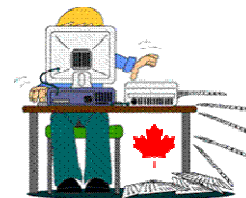


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to **Specialist Publications** and ‘Caring for a dying partner: The male experience’ (p.11), in *Journal of Palliative Care*.

Canada

Ontarians need better access to palliative care

ONTARIO | *The Ottawa Citizen* – 14 May 2018 – Palliative care (PC) is inadequately funded in the Ottawa region and, indeed, in the province of Ontario. Increasingly we are bearing witness to our patients’ and their families’ suffering at the hands of an overstretched system. Patients who are suffering and reaching the end of their lives from any disease other than cancer are not able to access a PC clinic because none exists. Studies tell us the majority of people would prefer to die at home; however, despite maximal efforts by our excellent home care colleagues, community physicians and unpaid caregivers, our patients cannot always get enough care or equipment to ensure that they remain comfortable at home. Make no mistake, these inadequacies are not due to a lack of willingness to care for patients. Every day we, in hospitals, clinics, hospices and homes, are doing more with less. Every day we face barriers to the provision of good PC. These barriers all arise from a lack of investment in PC. The year 2017 saw royal assent for Bill C-277 [Framework on Palliative Care in Canada Act] in [the federal] parliament and [the tabling of the Private Member’s] Bill 182 [Compassionate Care Act] in the provincial legislature. These bills both call for further study into how PC can be improved nationally and provincially. Both bills are a step in the right direction but neither goes far enough and neither will yield results soon enough. Everyone in the Ottawa

region needs and deserves better access to PC now. <https://goo.gl/4yShhF>

Case Study: OTTAWA

A Look at the End-of-Life-Care Landscape

Noted in the 14 May 2018 issue of Media Watch (#563, p.1) is ‘Case Study: Ottawa,’ a companion piece to a recent report by the faith-based think tank Cardus, “Renewing end-of-life,” which was noted in the 7 May 2018 issue of the weekly report (#562, p.1).
Download/view at: <https://goo.gl/njhsya>

Specialist Publications

‘Developing a palliative care competency framework for health professionals and volunteers: The Nova Scotian experience’ (p.12), in *Journal of Palliative Medicine*.

‘Exploring Canadian physicians’ experiences providing medical assistance in dying: A qualitative study’ (p.15), in *Journal of Pain & Symptom Management*.

Cont.

N.B. Health Canada launched its public consultation on Bill C-277 on the 7 May 2018, as noted in last week's issue of Media Watch (#563, p.2); download/view details at: <https://goo.gl/EUoqGL>. For the status of Ontario's Bill 182: <https://goo.gl/3WGo48>. The 14 May 2018 issue of Media Watch also referenced past reports, etc., on the development/evolution of palliative care from both a national and Ontario perspective.

[U.S.A.](#)

Choosing between death and deportation

KAISER HEALTH NEWS | Online – 18 May 2018 – What happens when an undocumented immigrant has a life-threatening diagnosis? Much depends on where the person lives. And even in states with generous care for a dire illness, a patient can face difficult life-and-death choices. <https://goo.gl/NvSYN4>

[Specialist Publications](#)

'Behavioral pain intervention for hospice and palliative care patients: An integrative review' (p.6), in *American Journal of Hospice & Palliative Medicine*.

N.B. Additional articles on undocumented immigrants in the U.S., in the context of palliative and end-of-life care, noted in the 5 March 2018 issue of Media Watch (#553, p.10).

New report on senior health shows rural health disparities persist...

MINNESOTA | United Health Foundation – 17 May 2018 – A new report benchmarking the health of seniors in America finds poorer health outcomes for rural senior citizens compared with their urban and suburban peers... An analysis within the report also highlights the risk of social isolation and its association with poor health for seniors. The report provides the latest check-up on the health and well-being of the nation's seniors. Using 34 measures of senior health, the report highlights successes and challenges this population faces on a national and state-by-state basis. **Download/view report (see pp.79-80) at:** <https://goo.gl/5DDW1F>

Ranking by Hospice Care

Rank	State	Value (%)
1	Arizona	65.8
2	Utah	65.5
3	Delaware	61.6
4	Florida	61.2
5	Georgia	60.1
6	Ohio	59.5
7	Rhode Island	59.2
8	South Carolina	58.5
8	Texas	58.5
10	Iowa	58.3

Where both patients and caregivers are prisoners

CALIFORNIA | *The New York Times* – 16 May 2018 – The hospice at the California Medical Facility is one of the nation's first and the only licensed hospice unit inside a California prison. Built in 1993 in response to the AIDS crisis and inmate-led demands for more humane care, the hospice was originally populated with young men dying of complications of the disease. Today, the 17-bed unit is filled with a different demographic: graying men with everything from end-stage cancer to Alzheimer's shuffle around with walkers, sit in wheelchairs watching television or lie curled up under heavy blankets. Prisoners older than 55 serving time in federal and state prisons make up the fastest-growing age group behind bars, increasing more than 500% since the 1990s, from 26,300 aging inmates in 1993 to 164,800 at the end of 2016. Criminal-justice experts point to a mix of policies that landed us here: long sentences from get-tough-on-crime laws, a steady increase of older adults entering prison, and challenges with the timely issuing of compassionate release and medical parole. One result is a different kind of death penalty for violent and non-violent offenders alike. Most prisons were never built to be nursing homes. Correctional officers often aren't equipped with the necessary training, and medical staff can be spread thin. At the California Medical Facility, that's where men like Lyman, Saephanh and Murillo come in. They are part of a cohort of about two dozen men called the Pastoral Care Service Workers. Most of them are convicted murderers serving life sentences who have been granted an unusual role: providing dignified deaths to their fellow inmates. <https://goo.gl/MPLK3s>

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report can be downloaded/viewed at: <https://goo.gl/YLckx6>

Per-capita end-of-life spending is decreasing rapidly, according to new study

SCIENCE DAILY | Online – 16 May 2018 – Health economists have long considered end-of-life (EoL) spending to be one of the major contributors to the overall increase in health spending in the U.S. That narrative has been supported by recent research findings that increased use of hospice care costs more than it saves, that EoL care intensity has been increasing, and EoL intensive care unit has accelerated. While those factors contributed to an overall rise in EoL costs through the mid-2000s, a new study by healthcare researchers from The Dartmouth Institute for Health Policy & Clinical Practice and Dartmouth-Hitchcock Medical Center found that, since 2008, *per-capita* EoL care costs have been declining rather dramatically.¹ What's more, the decrease in EoL spending significantly contributed to the moderation in growth of overall *per-capita* Medicare spending. Reductions in EoL spending were driven by substantially lower inpatient care expenditures as well as modestly lower physician and home health expenditures, without commensurate increases in other care areas... <https://goo.gl/8h5RGc>

1. 'Proportion of decedents' expenditures among recent reductions in Medicare expenditures,' *JAMA Internal Medicine*, 2018;178(5):717-719. **First page preview:** <https://goo.gl/ckdfZM>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | National Public Radio (Sacramento) – 16 May 2018 – '**Judge overturns assisted suicide law in California.**' A California law permitting physicians to prescribe life-ending drugs to terminally ill patients has been overturned by a judge who says it was passed unconstitutionally. Judge Daniel Ottholia, of the Riverside County Superior Court, did not challenge the legality of the nearly three-year-old law, but said California lawmakers should not have passed it during a special session on health care funding. However, the judge is holding his judgement for five days to give the state time to file an emergency appeal, something California Attorney General Xavier Becerra, who says he strongly disagrees with the ruling, says he plans to do. California is one of seven states and the District of Columbia that currently has legal protections for assisted suicide. They account for about one-fifth of the U.S. population. <https://goo.gl/7xRBB4>

International

Majority of Australians not prepared for end of life, study

AUSTRALIA (New South Wales) | *The Sydney Morning Herald* – 20 May 2018 – Only one in four Australians told their family what to do if they were to die or fall seriously ill, despite eight in 10 Australians thinking it's important to have that conversation. The statistics are from a new survey for Palliative Care Australia... Only 26% of Australians had talked to their family about their wishes for end-of-life care (EoLC), with 6% having discussed their wishes with a doctor. Two thirds of Australians had some type of end-of-life documentation in place, with the most common form being a will. According to the survey, 14% of Australians had made EoLC decisions for their family members, with 74% of these people saying they'd previously discussed their options or the family member had prepared documentation. According to the survey, 34% of Australians found it too difficult to start the conversation

about their end-of-life options. Less than half of Australians that had a family member die in the past 12 months were satisfied with the EoLC they received. The survey showed 19% of Australian had a family member die in the past 12 months, with only 47% reporting a good experience with the EoLC. When the survey was broadened out to those with a family member currently receiving palliative care (PC) or having received PC, 66% had a positive experience. <https://goo.gl/CV6Tgs>

Specialist Publications

'A snapshot of Australian social workers in palliative care and their work with estranged clients' (p.14), in *Social Work in Health Care*.

Critically ill “should not be made to die away from home”

U.K. (England) | Online – 19 May 2018 – One in three people who die in hospital could spend their final days at home if the government introduces and adequately funds a modern community-based health and social care system, a new report says.¹ The Institute for Public Policy Research says that, while most people would prefer to die at home or in a good care home, they are often unable to do so because of inadequate and underfunded local care. The researchers analysed investment in long-term care in several European countries, and concluded that there appears to be a correlation between funding levels, modern systems and the proportion of people dying in hospitals. **Abstract:** <https://goo.gl/T1AFZj>

1. ‘End of life care in England: A briefing paper,’ Institute for Public Policy Research, May 2018. **Download/view at:** <https://goo.gl/Ajwppg>

Volunteering on a hospital ship in Africa, Springfield nurse brings relief to the dying

AFRICA | *The Springfield News-Leader* (Springfield, Missouri, U.S.) – 16 May 2018 – Before joining the Africa Mercy, Jenni Nelson worked at Integrity Homecare & Hospice in Springfield, providing care to terminally ill patients and support for their families. She discovered the opportunity to meld her two loves of palliative care (PC) and Africa two years ago... The Africa Mercy is the world’s largest non-governmental hospital ship, according to Mercy Ships. It is dedicated solely to the continent of Africa, with an average volunteer crew of 1,000 from at least 40 different nations. Currently, the ship is docked in Douala, the commercial capital of Cameroon. Africa Mercy is primarily a surgery ship, but during the process of treating patients, health care professionals encounter patients who aren’t surgical candidates. An estimated 40

million people are in need of PC each year, with 78% of them living in low- and middle-income countries... For children, 98% of those who need PC live in economically disadvantaged countries. Almost half live in Africa. Since 1978, Mercy Ships has provided PC to more than 240 patients and has trained more than 160 caregivers. <https://goo.gl/Ww2HWp>

[Specialist Publications](#)

‘An analysis of palliative care development in Africa: A ranking based on region-specific macro-indicators’ (p.10), in *Journal of Pain & Symptom Management*.

Launch of new report: *A Road Less Lonely*

U.K. (Scotland) | Scottish Partnership for Palliative Care – 16 May 2018 – The new report, published jointly with the charity Good Life, Good Death, Good Grief, explores some of the different areas that can shape people’s experiences of death, dying and bereavement. It focuses particularly on: death education and bereavement support in schools; workplace culture and policies; the role of communities; the practicalities of planning ahead for deteriorating health and death; personal skills and knowledge relating to death, dying and bereavement; mass media campaigns; socio-economic disadvantage; and, funeral poverty. This report highlights a wide range of pro-

jects and initiatives ongoing in Scotland and further afield relevant to improving people’s experiences of death, dying and bereavement. **Download/view at:** <https://goo.gl/9ve7y2>

[Specialist Publications](#)

‘What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities approach’ (p.13), in *Palliative Medicine*.

Pressure to stay positive may be a negative for cancer patients – charity

U.K. (England, Northern Ireland, Scotland & Wales) | *The Guardian* (London) – 15 May 2018 – The perceived need to “fight” cancer and remain positive is having a negative effect on people living with the disease, especially those with a terminal diagnosis who are not getting the right support for the end of life... Research by YouGov found that three-quarters (76%) of people with cancer said they had thought about the fact they may die from the disease.¹ But Macmillan Cancer Support said its research showed there were a number of barriers preventing honest conversations about dying from taking place. It said one of the biggest barriers to introducing conversations about dying was the pressure to stay positive, even when patients received a terminal diagnosis. Of the people surveyed who had spoken to their healthcare team about dying, only 19% said the conversations were initiated by a health or social care professional. Furthermore, a quarter of people with cancer said they had not shared their thoughts about death and dying with anyone due to the pressure to see themselves as a “fighter.” <https://goo.gl/GzUWiq>

1. “Fighting talk” can leave cancer patients unable to talk about death and dying,’ Macmillan Cancer Support, May 2018. <https://goo.gl/LRxCMc>

Noted in Media Watch 21 August 2017 (#526, p.2):

- CANADA | CBC News (Toronto, Ontario) – 13 August 2017 – ‘**Cancer lingo: How one person’s thoughtful metaphor can be another’s cliché.**’ Warrior metaphors ... have been around for some time. But the language was thrust back into the public spotlight after the recent brain cancer diagnosis of U.S. Senator John McCain. On Twitter, well-wishers ... described the senator as a “brave fighter.” On TV newscasts, reporters suggested that while McCain was in for a tough battle, his disease had a “worthy opponent.” “Most of us are not real fans of using these battle metaphors,” says Dr. Elie Isenberg-Grzeda, a psychiatrist at Toronto’s Sunnybrook Health Sciences Centre. Warrior metaphors prevent a person with cancer from being honest with friends and family, he says. And the result is loneliness and isolation. <https://goo.gl/kP12Wx>

Number of care homes in England falls by more than 700 over two years with potentially “disastrous” effects for the elderly

U.K. (England) | *The Daily Mail* (London) – 14 May 2018 – The figures released by ministers come after a financial analysis showed 148 care home businesses became insolvent in the last financial year – nearly double the number in the previous year. The figures from care minister Caroline Dinenage show the number of residential care homes fell from 12,191 at the beginning of 2016 to 11,615 this year. Of the 576 homes lost, 453 disappeared last year. Among nursing homes, 159 were lost over the two years. In total there were 735 fewer care homes by the start of 2018. The figures from the Department of Health & Social Care show the number of care home places available in England in January was 237,229 and nursing home places 222,416 – overall, slightly more than 2,000 down on two years previously. Analysis of care home business insolvencies by the accountants Moore Stephens said the 148 recorded in the year to the end of March compared with 81 in the previous financial year. <https://goo.gl/E11j2S>

Noted in Media Watch 21 August 2017 (#526, p.6):

- U.K. (England) | *The Daily Telegraph* (London) – 16 August 2017 – ‘**More than 70,000 extra care home places needed by 2025.**’ More than 70,000 extra care home places will be needed by 2025, with pensioners now spending twice as long living without independence. Women over the age of 65 can now expect to spend the last three years of their lives in a care home, or receiving help several times daily, research shows. Two decades ago they could expect to spend the last 18 months of their lives in need of such help. <https://goo.gl/QnrQUw>
- U.K. (England) | *The Times* (London) – 14 August 2017 – ‘**Funding crisis leaves thousands of care homes facing collapse.**’ One in six care home companies is in danger of insolvency, according to a report warning that successive rises in the living wage have driven up costs to the point where they may bankrupt a large part of the system. About 420,000 people over the age of 65 are being looked after in Britain’s 11,000 residential care homes, including 220,000 of the most vulnerable patients, who are in 4,700 nursing homes. <https://goo.gl/vENpPf>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (Guernsey) | BBC News (St. Peter Port) – 18 May 2018 – ‘**Guernsey’s politicians vote to reject assisted dying.**’ Guernsey’s government has rejected proposals that could have seen assisted dying legalised in the future. Had it been approved, the island could have become the first place in the British Isles to allow assisted dying. After a three-day debate, the proposals were rejected. The plans would have prompted a consultation period before a legal framework was presented back to the island’s politicians. Politicians did agree to a review of palliative and end-of-life care due to an anticipated “substantial increase” in healthcare needs for the island’s ageing population. <https://goo.gl/gM3u8P>

Specialist Publications

Behavioral pain intervention for hospice and palliative care patients: An integrative review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 17 May 2018 – Despite the advances in pain management, achieving optimal pain control in hospice and palliative care (PC) is challenging. Patient/caregiver’s lack of pain management knowledge, poor pain reporting, and poor adherence to pain management regimens are all associated with inadequate pain control. The purpose of this integrated review is to examine behavioral interventions designed for patients and caregivers to improve pain control in hospice and PC settings. Ten studies were identified through a database search. Seven of the 10 studies found significant improvement in at least 1 pain marker. Of the 7 studies that looked at changes in pain knowledge, 5 had significant improvements in at least 1 knowledge subscale. The 2 studies that looked at adherence to pain management found significant improvements. One limitation of the reviewed studies was that the delivery of them would not be efficient across all health-care settings, and, as a consequence, more technologically sophisticated delivery methods are needed. Therefore, while it is clear from the review that effective pain management interventions have been developed for hospice and PC patients, it is also clear that future research needs to focus on providing these same interventions through a more technologically sophisticated delivery method. **Abstract:** <https://goo.gl/CKNpSc>

Noted in Media Watch 26 February 2018 (#552, p.16):

- *PALLIATIVE CARE: RESEARCH & TREATMENT* | Online – 20 February 2018 – ‘**Pain management: Time to minimize variations in practice.**’ The authors observe, in clinical care, a disconnect between the science, including pharmacology, of the use of opioids and the practice of pain management. The biggest variable seems to be clinical culture. Even when limiting the focus to managing the physical aspect of pain, there is great variation in treatment practices. Variations exist between individuals within a team, the measurement of symptoms, the choice of opioids to manage pain, the frequency and manner of dosage escalation, and the personal choices and comfort in the use of opioid conversions. **Full text:** <https://goo.gl/Mbx2BH>



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>

Care transitions from patient and caregiver perspectives

ANNALS OF FAMILY MEDICINE, 2018;16(3):225-231. In the transition from hospital to home, patients and caregivers seek clear accountability, continuity, and caring attitudes across the care continuum. One-hundred and thirty-eight patients and 110 family caregivers participating in focus groups and interviews identified three desired outcomes of care transition services: feeling prepared and able to implement care plans, unambiguous accountability from the healthcare system, and feeling cared for and cared about by clinicians. Five services or clinician behaviors were linked to these outcomes: providing actionable information; collaborative discharge planning involving patient and caregiver; using empathic language and gestures; anticipating the patient's need to support self-care at home; and providing uninterrupted care with minimal handoffs. When participants' desired outcomes were realized, they characterized care as excellent and trustworthy. In addition, caregivers experienced less distress and reported adherence to discharge plans increased. When desired outcomes were not met, patients and caregivers felt deserted by the health care system and perceived medical care as transactional and unsafe. Poor and fragmented care transition experiences, the authors suggest, can have substantial consequences, including creating patient and caregiver mistrust, anxiety, and confusion; precipitating family conflict; and contributing to inefficient care delivery, avoidable health system use, and delayed recovery. To ensure that care transitions are safe and supportive of patients' recovery, the authors state that health systems must better prepare patients and caregivers for self-care at home and design accessible means of ongoing care support when and where it is needed. **Full text:** <https://goo.gl/ETMFCS>

Related

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 15 May 2018 – ‘**Addressing cancer patient and caregiver role transitions during home hospice nursing care.**’ Nineteen unique home hospice visits were analyzed. Patient-caregiver conflict occurred in two major content themes: 1) Negotiating transitions in patient independence; and, 2) Navigating caregiver/patient emotions (e.g., frustration, sadness). Nurse responses to transition conflict included problem-solving, mediating, or facilitating discussions about conflicts. Nurse responses to emotional conflict included validation and reassurance. **Abstract (inc. list of references):** <https://goo.gl/R19eFg>

Noted in Media Watch 12 February 2018 (#550, p.14):

- *BMC PALLIATIVE CARE* | Online – 5 February 2018 – ‘**Transitions as experienced by persons in palliative care circumstances and their families: A qualitative meta-synthesis.**’ This study shows how persons with palliative care needs and their families experience transitions in a palliative context. Maintaining normality, experiencing changing roles, and anticipating the future are central phenomena for these groups. Based on the model discussed, health care professionals can identify available resources and support the family in their self-management strategies. **Full text:** <https://goo.gl/YGH3C8>

Noted in Media Watch 13 November 2017 (#538, p.12):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 6 November 2017 – ‘**Moving from place to place in the last year of life: A qualitative study identifying care setting transition issues and solutions in Ontario, Canada.**’ Moving from one care setting to another is common as death nears. Many concerns exist over these end-of-life care setting transitions, including low-quality moves as mistakes and other mishaps can occur. Delayed or denied moves are problematic, such as a move out of hospital for dying patients who want to spend their last days at home. **Abstract:** <https://goo.gl/o3gU7H>

Will palliative care ever be cool?

ANNALS OF SURGICAL ONCOLOGY | Online – 10 May 2018 – A considerable number of studies have been published demonstrating that palliative care (PC) can result in, or is at least associated with, less aggressive end-of-life care. More importantly, the integration of PC in advanced cancer patients can result in improved quality of life (QoL) and decreased symptom burden. PC may even be associated with improved survival, and it is not shocking that improved QoL can also lead to improved length of life. In-

Cont.

creasing recognition of these associations has led the American Society of Clinical Oncology (ASCO) to recommend dedicated PC services, early in the disease course, concurrent with active treatment.¹ Dissemination of PC is needed in oncology as many patients want to receive care at home at the end of their life, but also to meet the challenge of providing PC in combination with oncology care. PC in the hospital has an important role in symptom management and counseling on goals of care, but outpatient care is needed for early integration and also to provide effective continuous PC integrated with standard oncology care. Patients with advanced cancer will experience symptom changes and PC needs that will need to be addressed by their primary physicians and oncologists. We are scratching the surface in identifying what are the most important components of PC, but are in desperate need of a deeper dive to assist in training the current and future workforce to provide basic PC and utilize specialists appropriately. Surgical oncology has an even more difficult path forward in that there are limited studies that have identified the PC needs of surgical patients. **Full text:** <https://goo.gl/2uDGUa>

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

N.B. See 'Palliative care in the global setting: American Society of Clinical Oncology resource-stratified practice guideline,' *Journal of Global Oncology*, published online 8 May 2018. [Noted in the 14 May 2018 issue of Media Watch (#563, p.7)] **Full text:** <https://goo.gl/Hydd43>

Related

- *ANNALS OF SURGICAL ONCOLOGY*, 2018;25(6):1478-1487. '**Palliative care is associated with reduced aggressive end-of-life care in patients with gastrointestinal cancer.**' The cohort studied included 34,630 patients, of whom 74% had at least one palliative care (PC) service. Timing of the first PC service varied... Compared with patients not receiving PC, any PC was associated with a reduction in any aggressive end-of-life care; this association was similar regardless of timing of the first PC service. **Full text:** <https://goo.gl/wjVYz2>

Challenges in end-of-life dementia care

EVIDENCE-BASED MENTAL HEALTH | Online – 18 May 2018 – Dementia is a chronic, progressive disease that is now much more widely recognised and treated. Patients with dementia may require palliative care (PC) when they reach the end stage of their illness, or they may have mild-moderate cognitive symptoms comorbid with a life-limiting illness. The variety of presentations necessitates a highly individual approach to care planning, and patients should be encouraged to set their own goals and contribute to advanced care planning where possible. Assessment and management of distressing symptoms at the end of life (EoL) can be greatly helped by a detailed knowledge of the individuals' prior wishes, interdisciplinary communication and recognition of changes in presentation that may result from new symptoms, for example, onset of pain, nutritional deficits and infection. To navigate complexity at the EoL, open communication that involves patients and families in decisions, and is responsive to their needs is vital and can vastly improve subjective experiences. Complex ethical dilemmas may pervade both the illness of dementia and provision of PC; the authors consider how ethical issues (e.g., providing care under restraint) influence complex decisions relating to resuscitation, artificial nutrition and treatment refusal in order to optimise quality of life. **Abstract:** <https://goo.gl/VDXJYQ>

N.B. Additional articles on palliative care for people living with Alzheimer's and other forms of dementia noted in the 20 April and 7 May 2018 issues of Media Watch (#561, p.11 and #562, p.3, respectively).

Palliative Care Network

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

Ethical challenges in resuscitation

INTENSIVE CARE MEDICINE | Online – 10 May 2018 – This review describes challenges associated with the application of key principles of bioethics in resuscitation and post-resuscitation care; propose actions to address these challenges; and, highlight the need for evidence-based ethics and consensus on ethical principles interpretation. Respect for patient autonomy can be realized through honest provision of information, shared decision-making, and advance directives/care planning. Essential prerequisites comprise public and specific healthcare professionals' education, appropriate regulatory provisions, and allocation of adequate resources. Regarding beneficence/nonmaleficence, resuscitation should benefit patients, while avoiding harm from futile interventions; pertinent practice should be based on neurological prognostication and patient/family-reported outcomes. Regarding dignity, aggressive life-sustaining treatments against patients preferences should be avoided. Contrary to the principle of justice, resuscitation

quality may be affected by race/income status, age, ethnicity, co-morbidity, and location (urban versus rural or country-specific/region-specific). Current evidence supports family presence during resuscitation. Regarding emergency research, autonomy should be respected without hindering scientific progress; furthermore, transparency of research conduct should be promoted and funding increased. **Abstract (inc. list of references):** <https://goo.gl/uQ3h4d>

Following agreement on the article's outline...

...subgroups of 2-3 authors provided narrative reviews of ethical issues concerning autonomy and honesty, beneficence/nonmaleficence and dignity, justice, specific practices/circumstances such as family presence during resuscitation, and emergency research. Proposals for addressing ethical challenges were also offered.

Noted in Media Watch 12 March 2018 (#554, p.9):

- *JOURNAL OF MEDICAL ETHICS* | Online – 9 March 2018 – '**Resuscitation decisions at the end of life: Medical views and the juridification of practice.**' The authors of this article paper provide unique insights into how doctors respond to the changing medico-legal culture and the subsequent effects on patient care. It demonstrates how the juridification of medical practice can occur. It highlights the potential benefit of a structure to support clinicians, patients and relatives in discussing and navigating decisions around care at the end of life in line with the patient's wishes and preferences. **Abstract:** <https://goo.gl/WEAvL6>

Charlie Gard and the weight of parental rights to seek experimental treatment

JOURNAL OF MEDICAL ETHICS | Online – 17 May 2018 – The case of Charlie Gard, an infant with a genetic illness whose parents sought experimental treatment in the U.S., brought important debates about the moral status of parents and children to the public eye. After setting out the facts of the case, this article considers some of these debates through the lens of parental rights. Parental rights are most commonly based on the promotion of a child's welfare; however, in Charlie's case, promotion of Charlie's welfare cannot explain every fact of the case. Indeed, some seem most logically to extend from intrinsic parental rights, that is, parental rights that exist independent of welfare promotion. The author observes that a strong claim for intrinsic parental rights can be built on arguments for genetic propriety and children's limited personhood. Critique of these arguments suggests the scope of parental rights remains limited: property rights entail proper use; non-personhood includes only a small cohort of very young or seriously intellectually disabled children, and the uniqueness of parental genetic connection is limited. Moreover, there are cogent arguments about parents' competence to make judgements, and public interest arguments against allowing access to experimental treatment. Nevertheless, while arguments based on propriety may raise concerns about the attitude involved in envisioning children as property, the author concludes that these arguments do appear to offer a prima facie case for a parental right to seek experimental treatment in certain limited circumstances. **Full text:** <https://goo.gl/gFrE7k>

N.B. Additional articles on the Charlie Gard case noted in the 14 May 2018 issue of Media Watch (#563, p.8).

Dances with denial: Have medical oncology outpatients conveyed their end-of-life wishes and do they want to?

JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK, 2018;16(5):498-505. This study surveyed a sample of medical oncology outpatients to determine: 1) The proportion who have already discussed and documented their end-of-life (EoL) wishes; 2) When and with whom they would prefer to convey their EoL wishes; 3) The EoL issues they would want to discuss; and, 4) The association between perceived cancer status and advance care planning (ACP) participation.. EoL discussions occurred more frequently with support persons (47%) than with doctors (7%). Only 14% had recorded their wishes, and 45% had appointed an enduring guardian. Those who perceived their cancer as incurable were more likely to have participated in ACP. If facing EoL, patients indicated that they would want family involved in discussions (85%), to be able to write down EoL wishes (82%), and to appoint enduring guardians (91%). Many (45%) preferred the first discussion to happen when their disease became incurable. Slightly less than one-third thought discussions regarding EoL should be patient-initiated. Most agreed doctors should ask about preferred decision-making involvement (92%), how important it is that pain is managed well (95%), and how important it is to remain conscious (82%). Fewer (55%) wanted to be asked about the importance of care extending life. **Abstract:** <https://goo.gl/ozYt5o>

Related

- *BRITISH MEDICAL JOURNAL* | Online – 15 May 2018 – ‘**Should advance care planning enter the mainstream?**’ Around a third of adult patients in an National Health Service acute bed are in the last year of their lives, although many won’t know it, and nor can doctors necessarily predict it. About 40% of over 65s will die within 12 months of leaving hospital. Those with severe frailty are four times more likely to die within 12 months. You might think, when someone is becoming very frail or has a life limiting condition diagnosed, that this would open the way for specific decisions about end-of-life care and its limits. Yet such advance care planning is still not the norm. It’s clear to practitioners like me that these conversations just haven’t been had... **Full text:** <https://goo.gl/b97eTA>
- *JOURNAL OF BURN CARE & RESEARCH* | Online – 16 May 2018 – ‘**Burn surgeon and palliative care physician attitudes regarding goals of care delineation for burned geriatric patients.**’ Palliative physicians [i.e., survey respondents] rated being more familiar with goals of care, were more comfortable having a discussion with laypeople, were more likely to have reported high quality training in performing conversations, believed more palliative specialists were needed in intensive care units, and had more interest in conducting conversations relative to burn surgeons. Burn surgeons favored leading team discussions, whereas palliative specialists preferred jointly led discussions. Both groups agreed that discussions should occur within 72 hours of admission. **Abstract:** <https://goo.gl/Lo7BaA>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 15 May 2018 – ‘**Advance care planning in a multi-cultural family-centric community: A qualitative study of healthcare professionals’, patients’ and caregivers’ perspectives.**’ The participants were genuinely anxious about the implementation of advance care planning (ACP); they had positive and negative expectations. Many were confused about the legal framework for healthcare decision-making and expected ACP to be of limited value because family members, rather than the patient, were usually the key decision-makers. A nuanced approach to ACP which considers the family network is required in multi-cultural family centric communities. **Abstract (w. link to references):** <https://goo.gl/xZj88Z>

An analysis of palliative care development in Africa: A ranking based on region-specific macro-indicators

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 14 May 2018 – Data were obtained from the African Palliative Care Atlas of Palliative Care¹ ... and a comparative analysis conducted. Nineteen indicators were developed and defined through qualitative interviews with African palliative care (PC) experts and a two-round modified Delphi consensus process with international experts on global PC indicators. Indicators were grouped by the WHO public health strategy for PC dimensions. These were then sent as a survey to key informants in 52/54 African countries. Surveys were received from 89% (48/54) of

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African countries. The top three countries in overall PC development were, in order, Uganda, South Africa, and Kenya. Variability existed by dimension. The top three countries in specialized services were Uganda, South Africa, and Nigeria; in policies, it was Botswana followed by parity among Ethiopia, Rwanda, and Swaziland; in medicines, it was Swaziland, South Africa, then Malawi; in education, it was equivalent between Uganda and Kenya, then Ghana and Zambia. Uganda, South Africa, and Kenya are the highest performing countries and were the only ones with composite scores greater than 0.5 (50%). However, not one country universally supersedes all others across all four PC dimensions. The breakdown of rankings by dimension highlights where even high-performing African countries can focus their efforts to further PC development. **Abstract (w. link to bibliography):** <https://goo.gl/Q1k63G>

1. 'African Palliative Care Atlas of Palliative Care in Africa,' African Palliative Care Association, 2017. **Download/view at:** <https://goo.gl/y6USD2>

Noted in Media Watch 26 March 2018 (#556, p.13):

- *THE LANCET GLOBAL HEALTH*, 2018:6(Suppl.2):S21. 'The African Palliative Care Association (APCA) Atlas of Palliative Care Development in Africa: A comparative analysis.' The authors aimed to develop and deploy a set of indicators to measure the current state of palliative care (PC) development in Africa according to WHO's Public Health Strategy for integrating PC, including policies, availability and access to medicines, education, and service provision. Surveys were received from 48 countries. There is limited PC development in Africa, but there is also a significant improvement in the number of countries with hospice and PC services, compared to previous reports. Improvements in advocacy were identified, with more than half of countries reporting a national PC association. **Abstract:** <https://goo.gl/RPwVHc>

N.B. Additional articles on the development of palliative care in Africa noted in this issue of Media Watch.

Geriatric oncology, spirituality, and palliative care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 14 May 2018 – This review examines the influence of spirituality on aging in general and on the management of older cancer patients. A spiritual perspective has been associated with successful aging, and with better tolerance of physical and emotional stress, including the ability to cope with serious diseases and with isolation. It has also been associated with decreased risk of suicide and depression. Gerotranscendence, the more urgent search for meaning by older than younger individuals, confirm the importance of spirituality in this phase of life. Spirituality has also improved the quality of life and reduced the risk of disease and death for the patient's caregiver. Addressing patient and caregiver spirituality may render the palliative care of cancer more effective and may also aid in detection and management of spiritual pain, that may prevent healing at the end of life. **Abstract (w. link to references):** <https://goo.gl/tBLNc7>

Caring for a dying partner: The male experience

JOURNAL OF PALLIATIVE CARE | Online – 14 May 2018 – Caring for someone close who is dying, such as a spouse, is an emotive experience; however, there is little research examining the phenomenon of caregiving for a spouse at the end of life and of men's experiences specifically. Existing literature suggests that men who are providing care are less likely to seek help than women, especially psychological and emotional support for themselves. The aim of the current study was to explore the lived experiences of men caring for a dying spouse or partner and their help-seeking for themselves during this time. Three superordinate themes emerged from the data, "illness questions everything," "constructing the caring role," and "help-seeking at the limit." The arrival of a terminal illness into a partnership is traumatic, and while it can deepen relationships, it can also create distance. The carer role has conflicting demands and carers need to make sense of their experience in order for the carer role to be constructed as a source of purpose or meaning. Finally, the idea of seeking help for oneself as a carer during this time is seen as "incompatible," unmanageable, and can only be considered if constructed as a "last resort." Men care too; however, they can feel confused by this role and unsure as to how this fits with their identity as a man. They make sense of this by identifying as a partner whose "duty" or "responsibility" is to provide care. Although this is an understandable stance, it puts them at risk of further emotional, psychological, and physiological difficulties if their own needs are not met. **Abstract:** <https://goo.gl/cxpcJC>

Editorial

A new frontier in palliative medicine research is needed

JOURNAL OF PALLIATIVE MEDICINE, 2018;21(5):580. If our scientists are to help us, they must have the courage to perform research across a boundary that heretofore has not been crossed. As we face the certain prospect of limited resources available for healthcare, I think we need more than “it’s her choice” models of healthcare delivery. The emerging consumerism of “give them what they want at a price they can afford” is worse. I would rather be guided by medical science about this common but perplexing feature of human beings. What might this research look like? The development of validated tools that help us distinguish differences. Clinical trials, such as those testing communication algorithms, enroll an arm of patients and family members who believe in supernatural action and an arm of people who do not. Determining functional MRI patterns in people who believe in the supernatural versus those who do not when considering a serious health situation. What are the patterns of stress hormones? Outcomes of palliative care consultation teams are stratified by whether the patients and families (and clinicians) believe in a supernatural world. Those outcomes are not just “satisfaction,” but also symptom and economic outcomes. Patient/family satisfaction surveys are stratified by the belief in the supernatural. What helps? What hurts? As a clinician, I need better tools for this group of people I am asked to help. Currently, I have nothing better than my ability to be “diplomatic” or “culturally competent.” I fervently wish our next cohort of bright young clinician scientists take on this methodologically challenging frontier. **Access at:** <https://goo.gl/wciXJV>

End-of-life care in Canada

Developing a palliative care competency framework for health professionals and volunteers: The Nova Scotian experience

JOURNAL OF PALLIATIVE MEDICINE | Online – 15 May 2018 – In 2014, Nova Scotia released a provincial palliative care (PC) strategy and implementation working groups were established.¹ The Capacity Building & Practice Change Working Group, comprised of health professionals, public advisors, academics, educators, and a volunteer supervisor, was asked to select PC education programs for health professionals and volunteers. The first step in achieving this mandate was to establish competencies for health professionals and volunteers caring for patients with life-limiting illness and their families and those specializing in PC. In 2015, a literature search for PC competencies and an environmental scan of related education programs were conducted. The Irish Palliative Care Competence Framework serves as the foundation of the Nova Scotia Palliative Care Competency Framework.² Additional disciplines and competencies were added and any competencies not specific to PC were removed. To highlight interprofessional practice, the framework illustrates shared and discipline-specific competencies. Stakeholders were asked to validate the framework and map the competencies to educational programs. Numerous rounds of review refined the framework. The framework includes competencies for 22 disciplines, 9 nursing specialties, and 4 physician specialties. **Abstract:** <https://goo.gl/xXGV0P>

1. “Integrated Palliative Care: Planning for Action in Nova Scotia,” Government of Nova Scotia, 2014. **Download/ view at:** <https://goo.gl/2vJ1Vj>
2. ‘Palliative Care Competence Framework, 2014.’ Download/view at the All-Ireland Institute of Hospice & Palliative Care website: <https://goo.gl/WBpBpT>

N.B. Additional articles on the role of volunteers in hospice and palliative care noted in the 14 May 2018 issue of *Media Watch* (#563, p.9).



Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.16.

End-of-life care in Australia

“Death is difficult in any language”: A qualitative study of palliative care professionals’ experiences when providing end-of-life care to patients from culturally and linguistically diverse backgrounds

PALLIATIVE MEDICINE | Online – 16 May 2018 – Ethnic minority patients have unique challenges in accessing health services. These include language difficulties, unfamiliarity with the health system, lower rates of cancer screening and survival, higher rates of reported side effects from cancer treatment and poorer quality of life. Little is known about this patient group when transitioning to palliative care. The following themes emerged [in this study]: 1) Determining the rules of engagement around discussion of diagnosis and prognosis; 2) Navigating the challenge of language to patient understanding; 3) Understanding migration experiences to establish trust; 4) Maintaining the balance between patient safety and comfort care; 5) Providing a good death experience through accommodation of beliefs; and, 6) Navigating the important role of family members while privileging patient preferences. **Abstract:** <https://goo.gl/ezBDFx>

What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities approach

PALLIATIVE MEDICINE | Online – 14 May 2018 – This is the first study to quantify the amount of support received by the bereaved from their own social networks, how this support works and why it may work. The authors argue ... for the importance of adopting a primary public health approach to support the majority of bereaved people, as this care is already provided in community settings. Although this conclusion may seem rather obvious in most health policy and practice fields, it is important to note that, for the field of bereavement policy and practice, a public health approach is in its infancy. Furthermore, most research and practice development have to date been focussed on acute care models of therapeutic intervention and not ... with a population approach to grief. This study has revealed that most care comes from people already involved in the everyday lives of those recently bereaved. These people are assets already in place, contributing to each other’s resilience. Some of them are healthcare practitioners contributing through their everyday activities, not bereavement programmes *per se*. In providing bereavement care, it is therefore prudent to support these “everyday assets,” ensuring that their care is recognised, appreciated and not disrupted by overreach from professional services. These assets will complement quality bereavement care that identifies and offers counselling and therapy to those who need it. Much of the compassionate communities approach has been focussed on end-of-life care for ageing and dying, and it needs to be extended to bereavement. **Full text:** <https://goo.gl/EBxFXV>

New Italian law about end of life: Self-determination and shared care pathway

RECENTI PROGRESSI MEDICINA, 2018;109(5):267-271. The Italian Parliament recently approved the law concerning “rules on informed consent and advance directive (AD).” The authors discuss the new rules and the bioethical issues also in relation to the provisions stated by the Convention on Human Rights & Biomedicine (Convention of Oviedo). The new law deals with relevant issues that were confined to jurisprudential rulings so far, such as the informed consent, the withdrawal/withholding of medical treatment (including artificial nutrition and hydration), the content of medical information, including the modalities, the medical responsibility and, finally, the value of ADs. In the authors’ opinion this law provides essential rules to expressly strengthen the patients’ autonomy, eliminating the juridical uncertainty on many central issues (such as the refusal of life-sustaining treatments) that have been the subject of contradictory judgments ruled by the Italian Courts. **Abstract:** <https://goo.gl/Quezgeq>

N.B. Italian language article.

A snapshot of Australian social workers in palliative care and their work with estranged clients

SOCIAL WORK IN HEALTH CARE | Online – 14 May 2018 – The authors describe a mixed method survey that was administered to a group of Australian palliative care social workers. Specifically, it aimed to investigate the ways that social workers understood and worked with clients who were estranged from family at the end of life. Respondents suggested that estrangement potentially impacted clients emotionally, practically, and existentially. They were challenged to make clear assessments, provide emotional support, encourage new ways of thinking about estrangement, to manage practical issues, work with the client's family, and monitor their own professional role. Theories and models of intervention and levels of training are discussed. **Abstract:** <https://goo.gl/PuvfEu>

Knowledge, practices, attitudes and opinions of the health personnel of the Department of Pediatrics of a University Hospital in Colombia about the limitation of therapeutic effort in children

UNIVERSITAS MÉDICA, 2018;59(1):1-5. Coverage in palliative and end-of-life care (EoLC) in Colombia is limited, particularly for children, as the number of trained personnel is limited and there are no pediatric palliative care (PC) training programs. In the same way, within the medical school curriculum there are no subjects about PC for adults or children. In a study conducted in 2014 in Colombia it was found that less than 5% of the undergraduate medicine and nursing programs include PC as a specific subject, which is in accordance with the situation of the region. This is the first study about knowledge, practices, attitudes and opinions about limitation of therapeutic effort (LTE) in the Hospital Universitario San Ignacio (HUSI). Since 2011, there has been an awareness-raising process in this hospital – particularly in the pediatric service – and since 2016 the hospital has a pediatrician with formal training in pediatric PC. Although there is a limitation regarding training in pediatric palliative and EoLC in children in Colombia, the Department of Pediatrics at HUSI has achieved an awareness about the subject of end of life; this has allowed health personnel to recognize that this subject is essential for their professional practice and to consider that it is necessary to increase their formal and non-formal training. According to the data of this study, although there is a lack of knowledge on the subject, this is not a reason to consider LTE as taboo or inappropriate in children. **Abstract (inc. list of references):** <https://goo.gl/JeSXMv>

N.B. This is an extract from the English language, full text. To access click on pdf icon.

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 18 May 2018 – **'Communication during end-of-life care of pediatric patients.'** Findings from a review of 65 studies suggest that when a child enters end-of-life care (EoLC), many parents try to protect their child and/or themselves by avoiding discussions about death. Despite current recommendations, medical teams often refrain from discussing EoLC with pediatric patients until death is imminent for a variety of reasons (e.g., family factors and discomfort with end-of-life conversations). Parents consistently report a need for honest complete information, delivered with sensitivity. Pediatric patients often report a preference to be informed of their prognosis, and siblings express a desire to be involved in end-of-life discussions. **Abstract:** <https://goo.gl/PtV38Q>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 15 May 2018 – **'Healthcare users' experiences of communicating with healthcare professionals about children who have life-limiting conditions: A qualitative systematic review.'** This review included 29 studies conducted across 11 countries and involving at least 979 healthcare users... The four domains of communication experience identified through thematic synthesis are: 1) Information; 2) Emotion; 3) Collaboration; and, 4) Relationship. Although included studies were from a range of settings and diverse populations, further research is needed to explore whether and how domains of communication experience differ across settings and populations. In particular, further research about children's palliative care experiences is needed. **Abstract:** <https://goo.gl/pvQ4pW>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CANADIAN PSYCHOLOGY*, 2018;59(2):132-143. **‘Psychological aspects of medical assistance in dying...’** This article reviews those aspects of medical assistance in dying (MAiD) that are of particular relevance to psychologists... It includes a brief overview of the major legal cases that led the Supreme Court of Canada to overturn the laws against assisted suicide. It addresses such issues as the prevalence of the desire for death in the terminally ill, reasons for requesting MAiD, the concept of “intolerable suffering,” and the association between MAiD, depression, and suicide. Data from The Netherlands, Belgium, and Oregon are also reviewed briefly and contrasted; differences in the incidence of MAiD in these jurisdictions point to the importance of permitting MAiD to be provided by clinicians (euthanasia) rather than requiring patients to self-administer lethal medication (assisted suicide). It remains to be seen whether new legal challenges will lead to the extension of MAiD to other patient groups. **Abstract:** <https://goo.gl/yK4SdS>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 15 May 2018 – **‘Exploring Canadian physicians’ experiences providing medical assistance in dying: A qualitative study.’** In 2016, Canada was the latest country, following several European countries and American states, to legalize physician-assisted death. Although some studies report on physician attitudes towards medical assistance in dying (MAiD) or describe patient characteristics, there are few that explore the professional challenges faced by physicians who provide MAiD. Participants in this study described three challenges associated with providing MAiD: 1) Their relationships with other MAiD providers were enhanced and relationships with objecting colleagues were sometimes strained; 2) They received inadequate financial compensation for time; and, 3) They experienced increased workload, resulting in sacrifices to personal time. Although these providers did not intend to stop providing MAiD at the time of the interview, they indicated their concerns about whether they would be able to sustain this service over time. **Full text:** <https://goo.gl/UefRuf>

N.B. In October 2017, the Canadian Society of Palliative Care Physicians conducted a survey of its members regarding Medical Assistance in Dying (MAiD). Questions included: “How would you describe your current involvement in MAiD?” **Download/view survey findings at:** <https://goo.gl/UWb8rX>

- *POLICY SCIENCES* | Online – 16 May 2018 – **‘Between morality and rationality: Framing end-of-life care policy through narratives.’** This paper analyzes the nature of the debate generated prior to the implementation of the Act Respecting End-of-Life Care in 2015 in Québec (Canada). Including medical assistance in dying (MAiD) along existing palliative care services, the act is an important policy change on a very sensitive issue. As such, MAiD could be categorized as a morality policy issue, the latter being defined as a particular category of policy because of its specific features (issues of first principle, technical simplicity, high salience, public interest, and public participation). The authors’ research reconstructs four public opinion framings as advanced and transmitted through the media between 2005 and 2015. It shows that although opponents to the bill unsurprisingly framed the debate in deontological terms, mostly referring to sanctity of life as one of the most important values in society, they also framed it on rational-instrumental grounds in a similar proportion, alleging the danger of a slippery slope and potential abuse. As well, if some of the proponents favored a moral framing centered on the argument that dignity and individual autonomy take precedence over all other values, others put forward a rational-instrumental one, where the slippery slope/abuse argument is used as a cautionary statement against the artificial prolongation of life. **Abstract (inc. list of references):** <https://goo.gl/FwR22q>

Worth Repeating

Generalist plus specialist palliative care – creating a more sustainable model

THE NEW ENGLAND JOURNAL OF MEDICINE, 2013;368(13): 1173-1175. Although it may theoretically seem optimal for palliative medicine specialists to take on all palliative aspects of care, this model has negative consequences. First, the increasing demand for palliative care (PC) will soon outstrip the supply

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of providers. Second, many elements of PC can be provided by existing specialist or generalist clinicians regardless of discipline; adding another specialty team to address all suffering may unintentionally undermine existing therapeutic relationships. Third, if PC specialists take on all PC tasks, primary care clinicians and other specialists may begin to believe that basic symptom management and psychosocial support are not their responsibility, and care may become further fragmented. Furthermore, there are nowhere near enough PC specialists to provide all PC services for every very ill patient. At a time when many people are living longer with an increased illness burden, many patients will need both primary and specialty PC. Current levels of new trainees will barely replace retiring PC clinicians. Part of the solution is to increase fellowship funding and develop alternative pathways to fellowship training and certification, and the American Academy of Hospice & Palliative Medicine and other organizations are working to address the workforce challenge. In the current cost-conscious environment, expanding workforce may be a tough sell, but the proven ability of PC to simultaneously improve quality and save money makes it a critical part of the care plan for the most seriously ill (and expensive) patients. As part of this planned expansion of PC delivery, we need a care model that distinguishes primary PC (skills that all clinicians should have) from specialist PC (skills for managing more complex and difficult cases), so that they can coexist and support each other. [Noted in the 11 March 2013 issue of Media Watch (#296, p.10)] **Full text:** <https://goo.gl/35T3H6>

[Media Watch: Access on Online](#)

International



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

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

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

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

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

Asia

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

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

Australia

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

[Scroll down to 'International Websites']

Canada

BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION: <https://goo.gl/qw5ti8>

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[Scroll down to 'Palliative Care Network Community']

Europe



EUROPEAN JOURNAL OF PALLIATIVE CARE: <https://goo.gl/KjrR6F>

[March/April 2018 issue (Scroll down to 'The homeless: A vulnerable population with poor access to palliative care.')]

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

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



South America

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

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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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