will be forced to vote the party line on a subject that is traditionally considered a conscience issue, as parliamentarians from all parties wrestle with how to design and implement a new assisted-dying law. Liberal House Leader Dominic LeBlanc confirmed ... that the government plans to whip the vote on the upcoming doctor-assisted dying law. The party says it is a Charter of Rights issue... The Conservatives and NDP, however, view the issue as a personal one – and say they will allow MPs to vote according to their conscience. <http://goo.gl/6lPAbM>
- NOVA SCOTIA | CBC News (Halifax) – 11 February 2016 – **‘Hospice care needed, says head of Doctors Nova Scotia.’** The president of Doctors Nova Scotia says he’s convinced Nova Scotia needs better services for people at the end of life. This comes as the Department of Health & Wellness works on a framework for hospices in Nova Scotia, as it currently doesn’t have residential hospices. The Department of Health is looking at hospice care, but he feels a large push for hospices will have to come from the community. <http://goo.gl/lfzaxat>
- SASKATCHEWAN | *The Yorkton News* – 11 February 2016 – **‘Palliative care easy to ignore.’** The Canadian Cancer Society wants to bring palliative care (PC) to the forefront in the provincial election. They say that standards, training and funding are all lacking, and people are not receiving adequate end-of-life care in the province. As a result, with a provincial election looming, they’re pushing hard to get the political parties in the province to consider PC for their platforms. They’re going to face a challenge, because it’s not an issue that engages voters. <http://goo.gl/k7XV2r>

### Quebec looking at law to limit scattering of ashes

QUEBEC | CTV News – 9 February 2016 – Quebec is exploring the possibility of instituting a new law that limits the areas where people are allowed to scatter the ashes of their loved ones. The province’s proposed Bill 66 bans the dispersal of ashes in various public and private spaces as a way to respect “the dignity of the deceased.” <http://goo.gl/MTjWXZ>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NORTHWEST TERRITORY | CBC News (Yellowknife) – 7 February 2016 – **‘Northwest Territory not ready to implement assisted dying law, say health care leaders.’** A doctor and the chair of the Stanton Territorial Health Authority Elders’ Advisory Council both agree: there are still too many unanswered questions about physician-assisted dying and how it will work in the Northwest Territories. While the federal government is in charge of drafting the new legislation, it will be up to the provinces and territories to actually implement and manage the practice – creating guidelines for things such as how and where physician-assisted dying will be delivered, and the health care providers involved. “We’re not ready at all,” says Amy Hendricks, a doctor who’s worked in the Northwest Territories (NWT) for 14 years. According to Hendricks, there are fundamental questions integral to the unique geographical and cultural aspects of the NWT that still need to be answered. <http://goo.gl/0iCSja>

**N.B.** See ‘Health Minister Glen Abernethy on physician-assisted dying in the NWT,’ CBC News, 9 February 2016. <http://goo.gl/ovttps>

## U.S.A.

### California judge halts end-of-life decision making for incompetent nursing home residents

CALIFORNIA | *Long-Term Living* – 12 February 2016 – A California county judge has ordered state health officials to stop allowing doctors to make end-of-life decisions for nursing home patients. Superior Court of Alameda County Judge Evelio Grillo issued the order after ruling a 1992 state law violates residents’ constitutional rights to decide their own course of treatment, either themselves or through a surrogate. The 1992 law, the first of its kind in the nation, authorized nursing home physicians to administer psychiatric drugs or make end-of-life decisions for patients they consider mentally incompetent. Physicians are not required to tell residents they have been declared incompetent. <http://goo.gl/235QjS>

## Prison hospice

### Teaching *taharah* in prison

*THE JEWISH JOURNAL* | Online – 10 February 2016 – After we arrived [at California State Prison] and started speaking with the men who attended the class, we learned they were all people (mostly, if not all, inmates) who work in the [prison] medical facility's hospice. One of the things they do is sit vigil with those inmates who are near death, so there is someone there with them to witness their last breath. Also, although coffins are not allowed inside the prison, they are responsible for preparing the bodies of the dead to be sent to the funeral home. The medical staff will remove all IVs, devices, etc., from the body, and then turn the body over to the inmates for preparation. The folks attending the class told us that a number of months ago a

Jewish inmate had died, and wanted *taharah*, the Jewish tradition of washing and preparing a body for burial, performed on his body. However, none of the hospice inmates had been trained on how to do it. One of them had seen a *taharah* done, he said, about 50 years before, when he was in his teens, so the group did the best they could, based on what he remembered seeing. <http://goo.gl/r88OvU>

#### Specialist Publications

'End-of-life care behind bars: A systematic review' (p.8), in *American Journal of Nursing*.

## Elder care

### The crisis facing America's working daughters

*THE ATLANTIC* | Online – 9 February 2016 – For America's working moms, there is pretty much an endless stream of resources to guide and comfort them on how to tell the boss they're pregnant, how to find a private place to pump at work, how to negotiate flex time, how to split the chores at home, and whether or not to display pictures of their kids at the office. They can read all day and all night about the many stresses of working motherhood including pregnancy discrimination, the wage gap, the mommy wars, leaning in, and opting out. But for America's working daughters, there is little to help them navigate between their careers and the needs of their aging parents. There are currently 44 million unpaid eldercare providers in the U.S. according to the U.S. Census Bureau and the majority are women. And yet there are very few support programs, formal or informal, in place to support these family caregivers, many of whom are struggling at work and at home. Working

daughters often find they need to switch to a less demanding job, take time off, or quit work altogether in order to make time for their caregiving duties. As a result, they suffer loss of wages and risk losing job-related benefits such as health insurance, retirement savings, and Social Security benefits. <http://goo.gl/cvgC7t>

#### Worth Repeating

##### Daughters caring for dying parents

*QUALITATIVE HEALTH RESEARCH*, 2007;17(7): 932-944. Three types of turmoil (emotional, relational and societal) emerged as the central issue for the participants in this study. These findings fill a gap in knowledge related to daughters' caregiving for dying parents by contributing a theoretical framework that will inform women, health care providers, researchers, and health policy makers. <http://goo.gl/iA0Kbj>

## Related

- *THE WASHINGTON POST* | Online – 8 February 2016 – “**Promise you'll never put me in a nursing home.**” It is hard to say no to that request. But it often is even harder to honor it. For many, the idea of being sent to a facility implies abandonment. Older Americans remember the poorhouse, where the old and infirm were hidden away to die. But many younger people also are repelled by the idea. There's now a wider spectrum of facilities catering to different levels of need, but even the best ones can feel institutional. Daily life is often rigidly regulated, robbing residents of autonomy, and the familiar faces and spaces of a person's life are gone. <https://goo.gl/xPsv43>

## Many in hospice don't get medical visit in last 2 days of life: Study

*HEALTHDAY NEWS* | Online – 8 February 2016 –In the last two days before dying, many hospice patients cared for at home or in a nursing home were not seen by a doctor, nurse or social worker, a new study finds.<sup>1</sup> The researchers found that one in eight Medicare patients didn't get such visits, especially if they were black, dying on a Sunday, or were in a nursing home. The study, funded by the Centers for Medicare & Medicaid Services, led the agency to change its hospice care payment policy for 2016, according to study lead author Dr. Joan Teno [a professor of medicine at the University of Washington in Seattle]. Teno said her study only looked at the last two days of life "because symptoms escalate and pain worsens for patients who are cared for by families, and families need to be educated about how to care for the patient. Also families need support not only in the task of being the hands-on primary caregiver, but also bearing witness to the death of a loved one." The researchers looked at doctor visits, too. But most visits are from regis-

tered nurses and medical social workers, Teno said. These two members of the hospice team are the ones who have control over the care plan, she explained. <http://goo.gl/xJPyZ3>

### Specialist Publications

'Variability in hospice care at the very end of life' (p.12), in *JAMA Internal Medicine*.

N.B. Commentary on the Centers for Medicare & Medicaid Services funded research re-reported in *HealthDay*.

'A state-level assessment of hospital-based palliative care and the use of life-sustaining therapies in the U.S.' (p.12), in *Journal of Palliative Medicine*

'U.S. physicians' opinions about distinctions between withdrawing and withholding life-sustaining treatment' (p.13), in *Journal of Religion & Health*.

1. 'Examining variation in hospice visits by professional staff in the last 2 days of life,' *JAMA Internal Medicine*, 8 February 2016. Of the 661,557 patients including in the study, 81,478 (12.3%) received no professional staff visits in the last two days of life. State variation ranged from 590 of 15,399 patients (3.8%) in Wisconsin to 97 of 492 patients (19.7%) in Alaska. <http://goo.gl/l1SqGH>

### Related

- *THE NEW YORK TIMES* | Online – 12 February 2016 – 'In palliative care, comfort is the top priority.' Perhaps it's not surprising that many families know little about palliative care (PC); it only became an approved medical specialty in 2007. It has grown rapidly in hospitals.<sup>1</sup> More than 70% now offer PC services, including 90% of those with more than 300 beds. But most ailing patients aren't in hospitals, and don't want to be. Outpatient services like Mount Sinai's have been slower to take hold. A few hundred exist around the country, estimates Dr. Diane Meier, who directs the Center to Advance Palliative Care, which advocates better access to these services. Dr. Meier said she expects that number to climb as the Affordable Care Act and Medicare continue to shift health care payments away from the fee-for-service model. Because most people with serious illnesses are older, seniors and caregivers should understand that PC offers more care as needed, not less. Unlike hospice, patients can use it at any point in an illness – many will "graduate" as they recover – without forgoing curative treatment. <http://goo.gl/wNcgX6>

1. 'The growth of palliative care in U.S. hospitals: A status report,' *Journal of Palliative Medicine*, 29 September 2015, #430 (p.14). <http://goo.gl/jeg58d>

### 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.

## “The good death” – “When breath becomes air” and more

*THE NEW YORK TIMES* | Online – 8 February 2016 – Death goes in and out of fashion. The topic lingers behind euphemisms for a few years, and then someone calls it forth again: Elisabeth Kübler-Ross with her disciplined *On Death and Dying* in 1969; Susan Sontag with her angry but profound *Illness as Metaphor* in 1978 and the empathetic follow-up *AIDS and Its Metaphors*, in 1988; Derek Humphry, implausibly, with his suicide handbook *Final Exit* in 1991; Sherwin Nuland with his magisterial *How We Die* in 1993; more recently, Joan Didion with her agonizingly precise *The Year of Magical Thinking* in 2005; and Atul Gawande with his humane *Being Mortal* in 2014. Each of these books argues, one way or another, for a continuum between life and its conclusion. The gloss of youthful vitality can persuade us that life is for the living, but life is also for the dying, and repudiating that ultimate punctuation escalates our anxiety and deprives us of final dignity. Time and again, we must clarify our individual and collective beliefs about how the last chapter changes the rest of the narrative. “Or not to be” is not in fact a question. These recent weeks have seen the publication of five books about death: one by a historian; two by hospice workers; one by a widow; one by a man who is dying himself. <http://goo.gl/BpYUi5>

## International

### End-of-life care in England

#### Thousands who die with cancer spend last days in pain, study finds

U.K. (England) | *The Guardian* – 13 January 2016 – Nearly one in 10 people who died with cancer in England in 2014 spent the last 48 hours of their lives in pain, according to a survey.<sup>1</sup> The findings from the National Survey of Bereaved People (Voices) equate to more than 12,500 people spending their last days without adequate pain relief, Macmillan Cancer Support estimates. The charity said a lack of support at home, including pain relief, means that people with cancer at the end of their life do not have enough choice over where they would like to be cared for and many are spending their final days in oversubscribed hospital beds against their wishes. Macmillan urged the government to fix England’s “dismal” variation in the quality of end-of-life care (EOLC) by funding improvements recommended in an independent review of choice at the end of life published in February 2015. The review from the Choice in End of Life Care Programme Board concluded that a meaningful level of service improvement could be achieved for a relatively modest investment of £130 million in social care and National Health Service commissioned services to deliver a national choice offer in EOLC. It recommended that every local area establish 24/7 EOLC for people outside hospital and for details of people’s choices to be held electronically in a palliative care coordination system. <http://goo.gl/jPRw0F>

1. ‘National Survey of Bereaved People (VOICES), 2014,’ Office for National Statistics, for National Health Service England, July 2015. <http://goo.gl/ATlw6K>

#### Related

- U.K. (England) | *The Daily Mail* (London) – 8 February 2016 – ‘**National Health Trust encourages terminally ill patients to leave final wish list.**’ Terminally ill patients are to be encouraged by a National Health Trust to write their own “end-of-life plan” instructing doctors, nurses and family about their wishes for their final months, days and hours. A new document is based on birth plans that pregnant women commonly draw up with their midwives, and takes the form of a single-page grid detailing the personal wishes of the patient about every aspect of their care. <http://goo.gl/w67Tf4>

### Media Watch: Back Issues

Back issues of Media Watch are available on the International Palliative Care Resource Center website at: <http://goo.gl/frPgZ5>

## Elder care in France

### **Elderly patients rarely included in decision to use intensive care**

FRANCE | Reuters – 11 February 2016 – According to a study of 15 emergency departments, patients over age 80 who are admitted to intensive care are often not asked their opinion about admission.<sup>1</sup> “The relationship between physicians and their patients has changed over the last decades and patients’ empowerment has led to a greater self autonomy in medical decisions,” but apparently not when it comes to moving elderly patients into an intensive care unit, said lead author Dr. Julien Le Guen of Universite Paris Descartes in France. Legally, no medical decision should be made without the patient’s consent, Le Guen told Reuters Health... But based on the results of his team’s study, there seems to be a discrepancy between what doctors say is important, like the patient’s opinion, and what they actually do. The researchers used data from a previous study of patients over age 80 who came to emergency rooms at 15 hospitals in the Paris region between 2004 and 2006. All had conditions potentially requiring intensive care, and all were conscious and capable of expressing an opinion if asked. <http://goo.gl/G1aKHH>

1. ‘Are elderly patients’ opinions sought before admission to an intensive care unit? Results of the ICE-CUB study,’ *Age & Ageing*, 11 January 2016. <http://goo.gl/NXFqaQ>

## End-of-life care in Scotland

### **Deaths at home falling despite most wishing to end lives there**

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 9 February 2016 – A falling number of Scots are dying at home according to a decade-long study – despite most saying this is where they want to end their lives.<sup>1</sup> Researchers described a “mismatch” between the reality and dying people’s last wishes as the proportion of home deaths fell from 30% in 2000 to just 23% in 2010 among 20,000 people in Dumfries and Galloway. The findings are likely to have resonance across Scotland as death at home is often used as a marker of the quality of end-of-life care (EOLC), according to the team from Glasgow University. It comes after ministers announced a £3.5 million boost for EOLC to ensure everyone is able to have the death they want regardless of diagnosis, age or background. Those suffering from stroke or dementia were the least likely to die in their own homes, while patients with cancer and

heart disease were most likely to end their lives at home, the study revealed. The findings will help to inform health and social care providers as well as allowing patients to advocate for their wishes, said Professor David Clark, founder of Glasgow University’s End of Life Studies Group. <http://goo.gl/iCp7gg>

### **Corrections & Clarifications**

In Media Watch of 1 February 2016, #447 (p.6), a BBC report, ‘Short home care visits “plague system,”’ referred to a report by the trade union UNISON. ‘Suffering Alone at Home: A UNISON Report on the Lack of Time in Our Homecare System’ can be downloaded at: <http://goo.gl/5HEOis>

1. ‘Predictors of place of death in South West Scotland 2000-2010: Retrospective cohort study,’ *Palliative Medicine*, 8 February 2016. <http://goo.gl/Fwor2u>



### **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>



## End-of-life care in Ireland

### **All at sea: Rural doctors in crisis**

IRELAND | *The Independent* (Dublin) – 7 February 2016 – Anyone who has sat by the bedside of a loved one and seen them slowly slip away will appreciate the importance of good end-of-life care. But trying to ensure patients have a good death is becoming increasingly difficult and it's what motivated one of Dr. Liam Glynn's patients to get involved in the 'No Doctor, No Village' campaign. GPs are under more pressure than ever to work evenings and weekends, to see more patients, and to run their practices with less money. They are feeling unloved, overstretched, got at: caught between the ever-increasing demands of patients and what they believe to be unreasonable cuts from govern-

ment for rural practices. All the negative publicity is having an effect: complaints about GPs are rising and their stock has never been lower. <http://goo.gl/7SvGkn>

### Specialist Publications

**'Interviews with Irish healthcare workers from different disciplines about palliative care for people with Parkinson's disease: A definite role but uncertainty around terminology and timing'** (p.10), in *BMC Palliative Care*.

**N.B.** Selected articles on end-of-life care in rural communities and remote regions are noted in the issues of *Media Watch* of 30 November 2015, #438 (p.12); 14 September 2015, #427 (p.8); 7 September 2015, #426 (p.17); 17 August 2015, #423 (p.14), 11 May 2015, #409 (p.13), and 30 June 2014, #364 (p.15).

## Specialist Publications (e.g., in-print and online journal articles, reports, etc.)

### **Liminality in pediatric palliative care**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 9 February 2016 – Palliative care (PC) for infants, children, and adolescents encompasses numerous transitions and thresholds of uncertainty that challenge conventional clinical medicine. PC clinicians have opportunities to be more comfortable amid such challenges, or perhaps even overcome them, if they are attuned to the unique times and places in which patients, their families, and caregivers find themselves throughout illness and recovery or transitioning toward the end of life. Patient-clinician encounters often dwell in these liminal places. The concept of liminality gives validation to the patient or family's being "stuck in places betwixt and between" a past life rich with relationship and purpose and an acute, chronic, or critical illness. Or having resolved the acute crisis of hospitalization that place between the past bounds of illness and the uncertain path forward, perhaps even toward death. Liminality provides a framework for addressing the unbound spaces that patients and families occupy: What is past is behind – the present place is tenuous and temporary, and what is ahead uncertain. This place is where PC clinicians can offer clinicians and families guidance. <http://goo.gl/QVZGmn>

### **Related**

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 February 2016 – **'Parental perspectives of communication at the end of life at a pediatric oncology institution.'** This study helps to identify techniques that should be used by clinicians as they work with children with cancer and their families, particularly including patients in treatment decisions, ongoing relationship building, communicating with caring and empathy, using an interdisciplinary team for additional support, and pairing bad news with a plan of action. <http://goo.gl/pm0IXZ>

Cont.

- *PEDIATRIC CRITICAL CARE MEDICINE*, 2016;17(2):167-168. **‘Measuring and improving, not just describing – The next imperative for end-of-life care.’** Of the 41 publications that have emerged from the [U.S.] Collaborative Pediatric Critical Care Research Network since its inception over 10 years ago, it is interesting to note that nearly a quarter of them have studied issues related to end-of-life care (EOLC). This is an important signal that although the restoring the health of children remains the foundation of pediatric critical care medicine, there are times when curative care is not possible, and in these situations, we owe the same focus and rigor to delivering high quality EOLC. <http://goo.gl/Kph2Tj>

N.B. Collaborative Pediatric Critical Care Research Network: <http://goo.gl/Gk6hMp>

- *PEDIATRIC CRITICAL CARE MEDICINE*, 2016;17(2):110-120. **‘Limiting and withdrawing life support in the pediatric ICU: For whom are these options discussed?’** Clinical factors reflecting type and severity of illness, socio-demographics, and institutional practices may influence whether limitation or withdrawal of life support is discussed with families of PICU patients. Most children whose families discuss limitation or withdrawal of life support die during their PICU stay; survivors often have substantial disabilities. <http://goo.gl/7sX9Ct>

### End-of-life care behind bars: A systematic review

*AMERICAN JOURNAL OF NURSING* | Online – 11 February 2016 – Nineteen articles, all published between 2002 and 2014, met the inclusion criteria. Of these, 53% were published between 2009 and 2014, and 58% reported findings from qualitative research. One article reported on research conducted in the U.K.; the remaining 18 reported on research conducted in the U.S. Capacity (that is, the number of prisoners requiring end-of-life care (EOLC) and the ability of the prison to accommodate them) and the site of EOLC delivery varied across studies, as did the criteria for admission to end-of-life or hospice services. Care was provided by prison health care staff, which variously included numerous professional disciplines, corrections officers, and inmate caregivers. The inmate caregivers, in particular, provided a wide array of services and were viewed positively by both end-of-life patients and health care staff. There are insufficient data to characterize the patients’

and inmate caregivers’ perceptions of the EOLC staff and the quality of care they provided. The screening criteria applied to inmate caregivers and the training they received varied widely among care programs. Inmates providing EOLC viewed caregiving as a transformational experience. Likewise, prison administrators and health care staff viewed inmate participation positively. <http://goo.gl/zgocdi>

#### [Prison Hospice Backgrounder](#)

End-of-life care – or the lack of – in the prison system has been highlighted on a regular basis in Media Watch. An updated compilation of the articles, reports, etc., noted in past issues of the weekly report is available on the Palliative Care Community Network website at: <http://goo.gl/qgd4hp>

### The value of uncertainty in critical illness? An ethnographic study of patterns and conflicts in care and decision-making trajectories

*BMC ANESTHESIOLOGY* | Online – 9 February 2016 – Decision-making in critical illness involves a web of discussions regarding the potential outcomes and processes of care, across the whole disease trajectory. When measures oscillate between curative and comfort there is greatest conflict. This suggests a need to support early communication, especially around values and preferred care outcomes, from which other decisions follow, including DNAR (Do Not Attempt Resuscitation). Offering further support, possibly with expert palliative care, communication, and discussion of “trial of treatment” may be beneficial at this time, rather than waiting until the “end of life.” <https://goo.gl/eE59Am>

Cont.



## Related

- **COCHRANE DATABASE OF SYSTEMATIC REVIEWS** | Online – 12 February 2016 – ‘**End-of-life care pathways for the dying.**’ This is an updated version of a Cochrane review published in 2013 in the Cochrane Library.<sup>1</sup> In many clinical areas, integrated care pathways are utilised as structured multidisciplinary care plans that detail essential steps in caring for patients with specific clinical problems. Since the last update, there have been sustained concerns about the safety of implementing end-of-life care pathways, particularly in the U.K. <http://goo.gl/OY9j86>
  1. ‘End-of-life care pathways for improving outcomes in caring for the dying,’ *Cochrane Database of Systematic Reviews*, 18 November 2013. [Noted in Media Watch, 25 November 2013, #333 (p.15)] <http://goo.gl/lmbPIO>
- **FUTURE ONCOLOGY** | Online – 3 February 2016 – ‘**The importance of measuring customer satisfaction in palliative care.**’ In the last decades, palliative care (PC) has been more and more focused on the evaluation of patients’ and families’ satisfaction with care. However, the evaluation of customer satisfaction in PC presents a number of issues such as the presence of both patients and their families, the frail condition of the patients and the complexity of their needs, and the lack of standard quality indicators and appropriate measurement tools. The authors critically review existing evidence and literature on the evaluation of satisfaction in the PC context. Moreover, they provide – as a practical example – the preliminary results of their experience in this setting with the development of a dedicated tool for the measurement of satisfaction. <http://goo.gl/HBYxzz>
- **JOURNAL OF PALLIATIVE MEDICINE** | Online – 5 February 2016 – ‘**Making the case for palliative care at the system level: Outcomes data.**’ A recent trend in health care is to integrate palliative care (PC) programs across multiple hospitals to reduce variation, improve quality, and reduce cost. This study’s objective was to demonstrate the benefits of PC for a system. PC services within the first 48 hours of admission demonstrated a shorter length of stay, reduced costs 40%, and decreased mortality for one hospital. <http://goo.gl/7cXVY2>

## **Towards integration of palliative care in patients with chronic heart failure and chronic obstructive pulmonary disease: a systematic literature review of European guidelines and pathways**

*BMC PALLIATIVE CARE* | Online – 13 February 2016 – Overall, the results of this systematic study illustrate that there is a growing awareness for the importance of palliative care (PC) in patients with advanced chronic heart failure (CHF) and chronic obstructive pulmonary disease (COPD). At the same time, however, they signal the need for the development of standardized and conceptually unambiguous strategies so that existing barriers are alleviated. In this respect, given that prognostication for both CHF and COPD is difficult, emphasis should be placed on the determination of referral criteria that are independent of it and thus straightforward to realise in practice. Moreover, particular attention should be paid to the communication of end-of-life issues that consistently appears as a bottleneck in PC for patients with advanced CHF

and COPD. Further, it is critical that the nearly total absence of discussions concerning end-of-life issues is alleviated so that both the efficacy of PC services and the number of beneficiaries are enhanced. This is instrumental for the improvement of existing PC practices that have been consistently shown to be suboptimal. <http://goo.gl/YSVbDV>

### **Extract from *BMC Palliative Care* article**

Aspects such as referral criteria, advanced care planning, recommendations on the last hours of life and bereavement care are only partially touched or addressed.

### **[Media Watch: Palliative Care Network-e Website](http://goo.gl/8JyLmE)**

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. <http://goo.gl/8JyLmE>

## Interviews with Irish healthcare workers from different disciplines about palliative care for people with Parkinson's disease: A definite role but uncertainty around terminology and timing

*BMC PALLIATIVE CARE* | Online – 9 February 2016 – This study identified key barriers, and through suggestions to tackle these – facilitators, to delivering palliative care (PC) to people with Parkinson's disease (PD). Findings indicate that PC may be facilitated in this population by increased public awareness of the role of PC, education for healthcare workers (HCW) in both specialist and generalist settings, education for patients and families, better communication and integrated care models, and increased resources. A key clinical implication is that all HCWs need to be trained in the assessment of PC needs of their PD patients. The implication for policy is that clear evidence-based guidelines should be introduced to promote the adoption of a PC approach, including referral to specialist PC where needed. This current study, the largest and most comprehensive multiple discipline exploration of HCW views, adds to the previous qualitative literature in this area, together mandating that people with PD should be receiving PC from their HCW team. <http://goo.gl/hCxhzq>

Noted in Media Watch, 30 March 2015, #403 (p.11):

- *CURRENT NEUROLOGY & NEUROSCIENCE REPORTS* | Online – 22 March 2015 – '**Palliative care for Parkinson's disease: Has the time come?**' Although Parkinson's disease is traditionally viewed as a movement disorder which affects quality of life, recent literature has revealed an increased mortality, a high burden of difficult-to-manage non-motor symptoms, high caregiver distress, and a high utilization of medical services especially in the last year of life. <http://goo.gl/09pTbj>

Noted in Media Watch, 15 July 2013, #314, (p.11):

- *PALLIATIVE MEDICINE* | Online – 9 July 2013 – '**Palliative care for Parkinson's disease: A summary of the evidence and future directions.**' Despite calls for improved access to palliative care (PC) for people with Parkinson's disease, services have been slow in developing. Obstacles include poor understanding and recognition of PC needs, the role for specialist PC services, and an agreed structure for sustainable PC provision. An integrated model of care is discussed. <http://goo.gl/dN4FfK>

## People with disabilities and the Charter: Disability rights at the Supreme Court of Canada under the Charter of Rights & Freedoms

*CANADIAN JOURNAL OF DISABILITY STUDIES*, 2016;5(1):183-210. The inclusion of people with disabilities as a designated group for rights protection in the Canadian Charter of Rights & Freedoms was viewed as a triumph of disability advocacy in Canada. And yet, a number of commentators look back with disappointment over the 30 years since the Charter was passed. This paper ... examines an important subset of cases invoking the Charter of Rights & Freedoms to promote disability rights. Specifically, it examines 14 cases heard by the Supreme Court of Canada to uncover the types of disability issues that have been addressed, and the approach of Supreme Court justices to these issues. The current study shows a very limited impact of the Charter, despite expectations of a discernible shift in the position of people with disabilities within Canadian society. There is still no consistently applied "disability lens" in the policy environment, and there are relatively few

tangible indicators of the kinds of considerations offered to other enumerated groups, such as Ministry or oversight committees dedicated to their issues. <http://goo.gl/Wxbdel>

### Extract from *Canadian Journal of Disability Studies*

At the time this paper went to publication, the Supreme Court of Canada overturned much of the [Sue] Rodriguez [1993] decision in the matter of *Carter v. Canada* (Attorney General, 2015 SCC 5). In a unanimous decision the Court found that failure to provide assisted suicide for terminally ill and or disabled persons did violate the right to life, liberty and security of the person...

**N.B.** Rodriguez (1993) sought to have the Criminal Code of Canada amended to permit assisted suicide in the case of a terminal disabling condition.

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

*CLINICAL JOURNAL OF ONCOLOGY NURSING*, 2016;20(1):e16-e19. The general population and healthcare professionals in China have yet to realize the importance of palliative care (PC). This article describes the status of PC services in China, their historic development, and the barriers to their advancement. A significant amount of work is needed to meet the standards of international PC societies. Nurses and other health providers who are engaged in PC should be well trained regarding the principles and procedures of PC to ensure quality end-of-life care. <https://goo.gl/2K1w1O>

### Selected articles on end-of-life care in China

- *CHINESE MEDICAL JOURNAL*, 2015;128(2):279-281. **‘A review on problems of China’s hospice care and analysis of possible solutions.’** The supply of the hospice care service in China is still much less than the demand. There are three main reasons: 1) Obstructions from traditional Chinese culture; 2) Lack of support from the government; and, 3) Scarcity of hospice care specialists. The author proposes a number of possible solutions. [Noted in Media Watch, 26 January 2015, #394 (p.8)] <http://goo.gl/uhZNqc>

N.B. English language article.

- *ASIA PACIFIC JOURNAL OF HEALTH MANAGEMENT*, 2013;8(1):9-13. **‘Palliative care on Mainland China.’** Factors that have slowed development of palliative care in China include cultural values that encourage efforts to cure (even when such treatment is likely to be futile) over the alleviation of suffering, limited public policies and funding, and poor education of healthcare professionals about end-of-life care. [Noted in Media Watch, 9 September 2013, #322 (p.6)] <http://goo.gl/2ul8p6>

- *ASIAN JOURNAL OF GERONTOLOGY & GERIATRICS*, 2011;6(2):103-106. **‘End-of-life care in Hong Kong.’** The Hong Kong government does not have a clear policy on developing end-of-life care services as a critical part of health care, nor on promoting dying in place, either at home or in a residential care home. [Noted in Media Watch, 13 February 2012, #240 (p.8)] <http://goo.gl/HLwbNi>

N.B. China was ranked 71st of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ The Economist Intelligence Unit, October 2015, commissioned by the Lien Foundation of Singapore. [Noted in Media Watch, 12 October 2015, #431 (p.6)] See ‘Case Study: China – Greater Awareness’ (p.20). <http://goo.gl/nuPWll>

“

The biggest challenge is to change people’s minds, to let them know that society can take good care of their parents in the late stages of illness and help them die with dignity.

”

### End-of-life care in Canada

#### Autour de la souffrance soignante en soins palliatifs: Entre idéal de soin et juste distance

*FRONTIÈRES* | Online – Accessed 8 February 2016 – Emotional suffering and burnout amongst professionals in palliative care (PC) settings are increasingly discussed phenomena in the media and the specialized journals alike. However, we still lack anthropological understandings of the ways this distress is related to the dynamics, practices and representations of PC institutions. This article, based on a 2011-2012 fieldwork realized in one of the 27 independent hospices of the province of Quebec [Canada], aims to contribute to the question in showing how the ways the staff conceive their roles in caring for the dying can open the door to emotional strain. The authors explore how their suffering is related to the nature of these roles, the institutional framework, and what is perceived to be a “good death.” <http://goo.gl/QpNiqn>

N.B. French language article

### Related

- *PATIENT EDUCATION & COUNSELING* | Online – 10 February 2016 – **‘Practicing death.’** This narrative describes the struggle of a primary care physician contending with the challenge of remaining committed to his patient’s care despite a sense of burnout in relation to an intense period of patient deaths. The story presents two patient deaths and the physician’s reflections on how he handled both cases. <http://goo.gl/g2nmVr>

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

### Variability in hospice care at the very end of life

*JAMA INTERNAL MEDICINE* | Online Commentary – 8 February 2016 – More than 1.6 million individuals in the U.S. receive hospice care every year, which is provided by an increasing number of hospice agencies. What started with a few small non-profit hospice agencies in the 1970s is now a multibillion-dollar industry comprising non-profit and for-profit companies that have doubled in number in the last 10 years. With this growth comes concern about variability in services and the quality of care delivered by hospice agencies. The Centers for Medicare & Medicaid Services (CMS) is particularly concerned about this variability. Owing to worries about whether beneficiaries and their families are receiving needed hospice care and support at the very end of life, the CMS is planning to reform payments to hospice agencies. While we agree that the variability in the number of visits during the last two days of a patient's life should raise questions about the care being delivered by individual hospice agencies, we urge caution in linking this process measure too closely with quality of care. The study has several limitations: there is a lack of data regarding the quality of visits provided; the frequency of visits from other hospice support team members, such as aides, chaplains, and volunteers; the desire for skilled visits as determined by patients and caregivers; and, most important, correlation of frequency of visits with patient and caregiver satisfaction. <http://goo.gl/R20prl>

**N.B.** Scroll back to [U.S.A.](#) and 'Many in hospice don't get medical visit in last 2 days of life: Study' (p.0) for *HealthDay News* report on the recent Centers for Medicare & Medicaid Services funded research.

#### Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 12 February 2016 – '**A state-level assessment of hospital-based palliative care and the use of life-sustaining therapies in the U.S.**' State-level poverty rates were negatively correlated with the percent of hospitals with palliative care programs (PCPs). States with more hospital-based PCPs had significantly lower rates of prolonged acute mechanical ventilation, tracheostomies, and hemodialysis, but higher rates of nutritional support than states with fewer PCPs. <http://goo.gl/cCfRPg>

### "Am I dying doctor?": How end-of-life care is portrayed in television medical dramas

*JOURNAL OF PALLIATIVE CARE & MEDICINE* | Online – 25 January 2016 – The present study shows that healthcare professionals in television medical dramas talked with patients or loved ones about end-of-life. However, these discussions are often limited to discussions about the possibility of dying and treatment options. Topics such as preferences for life-sustaining treatments, advance directives, and palliative care were rarely discussed. Therefore television medical dramas don't seem to contribute in empowerment of patients and loved ones in the process of advance care planning (ACP) and don't facilitate behaviour change resulting in increased willingness to be engaged in end-of-life communication. However they could influence patients' and loved ones' attitudes regarding ACP, CPR, and dying. Therefore, healthcare professionals need to take into account this influence when having discussions about end-of-life. <http://goo.gl/uP9uqf>

Noted in Media Watch, 31 August 2015, #425 (p.15):

- *RESUSCITATION* | Online – 18 August 2015 – '**It isn't like this on TV: Revisiting CPR survival rates depicted on popular TV shows.**' Public perceptions of cardiopulmonary resuscitation (CPR) can be influenced by the media. Nearly two decades ago, a study found the rates of survival following CPR were far higher in popular TV shows than actual rates.<sup>1</sup> <http://goo.gl/4jZmLk>

1. 'Resuscitation on television: Realistic or ridiculous? A quantitative observational analysis of the portrayal of cardiopulmonary resuscitation in television medical drama,' *Resuscitation*, 2009;80(11):1275-1279. [Noted in Media Watch, 24 February 2014, #346 (p.6)] <http://goo.gl/2Z4F9O>

## The effects of advance care planning interventions on nursing home residents: A systematic review

*JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 6 February 2016 – The initial search yielded 4,654 articles. Thirteen studies fitted inclusion criteria for analysis. The advance care planning (ACP) interventions included: 1) 5 studies evaluating educational programs; 2) 5 studies introducing or evaluating a new ACP form; 3) 2 studies introducing an ACP program with a palliative care (PC) initiative; and, 4) 1 study observing the effect of do not resuscitate orders on medical treatments for respiratory infections. A range of effects of ACP was demonstrated in the study populations. Hospitalization was the most frequent outcome measure used across the included studies. Analysis found that in the nursing home population, ACP decreased hospitalization rates by 9%-26%. Of note, in the 2 studies that included mortality, the decrease in hospitalization was not associated with increased mortality. Place of death is another important effect of ACP. Analysis found significant increases in the number of

residents dying in their nursing home by 29%-40%. Medical treatments being consistent with ones' wishes were increased with ACP although not to 100% compliance. Two studies showed a decrease in overall health costs. One study found an increase in community PC use but not in-patient hospice referrals. <http://goo.gl/jySIFx>

### Extract from *Journal of Post-Acute & Long-Term Care Medicine* article

The types of ACP interventions vary, and it is difficult to identify superiority in effectiveness of one intervention over another. Outcome measures also vary considerably between studies although hospitalization, place of death, and actions being consistent with resident's wishes are by far the most common. Very few studies with high quality methodology have been undertaken in the area with a significant lack of randomized controlled trials.

**N.B.** Selected articles on end-of-life care in nursing homes noted in past issues of Media Watch are listed in the issues of the weekly report of 26 October 2015, #433 (p.10) and 15 December 2014, #388 (p.12).

## U.S. physicians' opinions about distinctions between withdrawing and withholding life-sustaining treatment

*JOURNAL OF RELIGION & HEALTH* | Online – Accessed 8 February 2016 – Decisions to withhold or withdraw life-sustaining treatment (LST) precede the majority of ICU deaths. Although professional guidelines generally treat the two as ethically equivalent, evidence suggests withdrawing LST is often more psychologically difficult than withholding it. The aim of this experiment was to investigate whether physicians are more supportive of withholding LST than withdrawing it and to assess how physicians' opinions are shaped by their religious characteristics, specialty, and experience caring for dying patients. Most U.S. physicians [i.e., survey respondents] find withdrawing LST not only more psychologically difficult, but also more ethically problematic than withholding such treatment. Physicians working in an end-of-life specialty and physicians with more experience caring for dying patients were less likely to endorse either a psychological or an ethical distinction between withdrawing and withholding LST. Physicians' opinions are to some extent shaped by their religious characteristics, specialty, and levels of experience caring for dying patients. <http://goo.gl/VEfgnF>

Noted in Media Watch, 11 January 2016, #444 (p.13):

- *SOINS: LA REVUE DE RÉFÉRENCE INFIRMIÈRE*, 2015;60(801):49-51. 'The decision to withhold and withdraw active treatments, an ethical approach.' Intensive care medicine is confronted with situations of suffering and dependence experienced as the appropriation of the body or medical futility. In this context, withholding and withdrawing active intensive care must be given a framework. The ethical challenge is to decide to continue or not with care considered vain or futile. The 'Leonetti Law,' in particular, helps to clarify the situation for professionals and families. <http://goo.gl/mWYjJ>

Cont.



Noted in Media Watch, 27 January 2014, #342 (p.14):

- *MEDICAL LAW REVIEW* | Online – 12 January 2014 – ‘**Does withdrawing life-sustaining treatment cause death or allow the patient to die?**’ Traditional medical ethics and the law are mistaken to take the view withdrawal merely allows the patient to die, rather than causing the patient’s death, describing such a view as “patently false.” The law’s continued position to the contrary stems from a moral bias, resulting in the moral and legal fiction withdrawal does not cause death, but lets the patient die. <http://goo.gl/4Su5nS>

### Neurologists as primary palliative care providers

*NEUROLOGY: CLINICAL PRACTICE* | Online – Accessed 8 February 2016 – The authors present current knowledge and recommendations regarding communication tasks and practice approaches for neurologists as they practice primary palliative care (PC), including discussing serious news, managing symptoms, aligning treatment with patient preferences, introducing hospice/terminal care, and using the multi-professional approach. Neurologists receive little formal PC training yet often need to discuss prognosis in serious illness, manage intractable symptoms in chronic progressive disease, and alleviate suffering for patients and their families. Because patients with neurologic disorders often have major cognitive impairment, physical impairment, or both, with an uncertain prognosis, their PC needs are particularly challenging and they remain largely uncharacterized and often unmanaged. <http://goo.gl/PELgMg>

Noted in Media Watch, 9 June 2014, #361 (p.15):

- *MEDSCAPE MEDICAL NEWS* | Online – 3 June 2014 – ‘**New European consensus on palliative care in neuro disease.**’ A consensus paper for palliative care (PC) for patients with progressive neurologic disease emphasizes the special needs of these patients and how neurologists and PC specialists can work together to fulfil them. The paper is the product of a joint effort of the European Federation of Neurological Societies and the European Association for Palliative Care. <http://goo.gl/1TAwqH>

### Falling together – Empathetic care for the dying

*NEW ENGLAND JOURNAL OF MEDICINE*, 2016;374(6):587-590. Empathy for the dying is different from, say, empathy for a patient who has frequent headaches or newly diagnosed but possibly treatable cancer. To feel the patient’s pain under the latter circumstances may be unpleasant, but it is tempered by a hope, or even certainty, that we might offer relief or cure. It is thus an empathy that is identity-affirming. To empathize with a dying person, by contrast, is to feel a pain that we can’t fix. To some physicians, death inevitability feels like a failure. In that sense, I suspect that my insensitivity to my dying patient had less to do with not wanting to feel his pain than with not wanting to feel my own. <http://goo.gl/flvVrk>

Noted in Media Watch, 1 February 2016, #447 (p.8):

- *BMC MEDICAL ETHICS* | Online – 27 January 2016 – ‘**Making space for empathy: Supporting doctors in the emotional labour of clinical care.**’ Physicians are routinely trained to remain detached from their own as well as their patients’ emotions, perpetuating the ideal of the skilled and cool-minded professional. They have to deal daily with distressing situations, heavy workload, and strict time constraints. Such an environment is not conducive to the development of empathy in the contact with patients. <http://goo.gl/r1uRKt>

**N.B.** Additional articles on empathy in end-of-life care are noted in this issue of Media Watch.

### Palliative care education in nurse practitioner programs: A survey of academic deans

*NURSING EDUCATOR* | Online – 9 February 2016 – The need for clinicians trained in palliative care (PC) will increase as more Americans live with life-limiting illness. Although multiple studies have described the nature of PC education in pre-licensure programs, there have been no similar studies of nurse practitioner programs. The authors surveyed 101 nurse practitioner programs. Most provide little instruction in PC; education is often limited to a few hours of lecture. One-third of programs offer no instruction. Although PC is an important component of advanced practice nursing practice, programs may not be providing adequate education. <http://goo.gl/eI2zC9>



## **“I think you just learnt as you went along” – Community clergy’s experiences of and attitudes towards caring for dying people: A pilot study**

*PALLIATIVE MEDICINE* | Online – 8 February 2016 – Fourteen clergy were interviewed from six Christian denominations. Participants described their experiences of ordination training and how helpful this had been for their work among Christian communities. Respondents were invited to discuss their knowledge of and involvement with palliative care (PC) services. Each interviewee also accounted for their understanding of pastoral care and spiritual care and considered whether any differences existed between these terms and, if so, what they were. Overall, clergy lacked any detailed formal training and had little experience of working with or relating to PC providers. <http://goo.gl/tKTFSw>

Noted in Media Watch, 5 October 2015, #430 (p.3):

- U.S. (New York State) | *The New York Times* – 29 September 2015 – **‘Where clergy need to tread: Helping make end-of-life medical choices.’** What are the most difficult and painful questions rabbis, priests, pastors or imams face at the bedside of a dying member? Helping make realistic and sensible medical decisions is becoming the single most important aspect in a clergy’s life. <https://goo.gl/467V0q>

Noted In Media Watch, 31 August 2015, #425 (p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 August 2015 – **‘Clergy views on a good versus a poor death: Ministry to the terminally ill.’** Study participants identified four primary determinants of good versus poor death: 1) Dignity; 2) Preparedness; 3) Physical suffering; and, 4) Community. They expressed appreciation for contextual factors that affect the death experience; some described a “middle death,” or one that integrates both positive and negative elements. Location of death was not viewed as a significant contributing factor. <http://goo.gl/1CFCR8>

## **No negative impact of palliative sedation on relatives’ experience of the dying phase and their well-being after the patient’s death: An observational study**

*PLOS ONE* | Online – 12 February 2016 – Based on the findings of this study, the use of sedation does not appear to have a negative influence on bereaved persons’ experience of the dying phase of their deceased relative or on their own well-being after the patient’s death. This finding might be attributed to relief of the patient’s severe suffering, or to relatives receiving sufficient information from their caregivers about palliative sedation. Nevertheless, palliative sedation is a far-reaching and ethically complex intervention that requires caregivers to focus on providing comfort, support and continuous information to both the patient and the patient’s family. <http://goo.gl/6jPWxm>

Noted in Media Watch, 21 July 2014, #367 (p.13):

- *SUPPORTIVE CARE IN CANCER* | Online – 15 July 2014 – **‘Making sense of continuous sedation in end-of-life care for cancer patients: An interview study with bereaved relatives in three European countries.’** While most relatives believed sedation had contributed to a “good death” for the patient, many expressed concerns. These related to anxieties about the patient’s well-being, their own wellbeing, and questions about whether continuous sedation had shortened the patient’s life, or whether an alternative approach would have been better. <http://goo.gl/cA1cYM>

## **End-of-life care for patients dying of stroke: A comparative registry study of stroke and cancer**

*PLOS ONE* | Online – 4 February 2016 – Although stroke is a significant public health challenge and the need for palliative care (PC) has been emphasized for these patients, there is limited data on end-of-life care (EOLC) for patients dying from stroke. Compared to patients dying of cancer, the patients dying of stroke had a significantly higher prevalence of having death rattles registered, but a significantly lower prevalence of, nausea, confusion, dyspnea, anxiety, and pain. Patients dying of stroke had significantly lower odds ratio of having informative communication from a physician about the transition to EOLC and of their family members being offered bereavement follow-up. The results indicate differences in EOLC between patients dying of stroke and those dying from cancer. <http://goo.gl/XALKff>

Cont.

## Selected articles on end-of-life care for patients dying of stroke

- *MEDSCAPE* | Online – 22 July 2014 – ‘**Caring for the “hidden patient” after stroke.**’ Post stroke interventions that combine skill-building, such as problem-solving and stress management, with practical education may improve quality of life for both stroke survivors and their caregiver, concludes a new American Heart Association/American Stroke Association Scientific Statement.<sup>1</sup> [Noted in Media Watch, 28 July 2014, #368 (p.10)] <http://goo.gl/LQgnKA>
  1. ‘Evidence for Stroke Family Caregiver and Dyad Interventions: A Statement for Healthcare Professionals From the American Heart Association and American Stroke Association,’ *Stroke*, 17 July 2014. <http://goo.gl/3EaYOQ>
- *STROKE* | Online – 27 March 2014 – ‘**Palliative and end-of-life care in stroke: A statement for healthcare professionals from the American Heart Association/American Stroke Association.**’ To optimally deliver primary palliative care (PC), stroke systems of care and provider teams should 1) Promote and practice patient- and family-centered care; 2) Effectively estimate prognosis; 3) Develop appropriate goals of care; 4) Be familiar with the evidence for common stroke decisions with end-of-life implications; 5) Assess and effectively manage emerging stroke symptoms; 6) Possess experience with palliative treatments at the end of life; 7) Assist with care coordination, including referral to a PC specialist or hospice if necessary; 8) Provide the patient and family the opportunity for personal growth and make bereavement resources available if death is anticipated; and, 9) Actively participate in continuous quality improvement and research. [Noted in Media Watch, 31 March 2014, #351 (p.10)] <https://goo.gl/7WUyo6>
- *BMC PALLIATIVE CARE* | Online – 9 November 2012 – ‘**Integrating palliative care within acute stroke services: Developing a programme theory of patient and family needs, preferences and staff perspectives.**’ This paper presents an explanatory framework for the integration of palliative and acute stroke care. [Noted in Media Watch, 12 November 2012, #279 (p.8)] <http://goo.gl/WnmWf>

## Understanding how bereaved parents cope with their grief to inform the services provided to them

*QUALITATIVE HEALTH RESEARCH* | Online – 4 February 2016 – The objective of this study was to develop a rich description of how parents experience their grief in the first year after the death of their child, and how various bereavement follow-up and support services helped them during this time, with the aim of informing follow-up and support services offered to bereaved parents. The authors’ findings situated parents’ individual experiences of coping within the social and institutional contexts in which they grieved. In the first year after the death of their child, parents [i.e., study participants] regulated their intense feelings of grief through loss-oriented, restoration-oriented, and/or meaning reconstruction strategies. Often, parents’ relationships with others and many of the bereavement follow-up and support services helped them in this regard. This article also explores how the results may aid service providers in accompanying parents in a way that optimizes outcomes for these parents. <http://goo.gl/oY0uuw>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *JAMA PSYCHIATRY* | Online – 10 February 2016 – ‘**Euthanasia and assisted suicide of patients with psychiatric disorders in The Netherlands 2011 to 2014.**’ Euthanasia or assisted suicide (EAS) of psychiatric patients is increasing in some jurisdictions such as Belgium and The Netherlands. However, little is known about the practice, and it remains controversial. Persons receiving EAS for psychiatric disorders in The Netherlands are mostly women and of diverse ages, with complex and chronic psychiatric, medical, and psychosocial histories. The granting of their EAS requests appears to involve considerable physician judgment, usually involving multiple physicians who do not always agree (sometimes without independent psychiatric input), but the euthanasia review committees generally defer to the judgments of the physicians performing the EAS. <http://goo.gl/n7Uo1f>

Cont.

- **MORTALITY** | Online – 8 February 2016 – ‘**Given that physician-assisted dying is ethical, should it be part of a doctor’s role?**’ Much has been written about the ethical issues involved in euthanasia, assisted suicide and other forms of assisted dying. Such discussions have often raised legitimate concerns and challenges to those arguing the case for some form of assisted dying to be legalised. A further concern, though, which relates only tangentially if at all to the ethical issues, is whether or not this is an acceptable part of a doctor’s role. The present paper outlines some of the concerns that have been raised regarding such a change or extension of role, and considers them from historical, societal, empirical and professional perspectives. It is concluded that there is no strong argument, in principle, which precludes assistance in dying from being part of a doctor’s role. <http://goo.gl/S6Vjfr>
- **NEDERLANDS TIJDSCHRIFT VOOR GENEESKUNDE** | Online – Accessed 8 February 2016 – ‘**The End-of-life Clinic: Results from the first year.**’ In 2012, the Dutch Dying with Dignity Society founded The End-of-life Clinic, which provides euthanasia or help with assisted suicide at the request of people whose own doctor will not carry out euthanasia, if the legal requirements of due care can be fulfilled. The authors looked at the applications received by The End-of-life Clinic during its first year and at the outcomes of these applications. They wrote an extensive article on this subject, which was published in *JAMA Internal Medicine*.<sup>1</sup> One of the most important outcomes is that The End-of-life Clinic rejected a large percentage of the requests for its services, mainly as these came from people with psychiatric conditions. This means that the fears that some people have concerning the alleged End-of-life Clinic policy “you ask, we comply,” appear to be unfounded. <http://goo.gl/O3Ph3K>
  1. ‘A study of the first year of the end-of-life clinic for physician-assisted dying in The Netherlands,’ *JAMA Internal Medicine*, 2015;175(10):1633-1640. <http://goo.gl/JpTv5q>

**N.B.** Dutch language article.
- **PROCEDIA: SOCIAL & BEHAVIORAL SCIENCES**, 2016;217:657-668. ‘**Euthanasia and the needs of the terminally ill: Merits and risks of voluntary workers in hospices.**’ Clinical cases show on condition the patients are provided good care, i.e., their biological, psychological, social as well as spiritual needs are saturated, they do not tend to think about euthanasia as an option. On condition the communication is satisfactory, they do not tend to think about euthanasia as an option. <http://goo.gl/8U0iqN>

### [Media Watch: Online](#)

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/zluyY9>

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

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

PALLIMED: <http://goo.gl/7mrgMQ> [Scroll down to ‘Aggregators’ and Barry Ashpole and Media Watch]

#### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

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

#### **Canada**

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <http://goo.gl/AhlqvD>

#### **Europe**

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

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1I9K>

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

## Worth Repeating

### **Last offices neglected in over half of hospital deaths**

*NURSING TIMES* | Online – 11 May 2010 – A dearth of training and guidance means nurses are failing to follow “last offices,” the simple procedures for treating dead patients with dignity and respect, a *Nursing Times* investigation has found. In more than half of hospital deaths, nurses neglect to follow procedures such as straightening patients’ limbs or closing their eyes and mouth before rigour mortis sets in [see insert below]. Such failures can mean patients have tubes and lines wrongly removed or are left with loose dressings, resulting in fluid leaks which can be distressing for relatives. [Noted in Media Watch, 17 May 2010, #149 (p.9)] <http://goo.gl/ewKOtB>

#### **Related**

- *ONCOLOGY NURSE ADVISOR* | Online – 25 April 2015 – **“Bathing & Honoring” nursing intervention benefits families after patients die in acute care setting.** “Bathing & Honoring” a patient who has died provides a final positive experience for family members and allows them to begin the grieving process.<sup>1</sup> [Noted in Media Watch, 4 May 2015, #408 (p.12)] <http://goo.gl/3H6EDK>
  1. ‘Beyond the Final Breath: Nursing Care at the Time of Death,’ Royal College of General Practitioners, April 2015. <http://goo.gl/xLkn5n>
- NATIONAL END-OF-LIFE CARE PROGRAMME & NATIONAL NURSE CONSULTANT GROUP (U.K.) | Online – 22 April 2015 – **‘Updated guidance for professionals who provide care after death.’** The physical care given by nurses following death in hospitals has traditionally been referred to as “last offices.” However, the authors refer to “care after death,” a term more befitting of a multi-cultural society. [Noted in Media Watch, 27 April 2015, #407 (p.7)] <http://goo.gl/P6uO6N>

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

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### 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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