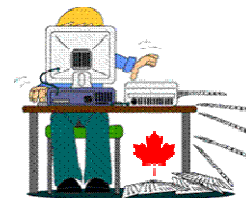


Media Watch...

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

End-of-life care is failing a large number of patients: Scroll down to [Specialist Publications](#) and 'Progressive dwindling in multiple sclerosis: An opportunity to improve care' (p.16), in *Plos One*.

Canada

Palliative care a pressing concern

ALBERTA | *The Edmonton Journal* (OpEd) – 26 July 2016 – Throughout Canada's struggles with the emotional, divisive and ethically complex debate over the legality of assisted dying, there has been consensus in one area: This country could do far more to look after those suffering from terminal illness and pain. Anyone who has watched a loved one struggle with a debilitating, life-ending illness can attest to the system's shortcomings. That's why a new cross-country initiative called Palliative Care Matters,¹ being led by Alberta's Covenant Health and a dozen other health-related organizations, is a most welcome conversation to see underway. The goal, according to Fred Horne, Alberta's former health minister who is serving as co-chairman of the venture, is to talk with Canadians about how they'd like to see palliative care (PC) improved

and then transfer that information to the Conference Board of Canada to develop a proposal to improve end-of-life care. Access to PC is uneven – an *ad hoc* approach, as Horne noted. Whether you have access to good care or not can depend on your geography. <http://goo.gl/r3FoTe>

Specialist Publications

'Implementing the first regional hospice palliative care program in Ontario: The Champlain region as a case study' (p.9), in *BMC Palliative Care*.

'Pediatric palliative care program versus usual care and healthcare resource utilization in British Columbia: A matched-pairs cohort study' (p.14), in *Journal of Palliative Medicine*.

1. Palliative Care Matters: www.palliativecarematters.ca

N.B. Nine key studies on access to PC in Canada, published between 1995 and 2014, are listed in Media Watch, 22 December 2014, #389 (p.4). In December 2015, the Canadian Cancer Society published 'Right to Care: Palliative Care for all Canadians.' [Noted in Media Watch, 18 January 2016, #445 (p.1)] <http://goo.gl/f3iFEB>

Cont.

Related

- PRINCE EDWARD ISLAND | CBC News (Charlottetown) – 26 July 2016 – **‘Palliative home care program big success so far, says province.’** Paramedics Providing Palliative Care at Home began last December and allows palliative care (PC) patients living at home to get care from paramedics, especially for pain and symptom management. Previously, a 911 call from a PC patient would typically lead to the patient being taken to a hospital. The province said paramedics have responded to 76 calls from in-home PC patients at night, and 27 patients – or 35% – have been able to remain in their home with support from paramedics, while 49 patients – 65% – asked to be taken to the Provincial Palliative Care Centre in Charlottetown or the nearest hospital. There are 354 PC patients registered with the program on P.E.I. <http://goo.gl/ac2MVI>

Palliative care doctors decry Ontario’s new opioid policy

ONTARIO | *The Globe & Mail* – 25 July 2016 – Palliative care (PC) doctors are calling on the Ontario government not to cut off access to high-dose opioid medications for their patients, saying those nearing the end of life or suffering from cancer pain “deserve better.” Ontario will become the first province to stop paying for all opioids that exceed the equivalent of 200 milligrams of morphine a day under its public drug plans. The policy change ... takes place against a backdrop of rising addiction rates and overdose deaths across Canada.

Stephen Singh, of the Canadian Society of Palliative Care Physicians, said he was “appalled” to read about the government’s decision to no longer fund high-dose opioids. Rather than eliminating funding altogether for these painkillers, he said, the government should allow PC physicians to continue providing the opioids for their patients at no cost. Darren Cargill, section chair of palliative medicine at the Ontario Medical Association, explained that he will have to “wallpaper” patients with multiple fentanyl patches to deliver the same pain relief they get from a single higher-dose patch. Dr. Cargill said the government needs to strike a balance between addressing the needs of PC patients who require these pain medications to remain comfortable and the widespread abuse of prescription opioids. Several other provinces are monitoring Ontario’s announcement. The Alberta government says it plans to conduct a formal review of the changes, while Saskatchewan will look at whether it should adopt similar measures. In British Columbia, the government says it is reviewing Ontario’s move, but has no immediate plans to change its coverage of the drugs. <http://goo.gl/CldjNX>



Related

- THE CANADIAN PRESS | Online – 26 July 2016 – **‘Health Minister not sure why Canada tops opioid-consuming countries.’** It remains a mystery why Canada and the U.S. are the world’s heaviest opioid users, but [Federal] Health Minister Jane Philpott says divining the answer may hold the key to solving what she considers a national public health crisis. Philpott, a physician herself, said the problem has only grown worse over the last several years as the number of overdoses and opioid-related deaths has continued to grow. <http://goo.gl/bdORRe>

Noted in Media Watch, 29 February 2016, #451 (p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 23 February 2016 – **‘The pendulum swings for opioid prescribing.’** For most of the 20th century, a common belief among the public, including physicians, is that an opioid like morphine, even if prescribed by a physician for a medical indication, causes addiction. The consequence was extraordinary and unnecessary suffering after surgical operations, trauma, and cancer. The worst thing I read was advice in the *Journal of the American Medical Association* in a paper written in the 1940s that, when a doctor prescribes morphine to a patient dying of cancer in the hospital, he should alternate “real” drug with *placebo* in order to see if the patient really needs the drug. Yikes! The 1990s and 2000s saw an increase in the willingness of physicians to prescribe opioids because of the correction of this fundamental misunderstanding. Although we learned that pain is complex, and multifactorial, and that opioids are good for some kinds of pain (e.g., cancer pain, postoperative and posttraumatic pain), there are other kinds of pain (e.g., muscle strain, low back pain without radiological abnormalities) where it doesn’t work at all. But nuance doesn’t make for good marketing, and opioids as all-around safe analgesics for everything that hurts made for promiscuous prescribing. <http://goo.gl/rDY6wn>

U.S.A.

Prison hospice

National survey of prison health care: Selected findings

NATIONAL HEALTH STATISTICS REPORTS (No. 96, p.6) | Online – 28 July 2016 – Hospice care followed a pattern similar to that of long-term or nursing home care, with 35 participating states providing hospice care exclusively on-site. Of these, 12 had either a specific hospice program or reserved beds for hospice care in at least one facility, and 6 of the 12 states jointly provided hospice care and long-term care in shared units or beds. The other 23 states providing hospice care on-site did not provide any qualifying information with their response. Respondents from 9 states reported hospice care was provided both on-site and off-site, though most stated that off-site care was rarely used. Two of the 9 states sent all or most female prisoners off-site for long-term or hospice care to ensure the safety of female prisoners who would otherwise be cared for in areas with mostly male prisoners. <https://goo.gl/CwPYbv>

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

Terminally ill homeless people in Salt Lake City face death with dignity at unique hospice: “They deserve peace of mind”

UTAH | *PEOPLE Magazine* – 27 July 2016 – Funded primarily through private donations, The INN Between opened one year ago in a renovated school “so that terminally ill homeless people would have a place to die in dignity, instead of on the streets,” Kim Correa, executive director of the hospice, tells *PEOPLE*. “Last year, we had 47 people die on the streets in Salt Lake City. That’s 47 too many. Society has turned its back on these people,” she adds. “We spend more time and money on homeless pets living at animal sanctuaries than we do on people living on the streets. They’re not homeless people, they’re abandoned people. At their end of their lives, they deserve a little peace of mind.” With room for 16 residents (there is

sometimes a wait list), The INN Between looks more like a bed-and-breakfast than a hospice, with sunny bedrooms and a community dining room and living area where men and women gather (as they’re able) to share meals and swap stories about their unconventional lives. <http://goo.gl/ov0kil>

Specialist Publications

‘Physician burnout and the calling to care for the dying: A national survey’ (p.7), in *American Journal of Hospice & Palliative Medicine*.

N.B. Selected articles on end-of-life care for the homeless noted in Media Watch 14 March 2016, #453 (pp.14-15). **BRA**

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.¹ 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>

1. Ashpole BR. ‘Communications with the Public, Politicians, and the News Media,’ *Oxford Textbook of Palliative Medicine*, 5th Edition (pp.357-359), Oxford University Press, 2015. <https://goo.gl/Vi07RS>.



International

End-of-life care in Australia

Tasmania's health system under pressure as federal funding dries up

AUSTRALIA (Tasmania) | ABC News (Hobart) – 28 July 2016 – There are concerns gaps are being left in Tasmania's health system after a large Commonwealth cash injection dried up at the end of June. The [2012] \$325 million Tasmanian Health Assistance Package included money for palliative care ... but the money ran out on 30 June. Palliative Care Tasmania was one of the services funded by the package. It offered support and training on end-of-life care to more than 13,000 Tasmanians in the past 18 months. General manager Colleen Johnstone said Tasmania's ageing population and high rate of complex chronic diseases meant end-of-life planning was particularly important in the island state. <http://goo.gl/IFw9c9>

Noted in Media Watch, 7 April 2014, #352 (p.6):

- AUSTRALIA (Tasmania) | *The Herald-Sun* (Melbourne) – 1 April 2014 – **'Care of dying to happen at home under new palliative care program.'** A new \$35 million palliative care (PC) package has been rolled out to allow more Tasmanians to die in their homes. The new Hospice@Home program was launched with Federal Government funding from the Tasmanian Health Assistance Package. Delivered by district nurses, it will not only benefit patients and their families but also free up hospital beds. Up to \$35.2 million will be spent over three years delivering 2,000 community-based packages of PC. <http://goo.gl/TxUbo5>

Taking care of cancer patients “more stressful than in West”

SINGAPORE | *The Straits Times* – 25 July 2016 – Caregivers of cancer patients ... [in Singapore] ... feel more burdened and stressed compared with their counterparts in the West, a study has found.¹ And bucking the trend highlighted by previous such studies, male caregivers were found to have poorer qualities of life than their female counterparts. The two-year study of 258 caregivers in Singapore involved the answering of 35 questions on their physical and emotional state, as well as on things such as the level of social support they received. When the results were compared with those of similar studies overseas, Singaporean caregivers were found to fare worse than those in Britain, Canada and the U.S., but better than those from Iran and Korea. Associate Professor Rathi Mahendran of the

Yong Loo Lin School of Medicine at the National University of Singapore, who co-led the study, said cancer patients in the West might rely less on their family, hence their family members are not taxed as much. In Canada, a family caregiver can take up to eight weeks of unpaid but job-protected leave per calendar year for each specified family member. <http://goo.gl/M4HeLS>

Specialist Publications

'Singaporean caregivers' experiences of placing a relative into long term care' (p.11), in *Clinical Gerontologist*.

1. 'Quality of life of family caregivers of cancer patients in Singapore and globally,' *Singapore Medical Journal*, published online 19 April 2016. <https://goo.gl/Tsler6>

Noted in Media Watch, 13 June 2016, #466 (p.8):

- SINGAPORE | AsiaOne – 8 June 2016 – **'Almost 8 in 10 Singaporeans wish to die at home: Survey.'** A new study ... found that 77% of Singaporeans wish to die at home, but only 27% of Singaporeans do so. Of those who want to die at home, most said they would still choose to do so even if there was insufficient support from family, friends or medical professionals. The study ... also found that they wish to die affordably and not leave financial burdens behind. <http://goo.gl/ob8fek>

Cont.

Related

- THE NETHERLANDS | *The Netherland Times* (Amsterdam) – 27 July 2016 – ‘**Informal caregivers’ workload “irresponsibly” high: Nurses organization.**’ Over 30% of nurses and caregivers think that an “irresponsible” number of tasks are left up to informal caregivers, according to a survey by the ... Verpleegkundigen & Verzorgenden Nederland (Dutch Nurses’ Association). Three out of five of the survey respondents indicated that they sometime pick up a task that is not their responsibility, to give the informal caregivers a bit of a break. There is a gap between the help needed by clients in the neighborhood and the support municipalities offer. <http://goo.gl/mxG98o>

End of life from the perspective of an intensive care nurse

I have seen death unite families and spill secrets that tear them apart

U.K. | *The Guardian* – 25 July 2016 – Death is ugly. It’s not glamorous, and most people do not close their eyes and slip away peacefully at home in their beds, surrounded by loving family. The death I see comes with plastic tubes and cannulas shoved into oozing blood vessels, giant machines that hiss, click and shriek alarms as they mechanise the life of a human being, and a rainbow of bad smells. It comes with cheap fabric curtains, stiff white sheets and sunken, fluid-swollen skin. It comes with an unexpected phone call that drags you from your bed into cold and uncomfortable waiting rooms at 3 a.m. Even if it is expected, it still comes with an icy shock and a deep, gut-wrenching sadness. I have seen death unite families that haven’t spoken to each other for 10 years – arguments forgotten, old grudges meaningless. I have seen death spill secrets that tear families apart. I have seen a woman bring her lover to the bedside for comfort while her husband lay unconscious. I have called security for two brothers who started to fight about inheritance over the top of their dying mother’s body. I have held in my arms a young woman after her father died, who cried tears of relief at a future without his constant abuse. I have caught grown men from hitting the floor when they faint at the sight of their best mate lying unconscious on a ventilator. I have broken the ribs of patients by doing chest compressions as I am trying to resuscitate them, and not regretted a single one even if they don’t make it. One man, after several hours of stoic silence at his dying wife’s bedside, suddenly broke down in tears and told me in detail about the last time they made love before she collapsed on the way to work with a massive heart attack. I have had a chair thrown at me by the son of a woman who couldn’t be saved, even after 50 bags of blood and three hours of non-stop resuscitation. Death makes you behave in ways you didn’t realise were inside you. <https://goo.gl/w8mMAh>

Noted in Media Watch, 9 November 2015, #435 (p.13):

- *INTENSIVE CARE MEDICINE EXPERIMENTAL*, 2015,3(Suppl):A649. ‘**Work-related experiences in intensive and palliative care units and their relation to burnout.**’ Out of the 355 professionals included in this study, 27% were in burnout (defined as being in burnout and in high risk of developing this syndrome). Higher burnout levels were significantly associated with the following work-related experiences: night shifts, conflicts, decisions to withhold treatment, decisions to withdraw treatment, and implementing terminal sedation. Experiencing conflicts in the workplace was the most significant variable associated to higher burnout levels. These findings suggest that team-dynamics and conflict-management are paramount in the implementation of strategies and programs aiming at preventing or minimizing burnout. <http://goo.gl/nVKNQG>

N.B. Official statement of the U.S.-based Critical Care Societies Collaborative, ‘Burnout Syndrome in Critical Care Health-care Professionals,’ published in *Chest*, 2016;150(1):17-16. <http://goo.gl/6g7Hfd>



World hospice &
palliative care day

‘Living and dying in pain: It doesn’t have to happen’

8 October 2016

<http://goo.gl/iKZH4k>

End-of-life care in England

Doctors at leading hospital put great-grandfather with a chest infection on notorious “death pathway” after wrongly deciding he could not be saved

U.K. (England) | *The Daily Mail* – 23 July 2016 – Doctors at one of the country’s leading hospitals condemned a veteran to die on a notorious “death pathway” after they wrongly decided he could not be saved. Great-grandfather Josef Boberek was admitted to Hammersmith Hospital in West London with a chest infection, but died days later after doctors incorrectly told his family that he was at death’s door and deliberately withdrew his fluids and normal medication. Now an official health watchdog report ... has revealed that the pensioner would have lived and returned to his normal life had he received proper treatment and not been placed on the

discredited Liverpool Care Pathway.^{1,2} The damning report by the Health Service Ombudsman found a litany of failings at the hospital... <http://goo.gl/07mogd>

Specialist Publications

‘Inpatient transfer to a care home for end-of-life care: What are the views and experiences of patients and their relatives? A systematic review and narrative synthesis of the U.K. literature’ (p.16), in *Palliative Medicine*.

1. ‘Review of Liverpool Care Pathway for Dying Patients,’ Department of Health, July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://goo.gl/ujDKOT>
2. ‘End of Life Care Audit – Dying in Hospital National report for England 2016,’ Royal College of Physicians, May 2016. [Noted in Media Watch, 9 May 2016, #461 (p.6)] <https://goo.gl/x2qSih>

N.B. The audit is the first to be carried out following the official withdrawal of The Liverpool Care Pathway in 2014. The audit is a detailed investigation of the care of dying people against five priorities of care established in ‘One Chance to Get it Right: Improving People’s Experience of Care in the Last Few Days and Hours of Life,’ published by the Leadership Alliance for the Care of Dying People, June 2014. [Noted in Media Watch, 30 June 2014, #364 (p.7)] <https://goo.gl/7iBIUy> **BRA**

Specialist Publications

End-of-life care in Wales

Unscheduled care admissions at end-of-life: What are the patient characteristics?

ACUTE MEDICINE, 2016;15(3):68-72. Unscheduled acute hospital admissions and subsequent deaths in hospitals of patients considered palliative are increasing, despite many patients’ preference to die at home. A large proportion of these patients are admitted via acute medical units or emergency departments. The integration of primary and secondary care within Wales should enhance the delivery of end-of-life care at home but unscheduled admission for patients with palliative care needs remains prevalent. A retrospective, observational study was conducted in all unscheduled admissions at end-of-life at a single health board in South Wales, U.K. over a period of one month. The result showed that 47% of patients who died within 48 hours of unscheduled admission are considered to be palliative. They were elderly (median age 80) and had a poor performance status (78%). Over 1/3 (39%) were admitted from a nursing or residential home. Less than a quarter (22%) had an advance care plan in place. <http://goo.gl/QSih9Z>

N.B. Additional articles on the avoidability of hospital readmissions in the context of end-of-life care noted in Media Watch 25 July 2016, #472 (p.5), 18 July 2016, #471 (p.14) and 14 March 2016, #455 (p.12).

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

Physician burnout and the calling to care for the dying: A national survey

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 27 July 2016 – The authors assessed whether physicians in end-of-life specialties had higher rates of burnout and/or calling to care for the dying. They also examined whether the patient centeredness of the clinical environment was associated with burnout. Nearly a quarter of physicians (i.e., survey respondents) experienced burnout, and rates were similar across all specialties. Half of the responding physicians agreed that they felt called to take care of patients who are dying. Burned-out physicians were more likely to report working in profit-centered clinical environments... Physicians who identified their work as a calling were more likely to work in end-of-life specialties, to feel emotionally energized when caring for the dying, and to be religious. <http://goo.gl/AAD2d6>

Noted in Media Watch, 27 June 2016, #468 (p.9):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 23 June 2016 – ‘**Personally meaningful rituals: A way to increase compassion and decrease burnout among hospice staff and volunteers.**’ Three hundred ninety hospice staff and volunteers from across 38 [U.S.] states completed an online survey. The majority of respondents used personally meaningful rituals after the death of their patients to help them cope (71%). <http://goo.gl/AoElto>

Noted in Media Watch, 25 April 2016, #459 (p.11):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2016;51(4):690-696. ‘**Prevalence and predictors of burnout among hospice and palliative care clinicians in the U.S.**’ Overall, the authors observed a burnout rate of 62% [among survey respondents], with higher rates reported by non-physician clinicians. Most burnout stemmed from emotional exhaustion, with depersonalization comprising a minor portion. Factors associated with higher rates of burnout include working in smaller organizations, working longer hours, being younger than 50 years, and working weekends. <http://goo.gl/amM8OB>

N.B. Additional articles on burnout among hospice and palliative care professionals noted in the issue of Media Watch of 9 November 2015, #435 (pp.13-14).

End-of-life care in Australia

Palliative care in undergraduate medical education: How far have we come?

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 27 July 2016 – A systematic review was undertaken on articles published from December 2001 to November 2015 on palliative care teaching for undergraduate medical students. In all, 650 abstract citations were obtained, of which 126 were relevant to the research questions. There is greater consistency in the content being delivered as part of end-of-life care education within medical schools. The most frequently taught topics include attitudes to death and dying, communication skills, and pain management. Pediatric care and religious/cultural issues are less frequently addressed. Teaching institutions are also utilising a broader range of teaching modalities. Ongoing challenges relate to correlating our current practice in medical education to professional recommendations and the expressed needs of junior doctors to practice competent end-of-life care. <http://goo.gl/il10hx>

Noted in Media Watch, 25 April 2016, #459 (p.9):

- *BMC MEDICAL EDUCATION* | Online – 14 April 2016 – “‘**That’s not what you expect to do as a doctor, you know, you don’t expect your patients to die.**’ **Death as a learning experience for undergraduate medical students.**’ The authors could not find any medical education literature that discusses medical students learning about the social working environment of clinical institutions regarding how death is viewed and worked with on a daily basis. Given the reactions by students to their social working environment, this is an important area to consider so that novice clinical students can have another way of interpreting, and making sense of, their new and sometimes strange clinical environment. <https://goo.gl/UkRbsR>

Dying well with reduced agency: A scoping review and thematic synthesis of the decision-making process in dementia, traumatic brain injury and frailty

BMC MEDICAL ETHICS | Online – 27 July 2016 – Three major themes arose from the review: First, the process of end-of-life decision-making took place in the context of the rhetoric of shared decision-making that included families and clinicians, but not, directly, the patients themselves. Patient wishes were sometimes overruled by doctors or families, which raises concerns about the fragility of the patient's autonomy within this process. Nevertheless, patients lacking capacity influenced the decisions of others through a variety of passive and active means, and this dynamic is little studied in the papers reviewed here. Secondly, academic, public and professional discourse that presumed equivalence between minimal medical intervention in the dying process and a "good death" vied with counterfactual requests and behaviours when faced with death in reality. Poor understanding of death may drive this paradox, not just among the public, but among policy makers and healthcare professionals, suggesting that corrective intervention to increase understanding is a major challenge. Finally, the authors noted the tension between the increasingly international adoption of antecedent end-of-life decision-making and the difficulties in progressing this approach in countries where it is well established. While containing some interventions to promote antecedent end-of-life decision-making, the studies also documented widespread barriers to their use. Not least of these was the variety of personal perspectives on death, which suggests that parallel approaches require development. Together these three themes indicate a number of directions for future research in this area, which are likely to be broadly applicable to other conditions that result in reduced agency. Above all, this review emphasises the limits of current concepts and approaches to end-of-life decision-making, and the need for fresh approaches. <http://goo.gl/lZFjtI>

Related

- *JOURNAL OF MEDICAL ETHICS* (Institute of Medical Ethics), 2016;42(8):481. **'Health law and policy: The scope and bounds of liberty?'** A number of contributions to this month's issue [noted in past issues of Media Watch] tackle questions pertinent to the place of and limits to individual liberty in different health domains. These include the new medically assisted dying law in Canada, organ donation euthanasia in Belgium and The Netherlands, adolescent autonomy and refusals of treatment, and public health policy. Although spanning diverse areas of enquiry, each of these papers confronts aspects of the ongoing debate about how health-related law and policy ought to take account of competing moral claims and obligations within liberal society. <http://goo.gl/q6uqfo>

N.B. Journal contents page: <http://goo.gl/Q3lOSd>

- *JOURNAL OF MEDICINE & PHILOSOPHY* | Online – 26 July 2016 – **'Autonomy and the moral authority of advance directives.'** Although advance directives (AD) are widely believed to be a key way to safeguard the autonomy of incompetent medical patients, significant questions exist about their moral authority. The main philosophical concern involves cases in which an incompetent patient no longer possesses the desires on which her AD was based (e.g., in cases of severe dementia). The question is, does that entail that prior expressions of medical choices are no longer morally binding? The author believes that the answer is "yes." He argues a patient's autonomy is not respected by honoring the desires she used to have but no longer does. The author also considers and rejects the view that honoring an AD that reflects the patient's previous values must be in that patient's best interests. If that is correct, then ADs in the kind of case at issue are not morally binding. <http://goo.gl/MPZU2R>
- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2016;12(3):289-306. **'Exhaust all measures: Ethical issues in pediatric end-of-life care.'** Unique challenges are faced by parents of seriously ill children as they must serve as the legal authority for health care decisions of children under 18, although the child's wishes must also be considered. Social workers must balance core social work values, bioethical values and psychosocial issues presented by such situations. While studies have been conducted with physicians and nurses regarding ethical issues in pediatric end-of-life care settings, little is known about how social workers experience these conflicts. <http://goo.gl/r2r2Uv>

Cont.

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2016;12(3):259-276. ‘**Detained and dying: Ethical issues surrounding end-of-life care in prison.**’ This article examines prominent ethical issues that emerge for prison personnel who are tasked with providing care to terminally ill offenders by presenting three offender composite characters that exemplify dying offenders and emergent ethical issues surrounding their care. Identification and critical analysis of these ethical issues demonstrate the need for strong commitment to ethical practice and highlights specific issues for prisons to examine in their own end-of-life care practice. <http://goo.gl/dawUDt>
- *MEDICAL LAW INTERNATIONAL* | Online – 22 July 2016 – ‘**Council of Europe: Guide on the decision-making process regarding medical treatment in end-of-life situations.**’ The Guide,¹ published by the Committee on Bioethics of the Council of Europe, has been analyzed by taking into consideration different perspectives, such as medical, ethical, and legal views. In this commentary, reasons why this guide should be applied not only by the care team but also by patients, his or her family, relatives, or legal proxies have been examined. In addition, some argumentations why this guide should also include physician-assisted suicide and euthanasia have been explained. The application of ethical principles and the balance between the patient’s right to self-determination and the physician’s duty of care have been studied under the general principle of fair distribution of public resources in palliative care. Moreover, some examples from national legislations of some Western European countries have been given to illustrate and support these guidelines. <http://goo.gl/eNTx9e>



1. ‘Guide on the decision-making process regarding medical treatment in end-of-life situations,’ Council of Europe, 2014. [Noted in Media Watch, 12 May 2014, #357 (p.5)] <http://goo.gl/zqjPTv>

Implementing the first regional hospice palliative care program in Ontario: The Champlain region as a case study

BMC PALLIATIVE CARE | Online – 26 July 2016 – The implementation of the Champlain Hospice Palliative Care Program provides a case study for a systems approach and change management in a health care system that requires collaboration and coordination between many independent service providers. Unlike other jurisdictions in Canada where a single regional health authority is responsible for delivering health services, the system in the province of Ontario has no single service provider. This requires a participative approach to developing regional structures and programs to provide services in specific areas such as hospice palliative care. The Champlain Hospice Palliative Care Program has largely followed best practices as described in various models of change management and health systems implementation. However, it is still a relatively young program and very much in its infancy. The long-term success of the Regional Program depends on its ability to demonstrate measurable benefits. To this end, the custodians of the Program – as well as its funders, stakeholders and partners – strive to maintain the processes set in motion to allow the Program to mature. <http://goo.gl/yeMN3A>

[Media Watch: Online](#)

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

[Media Watch: Palliative Care Network-e Website](#)

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>

The “problematization” of palliative care in hospital: An exploratory review of international palliative care policy in five countries

BMC PALLIATIVE CARE | Online – 26 July 2016 – Findings suggest a “problematization” of palliative and end of life care in acute hospital settings. This approach to policy development influences service recommendations, many of which are designed to solve the “problem” of people being cared for and dying in hospital. However, little is known about patient preferences for place of care during periods of acute illness or the benefits they experience from being in hospital. It has been suggested that without a better understanding of patient’s priorities and preferences at the end of life, there is a risk that the model of palliative care (PC) outlined in policy will be applied “blanket-fashion” and prove to be ineffective and inequitable. As far as the authors are aware, this is the first study of how policy positions the acute hospital within a PC context. However, there are a number of limitations that need to be acknowledged. The review was limited to those policies that were available in English. The differences in health care systems may impact on the way in which policies are developed and implemented. In addition the policies were written over a decade during which PC has continued to evolve. Therefore, the themes identified cannot be applied across all countries nor would they necessarily be applicable in resource-poor countries. Nevertheless, the findings provide useful insights and provide a

baseline for future more comprehensive reviews which is inclusive of non-English speaking countries. <http://goo.gl/bOnwZ3>

“Tu souffres, cela suffit”

The compassionate hospital

JOURNAL OF PALLIATIVE MEDICINE, 2012;15(4): 457-462. The authors define a “compassionate hospital” as 1) The presence of a healing environment; 2) A sense of connection among people; and, 3) A sense of purpose and identity. They suggest how a “top down” focus on compassion as a core value by clinical leaders could maximize the compassion of health care workers, and reduce the suffering expressed and/or experienced by health care workers and patients in today’s health care facilities. The concept is intended to act as a proposition for health policy researchers and decision-makers in health care so as to reduce the suffering of sick patients, and to restore a sense of well-being, meaning, and purpose among health care workers. [Noted in Media Watch, 11 February 2013, #292 (p.14, under ‘Worth Repeating.’ <http://goo.gl/ppgW6k>

N.B. “Tu souffres, cela suffit” translates to “You are suffering – that is enough,” the words of Louis Pasteur. Pasteur stated: “One does not ask a sick person from what country or of what religion are you. You are sick, that is enough. Put yourself in my care and I will treat you.”

N.B. Countries included in the study were the U.K., Australia, Switzerland, Ireland and Singapore. The U.S. was not included as there is no Federal-based policy in PC. **BRA**

Mismatch between physicians and family members views on communications about patients with chronic incurable diseases receiving care in critical and intensive care settings in Georgia: A quantitative observational survey

BMC PALLIATIVE CARE | Online – 22 July 2016 – The survey, conducted in four cities of Georgia, revealed the mismatch between the views of clinical and intensive care (CIC) physicians and family members of the patients with chronic incurable diseases receiving care in CIC settings – on communication topics covering possible deterioration of a patient’s condition, future treatment plan, how death may occur, and respect to patients’ spiritual attitudes and religiousness. Only one quarter of patients family members were satisfied with the communication level. The reason for their dissatisfaction was sense of inadequate appreciation of their needs and requirements. In contrast, 78.5 % of physicians considered their communication with patients’ family members as positive. This mismatch indicates that in order to provide the best care for chronic incurable patients and their family members in a holistic way the physicians of CIC settings must have both relevant clinical knowledge and skills as well as the ability to provide effective communication with patients and their families. <http://goo.gl/li6rGc>



Palliative psychiatry for severe persistent mental illness as a new approach to psychiatry? Definition, scope, benefits, and risks

BMC PSYCHIATRY | Online – 22 July 2016 – Despite psychiatrists’ efforts to prevent mental illness and to promote recovery, some patients will develop “severe persistent mental illness” (SPMI). These represent a particularly vulnerable population, at risk of either therapeutic neglect or overly aggressive care. As proposed, a new variation on an old approach – the explicit application of palliative care principles to psychiatric illnesses – has the potential to improve quality of care, person-centredness, and autonomy for these patients. The working definition of palliative psychiatry suggested here may serve as a starting point for further development of a conceptual framework and clinical approach. Important milestones will include consensus around definitions of SPMI, palliative approaches, care decisions, and futility judgments, along with international acceptance of these concepts among psychiatrists and service users. Establishing an evidence-based staging model of mental illness may be an important prerequisite for these tasks. <http://goo.gl/M1GRkY>

Singaporean caregivers’ experiences of placing a relative into long term care

CLINICAL GERONTOLOGIST, 2016;39(3):167-189. Caregivers [i.e., study participants] were found to place significant emphasis on cultural values, specifically on filial piety. This impacted their caregiving role prior to placement, when making the decision to place their relative into a nursing home and in their continued involvement after placement. Despite the changing role, the placement experience was fraught with persisting difficulties involving maintaining the relationship with the resident and developing a new relationship with the nursing home. <http://goo.gl/u5BTql>

The extended palliative phase of dementia: An integrative literature review

DEMENTIA | Online – 26 July 2016 – The aim [of this literature review] was to highlight how dementia is defined in the literature and describe what is known about the symptomatology and management of advanced dementia regarding the needs and preferences of the person with dementia and their family carer/s. There was no consistent definition of advanced dementia. The extended palliative phase was generally synonymous with end-of-life care. Advanced care planning is purported to enable professionals to work together with people with dementia and their families. A lack of understanding of palliative care among frontline practitioners was related to a dearth of educational opportunities in advanced dementia care. There are few robust concepts and theories that embrace living the best life possible during the later stages of dementia. These findings informed our subsequent work around the concept, “ementia palliare.” <http://goo.gl/ujukhx>

Related

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 26 July 2016 – ‘**Aggressiveness of end-of-life care for hospitalized individuals with cancer with and without dementia: A nationwide matched-cohort study in France.**’ Older individuals with cancer with dementia [i.e., the patient population studied] were less likely to receive aggressive treatment in their last month of life than those who were not diagnosed with dementia. This discrepancy raises important ethical questions for clinicians and healthcare policy-makers. <http://goo.gl/XZJh0h>

N.B. Additional articles on end-of-life care for people living with dementia noted in Media Watch, 4 July 2016, #469 (pp.15-16).

[Media Watch: Back Issues](#)

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

Defining volunteering in hospice and palliative care in Europe

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(7):184-191. The Taskforce on Volunteering in Hospice & Palliative Care (HPC), created in 2013 within the European Association for Palliative Care, presents a White Paper on the definition, typology, role, position, identity and value of HPC volunteering. The White Paper is based on a literature review, focus group discussions and a Delphi-like consultation of six European experts. Consensus was reached, among others, on the fact that volunteering in care-focused roles is best understood as a relational activity and that the contribution of volunteers in such roles lies in “being there” and creating value through encounters. The concept of “being there” used by volunteering organisations in several countries seems to offer a good base from which to research the theoretical framework

of HPC volunteering, as well as develop training, supervision and self-reflection.

Extract from *European Journal of Palliative Care* article

While the concept of “being there” was embraced ... some interesting reflections emerged. Clearly, the concept does not capture the whole extent of volunteer activity; for example, volunteers who mostly support an organisation through fundraising or administration will have a more task-oriented understanding of their role. Some volunteers would be more comfortable with the concept of ‘being there’ because it suits their personality, while others would prefer to think about their role as focused on performing tasks.

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 29 July 2016 – ‘**Nationwide survey on volunteers’ training in hospice and palliative care in Poland.**’ 79% of volunteers worked alongside patients and performed the following services: accompanying patients (76%), feeding patients (61%), cleaning rooms (48%), dressing and bathing (42%) and organising leisure time (40%). Fewer volunteers were involved in activities outside of patient support; for example, charity work and fundraising (34%), cleaning hospice buildings (23%), as well as providing information and education (22%). According to volunteers, prior to undertaking their duties, 64% participated in theoretical training and 37% took part in a practical course. The majority attended courses relating to general knowledge of hospice and palliative care (64%) and volunteer rights and duties (55%). <http://goo.gl/qtS7lm>

N.B. Selected articles on HPC volunteers noted in Media Watch, 25 July 2016, #476 (pp.5,6,11).

Cure or care – diagnosing death in the modern era

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(7):192-194. In a healthcare system where primary objectives are geared towards prolonging life, death has come to represent failure. As physicians, our fear to engage in discussions about death leads us to focus solely on managing abnormal disease physiology. We must move to harness the influence of compassionate human relationships, placing them at the core of a system that recognises suffering beyond physical parameters.

THE JOURNAL OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE

European Journal of
Palliative Care 

Access requires a subscription. Contents page for the July/August issue: <http://goo.gl/wo8sxe>

Cont.

Related

- *CRITICAL CARE MEDICINE* (Society of Critical Care Medicine) | Online – 15 July 2016 – ‘**Quality of life and recommendations for further care.**’ Physician recommendations for further medical or palliative treatment only at the end of life may influence patient decisions. Little is known about the patient characteristics that affect physician-assessed quality of life or how such assessments are related to subsequent recommendations. Physicians [i.e., survey respondents] who recommended continuing full medical treatment rated quality of life three times higher than those recommending palliative treatment only... <http://goo.gl/MpnXGf>
- *THE LANCET*, 2016;388(10043):444-446. ‘**End-of-life care across the world: A global moral failing.**’ The Economist Intelligence Unit ... [has] ... served humanity well by creating a thoughtful way to grade the availability and quality of care for patients near the end of life across the world; their results expose a dismal situation. Modern medicine’s focus on mastering each part of the human body and the diseases that make them malfunction has generated remarkable power to sustain life. But this focus, shared by governments and health-care planners, has neglected the dying and their suffering, as if repressing a shameful secret. <http://goo.gl/7mqiQ9>
 1. ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ The Economist Intelligence Unit, October 2015. Commissioned by the Lien Foundation of Singapore. [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/bT3PV5>

Experiences of bereaved carers: Insights from the literature

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(7):200-203. The aftermath of caregiving is a period shaped by situational, temporal and relational factors, giving rise to a fluid and diverse set of experiences. Carers are not uniform in their responses to the end of their caregiving. Although there is evidence that former carers may benefit from supportive interventions, this is by no means universal as bereavement is an individual experience characterised by different emotions and different responses to the loss. While the death of the care recipient is inextricably coupled with grief, it is increasingly recognised that the circumstances of the death – for example, whether it was a “good” or a “bad” death – will have an impact on the bereaved carer’s ability to adjust to the loss. What does emerge from the literature is that bereavement is not perceived by the former carer as an endpoint, but as a transition within an ongoing care-related life course trajectory. The post-caregiving period should be viewed as an integral part of the caregiving career, with recognition that former carers continue to have practical and psychological needs once caregiving comes to an end. It is argued that improving support for them should be a policy priority.

Considering the impact of stigma on lesbian, gay and bisexual people receiving palliative and end-of-life care

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING | Online – 22 July 2016 – Stigma is a common characteristic among lesbian, gay and bisexual (LGB) people’s lives. The LGB population faces a challenge in finding ways to adapt to its stigmatised identity. Stigma and its related processes can have an isolating and negative affect on the LGB individual, who is seen as and often perceives themselves as different. Stigma can also have a negative effect on health and wellbeing and can influence the type of care received from health and social care professionals, including those working in palliative care. This paper presents a discussion of the impact that stigma has on LGB people who access and receive palliative and end-of-life care. <http://goo.gl/uJJ0Qx>

N.B. Selected articles on end-of-life care for lesbian, gay, bisexual and transgender communities noted in Media Watch, 13 June 2016, #466 (pp.7-8), and 8 February 2016, #448 (p.16).

Intellectual disabilities and decision making at end of life: A literature review

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Online – 25 July 2016 – Individuals with an intellectual disability are vulnerable to having end-of-life decisions made for them merely due to the presence of a disability. As a result, decisions made by others may not reflect the exact wishes of the individual. The emerging themes include the following: 1) Assumption of lack of capacity; 2) Inconsistency in evaluating capacity and communication challenges; and, 3) Third party decisions. Earlier discussions about end-of-life planning before the diagnosis of a life-limiting illness would be beneficial. Lacking is a consistent approach to determining capacity for individuals with an intellectual disability. The findings from this review provide a foundation for a decision tree in end-of-life decision making for individuals with an intellectual disability. <http://goo.gl/sCALxr>

Noted in Media Watch, 8 February 2016, #448 (p.12):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(1):45-47. **‘Palliative care for people with intellectual disabilities: The European Association for Palliative Care White Paper in a nutshell.’** The Taskforce on Palliative Care for People with Intellectual Disabilities of the European Association for Palliative Care (EAPC) recently published a White Paper containing 13 norms and related statements, real-life examples, and available resources. ¹ Journal contents page: <http://goo.gl/qIWex7>

1. ‘Defining Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe, Using Delphi Methods: A White Paper from the European Association of Palliative Care,’ *Palliative Medicine*, 11 August 2015. [Noted in Media Watch, 17 August 2015, #423 (p.19)] <http://goo.gl/FQUsti>

N.B. Additional articles on palliative care for people living with intellectual disabilities are listed in this issue of Media Watch.

Pediatric palliative care program versus usual care and healthcare resource utilization in British Columbia: A matched-pairs cohort study

JOURNAL OF PALLIATIVE MEDICINE | Online – 25 July 2016 – Evidence on the impact of pediatric palliative care programs (PPCP) on resource utilization is scarce and requires broader measures to include utilization beyond the hospital setting. This research provides a Canadian comparative analysis between children in a PPCP with those under usual care, including hospice use to inpatient resource use measurement. PPCP users [i.e., patient population studied] were more likely to have advanced directives (100% vs. 27%). The authors found no significant difference in number of admissions; however, PPCP users had an increase in admissions post-referral compared to pre-referral, driven by the need for critical care. They did not find a significant difference in length of stay, but observed longer admissions among PPCP users pre- (1.91 days/month) and post-referral (3.66 days/ month) compared to usual care. Over 60% of inpatient utilization shifted to the hospice post-referral. <http://goo.gl/h5o3KV>

A time and place: The role of social workers in improving end-of-life care

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE, 2016;12(3):185-194. Despite waves of public and professional activity targeted toward improving care for the dying and supporting the families, gaps in care and challenges in end-of-life care (EOLC) persist. Contentious issues such as the so-called “death panels” or physician payment for discussion of advance directives and care wishes at the end of life; aid in dying; and, regarding individuals who actively choose death ... are continually debated in the public media. Progress toward improvement in the experience of dying remains incremental and change has been slow. With the release of a second Institute of Medicine report devoted to what it means to die in America in the 21st century,¹ momentum and opportunity for change may increase. If this is to happen, social workers will need to deliver the range of bio-psychosocial care that patients and families so desperately need. However, holistic care of the individual will only improve if the nation also addresses ongoing systemic problems in financing, policy, and service delivery in EOLC. <http://goo.gl/2hrcbo>

1. ‘Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,’ Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://goo.gl/mm4o6W>

Managing bodies, managing persons: Post-mortem care and the role of the nurse

THE NEW BIOETHICS | Online – 21 July 2016 – This paper addresses how interactions between U.K. palliative care nursing staff and the bodies of the deceased they care for function as a mechanism to help them make sense of death in line with their work as carers. Through an analysis of post-mortem care rituals, the author argues that nurses play an integral role in the “making of the dead,” and look at how this functions in relation to their role as carers of bodies in line with associated states of personal wellbeing. Further to this, there is an argument to be made for the recognition of the nurse’s place in biomedical models as managers of the transient body; as the constructors of the well, sick, living and dead body. <http://goo.gl/iJhJr9>

Related

- *ONCOLOGY NURSE ADVISOR* | Online – 25 April 2015 – “**Bathing & Honoring**” nursing intervention benefits families after patients die in acute care setting.’ Although nurses are expected to give compassionate care around the time of death, the literature lacks specific evidenced-based interventions for care after death. [Noted in Media Watch, 4 May 2015, #408 (p.12)] <http://goo.gl/xuz95N>
- NATIONAL END-OF-LIFE CARE PROGRAMME & NATIONAL NURSE CONSULTANT GROUP (U.K.) | Online – 22 April 2015 – ‘**Updated guidance for professionals who provide care after death.**’ The physical care given by nurses following death in hospitals has traditionally been referred to as “last offices.” The authors refer to “care after death,” a term more befitting a multi-cultural society. [Noted in Media Watch, 27 April 2015, #407 (p.7)] <http://goo.gl/Lq3kDN>
- *NURSING TIMES* (U.K.) | Online – 11 May 2010 – ‘**Last offices neglected in over half of hospital deaths.**’ A dearth of training and guidance means nurses are failing to follow “last offices,” the simple procedures for treating dead patients with dignity and respect. [Noted in Media Watch, 16 June 2014, #362 (p.14, under 'Worth Repeating')] <http://goo.gl/Azrsg5>

Media Watch: Editorial Practice

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

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

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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.

Inpatient transfer to a care home for end-of-life care: What are the views and experiences of patients and their relatives? A systematic review and narrative synthesis of the U.K. literature

PALLIATIVE MEDICINE | Online – 28 July 2016 – Transfers from hospital or “hospice palliative care units” to care homes for end-of-life care are an increasingly common part of clinical practice but are a source of anxiety and distress for patients, relatives and healthcare professionals. The published literature is limited: only three papers and one conference abstract were identified, all of low quality... No papers examined transfer from hospital: all were of transfers from hospices and were retrospective case note reviews. Many patients were reported to have been negative or ambivalent about moving and experienced feelings of anxiety or abandonment when transferred. Relatives were often either vehemently opposed or ambivalent. Although some came to accept transfer, others reported the transfer to have seriously affected their loved one’s quality of life and that the process of finding a care home had been traumatic. No studies investigated patients’ views prospectively, the views of staff or the processes of decision-making. Further research is urgently needed in this area, especially studies of patients themselves, in order to understand their experiences and views. <http://goo.gl/3BsLhu>

Progressive dwindling in multiple sclerosis: An opportunity to improve care

PLOS ONE | Online – 21 July 2016 – End-of-life care has been failing a large number of patients because of uncoordinated services, lack of communication and lack of identification of people who are dying. Formative care, when not properly designated as such can be disjointed and inadequate from the patient and family’s perspective and unnecessarily expensive from a service provider’s angle. This study concludes that these failings might impact particularly upon people with multiple sclerosis (pwMS), as 73.7% of pwMS [i.e., the patient population studied] followed the progressively dwindling trajectory to death. A marker of these failings lies in the finding that pwMS who progressively dwindle are no less likely to die in hospital than those with other trajectories to death. Ideally, those who progressively dwindle should have lower rates of hospital deaths, as a result of well-timed discussions, adequate planning and well-coordinated formative and palliative care (PC) services. This study aimed to identify factors associated with progressive dwindling and found that early disease milestones such as age at onset, progression and wheelchair use can be used as potential predictors, thus allowing timely discussions, a vital step towards providing formative care to those who need it. This study found that 72.5% of pwMS died an MS-related death, and this too was associated with an aggressive early disease course. The use of predictors of progressive dwindling, with a transfer to formative care pathways for years prior to death may improve quality of life for patients in the progressive stage of their disease and their caregivers, and may increase scope for smooth transition into PC in the home or hospice environment. The results from this study provide a frame work on which to base subsequent care strategies, and to target those who might benefit most from formative care. <http://goo.gl/Jmo5yK>

N.B. Selected articles on PC for people living with progressive neurologic disease noted in Media Watch, 16 May 2016, #462 (p.8).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *REVISITA BIOÉTICA*, 2016;24(2):375-87. ‘**Euthanasia and assisted suicide in western countries: A systematic review.**’ In 2015 the issue of assisted death was widely publicized by the international media after the first legal euthanasia case was held in Colombia. Also in this same year, assisted suicide was legalized in Canada and in the state of California in the United States. Currently, assisted death is allowed in four Western European countries: Netherlands, Belgium, Luxembourg and Switzerland; two North American countries: Canada and the US, in the states of Oregon, Washington, Montana, Vermont and California; and Colombia, the sole representative in South America. From a systematic literature review, this work aims to establish the prevalence and the criteria adopted for the practice of euthanasia and assisted suicide in western countries and to discuss the position of similar countries where this practice is not recognized. A better understanding of the subject appears to be critical to the formation of opinions and the encouragement of further discussions. <http://goo.gl/kg0Kim>

N.B. English language article.

[Media Watch: Online](#)

International

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

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/5d1l9K>

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

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