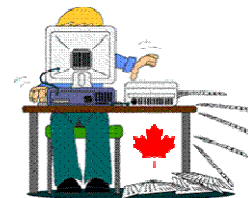


## Media Watch...

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 2008-2016 ©

Compiled & Annotated by Barry R. Ashpole

**Illness experience: Scroll down to [Specialist Publications](#) and 'Engaging terminally ill patients in end-of-life talk: How experienced medicine doctors navigate the dilemma of promoting discussions about dying' (p.15), in *Plos One*.**

## Canada

### Ontario unveils proposal for community and home care overhaul

ONTARIO | *The Globe & Mail* – 2 June 2016 – The Ontario government unveiled legislation ... that would overhaul how community and home care is delivered in the province. Under the new legislation, tabled by Health Minister Eric Hoskins, the existing Community Care Access Centre (CCAC) model would be dismantled and the role of Local Health Integrated Networks (LHINs) would be greatly expanded to include oversight of home and community care. The proposed changes are designed to make it easier for patients to access the health-care system, regardless of where they live. According to the Ontario Ministry of Health and Long-Term Care, this would be accomplished by establishing a formal link between local health units and LHINs, establishing a single phone number for residents to call when they need to find a new care pro-

vider closer to home and making transitions between the hospital, community care, mental health services and other services easier. Under the current system, CCACs oversee home and community care. Many health experts have criticized the CCAC model for years, saying they deliver varying levels of care across the province and add an unnecessary layer of bureaucracy. <http://goo.gl/eWhIHE>

### Specialist Publications

**'The CaregiverVoice Survey: A pilot study surveying bereaved caregivers to measure the caregiver and patient experience at end of life'** (p.9), in *Journal of Palliative Medicine*.

### Related

- ONTARIO | CBC News (Thunder Bay) – 2 June 2016 – **'Hospice Northwest concerned over health care changes.'** The Northwest Local Health Integration Network is changing how health care is delivered in the region, so that hospitals will now decide on how care will be delivered by other agencies. Not all groups are pleased with the changes, including Hospice Northwest, which uses 250 volunteers to provide end-of-life services to over 370 clients... Joan Williams, the Executive Director of Hospice Northwest, is worried her primarily volunteer based organization, may not fit well with the hospital. <http://goo.gl/EGLa0y>

Cont.

Noted in Media Watch, 21 December 2015, #441 (p.1):

- ONTARIO | *The Globe & Mail* – 17 December 2015 – ‘Ontario moves to scrap troubled health agencies, reorganize primary care.’ Ontario is moving to scrap the troubled agencies responsible for home care and is proposing changes to the way primary care is organized to make it easier for people to find family doctors and get an appointment when they are sick. The move, made public ... in a discussion paper,<sup>1</sup> comes as the Liberal government faces mounting pressure to make changes to home care following a string of scathing reports. <http://goo.gl/4xWhXc>

1. ‘Patients First: A Proposal to Strengthen Patient-Centred Health Care in Ontario: Discussion Paper,’ Ministry of Health & Long Term Care, Ontario Provincial Government, 17 December 2015, <http://goo.gl/XVoGO3>

**N.B.** Listed in Media Watch of 11 April 2016, #457 (p.1) are links to *The Globe & Mail* series on Ontario’s home care system.

### Connecting patients with home care and community services among biggest challenges for Ontario family doctors

ONTARIO | Health Quality Ontario – 1 June 2016 – Less than a third (29%) of family doctors in Ontario say they, or staff, in their practice routinely communicate with their patients’ community case manager or home care provider. This is just one of the findings of a new report on coordinated care by Health Quality Ontario, the provincial advisor on the quality of health care.<sup>1</sup> According to the report ... Ontario has one of the lowest reported percentages of family doctors communicating with home care and community services when compared to family doctors in other parts of Canada as well as those in Australia, France, Germany, The Netherlands, New Zealand, Norway, Sweden, Switzerland, the U.K., and the U.S. The new report ... shows that family doctors are experiencing systemic barriers when coordinating care for their patients in home and community services, which affects the experiences of patients and caregivers. The report also shows positive results in coordinating care with hospitals and specialists. Increasingly, often due to chronic conditions, people need multiple types of care in more than one setting –

an office setting, rehabilitation center, emergency department, hospital ward, outpatient hospital clinic, their own home, or other. Poor care coordination can contribute to hospital admissions that could have been prevented, unnecessary emergency department visits, medical errors, repeated tests and poor health outcomes for the patient. <http://goo.gl/4Uo5qU>

#### Extract from Health Quality Ontario report

##### Dr. Pham: Dedicated case manager on the team

The practice of Dr. Thuy-Nga (Tia) Pham, a family doctor in east Toronto, sets a high bar for coordination with home care compared to the average experience in primary care in Ontario, especially for patients who wish to die at home. That’s because Dr. Pham’s team includes a dedicated community and home care case manager who is involved in developing and implementing treatment plans for their most gravely ill patients.

1. ‘Connecting the Dots for Patients,’ Health Quality Ontario, June 2016. <http://goo.gl/kE0lh6>

### Media Watch: Back Issues – <http://goo.gl/frPgZ5>

The screenshot shows the website for IPCRC.NET, the International Palliative Care Resource Center. The page features a navigation menu with links for Home, About IPCRC, CMA, NCI, Partners, Contact, and Acknowledgements. Below the menu, there is a section for 'GLOBAL PALLIATIVE CARE NEWS ARCHIVE' and a sub-section for 'MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE'. A 'Media Watch Archives' sidebar lists back issues from 2014 to 2011. The main content area displays a featured article titled 'MW 452: Dying better, even if it means sooner' with a download link for the complete issue (PDF 275 KB). A small text box at the bottom of the article provides context about a report on U.S. Medicare and Medicaid expenditures.

## How mental illness complicates medically assisted dying

*THE GLOBE & MAIL* | Online OpEd – 30 May 2016 – Do no harm. How do we square this guiding tenet with medically assisted death? Which is the greater harm – helping a person to end his life, or allowing continued suffering when he seeks death? When it comes to mental illness, it is even more complicated. The 2015 Supreme Court decision emphasized the need to protect the vulnerable from seeking suicide at a time of weakness. Less clear is how we actually do that. Mental illness can affect how a person thinks. Depression fuels negative self-thoughts, self-blame, hopelessness and struggling with one's place in the world. Negative events are dwelt upon and positive ones discounted, with emotional resilience lowered until mundane stresses seem overwhelming. This is not to deny the real pain and suffering of mental illness, nor to imply that it invariably compromises clarity of thought. However, in severe cases, teasing apart how illness-based cognitive distortions can influence decision making is a formidable challenge. <http://goo.gl/rHvjYH>

### Extract from *The Globe & Mail* OpEd

The Canadian Psychiatric Association has cautioned that there is no established standard of care in Canada for defining when typical psychiatric conditions are irremediable. We are not alone in struggling with this. I have spoken with leaders of psychiatric associations from Australia, New Zealand, the U.K. and the U.S., and none is any further ahead at defining this. This lack of standards is troubling for medically assisted dying assessments based on irremediability.

### [Specialist Publications](#)

'Addressing existential suffering' (p.9), in *British Columbia Medical Journal*.

Noted in Media Watch, 22 September 2015, #428 (p.3, under 'From the Archives'):

- *THE HASTINGS REPORT*, 1998;28(4):24-31. '**Should psychiatrists serve as gatekeepers for physician-assisted suicide?**' Mandating psychiatric evaluation for patients who request physician-assisted suicide may not offer the clear cut protection from possible coercion or other abuse that proponents assert. Competence itself is a complex concept and determinations of decision making capacity are not straightforward, nor is the relationship between mental illness and decision making capacity in dying patients clearly understood. And casting psychiatrists as gatekeepers in end-of-life decisions poses risks to the profession itself. [Noted in Media Watch, 22 September 2015, #428 (p.3, under 'From the Archives.')] <http://goo.gl/Fe2xuu>

## Doctors urge improvement in end-of-life care

RADIO CANADA INTERNATIONAL | Online – 30 May 2016 – Palliative care (PC) doctors are urging the Canadian government to improve and standardize end-of-life care across the country. A big bulge of the population is getting old and as they do so medical problems increase. The Canadian Society of Palliative Care Physicians says the medical system is poorly equipped to handle the increasing demand. There is a lack of PC service and it is unevenly distributed, says Dr. David Henderson, president of the society. "Right now it tends to be quite broken up across the country, meaning there are great people out there doing great work in pockets across the country but there's been no national or provincial oversight to really build a system that is stan-

ardized and that can extend across the country." In Canada, the central government provides guidelines on health services and funding, but the provinces and territories manage them. PC doctors would like to see one body set up to decide what are best practices in PC, how to mobilize them and set standards, and to collect data. <http://goo.gl/GKnk5z>

### [Specialist Publications](#)

'Palliative care: Therapy for the living' (p.9), in *British Columbia Medical Journal*.

**N.B.** Canadian Society of Palliative Care Physicians website: <http://goo.gl/bHD659>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC NEWS | Online – 1 June 2016 – **‘Liberals may accept Senate amendment to pass assisted dying bill.’** Health Minister Jane Philpott hinted ... that her government may be willing to accept a compromise Senate amendment to its assisted dying bill that would help C-14 pass in the Red Chamber. She said including an amendment that commits Parliament to studying the possible expansion of eligibility beyond patients suffering a terminal illness, within 180 days of the bill’s passing, may be in the cards. <http://goo.gl/N9YDtH>
- THE TORONTO STAR | Online – 31 May 2016 – **‘MPs vote 186-137 to send assisted-dying bill to the Senate.’** Among those who opposed Bill C-14 were four Liberals. There were 14 opposition MPs who voted to support the government’s bill. <https://goo.gl/NPTtZB>
- ONTARIO | *The Globe & Mail* – 30 May 2016 – **‘Ontario court ruling challenges federal assisted-dying bill.’** A new court ruling on assisted death is raising questions about whether the Liberal government’s proposed law is constitutional, as the House of Commons prepares to vote on a historic bill to legalize the practice. An Ontario court, while not ruling directly on the bill, echoed a decision by the Alberta Court of Appeal earlier this month, when it said that the Supreme Court’s minimum standard for the right to an assisted death is the loss of quality of life, not whether natural death is “reasonably foreseeable,” as stated in the Liberal bill. <http://goo.gl/HfGZTH>
  - ALBERTA | The Canadian Press – 18 May 2016 – **‘Federal rationale for restricting assisted dying shot down by Alberta appeal court.’** The federal government’s rationale for a restrictive approach to medically assisted dying has been shot down in flames by the Alberta Court of Appeal, even before its controversial legislation is put to a vote in the House of Commons. <http://goo.gl/RS9V53>

## U.S.A.

### Family caregivers become more crucial as elderly population grows

THE WALL STREET JOURNAL | Online – 3 June 2016 – Strain on family caregivers is alarming many lawmakers and social-service providers... They are pushing for new ways to assist the vast unpaid workforce of people who are crucial in part because they allow more seniors to age in place and reduce reliance on public subsidies such as Medicaid, a major funder of institutional health care for older Americans. About 40 million U.S. family caregivers provided unpaid care, valued at \$470 billion, to an adult with limitations in daily activities in 2013... In Maine, the state with the oldest median age in the U.S. – 44.2 years – the pressure on families is palpable. The percentage of the state’s population that is 65 and over is climbing and tops 18%, compared with nearly 15% for the U.S. as a whole, according to the most recent census data. The massive baby boom generation is barreling into old age with a smaller generation behind it, meaning a shrinking number of family caregivers will have to do more to help older people who require some support to remain at home. <http://goo.gl/sLSflb>

### Iowa’s largest hospice a victim of nationwide trend

IOWA | WHO TV News (Des Moines) – 1 June 2016 – The Bright Kavanagh House is the state’s largest inpatient hospice facility, and it can hold up to 24 patients. But it hasn’t been that full in years. Three weeks ago, only two patients were living there. That’s when officials chose to consolidate with another facility. Wade said the shrinking numbers are part of a growing trend. “Right now, we’re serving more people in their homes a lot more frequently,” he said. It’s also a nationwide trend. In 2013, patients were twice as more likely to choose in home hospice care over inpatient or hospitalized hospice care, a slight increase from 2012. <http://goo.gl/CE7qww>

Cont.

**Related**

- PENNSYLVANIA | *The Times-Tribune* (Scranton) – 1 June 2016 – ‘**Inpatient hospice centers decline for more end-of-life care at home.**’ Only one inpatient hospice center remains in Lackawanna County after two closed in the last year. While more people across the country seek hospice care every year, closures reflect a trend that more people would rather die at home. <http://goo.gl/G9Kp71>

**CancerCare Patient Access & Engagement Report**

**New cancer study provides a sobering look at problems in end-of-life care**

GEORGIA | *The Augusta Chronicle* – 28 May 2016 – A new survey of 3,000 people who have been diagnosed with cancer ... reveals serious communication problems between health care providers and cancer patients that compromise their end-of-life care.<sup>1</sup> It is the first study of its kind to tackle this issue across a diverse population in terms of ethnicity, income, education, geography, age, insurance, cancer type and treatment stage. The communications problems the report identified include: 1) Less than half of respondents said their care team knew their end-of-life wishes; 2) About a third or less of the respondents said they felt adequately informed about other treatment options their care team considered, the responsibilities of their caregivers and clinical trial opportunities; and, 3) Between 22 and 37% of respondents said that additional information about palliative care, living wills or hospice care would have been helpful to them. <http://goo.gl/3h9HQV>

**Specialist Publications**

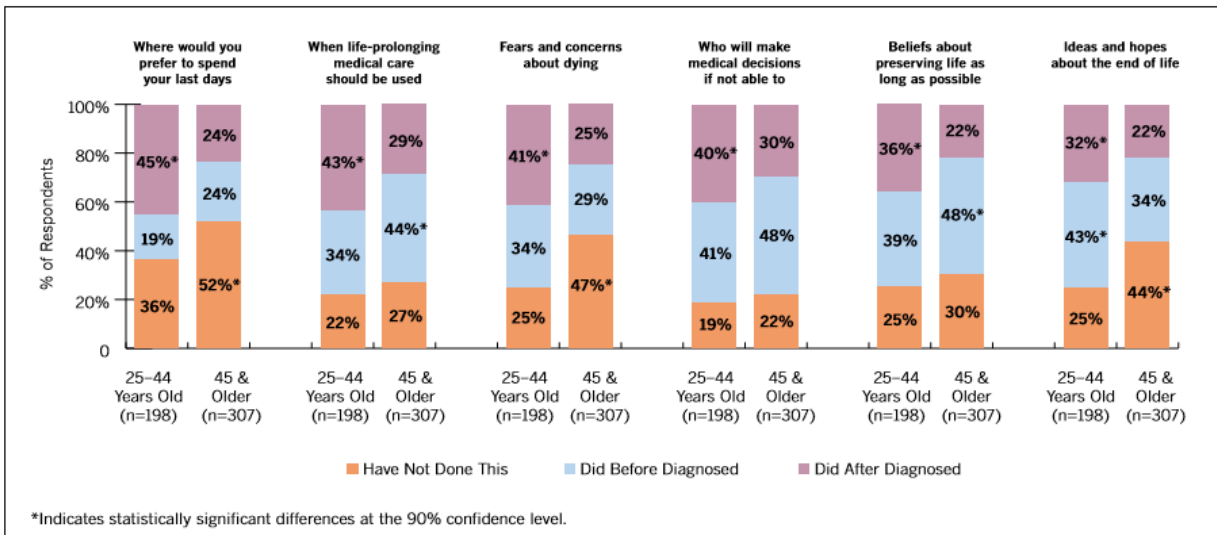
‘**Public opinion regarding financial incentives to engage in advance care planning and complete advance directives**’ (p.13), in *American Journal of Hospice & Palliative Medicine*.

‘**Better palliative care for all: Improving the lived experience with cancer**’ (p.12), in *Journal of the American Medical Association*.

‘**Impact of inpatient palliative care on treatment intensity for patients with serious illness**’ (p.13), in *Journal of Palliative Medicine*.

‘**The spectrum of caregiving in palliative care for serious, advanced, rare diseases: Key issues and research directions**’ (p.13), in *Journal of Palliative Medicine*.

**Figure 4: Discussion Topics With Family Since Being Diagnosed With Cancer**



1. ‘2016 CancerCare Patient Access & Engagement Report,’ CancerCare, New York, NY. [Noted in Media Watch, 16 May 2016, #462 (p.13)] <http://goo.gl/Krs61L>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | *The Washington Post* – 3 June 2016 – ‘**California doctors uneasy about prescribing lethal drugs.**’ Many in California’s medical community are grappling with the law that goes into effect 9 June. Some physicians have told their patients they are not willing to play a role in intentionally ending a person’s life. Catholic hospitals will not provide the prescriptions because it goes against the church’s stance on the issue, according to Alliance of Catholic Health Care, representing 48 facilities, 27 of which provide hospice services. The organization, though, cannot bar its affiliated physicians from talking about it, or referring patients to medical offices willing to prescribe such drugs. How it plays out in trend-setting California, the country’s most populous state, could determine whether the practice spreads nationwide. <https://goo.gl/dXduiY>

## International

### Home care in Ireland

#### **Government “not providing proper support” for people who want to age at home**

IRELAND | BreakNews.ie (Blackpool, Cork) – 3 June 2016 – The Government has been accused of only paying lip-service to their promise to help the elderly stay in their own homes, as they age. A new report claims half of all nursing home residents could still be living at home, if they were given the right support.<sup>1</sup> The research by social workers, Age Action and the Alzheimer Society claims the home care system here is disorganised, fragmented and underfunded. It shows that acute hospitals and nursing homes are being prioritised over community care, at around three times the cost. The most commonly quoted supports to allow them to stay at home were night-time care and intensive home care packages, according to social workers who were surveyed for the report. <http://goo.gl/KE0ZKb>

1. ‘Meeting Older People’s Preference for Care: Policy, but what about practice?’ Irish Association of Social Workers, Age Action, the Alzheimer Society of Ireland, and the School of Social Policy, Social Work & Social Justice, University College Dublin, 2016. <https://goo.gl/BwnVaa>

### Elder care in the U.K.

#### **Two years ago we called for reform in care homes. We’re still waiting**

U.K. | *The Guardian* – 31 May 2016 – Last year, Jeremy Hunt told a local government audience that families should take more responsibility for the care of their loved ones. It was a statement that offended many and a recent Carers UK report makes plain why: the price paid, physically, psychologically and financially, is huge.<sup>1</sup> There are many of course who don’t have a family – findings from the Beth Johnson Foundation ... highlighted that as many as one in five people aged 50 and over have not had children.<sup>2</sup> The question must then turn to formal care services. Will there be enough good quality care to support those without families in their old age? Will it meet their needs and lifestyles? There is undoubtedly a growing fear in the care home sector that a major provider will collapse. Certainly the news has been bleak... According to re-

search by Opus Business Services for BBC Radio Fours ‘You and Yours’ programme, one in four care homes – that’s around 5,600 – could go bust within three years.<sup>3</sup> Earlier this month, care home leaders lobbied the Department of Health about the continued squeeze on fees and warned that the national living wage would lead to many care businesses struggling with cash flow and facing bankruptcy.<sup>4</sup> <http://goo.gl/iyOqfO>

#### **Specialist Publications**

‘Improving end-of-life care in care homes: An evaluation of the six steps to success programme’ (p.11), in *BMC Palliative Care*.

Cont.

1. 'State of Caring 2016,' Carers UK, May 2016. [Noted in Media Watch, 16 May 2016, #462 (p.6)] <http://goo.gl/yx1e4V>
2. 'Ageing Without Children,' Beth Johnson Foundation, May 2016. <https://goo.gl/WMXWwg>
3. 'Quarter of U.K. care homes "at risk of closure,"' BBC News, 4 May 2016. [Noted in Media Watch, 9 May 2016, #461 (p.5)] <http://goo.gl/rKWV9Y>.
4. 'Cataclysmic or positive? The impact of the national living wage on social care,' *The Guardian*, 12 April 2016. <http://goo.gl/Bmm3EB>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Economist* – 30 May 2016 – '**The British Medical Association prepares to revisit its opposition to assisted dying.**' A survey for *The Economist* last year showed seven in ten Britons thought doctors should be allowed to help patients end their lives, subject to safeguards.<sup>1</sup> So what is a doctor to do? The stance of the British Medical Association (BMA) is clear: doctor-assisted dying should not be made legal. But the organisation's policy was drawn up a decade ago, and the wider discussion has moved on since then. Two assisted-dying bills were brought before parliament last year alone, though neither was successful. The topic has been debated at seven of the BMA's 13 annual meetings since 2003. So the medical union has set about investigating doctor-assisted dying in the broader context of end-of-life care. The first two instalments of its findings were released in January, and a final report last month.<sup>2</sup> <http://goo.gl/2n16EM>
  1. 'Attitudes towards assisted dying,' *The Economist*, 27 June 2015. <http://goo.gl/BHXjJy>
  2. 'End-of-Life Care and Physician-Assisted Dying,' British Medical Association, January 2016. [Vol. 1: Setting the scene & Vol. 2: Public dialogue research noted in Media Watch, 18 January 2016, #445 (p.4); Vol. 3: Reflections and recommendations noted in the weekly report of 25 April 2016, #459 (p.9)] <http://goo.gl/N4Cldm>

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

#### When is depression a terminal illness? Deliberative suicide in chronic mental illness

*AMA JOURNAL OF ETHICS* (American Medical Association), 2016;18(6):594-600. This commentary explores the utility of hope as a therapeutic tool for intervention in the case of a patient with a mental illness that is refractory to treatment over time, who expresses her intention to commit suicide. It begins with a short discussion differentiating a deliberative consideration of suicide from an impulsive act. Then the commentary defines hope, how it might be used as a therapeutic tool, and which limitations a clinician might confront in such a case. It also considers the role of a physician in orientation not only to the patient but also to her own thoughts, feelings, and emotions regarding a patient's expressed desire to end her life. <http://goo.gl/QfEI7N>

#### Selected articles on suicide-related competences in end-of-life care

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 23 May 2016 – '**Hospice and palliative social workers' experiences with clients at risk of suicide.**' The study results suggest that suicide-related competencies are important in the practice of hospice and palliative social work. [Noted in Media Watch, 30 May 2016, #464 (pp.13)] <http://goo.gl/cqO19m>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 April 2016 – '**A survey of home hospice staff knowledge of suicide risk factors, evaluation, and management.**' Access requires a subscription. Alternatively, a college or university library may be able to gain access depending on the terms of its licensing agreement. [Noted in Media Watch, 30 May 2016, #464 (p.14)] <http://goo.gl/QUQ8fv>

Cont.

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2014;10(1):95-105. ‘**Suicide prevention training program for gatekeepers working in community hospice settings.**’ This study evaluated a promising, evidence-based suicide prevention program. Satisfaction and need for additional time for suicide prevention training were highly rated by study participants. [Noted in Media Watch, 24 March 2014, #350 (p.13)] <http://goo.gl/xmLqx0>

### **The American Medical Association Code of Medical Ethics’ opinions on patient decision-making capacity and competence and surrogate decision making**

*AMA JOURNAL OF ETHICS* (American Medical Association), 2016;18(6):600-603. Although the Code of Medical Ethics does not have much to say about mental health *per se*, the Code does consider patient decision-making capacity, mental competence, and surrogate decision making for those who are unable – over the short-term or the long-term – to make their own health care decisions. These concepts are discussed in opinions 2.20, ‘Withholding or Withdrawing Life-Sustaining Medical Treatment,’ 8.08, ‘Informed Consent,’ and 8.081, ‘Surrogate Decision Making,’<sup>1-3</sup> <http://goo.gl/SZlwmp>

1. Opinion 2.20 <http://goo.gl/AzVW0K>
2. Opinion 8.08 <http://goo.gl/rTXVND>
3. Opinion 8.081 <http://goo.gl/1jHPOv>

### **Paediatric palliative care in the U.K.**

#### **Palliative care services for children and young people: Realist review of the literature**

*ARCHIVES OF DISEASE IN CHILDHOOD*, 2016;101(Suppl):A305-A306. The delivery of palliative care (PC) services for children and young people (CYP) in the U.K. is inconsistent, despite the development of guidance, recommendations and service standards. Twenty articles were identified for inclusion. Four major themes were identified: 1) CYP wish to be involved in decisions about their care when possible; 2) Families value both practical and emotional support for siblings and wish for support that continues into bereavement; 3) Continuity of care allows families to have open and honest conversations with health-care professionals who they know; 4) There is opportunity for more effective integration and effective communication between professionals. This review provides an in-depth insight into how and why services are seen as effective by CYP and their families. <http://goo.gl/W6g29j>

### **End-of-life care in Germany**

#### **Caring for frail older people in the last phase of life – the general practitioners’ view**

*BMC PALLIATIVE CARE* | Online – 2 June 2016 – General practitioners (GPs) show a strong commitment to caring for frail older patients until the end of life. This is a challenging and complex task that can take family doctors to the limits of their capacity, but GPs have developed certain strategies to manage these challenges individually in their practice routines. On the healthcare level, there is a significant need for improvement regarding communication and the flow of information between GPs and their various health partners, such as outpatient care, specialist doctors, hospitals and nursing homes. The delegation of activities to specifically qualified physician assistants is already partially underway, but is still underdeveloped in Germany. Strengthening the team approach in primary care could help to relieve the burden on GPs, particularly in rural areas, while simultaneously helping to improve the care for frail older patients. <http://goo.gl/W8rsDB>

### **Selected articles on frailty and end-of-life care**

- *FRAILTY IN AGING: BIOLOGICAL, CLINICAL & SOCIAL IMPLICATIONS*, 2015;41:151-160. ‘**End-of-life care in frailty.**’ The authors review the history of palliative care (PC) and the elements of frailty that require the modification of current models of PC. [Noted in Media Watch, 3 August 2015, #421 (p.8)] <http://goo.gl/zNXY1B>

Cont.



- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS*, 2013;14(6):392-397. '**Frailty consensus: A call to action.**' A consensus group consisting of delegates from six major international, European and U.S. societies created four major consensus points on a specific form of frailty. [Noted in Media Watch, 24 June 2013, #311 (p.11)] <http://goo.gl/JmWQQp>
- *JOURNAL OF NURSING EDUCATION & PRACTICE*, 2013;3(7):75-91. '**When frailty should mean palliative care.**' The aim of this work is to assist physicians in providing proper care for the frail elderly. [Noted in Media Watch, 21 January 2013, #289 (p.8)] <http://goo.gl/55Gj9e>

### End-of-life care in Canada

#### **Palliative care: Therapy for the living**

*BRITISH COLUMBIA MEDICAL JOURNAL*, 2016;58(5):256-261. Studies have confirmed that suffering can be relieved and patients can live well until they die when palliative care (PC) is introduced early and integrated into the management of serious illness. PC arose as a movement from outside academic medicine in the middle of last century as a response to "bad dying." Today, PC improves quality of life, patient and family satisfaction, length of hospital stay, and health care costs near the end of life. Newer studies have demonstrated a survival advantage when PC is introduced early in the illness trajectory. In British Columbia, physicians wishing to acquire more PC knowledge and skills can use practice supports provided by the General Practice Services Committee, including a useful algorithm and other clinical tools.<sup>1</sup> <http://goo.gl/dgrtsa>

1. 'End-of-Life module helps family doctors discuss planning for death with patients,' General Practice Services Committee (A partnership of the Government of BC and Doctors of BC). <http://goo.gl/20KVr4>

#### **Related**

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 June 2016 – '**The CaregiverVoice Survey: A pilot study surveying bereaved caregivers to measure the caregiver and patient experience at end of life.**' Most patients [i.e., study participants] received care from multiple settings in the last three months of life, including 60% for which a hospital stay was reported. This pilot study provides preliminary evidence that it is feasible to capture the patient and caregiver experience at end of life using a comprehensive survey... The majority of responses rated care as excellent or very good, although several specific areas for improvement were identified. <http://goo.gl/dzFXBD>

#### **Addressing existential suffering**

*BRITISH COLUMBIA MEDICAL JOURNAL*, 2016;58(5):268-273. Existential distress is often present in terminal illness and may be associated with syndromes such as depression, anxiety, and desire for hastened death. Physicians with expertise in managing physical pain may feel unequipped to address social, psychological, and spiritual aspects of pain. Through a brief exploration of the foundations of existentialism and existential psychotherapy, this article aims to demystify existentialism and provide practical tips for addressing existential suffering, even in parents and children with terminal illness. Formalized interventions that assist patients with existential issues are recommended. Physicians are encouraged to get support in exploring domains that they may feel are outside their scope of practice, such as spirituality, and encouraged to adjust boundaries in the doctor-patient relationship in palliative care settings. With the aid of a physician who addresses existential suffering, it is possible for patients to transition from feeling hopeless to feeling more alive than ever. <http://goo.gl/NrmH2e>

#### **Related**

- *INTERNATIONAL ARCHIVES OF MEDICINE*, 2016;9(87):1-12. '**Family relations and spiritual response to palliative care: A review of literature.**' The authors concludes that it is necessary to include the family into the routine of end-of-life care; studies show that the holistic view of the patients involves their family wellbeing. They must have spiritual guidance, psychological and social help, and also a good and open communication with the health professionals. <http://goo.gl/Xks7bv>

**N.B.** To access full text click on PDF icon.

## Palliative cancer care in Brazil: The perspective of nurses and physicians

*CANCER NURSING* | Online – 11 May 2016 – In Brazil, a growing number of people with cancer require palliative care (PC), emphasizing the need for investment in this aspect of health to increase the quality of life of patients during the dying process. As a developing country, Brazil lacks knowledge regarding the themes, material and financial resources, and policies of PC. The perspectives of the participants were characterized by three themes regarding the initial phase of development of palliative cancer care in Brazil: 1) Controversies about when palliative cancer care should be initiated; 2) The World Health Organization recommendations and current practices; and, 3) The need to invest in palliative cancer care education in Brazil. Knowledge about these challenges to PC could contribute to the development of strategies, such as the establishment of service organizations and networks, as well as educational and political investments for the advancement of PC. <http://goo.gl/Hq0141>

### Related

- *BMC PALLIATIVE CARE* | Online – 1 June 2016 – ‘**Identification and characteristics of patients with palliative care needs in Brazilian primary care.**’ Despite the available health care support and some limited initiatives in palliative care (PC) development, improvements in the access to PC services to patients with life-limiting conditions and their families are required in the Brazilian health care system. Specific public health policies should stimulate the PC development and define its role in NCD care; professional training structure need to be expanded; and social awareness and community engagement with PC issues must be debated. <http://goo.gl/Ezzpfl>

**N.B.** Listed in Media Watch of 21 March 2016, #454 (p.9) are selected articles on end-of-life care in Brazil are noted. Brazil was ranked 42nd of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit. [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/JsSbW3>

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

#### **Ambitions for palliative and end-of-life care**

*CLINICAL MEDICINE* (Royal College of Physicians), 2016;16(3):213-214. The publication of the ‘Ambitions for Palliative and End-of-Life care: A national framework for local action 2015–2020’ in September 2015 represents a new milestone in England for all who want to ensure that everyone with advanced, progressive, life-limiting illness has the best possible experience of care throughout their remaining life, and in death.<sup>1</sup> This comes less than 30 years after palliative medicine was formally recognised as a specialty within the Royal College of Physicians and less than 10 after the term “end-of-life care” was formally defined as “last year of life” in the first national End-of-Life-Care Strategy in 2008.<sup>2</sup> In practice, although the definition of “end-of-life care” is time-based and “palliative care” (PC) is needs-based, the approach is similar. Like respiratory, cardiac, renal and most other specialties, PC has both generalist and specialist components, so all doctors need to be able to deliver this kind of care well, involving palliative medicine specialists when they reach the limits of their competence and confidence. This issue of *Clinical Medicine* carries a piece on the National Institute for Health & Care Excellence clinical guideline for care of the dying adult.<sup>3</sup> <http://goo.gl/evm1h4>

1. ‘Ambitions for Palliative and End-of-Life Care: A national framework for local action 2015-2020,’ National Palliative & End-of-Life Care Partnership, September 2015. [Noted in Media Watch, 14 September 2015, #427 (p.14)] <http://goo.gl/1cXKFe>
2. ‘End of Life Strategy: First Annual Report,’ Department of Health, July 2009. <http://goo.gl/5ISIKT>
3. ‘Care of dying adults in the last days of life,’ *Clinical Medicine* (Royal College of Physicians), 2016; 16(3):254-258. <http://goo.gl/3Wwipw>

Cont.

## Related

- *BMC PALLIATIVE CARE* | Online – 3 June 2016 – ‘**Improving end-of-life care in care homes: An evaluation of the six steps to success programme.**’ This evaluation of the North West of England’s Six Steps End of Life programme suggests that this flexible and adaptable model of training for care home staff, is starting to improve end-of-life care (EoLC) in care homes. The qualitative data, has suggested an overall positive impact from the programme. Care home staff reported it had increased their personal confidence in having EoLC conversations, this will undoubtedly go some way to help residents in their care to experience a “good death.” <http://goo.gl/911c6r>
- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 3 June 2016 – ‘**Loss, transition and trust: Perspectives of terminally ill patients and their oncologists when transferring care from the hospital into the community at the end of life.**’ Transfer of care from the acute sector to the community represents a delicate crossroad where complex notions of loss should not be underestimated. A gradual transfer of care may improve this if the patient’s condition allows. Therefore, introductions to the community team should be timely, and a staggered transfer should be planned. This would improve the experience of the patient, carer and oncologist. <http://goo.gl/bKGUpq>

## Legal aspects of end-of-life care in Australia

### **Knowledge of the law about withholding or withdrawing life-sustaining treatment by intensivists and other specialists**

*CRITICAL CARE & RESUSCITATION*, 2016;18(2):115. Decisions about withholding or withdrawing life-sustaining treatment (WWLST) from adults who lack capacity are an integral part of intensive care (IC) practice. The authors compare the knowledge, attitudes and practice of intensivists in relation to the law about WWLST with six other specialties most often involved in end-of-life care. Intensivists performed better than average in legal knowledge but important knowledge gaps remain. Intensivists had a more negative attitude to the role of law in this area than other specialty groups, but reported being seen as a leading source of information about legal issues by other medical specialists and nurses. Intensivists also reported being the specialists most frequently making decisions about end-of-life treatment. Improved legal knowledge and open engagement with the law can help manage the risk of harm to patients and protect intensivists from liability. <http://goo.gl/qw22hG>

### **Selected articles on legal aspects of end-of-life care in Australia**

- *QUT LAW REVIEW* (Queensland University of Technology), 2016;16(1):54-75. ‘**Futility and the law: Knowledge, practice and attitudes of doctors in end-of-life care.**’ The findings of this study reveal that doctors have poor knowledge of their legal obligations and powers when making decisions about withholding or withdrawing futile treatment at the end of life; their attitudes towards the law were largely negative; and, the law affected their clinical practice and had or would cause them to provide futile treatment. [Noted in Media Watch, 25 April 2016, #459 (p.12)] <https://goo.gl/iifv1>
- *AUSTRALIAN HEALTH REVIEW* | Online – 16 November 2015 – ‘**Advance care planning in Australia: What does the law say?**’ Formal documentation of wishes increases the chances that a person’s wishes will be known and followed. However, one of the biggest impediments for doctors following the person’s wishes is uncertainty surrounding the law, which is complicated and varies between the states and territories of Australia. [Noted in Media Watch, 23 November 2015, #437 (p.8)] <http://goo.gl/Y1X5vl>
- *MEDICAL JOURNAL OF AUSTRALIA*, 2014;201(4):1-4. ‘**Doctors’ knowledge of the law on withholding and withdrawing life-sustaining medical treatment.**’ Among doctors who practise in the end-of-life field there are some significant knowledge gaps about the law on withholding and withdrawing life-sustaining treatment from adults who lack decision-making capacity. Significant consequences for both patients and doctors can flow from a failure to comply with the law. [Noted in Media Watch, 18 August 2014, #371 (p.6)] <https://goo.gl/FGg75b>

## End-of-life care in Scotland

### **Why do older people get less palliative care than younger people**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(3):132-137. This study highlights potential areas of inequality in end-of-life care (EOLC). In older persons generally, there are less clear early signs indicating that they need, and triggering their referral to, palliative care (PC); this is likely to be one of the reasons why they do not receive as much PC as younger people. The lack of a clear diagnosis of dying and the association of PC with cancer and imminent death also hinder older people's access to good EOLC. More efforts should be made to identify older patients who would benefit from a PC approach in all settings. This overview of age disparities in PC provision sets an important research agenda. We need to understand more fully the nature of age-related inequalities in order to build an evidence base informing the provision of good-quality, timely PC across all age groups and conditions.

**N.B.** Access to this article requires a subscription to the journal. Contents page: <http://goo.gl/XfHTo0>

### **Community gardens as sites of solace and end-of-life support: A literature review**

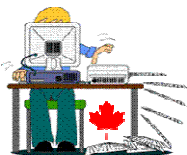
*INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 27 May 2016 – In a pilot project, members of a community garden explored how they might provide better end-of-life support for their regional community. As part of the project, a literature review was undertaken to investigate the nexus between community gardens and end-of-life experiences (including grief and bereavement) in academic research. The authors discovered there is little academic material that focuses specifically on community gardens and end-of-life experiences, but nonetheless the two subjects were seen to intersect. The authors found three points of commonality: both share a need and capacity for a) social/informal support, b) therapeutic space, and c) opportunities for solace. <http://goo.gl/eV99nl>

## Palliative care in the U.S.

### **Better palliative care for all: Improving the lived experience with cancer**

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 31 May 2016 – A growing body of evidence not only points to better quality of life and function for patients with cancer receiving concurrent cancer-directed therapies and consultative palliative care (PC) as part of their treatment, but also points to prolonged survival. This counter intuitive finding suggests that relief from the pain, symptoms, and stresses of a serious illness and the prevention of the crises that result in avoidable hospitalizations actually helps patients with cancer complete their course of treatment and live longer. Several randomized clinical trials have demonstrated significant improvements in the patient or family experience (quality of life, depression, survival) with early PC compared with usual-oncology-care alone. Additional emphasis on and attention to concurrent PC yield clinically important returns. If PC were a cancer drug, it could possibly be equivalent to a billion-dollar blockbuster. <http://goo.gl/4wrXy1>

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### **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>

#### Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 1 June 2016 – ‘**Public opinion regarding financial incentives to engage in advance care planning and complete advance directives.**’ The Centers for Medicare & Medicaid Services (CMS) recently instituted physician reimbursements for advance care planning (ACP) discussions with patients. Americans view payments for advance directives completion or ACP more skeptically than for other health behaviors and prefer that such payments go to patients rather than physicians. The current CMS policy of reimbursing physicians for ACP conversations with patients was the least preferred of the programs evaluated. <http://goo.gl/BEmPRN>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 June 2016 – ‘**Impact of inpatient palliative care on treatment intensity for patients with serious illness.**’ The authors compared 295 hospitals with PC programs to 679 hospitals without. The former were higher volume, more likely to be teaching hospitals, and have oncology services, and less likely to be located in rural areas. Hospital-based PC programs alone may not be sufficient to impact ICU length of stay or hospice length of enrollment for all chronically ill older adults admitted to hospitals. Future work should measure hospital-wide PC outcomes and effects of core palliative knowledge and skills provided by non-palliative care specialists. <http://goo.gl/fSzhqY>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 June 2016 – ‘**The spectrum of caregiving in palliative care for serious, advanced, rare diseases: Key issues and research directions.**’ In June 2015, the National Institute of Nursing Research, the lead institute at the National Institutes of Health for end-of-life research, in conjunction with the National Center for Advancing Translational Sciences, Office of Rare Diseases Research, held an interdisciplinary workshop on the unique challenges of caregiving and palliative care in adult and pediatric rare diseases. This report presents a summary of the workshop. <http://goo.gl/yXwMOr>

#### Palliative care: When and how, and what are the implications for global cancer policy?

*JOURNAL OF CANCER POLICY* | Online – 31 May 2016 – The nature of illness is changing. As a population, we are living longer and survival from disease is prolonged. This, together with a projected increase in the annual number of deaths, presents an unprecedented challenge for health care systems. While the search for a cure for cancer occupies many newspaper headlines, the fact that roughly 50% of people diagnosed with cancer will die from it is barely acknowledged. Our societal focus on cure must not come at the expense of openness about what to do when cure is no longer an option. When Aneurin Bevan founded the U.K.’s National Health Service in 1948, his vision was of a cradle to grave health service, freely available to all. However, the huge progress in maternity care in the intervening decades has not been matched by progress in palliative and end-of-life care. Investment in palliative care has the potential to transform the quality of life and death for patients, and lead to improved outcomes in bereavement for their carers, while potentially avoiding burdensome (and expensive) hospital care. As the world’s population ages, and costs of care become an important component of health care planning, policy makers must turn their attention to care of the dying. The question is no longer why, but how, effective palliative and end-of-life care is provided. <http://goo.gl/t0zbkA>

#### Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 31 May 2016 – ‘**Characteristics of the case mix, organisation and delivery in cancer palliative care: A challenge for good-quality research.**’ Thirty centres in 12 countries participated [in this study]; 24 hospitals, 4 hospices, 1 nursing home, 1 home-care service. Twenty-two centres (73%) had PC in-house teams and inpatient and outpatient services. Twenty (67%) had integral chemotherapy/radiotherapy services, and most (28/30) had access to general medical or oncology inpatient units. Physicians or nurses were present 24 hours/7 days in 50% and 60% of centres, respectively. Fifty centres (50%) had professorships, and 12 centres (40%) had full-time/part-time research staff. <http://goo.gl/FVKnlP>

## Accelerated medical education: Impact of a 48-hour hospice home immersion

*JOURNAL OF GERONTOLOGY & GERIATRIC RESEARCH* | Online – 13 May 2016 – The 48-Hour Hospice Home Immersion project is in the pilot stage with plans to expand the program so that all University of New England College of Osteopathic Medicine medical students participate in this project. Students who conducted this immersion research reported that this unique educational and research experience accelerated their learning about palliative and end-of-life care. Although being immersed in the Hospice Home [project] and experiencing death and dying first hand was at times overwhelming and intense, it allowed these students to become more comfortable with death. Being present with older adults during decision making about treatment and care while in the Hospice Home [project], often times with decisions made by the older adults, provided the students with life altering experiences and lessons that will aid their journey to becoming compassionate and competent physicians. <http://goo.gl/fn0aCO>

**N.B.** To access full text click on PDF icon.

## The development of a hospital-wide bereavement program: Ensuring bereavement care for all families of pediatric patients

*JOURNAL OF PEDIATRIC HEALTH CARE* | Online – 28 May 2016 – Although grief is a normal response to loss, the death of a child is believed to be one of the most difficult losses a person can endure, and bereaved parents are considered to be an “at-risk” group. Even though most deaths of children in the U.S. occur in hospitals, bereavement care provided by hospitals is highly variable, and little attention has been directed to how hospitals can best support grieving parents. The authors describe the development of a hospital-wide bereavement program at Boston Children’s Hospital, where they conceptualize bereavement care as a preventive model of care. The authors identify the primary constructs of the program as education, guidance, and support and outline a template for use by other hospitals. They recommend that all pediatric hospitals implement basic, coordinated bereavement programs as the standard of care to ensure that all families receive bereavement care after the death of a patient. <http://goo.gl/QP19z8>

### Selected articles on hospital bereavement programs

- *BEREAVEMENT CARE*, 2015;34(2):69-75. ‘**Qualitative evaluation of a hospital bereavement service: The perspective of grieving adults.**’ The Australian hospital bereavement service studied provides three consecutive tiers of support to palliative care patients and families including information and compassion, non-specialised bereavement support, and specialist intervention referral to external agencies. [Noted in Media Watch, 24 August 2015, #424 (p.10)] <http://goo.gl/1WaLSq>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 14 August 2015 – ‘**Adding value to palliative care services: The development of an institutional bereavement program.**’ The authors describe the development of the program at Dana-Farber Cancer Institute (Boston, Massachusetts) where they conceptualized bereavement services as a preventive model of care. [Noted in Media Watch, 17 August 2015, #423 (p.16)] <http://goo.gl/3RA49H>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 November 2014 – ‘**An evaluation of a bereavement program in a U.S. research hospital.**’ The Bereavement Program at the National Institutes of Health Clinical Center (Bethesda, Maryland) makes contact with the next of kin on four occasions post-notification of death. [Noted in Media Watch, 17 November 2014, #384 (p.11)] <http://goo.gl/UXtwJT>

### Related

*CANCER* | Online – 31 May 2016 – ‘**Helping parents live with the hole in their heart: The role of health care providers and institutions in the bereaved parents’ grief journeys.**’ Bereaved parents [i.e., study participants] consistently identified the critical role played by medical staff and medical institutions throughout the grief journey. Key components of bereavement support identified by parents should serve to guide the actions of providers as well as provide a template for the development of a comprehensive bereavement program within an institution. <http://goo.gl/xIsPQa>

Cont.

*JOURNAL OF FAMILY COMMUNICATION* | Online – 23 May 2016 – ‘**Grief communication and privacy rules: Examining the communication of individuals bereaved by the death of a family member.**’ The authors ... examine how bereaved individuals manage the revelation and concealment of private information about the death of a parent or sibling. <http://goo.gl/MNw2Qt>

### **Advance care planning, palliative care, and end-of-life care interventions for homeless people: A systematic review**

*PALLIATIVE MEDICINE* | Online – 3 June 2016 – Homeless individuals have a high prevalence of multiple chronic co-morbidities and early mortality compared to the general population. They also experience significant barriers to access and stigmatization in the healthcare system. Providing advance care planning (ACP), palliative care (PC), and end-of-life care (EOLC) for this underserved population is an important health issue. Two studies were randomized controlled trials involving advance directive (AD) completion. Two cohort studies investigated the costs of a shelter-based PC intervention and predictors for completing ADs. These studies were rated low to fair quality. Two qualitative studies explored the interface between harm-reduction services and EOLC and the conditions for providing PC for homeless persons in a support home. The effectiveness of ACP, PC, and EOLC interventions for homeless individuals is uncertain. High-quality studies of interventions that reflect the unique and complex circumstances of homeless populations and investigate patient-related outcomes, caregiver burden, and cost-effectiveness are needed. <http://goo.gl/z6MGON>

Noted in Media Watch, 16 March 2015, #401 (p.10):

- *PALLIATIVE MEDICINE* | Online – 11 March 2015 – ‘**Chronically homeless persons’ participation in an advance directive intervention: A cohort study.**’ Participants were more likely to complete an advance directive if they reported thinking about death on a daily basis, believed thinking about their friends and family was important, or reported knowing their wishes for end-of-life care but not having told anyone about these wishes. <http://goo.gl/0gW2BN>

### **Engaging terminally ill patients in end-of-life talk: How experienced medicine doctors navigate the dilemma of promoting discussions about dying**

*PLOS ONE* | Online – 31 May 2016 – Doctors [i.e., study participants] most commonly promoted end-of-life (EoL) talk through open elaboration solicitations; these created opportunities for patients to introduce – then later further articulate – EoL considerations in such a way that doctors did not overtly ask about EoL matters. Importantly, the wording of elaboration solicitations avoided assuming that patients had EoL concerns. If a patient responded to open elaboration solicitations without introducing EoL considerations, doctors sometimes pursued EoL talk by switching to a less participatory and more presumptive type of solicitation, which suggested the patient might have EoL concerns. These more overt solicitations were used only later in consultations, which indicates that doctors give precedence to patients volunteering EoL considerations, and offer them opportunities to take the lead in initiating EoL talk. There is evidence that doctors treat elaboration of patients’ talk as a resource for engaging them in

EoL conversations. However, there are limitations associated with labelling that talk as “cues” as is common in EoL communication contexts. The authors examine these limitations and propose “possible EoL considerations” as a descriptively more accurate term. <http://goo.gl/HuVX7A>

#### **Family communication at the end of life**

*JOURNAL OF FAMILY COMMUNICATION* | Online – 21 May 2016 – This brief review examines what research has been conducted exploring family communication at the end of life (EOL). Future research areas recommended include: 1) The role of culture; 2) Family member role and relational climate; 3) Ethical considerations in regard to methodological choices; 4) The role of emotional and cognitive development on EOL communication; 5) EOL backstage communication; 6) Death circumstances; and, 7) The use of interdisciplinary research teams. <http://goo.gl/eZSAkt>

Cont.

## Related

- *BRITISH COLUMBIA MEDICAL JOURNAL*, 2016;58(5):262-267. '**Communication in life-limiting illness: A practical guide for physicians.**' Evidence supports using thoughtful and deliberate communication approaches that balance hope and reality in a caring and honest way. Clinical resources for everyday practice are available and include information about advance care planning, goals-of-care discussions, and support for patients and families in the final days of life. Physician-patient conversations will vary with the cultural, personal, and disease diversity encountered across clinical practice. What matters most is that these conversations occur and are not avoided. <http://goo.gl/RGp4Oc>
- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 27 May 2016 – '**Barriers and facilitators to end-of-life communication in advanced chronic organ failure.**' A total of 158 patients and family caregiver dyads were included [in this study]. The most important barriers for family caregivers were related to uncertainty about expected care and focus on staying alive instead of dying. The facilitators were related to trust in and competence of their physician and earlier experiences with death in their (social) environment. For most barriers and facilitators, agreement between patients and family caregivers was fair to moderate. <http://goo.gl/3pKeh4>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 30 May 2016 – '**Patient and caregiver characteristics related to completion of advance directives in terminally ill patients.**' There is a growing body of literature describing the characteristics of patients who plan for the end of life, but little research has examined how caregivers influence patients' advance care planning (ACP). Over half of the authors' patient sample (59%) had completed an advance directive (AD). Patients who were older, diagnosed with amyotrophic lateral sclerosis, and with a caregiver who was Caucasian or declined to report an income level were more likely to have an AD in place. Results of this study suggest that both patient and caregiver characteristics may influence patients' decisions to complete an AD at the end of life. When possible, caregivers should be included in ACP for patients who are terminally ill. <http://goo.gl/eK982y>

## Continuous sedation until death. A French way for the end-of-life care?

*LA PRESSE MÉDICALE* | Online – 20 May 2016 – France has adopted a unique international position for the end-of-life care. However, several ethical problems raised by continuous sedation until death (CSUD), which corresponds to a psycho-social death preceding the biological one, have been raised in the literature. The legitimacy of CSUD, especially if sedation is deep and not proportional to the degree of suffering, or if it is performed in case of a purely existential distress, is a matter of discussion. The primacy allocated to autonomy is questionable for the more vulnerable patients, who deserve mainly a social solidarity. The double-effect principle is replaced actually in CSUD by a co-intention both to relieve suffering and meanwhile eventually to hasten death, especially when stopping nutrition and hydration. CSUD is thus located in a grey zone between palliative care and euthanasia. <http://goo.gl/YpsPLB>

**N.B.** French language article.

Noted in Media Watch, 12 May 2014, #357 (p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 May 2014 – '**Palliative sedation: Analysis of international guidelines and position statements.**' Guidelines, etc., have been published by the American College of Physicians-American Society of Internal Medicine (2000), Hospice & Palliative Nurses Association (2003), American Academy of Hospice & Palliative Medicine (2006), American Medical Association (2008), Royal Dutch Medical Association (2009), European Association for Palliative Care (2009), National Hospice & Palliative Care Organization (2010), and National Comprehensive Cancer Network (2012). <http://goo.gl/2Nhfwi>

### [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>



## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *JOURNAL OF MEDICAL ETHICS* | Online – 2 June 2016 – ‘**Intending, hastening and causing death in non-treatment decisions: A physician interview study.**’ The physicians’ chief dilemma in non-treatment decisions was the attempt to achieve the proper balance for the level of treatment at life’s end. Respondents framed their challenges in medical and not ethical terms. They treated the concepts of intending, hastening and causing the patient’s death as alien to their practical deliberations and, for many, irrelevant to the moral appraisal of their end-of-life practices. <http://goo.gl/yPzLJc>
- *NATURE REVIEWS CLINICAL ONCOLOGY* | Online – 24 May 2016 – ‘**Health policy: The right to try is embodied in the right to die.**’ A patient’s right to obtain medication that will be ineffective against his/her terminal illness and will cause his/her death should also encompass the right of that patient to be prescribed medication that might be ineffective and might cause his/her death. The “right to die” should embody the “right to try” experimental agents for treatment of cancer. <http://goo.gl/3O48Op>
- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 31 May 2016 – ‘**The traditional model does not explain attitudes toward euthanasia: A web-based survey of the general public in Finland.**’ The debate about euthanasia is ongoing in several countries including Finland. However, there is a lack of information on current attitudes toward euthanasia among general Finnish public. The traditional model for predicting individuals’ attitudes to euthanasia is based on their age, gender, educational level, and religiosity. However, a new evaluation of religiosity is needed due to the limited operationalization of this factor in previous studies. This study explores the connections between the factors of the traditional model and the attitudes toward euthanasia among the general public in the Finnish context. <http://goo.gl/jiWzKB>

### [Media Watch: Editorial Practice](#)

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

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5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### [Something Missed or Overlooked?](#)

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

## Worth Repeating

### **Initiating palliative care conversations: Lessons from Jewish bioethics**

*JOURNAL OF SUPPORTIVE ONCOLOGY* | Online – 22 October 2012 – What are the ethical responsibilities of the medical staff (doctors, nurses, social workers, and chaplains) regarding the preservation of meaningful life for their patients who are approaching the end of life? In particular, what is the staff's ethical responsibility to initiate a conversation with their patient regarding palliative care? By subjecting traditional Jewish teachings to an ethical analysis and then exploring the underlying universal principles, the authors will suggest a general ethical duty to inform patients of the different care options, especially in a manner that preserves hope. The principle that we can derive from Jewish bioethics teaches that the medical staff has a responsibility to help our patients live in a way that is consistent with how they understand their task or responsibility in life. For some patients, the best way to preserve a meaningful life in which they can fulfill their sense of purpose in the time that remains is to focus on palliation. For this reason, although palliative and supportive care are provided from the time of diagnosis, it is critical we make sure our patients realize that they have the opportunity to make a decision between either pursuing additional active treatments or choosing to focus primarily on palliative therapies to maximize quality of life. The Jewish tradition and our experience in spiritual care suggest the importance of helping patients preserve hope while, simultaneously, honestly acknowledging their situation. Staff members can play a vital role in helping patients make the most of this new period of their lives. [Noted in Media Watch, 29 October 2012, #277 (p.8)] <http://goo.gl/qhs6fX>

#### Media Watch: Online

##### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/0Q1Mh4>

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>

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