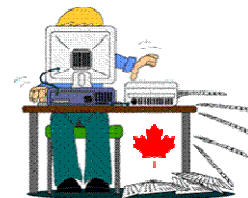


Media Watch...

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

Loss and separation: Scroll down to [Specialist Publications](#) and ‘A scoping review of bereavement service outcomes’ (p.16), in *Palliative & Supportive Care*.

Canada

How much should Ottawa spend on health? It’s complicated

THE GLOBE & MAIL | Online – 28 June 2016 – Federal Health Minister Jan Philpott has said repeatedly that she would like a new Health Accord to be signed, sealed and delivered by year’s end. On the surface, the issue is pretty simple: The provinces and territories want more money. They always do. Ottawa, for its part, wants to control spending. But more importantly, it wants political payoff for the health dollars it transfers, and the way to do that is to put strings on how the money is spent. In 2004, then prime minister Paul Martin signed a 10-year, \$41 billion Health Accord that promised to be the “fix for a generation.” While it promised to fix wait times, home care, and a host of other problems plaguing the health system, there were few accountability measures. Naturally, the provinces and territories say that [a projected increase of] 3%

[a year] is not enough – after all, there is a relentless clamour for more health spending. However, the reality is that health spending increased only 1.6% last year, thanks to holding the line on drug spending and increases in payments to health workers, and doctors in particular. <http://goo.gl/z49glv>

Extract from *The Globe & Mail* article

Despite the “hold-the-line” approach, Ottawa is actually open to spending more on specific programs, particularly home care, where it has promised \$3 billion over four years. Other federal priorities include pharmacare, mental health, and **palliative care**, all of which have some traction in various provinces.

N.B. Canada was ranked 11th of the 80 countries surveyed in the ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/JsSbW3>

Media Watch: Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.19.

Ontarians are talking about end-of-life care, yet for many, palliative care may begin too late or not at all, new report finds

ONTARIO | Health Quality Ontario – 28 June 2016 – Almost 60% of people in Ontario who die receive palliative care (PC) services, according to a new report by Health Quality Ontario, the provincial advisor on the quality of health care.¹ And among those who have a record of receiving PC, about half begin to receive it in their last month of life. According to a survey highlighted in the report, Ontarians are thinking about end-of-life care. Nearly two-thirds (64%) of older adults surveyed in Ontario say they've had discussions with family, friends or health care professionals about health care treatments in the event they become ill and cannot make decisions on their own – higher than the Canadian average and many countries around the world. But the report suggests there could be gaps in PC services. In surveys of patients and caregivers in Ontario, most people say they would prefer to die at home, but the report found most patients in Ontario who receive PC die in hospital. More than 95,000 people died in Ontario between April 2014 and the end of March 2015, and, based on the best available data, about 54,000 – or almost 60% – of them had a record of receiving a PC service. <http://goo.gl/4iQXTu>

End-of-life care in Ontario

Among a Health Quality Ontario survey respondents who were determined to have received palliative care (PC) services:

- About half (47.9%) began receiving PC in their last month of life
- Nearly two-thirds (64.9%) died in hospital
- About one-quarter (25.8%) spent half or more of their last month of life in hospital
- Nearly two-thirds (62.7%) had unplanned emergency department visits in their last month of life
- Less than half (43.3%) received palliative home care services in their last month of life
- About one-third (34.4%) received a home visit by a doctor in their last month of life

Source: Health Quality Ontario

[Specialist Publications](#)

'Staffing in Ontario's long-term care homes: Differences by profit status and chain ownership' (p.11), in *Canadian Journal on Aging*.

1. 'Palliative Care at the End of Life,' Health Quality Ontario, June 2016. <http://goo.gl/GW0Xh9>

Selected articles on end-of-life care in Ontario

- ONTARIO | *The Windsor Star* – 23 June 2016 – **'Ontario has "long way to go" to improve end-of-life care, says researcher.'** 52% of people dying in Ontario between 2010-2012 had at least one instance of palliative care (PC) in their last year of life, says an Institute of Clinical & Evaluative Sciences study.¹ Despite the fact 80% of people say they'd prefer to spend their final days at home and die in their own bed, only 20% of dying patients receive PC at home and just 10% receive a single palliative house call from their doctor. More than 50% of Ontarians die in acute care hospitals, 24% die in long-term care and 25% die at home. [Noted in Media Watch, 27 June 2016, #468 (p.1)] <http://goo.gl/lyfJ1K>
 1. 'Palliative care delivery across health sectors: A population-level observational study,' *Palliative Medicine*, 16 June 2016. [Noted in Media Watch, 20 June 2016, #467 (p.15)] <http://goo.gl/JyPCE6>
- *JOURNAL OF PALLIATIVE CARE*, 2015;31(2):76-88. **'Predictors of place of death for those in receipt of home-based palliative care services in Ontario, Canada.'** Patients with high nursing costs and patients with high personal support worker costs were more likely to die at home than those with low costs. Patients who lived alone were less likely to die at home than those who cohabitated, and those with a high propensity for a home-death preference were more likely to die at home than those with a low propensity. [Noted in Media Watch, 8 June 2015, #413 (p.15)] <http://goo.gl/z8PqEF>

Cont.

- *PLOS ONE* | Online – 26 March 2015 – ‘**The health care cost of dying: A population-based retrospective cohort study of the last year of life in Ontario, Canada,**’ The study is descriptive in nature and does not directly address quality of care; nevertheless, it can be inferred that a proportion of health care utilization near the end of life, such as certain emergency room visits, hospital admissions and medications, are potentially preventable and burdensome for the patient. [Noted in Media Watch, 13 April 2015, #405 (pp.1-2)] <http://goo.gl/8BnvCd>

N.B. Additional reports on home care and end-of-life care in Ontario are noted in Media Watch of 19 October 2015, #432 (pp.1-2).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | *The Montreal Gazette* – 29 June 2016 – ‘**Palliative care centres can opt out of assisted dying.**’ While the McGill University Health Centre is facing a backlash for a policy exempting its palliative care (PC) unit from providing medical aid to die, † private hospices like the West Island Palliative Care Residence are allowed to opt out of providing that service to dying patients – despite the province’s landmark right-to-die legislation. <http://goo.gl/E6tKZb>
 1. ‘McGill University Health Centre rethinking palliative care unit’s exemption from providing assisted death,’ CBC News, 28 June 2016. The McGill University Health Centre (MUHC) is reconsidering a policy that requires patients seeking a doctor-assisted death to transfer out of its palliative care (PC) unit. <http://goo.gl/TM5aBR>
- BRITISH COLUMBIA | *The Globe & Mail* – 27 June 2016 – ‘**British Columbia woman, rights group file legal challenge against assisted-dying law.**’ In a test case on the highly charged issue of whether the right to a medically assisted death should belong only to those who are already dying, a 25-year-old woman with a muscle-wasting disease is claiming the constitutional right to be protected from suffering that could last decades. Julia Lamb ... filed a constitutional challenge to the Liberal government’s assisted-dying law in British Columbia. Supreme Court on Monday, just 10 days after Parliament passed the law. She does not wish to die now, but says the law denies her the peace of mind of knowing that if her suffering becomes intolerable, she has a way out. <http://goo.gl/gcNJe0>

U.S.A.

What doctors know about how bad it is, and won’t say

THE NEW YORK TIMES | Online – 1 July 2016 – We’ve known for years doctors hesitate or even decline to discuss a poor prognosis with patients and their families. They fear that bad news will dash hopes; they don’t want to appear to be giving up. Often, their training hasn’t prepared them for sensitive conversations. One researcher told me oncologists believe that if they fail to offer yet more chemotherapy, even when that’s futile, patients will leave, seeking another doctor who will. Yet the supposed cornerstone of contemporary medicine – patients making informed decisions about their care – depends on their understanding their situation, their life expectancy, their probable quality of life, the pros and cons of any proposed treatment. (Or, when patients themselves are incapacitated, it depends on their surrogate decision-makers’ understanding.) Experts have repeatedly urged doctors to talk about the elephants in the room, especially at the end of life. But two recent studies show how achingly slow progress has been.^{1,2} Even terminally ill patients still receive scant information, researchers have found, while family members acting for ICU patients commonly contend with confusion and misinformation. The studies uncover some reasons for the disconnect. Doctors, it seems, shouldn’t get all the blame. <http://goo.gl/sXnslm>

1. ‘Discussions of life expectancy and changes in illness understanding in patients with advanced cancer,’ *Journal of Clinical Oncology*, 23 May 2016. [Noted in Media Watch, 30 May 2016, #464 (p.3)]
2. ‘Prevalence of and factors related to discordance about prognosis between physicians and surrogate decision makers of critically ill patients,’ *Journal of the American Medical Association*, 2016;315(19): 2086-2094. [Noted in Media Watch, 2016, #463 (p.4)] <http://goo.gl/VG6Xf3>

Study: Racially biased oncologists spend less time with Black cancer patients

GEORGIA | *The Atlanta Black Star* – 30 June 2016 – Many studies have shown the negative effect health providers' underlying prejudices can have on the doctor-patient relationship and the decisions patients make about their care. And according to a new study, oncologists are not immune.¹ Some cancer physicians are letting their implicit racial biases get in the way of quality treatment for Black patients. Researchers at the Karmanos Cancer Institute in Detroit, Michigan, studied video-recorded interactions between 18 non-Black medical oncologists and 112 of their new African American patients to see whether the doctors' unconscious beliefs might come into play. The scientists took notes during the sessions at Detroit-area cancer hospitals, rating the doctors' bedside manner and tracking the length of the meeting, including the amount of time doctors and patients spoke. Patients filled out a survey following the appointment, which asked questions about the physician's communication skills as well as the participants' level of distress, trust and feelings about the suggested treatment options. The findings ... revealed that oncologists who had previously tested higher for implicit racial bias spent less time with their patients, leaving them unsat-

isfied and often unable to remember what was discussed during the meetings. African American patients rated those doctors' communications as less patient-centered and supportive and reported less confidence in recommended treatments. The patients also perceived the treatments as being more difficult to get through. <http://goo.gl/P0Qm2q>

Specialist Publications

'Racial disparities in end-of-life communication and preferences among chronic kidney disease patients' (p.10), in *American Journal of Nephrology*.



The focus of the February 2016 issue is on palliative and end-of-life care for African Americans. [Noted in Media Watch, 8 February 2016, #448 (p.15).] Contents page: <http://goo.gl/6fapNx>

1. 'The effects of oncologist implicit racial bias in racially discordant oncology interactions,' *Journal of Clinical Oncology*, 20 June 2016. <http://goo.gl/Mt8DYo>

At the end of life, what would doctors do?

THE NEW YORK TIMES | Online Commentary – 30 June 2016 – The terminally ill colleagues I've known, including those I've been privileged to care for, have usually been willing to use medical treatments aplenty as long as life was worth living, and took great pains to avoid medicalizing their waning days. In any event, the public's interest in the medical treatments that doctors choose must not be allowed to reinforce our culture's tendency to see dying solely through medical lenses. More to the point is the question, how do dying doctors live? What dying doctors do with their time and limited energy, and what they say, are deeply personal, sometimes raw and often tender. Like everyone else, doctors experience pain and suffering – yet many speak of a deepening moment-to-moment sense of life and connection to the people who matter most. <http://goo.gl/Z2rbFi>

N.B. Selected articles on physician personal preferences in the context of end-of-life care are noted in Media Watch of 28 March 2016, #455 (pp.13-14) and 25 May 2015, #411 (p.2).

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>

End-of-life care better for patients with cancer, dementia: Study finds

MASSACHUSETTS | Kaiser Health News – 27 June 2016 – A new study offers surprising findings about end-of-life care (EOLC)¹ – specifically, physicians tend to be more likely to accommodate the advanced-care wishes of patients with cancer or dementia than renal disease, congestive heart failure, pulmonary disease or frailty “There’s been a lot of focus on EOLC for cancer,” said Melissa Wachterman, the study’s principal author and a physician at the Veteran’s Affairs Boston Healthcare System and the Boston-based Brigham & Women’s Hospital. “But most people don’t die of cancer. And the quality of EOLC for those dying of other conditions ... is not as good.” Researchers examined survey data from the families of about 34,000 people who died in the Veterans Affairs health system between 1 October and 30 September 2012. They looked at how those families rated the quality of medical care and whether patients had access to things like a palliative care consultation, whether they died in hospice or the intensive care unit – a majority prefer the former – and whether they had a do-not-resuscitate order in place, since those usually stem from end-of-life planning conversations. About 60% of people with a relative dying of cancer or dementia said their relative got excel-

lent end-of-life treatment, with about 80% saying the relative always got the care he or she wanted. Those figures drop off for other conditions: About 55% of people reported excellent EOLC for relatives who died of renal, cardiovascular or pulmonary conditions, and about 54% indicated that for family members dying of “frailty.” Those same groups ranged between 73% and 77% in saying doctors always gave desired care. <http://goo.gl/HuUEI6>

Commentary on Veterans Affairs study

Family assessment of quality of care in the last month of life

JAMA INTERNAL MEDICINE | Online – 26 June 2016 – There is often a fog that descends on patients, families, and health care professionals when they are navigating the difficult situation at the end of life. There is a lack of clarity regarding the trajectory of the illness, the true burdens and benefits of the myriad interventions, and how best to integrate palliative care into the overall care plan. In some illnesses, such as progressive cancer and dementia, there may be more clarity than in other conditions, such as advanced organ failure; this clarity can make overall decision making easier. <http://goo.gl/OyrDWJ>

1. ‘Quality of end-of-life care provided to patients with different serious illnesses,’ *JAMA Internal Medicine*, 26 June 2016. <http://goo.gl/IJNYLI>

When the seriously ill want to donate organs

THE WALL STREET JOURNAL | Online – 24 June 2016 – The issue of seriously ill people who want to donate organs – either as living donors or as part of an end-of-life decision – is gaining attention, both in the U.S. and in Europe. The ethics committee of the United Network for Organ Sharing, which manages the nation’s organ transplant system, and the Organ Procurement & Transplantation Network is examining the question of terminally ill patients who want to be living donors; a white paper on the topic is expected to be posted for public comment in January. European researchers [recently] published a paper ... looking at cases involving requests for organ donation in Belgium and The Netherlands as part of euthanasia, which is legal in those countries.¹ The paper reported that the procedure has been performed more than 40 times, and suggested legal changes to further facilitate the process. <http://goo.gl/ZaWxgE>

1. ‘Legal and ethical aspects of organ donation after euthanasia in Belgium and The Netherlands,’ *Journal of Medical Ethics*, 24 March 2016. <http://goo.gl/C8WCtE>

Noted in Media Watch, 9 July 2012, #261 (p.9):

- *END OF LIFE JOURNAL*, 2012;2(2). **‘The barriers to organ and tissue donation in palliative care.’** This article explores the involvement of palliative care patients in decisions about donating their tissues, why families may be reluctant to consent to donating organs/tissues of deceased loved ones, and reasons why nurses are wary of discussing the possibility of donation with patients and/or their next of kin. <http://goo.gl/dOua0l>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW MEXICO | Associated Press – 1 July 2016 – **‘New Mexico high court: Doctors can’t help patients end lives.’** The New Mexico Supreme Court ruled that terminally ill patients cannot end their lives with help from doctors, ending what right-to-die advocates thought would be a successful legal fight. In a 5-0 opinion, the high court overturned a previous district court decision that doctors could not be prosecuted under the state’s assisted suicide law, which classifies helping with suicide as a fourth-degree felony. “If we were to recognize an absolute, fundamental right to physician aid in dying, constitutional questions would abound regarding legislation that defined terminal illness or provided for protective procedures to assure that a patient was making an informed and independent decision,” Justice Edward Chavez wrote for the court. <http://goo.gl/lk5KNU>
- STATE OF NEW YORK | *Fairfield County Business Journal* – 30 June 2016 – **‘What you need to know about New York’s Medical Aid in Dying Act .’** The 2016 legislative session ended without the bill being put to a vote in either chamber. Its sponsors expect it will advance to a floor vote during the next session. The major distinction between euthanasia and physician-assisted dying (PAD) is who administers the lethal dose. With euthanasia, the physician or other third party administers the lethal dose, whereas with PAD, the lethal dose is self-administered by the patient and the patient determines whether and when to administer it. Under the Medical Aid in Dying Act, the Public Health Law of New York would be amended to include a new Article 28-F “Aid in Dying” provision. <http://goo.gl/a2L7zk>
- MASSACHUSETTS | *The New Boston Post* – 29 June 2016 – **‘Physician-assisted suicide bill fails to advance.’** A controversial bill aimed at legalizing physician-assisted suicide in the Bay State appears to be off the table for the current legislative session. The proposal was facing a key deadline, in which the joint legislative committee tasked with its review had to determine whether or not to issue a favorable report. Joint Committee on Public Health – the body tasked with responding to the deadline – voted to recommend that the bill undergo further review. <http://goo.gl/uWmXa4>

International

National Institute for Health & Care Excellence

Doctors and nurses should cuddle and comfort dying children...

U.K. (England) | *The Daily Telegraph* – 1 July 2016 – The proposed guidelines ¹ ... suggest that physical contact such as “touch, holding and massage” should be offered as non-pharmacological interventions for pain and agitation. In recent years, healthcare professionals have become wary of personal interaction with children following a spate of child abuse scandals. But the new guidance makes it clear that physical contact is important, particularly for children. It is estimated that more than 40,000 children and young people in England are living with incurable conditions. The report suggests that parents are offered locks of their children’s hair, or palm and footprints as keepsakes. It also recommends that, where possible, dying children should be moved out of hospital wards and allowed to return home, or to hospices to die. And it suggests that doctors and nurses include using art, music and play to explain the concept of death to children. <http://goo.gl/G2x3UG>

1. ‘End of Life Care for Infants, Children and Young People: Draft Guidance Consultation,’ National Institute for Health & Care Excellence, June 2016. <https://goo.gl/lrQJJJ>

High number of terminal patients unnecessarily treated, study finds

AUSTRALIA | ABC News (Sydney) – 27 June 2016 – Doctors have called for the public to discuss end-of-life care (EOLC) with their loved ones after a study revealed one third of elderly patients with an advanced or terminal illnesses receive unnecessary treatment in the last six months of their lives. ¹ The global analysis of 38 studies of EOLC ... found a significant number of patients received treatments that were of no benefit to them. These included chemotherapy, radiotherapy and CPR, when a person had a not-for-resuscitation order. Lead author Dr. Magnolia Cardona-Morrell, a senior research fellow at the University of New South Wales, found some non-beneficial treatments prevented patients from having a comfortable death. “Some of these treatments are geared towards making the patient more comfortable, but the idea is that some of them are too aggressive to be of benefit to the patient,” she said. “For example, applying CPR on an elderly [person] who has a not-for-resuscitation order, or admitting them to intensive care for over a week, or starting chemotherapy, or dialysis in the last days of life.” Non-

beneficial treatment was defined in the research as medicine, procedures, or tests administered when a patient was naturally dying, but which did not improve their chances of survival or their quality of life. <http://goo.gl/rBeFJ2>

Extract from *International Journal for Quality in Healthcare* article

The results of this review of English language medical literature (published 1995-2015) were broadly similar across the countries analysed, which included the U.S., the U.K., and Australia.

Specialist Publications

‘Ethics in practice: Is it futile to talk about “futility”?’ (p.12), in *European Journal of Anaesthesiology*.

‘Bioethics in practice: Unilateral do-not-resuscitate orders’ (p.12), in *The Ochsner Journal*.

1. ‘Non-beneficial treatments in hospital at the end of life: A systematic review on extent of the problem,’ *International Journal for Quality in Healthcare*, 27 June 2016. <http://goo.gl/4mwplS>

Noted in Media Watch, 10 November 2014, #383 (p.14):

- *MAYO CLINIC PROCEEDINGS* | Online – 28 October 2014 – ‘**Medical futility and non-beneficial interventions.**’ In 2005, 87% of Canadian intensivists surveyed believed that they had provided futile medical interventions during the past year. A 2013 study of 5 academic intensive care units found that physicians considered nearly 20% of all interventions provided over a 3-month period to be futile. The duration of futile interventions ranged from 1 to 58 days, with an estimated cost of \$2.6 million during the 3-month study. More than half of the cases were considered futile because even with intervention the physician believed that the patient’s goals were unreachable. <http://goo.gl/vqEjKL>
- *CRITICAL CARE MEDICINE* | Online – 5 November 2014 – ‘**Non-beneficial treatment in Canada: Definitions, causes, and potential solutions from the perspective of healthcare practitioners.**’ Canadian nurses and physicians [i.e., survey respondents] perceive current means of resolving non-beneficial treatment are inadequate, and we need to adopt new techniques of resolving non-beneficial treatment. Most promising strategies to reduce non-beneficial treatment are felt to be improved advance care planning and communication training for healthcare professionals. <http://goo.gl/oxOlqJ>



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>

Ageing behind bars: What are the healthcare challenges

IRELAND | *The Irish Times* (Dublin) – 27 June 2016 – The relatively recent phenomenon of ageing prison populations brings unique healthcare challenges for prison services worldwide. These include accommodating the needs of frail older prisoners and the provision of end-of-life care. Due to the accelerated ageing process caused by prison life and other factors, prisoners are usually referred to as “older” if they are over the age of 50. In July 2014 this category of “older prisoners” made up 10% of the prison population in Ireland, and between 2008 and 2014 there was a 75% increase in the Irish daily prison population aged over 50. As the prison population ages worldwide, it is expected that more prisoners will die of natural causes in prisons and have active palliative care (PC) needs. In Irish prisons when a prisoner needs PC “all prisoners are treated on the basis of equivalence of care in the community”, says the Irish Prison Service (IPS). “As far as possible all services that are required by a prisoner are facilitated in the prison. “When the care requirements exceed that available in the prison, the prisoner is transferred to the appropriate clinical setting. This will be based on clinical factors and influenced only by clinical requirements. “The most appropriate clinical setting is based on the clinical advice from the treating physician and it is not uncom-

mon for prisoners to be moved to a hospice setting for a peaceful and dignified death,” says the IPS. <http://goo.gl/s8MP9R>

Extract from *The Irish Times* article

A study presented at the recent European Association of Palliative Care World Research Congress, held in Dublin, looked at palliative care in prisons and the healthcare needs of older prisoners. Organised by the Irish Association of Palliative Care, the event was attended by more than 1,200 delegates from 47 countries. The study presented forms part of a three-year initiative.¹

1. ‘Improving palliative care for prisoners: The ‘Both Sides of the Fence’ study.’ *Prison Service Journal*, 2016;224:42-47. [Noted in Media Watch, 7 March 2016, #452 (p.13)] <http://goo.gl/lnu6xa>

[Prison Hospice Backgrounder](#)

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

[Opinion on Palliative Care in the European Union](#)

*With its origins in the meeting of a young woman with a man receiving inadequate relief from acute pain who was dying prematurely with the feeling that his life was being cut short, palliative care (PC) has shown itself to be a work of great humanity, demonstrating the solidarity of society with those of its members undergoing hardship, showing consideration of their vulnerability and recognition of their dignity. It deserves to be actively supported in such a way that it can be developed and respond to the growing needs of ageing societies that include a constantly increasing proportion of people suffering from chronic diseases and in need of PC. Let us hope that it will remain faithful to its original intention, combining medical competence with solicitude for people in circumstances of enormous vulnerability, perceived as individuals in their suffering. Much has been done in this field in the majority of European Union countries. A great deal remains to be done. PC can only be developed if volunteers will come forward for this mission, offering their time and their capacities for listening. Healthcare professionals are also needed, those ready to devote a major part of their career to this mission, which is both enriching but also stressful because of the daily confrontation with the reality of the finitude of human life. To encourage their recruitment in sufficient numbers, it is necessary that the greatness of this task should be recognised and valued, especially in the media, and that political decision-makers should have the courage to commit to this idea and take the necessary decisions.*¹

1. ‘Opinion of the Working Group on Ethics in Research and Medicine on Palliative Care in the European Union,’ Commission of the Bishops’ Conferences of the European Community, Brussels, February 2016. <http://goo.gl/0PiqIj>

End-of-life care in India

Don't torture the dying: Health ministry's draft law confuses between euthanasia and withdrawal of life support

INDIA | *The Times of India* (Delhi) – 20 June 2016 – The Constitution of India guarantees life with dignity as a fundamental right. Generally speaking, we enjoy this right. But it all changes if we get an incurable disease. Or when we eventually wither and die of old age. In those circumstances, we should still have the right to live the way we want to and die where we want to. But we find that we no longer have any choice. An *Economist* study found that India was one of the worst 15 countries in the world to die in, coming 67th out of 80 in “quality of death.”¹ In India, as we near the end of life, we cease to be treated as human beings and become mere containers of disease. Until it is seen or experienced, it is not easy to understand the degree of assault on dignity by inappropriate medical treatment in incurable diseases. Typically, even if one is fully alert and able to take decisions for oneself, one finds oneself stripped of that privilege. Whether it is advanced cancer or some other illness, the family takes over and makes decisions, and the “patient” is bundled into a hospital. There, in turn, the family loses control; hospital protocol takes over and transfers the patient to an intensive care unit. <http://goo.gl/7UiV3q>

1. ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ *Economist Intelligence Unit* (Commissioned by the Lien Foundation of Singapore), October 2015. [Noted in *Media Watch*, 12 October 2015, #431 (p.6)] <http://goo.gl/JsSbW3>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MALTA | *The Times of Malta* – 30 June 2016 – ‘**11.9% of doctors received requests for euthanasia, study shows.**’ Just under 12% of doctors have reported receiving requests for euthanasia, a survey published in the *Malta Medical Journal* shows.¹ It also shows that half of the doctors surveyed agreed to intensifying analgesia (painkillers) at the end of life with the possibility of hastening death, but 90.2% would never consider euthanasia. <http://goo.gl/27Hro0>

1. ‘Maltese doctors: views and experiences on end of life decisions and care,’ *The Malta Medical Journal*, 2016;28(2):16.-26. <http://goo.gl/U5bBIX>

Extract from *The Times of India* article

The government of India has prepared a draft law on the subject... Its objective is to “protect” the terminally ill; to ensure life and death with dignity and to provide for palliative care as the humane, viable alternative to intensive care. However, as drafted, the law confuses between euthanasia, which is wilful termination of life, and withdrawal of life support, which is only permitting natural death.

Specialist Publications

‘Palliative care standards for health care’ (p.13), in *Indian Journal of Palliative Care*.

INDIAN JOURNAL OF MEDICAL ETHICS

An issue of the *Indian Journal of Medical Ethics* published earlier this year, and noted in *Media Watch* of 8 February 2016, #448 (p.14), includes several articles which offer insights into the complexities of end-of-life care in India from an ethical, legal and medical perspective against the backdrop of the country's healthcare system and the inequities in access to healthcare. Contents page (scroll down to ‘Theme: Healing & Dying with Dignity’): <http://goo.gl/O2k0pa>

Specialist Publications

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

Racial disparities in end-of-life communication and preferences among chronic kidney disease patients

AMERICAN JOURNAL OF NEPHROLOGY, 2016;44(1):46-53. The authors explore racial variability in end of life (EOL) communication, care preferences and advance care planning (ACP) among patients with advanced chronic kidney disease (CKD) prior to decisions regarding the initiation of dialysis. Among 152 [study] participants, 41% were Black. Black patients were younger, had less education and lower income than White patients. Black patients also had less knowledge of hospice compared to White patients. A small fraction of patients (8%) reported having EOL discussions with their nephrologists and the majority had no advance directives. Blacks were more likely to have not communicated EOL preferences and more likely to prefer life-extending treatments vs. Whites. As Black and White patients with advanced CKD differ in areas of EOL communication, preferences, and hospice knowledge, future efforts should aim to improve patient understanding and promote informed decision-making. <https://goo.gl/GFGYo9>

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 26 June 2016 – ‘**Primary care residents improve knowledge, skills, attitudes, and practice after a clinical curriculum with a hospice.**’ The authors examined the feasibility and impact of a single palliative care (PC) residency curriculum, including a clinical rotation with a hospice program, across 5 cohorts of residents in 7 divergent primary care residency programs (both family medicine and internal medicine). A large effect size was seen in measures of knowledge change ... when compared to a national sample of primary care residency programs. <http://goo.gl/d771Bb>

Early experience with digital advance care planning and directives, a novel consumer-driven program

BAYLOR UNIVERSITY MEDICAL CENTER PROCEEDINGS, 2016;29(3):263-267. Barriers to traditional advance care planning (ACP) and advance directive (AD) creation have limited the promise of ACP/AD for individuals and families, the healthcare team, and society. The authors chose 900 users of MyDirectives, a digital ACP/AD tool, to achieve proportional representation of all 50 states by population size and then reviewed their responses. The participants had an average age of 50.8 years; 84% of the men and 91% of the women were in self-reported good health when signing their ADs. Among the respondents, 94% wanted their physicians to consult a supportive and palliative care team if they were seriously ill; nearly 85% preferred cessation of life-sustaining treatments during their final days; 76% preferred to spend their final days at home or in a hospice; and 70% would accept attempted cardiopulmonary resuscitation in limited circumstances. Most respondents wanted an autopsy under certain conditions, and 62% wished to donate their organs. Analysis of early experience with this ACP/AD platform demonstrates that individuals of different ages and conditions can engage in an interrogatory process about values, develop ADs that are more nuanced than traditional paper-based ADs in reflecting those values, and easily make changes to their ADs. Online ADs have the potential to remove barriers to ACP/AD and thus further improve patient-centered end-of-life care. <http://goo.gl/JyWptj>

Noted in Media Watch, 19 October 2015, #432 (p.14):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 October 2015 – ‘**Toward evidence-based end-of-life care.**’ More than two thirds of U.S. states have implemented Physician (or Medical) Orders for Life-Sustaining Treatment (POLST/MOLST) programs despite the absence of compelling evidence that they improve patient outcomes. Even less evidence is available to support such well-intentioned private initiatives as the Institute for Healthcare Improvement Conversation Project, the efforts of the Coalition to Transform Advanced Care, the Gundersen Health System’s Respecting Choices program, the widely used Five Wishes advance directive of the Aging with Dignity organization, and the services provided by for-profit companies such as Vital Decisions and Common Practice. <http://goo.gl/9gFs4X>

Elder care in Canada

Staffing in Ontario's long-term care homes: Differences by profit status and chain ownership

CANADIAN JOURNAL ON AGING, 2016;35(2):175-189. Ontario has the highest proportion of for-profit nursing homes in Canada. These facilities, known in Ontario as long-term care (LTC) homes, offer 24-hour custodial as well as nursing care to individuals who cannot live independently. Increasingly, they are also operating as members of multi-facility chains. The authors found for-profit LTC homes – especially those owned by a chain organization – provided significantly fewer hours of care, after adjusting for variation in the residents' care needs. Findings from this study offer new information on the impact of organizational structure on staffing levels in Ontario's LTC homes and have implications for other jurisdictions where a growing presence of private, chain-affiliated operators has been observed. <https://goo.gl/cAg8kr>

N.B. See 'Integrating Long-Term Care into a Community-Based Continuum: Shifting from "Beds" to "Places,"' Institute for Research on Public Policy, February 2016. The authors draw upon research in Ontario and overseas. [Noted in Media Watch, 14 March 2016, #453 (p.2)] <http://goo.gl/GVH5ff>

A positive risk approach when clients choose to live at risk: A palliative case discussion

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 29 June 2016 – Historically, safety plans to consider risk management involved a culture of risk aversion supported by sometimes paternalistic motives intended to protect vulnerable clients. New findings in the literature engage in a process that respects the ethical principles underlying harm reduction philosophies. The literature also argues for a perspective that moves away from viewing risk as only harmful, to one that supports a positive understanding of risk as part of a client's informed choice. A risk support management plan, based on a positive approach, can provide a way to both support a client's choice to live at risk, anticipate for expected complications, and inform the creation of a contingency plan to address concerns as they may arise. <http://goo.gl/VWNSVg>

Withholding versus withdrawing treatment: Artificial nutrition and hydration as a model

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 24 June 2016 – In the U.S., there is a general consensus in the medical, ethical and legal communities that the withholding and withdrawing of life-sustaining treatment are morally equivalent at the end of life. Despite this consensus, the withdrawal of treatment is still emotionally difficult... Recent literature challenges the evidence base that feeding tubes for people with advanced dementia lead to significant harm. In light of these new findings, the authors reconsider end-of-life decision making that concerns ANH to determine whether these new findings undermine previous ethical arguments and to consider how to best educate and support patients and families during the decision-making process. <http://goo.gl/kAcxdx>

Noted in Media Watch, 6 June 2016, #465 (p.8):

- *AMA JOURNAL OF ETHICS*, 2016;18(6):600-603. 'The American Medical Association Code of Medical Ethics' opinions on patient decision-making capacity and competence and surrogate decision making.' The Code considers patient decision-making capacity, mental competence, and surrogate decision making for those unable to make their own health care decisions. These concepts are discussed in a variety of contexts, including withholding and withdrawing of life-sustaining treatment.¹ <http://goo.gl/SZlwmp>

1. 'Withholding or Withdrawing Life-Sustaining Medical Treatment.' <http://goo.gl/AzVWOK>

Noted in Media Watch, 4 April 2016, #456 (p.10):

- *CLINICAL NUTRITION* | Online – Accessed 31 March 2016 – 'European Society for Clinical Nutrition & Metabolism guidelines on ethical aspects of artificial nutrition and hydration.' Principles of bioethics like beneficence, non-maleficence and justice are presented in the context of artificial nutrition and hydration. In this respect the withholding and withdrawing of artificial nutrition and/or hydration is discussed. <https://goo.gl/JbBOLI>

Ethics in practice: Is it futile to talk about “futility”?

EUROPEAN JOURNAL OF ANAESTHESIOLOGY, 2016;33(7):473-474. Within current medical practice, as the lines between life and death become increasingly blurred, we, as physicians, often find ourselves facing the decision whether to continue treating a critically unwell patient. These patients have often lost decision-making capacity because of a combination of the severity of their illness and the medication used for sedation and analgesia. A point may come when we feel that ongoing life-sustaining treatment should be withdrawn, or further interventions withheld, and we may justify this decision on the grounds that ongoing treatment is “futile.” The concept of medical futility has existed for millennia. Hippocrates advised physicians “to refuse to treat those who are overmastered by their disease,” realising that in such cases medicine is powerless. The state of being “overmastered” by a disease is subjective, as what may be intolerable to one person may be acceptable to another. Owing to this inherent subjectivity in defining what constitutes a burdensome existence, defining when a patient has been “overmastered” is not straightforward. The fact that many critically unwell patients lack capacity and cannot engage in decision making (defined in legal parlance as “incapax”) with their physicians only adds to the difficulty of deciding when ongoing treatment of that patient should stop. <http://goo.gl/FqxyOW>

Related

- *BMC MEDICAL ETHICS* | Online – 29 June 2016 – ‘**Controversies surrounding continuous deep sedation at the end of life: The parliamentary and societal debates in France.**’ France is currently in the midst of a fierce debate on what constitutes a dignified end of life and which practices are acceptable for physicians to perform. At the very core of the debate is the practice of continuous deep sedation. As argued in this paper, what is playing out is a unique opportunity to clarify the legality of continuous deep sedation as an end-of-life practice. Recognizing continuous deep sedation as a *sui generis* practice could remove the need to portray the practice either as symptom control or as a form of euthanasia. This might make it less difficult to focus on the issues that are most relevant and pertinent to continuous deep sedation. <http://goo.gl/LT95qy>
- *THE OCHSNER JOURNAL*, 2016;16(2):111-112. ‘**Bioethics in practice: Unilateral do-not-resuscitate orders.**’ Many states [in the U.S.] have enacted comprehensive laws about the creation of advance directives (AD), the need for their recognition by healthcare providers, and how AD are to shape a patient’s last days. Many of these laws address not only living wills (called declarations in Louisiana) but also interhospital physician orders for life-sustaining treatment, such as the Louisiana Physician Orders for Scope of Treatment (LaPOST). But what of traditional do-not-resuscitate (DNR) orders? Do laws govern the execution of DNR orders, particularly in challenging circumstances, such as when no evidence exists to establish the patient’s wishes, and the physician’s medical opinion of the value of continued care is in disaccord with the family’s desires? The answer is, generally, no. However, the ethical principles and analogous laws discussed [in this article] ... may be useful in directing physicians and other providers in the implementation of DNR orders. <http://goo.gl/RxUJby>

Palliative care in cancer: The challenge for how professionals can best meet patients’ and families’ needs

EUROPEAN JOURNAL OF CANCER CARE, 2016;25(4):531-533. In this issue [of the journal], is present several articles, from across Europe, which share a theme: the importance of early palliative care (PC) and assessment in meeting the needs of patients’ and those closest to them.¹ The studies presented highlight how we need to see beyond the disease to better understand the person, to assess and treat symptoms, and identify unmet palliative care needs. While not intervention-focused, these articles provide further evidence for early assessment of needs, the impact that advanced cancer can have on psychological well-being, and the importance of supporting patients, and those closest to them, emotionally and physically. We see how unmet needs vary over time, and how professionals play a pivotal role in identifying these and exploring patient preferences for treatment. One of the recurring themes is that of maintaining hope and normality for patients and carers, with many of the authors alluding to this in their work. <http://goo.gl/RkXwal>

1. Journal contents page: <http://goo.gl/UEKjRw>

End-of-life care in India

Palliative care standards for health care

INDIAN JOURNAL OF PALLIATIVE CARE, 2016;22(3):239-243. The Economist Intelligence Unit, in 2015, published the Quality of Death Index, which ranked the end-of-life care (or lack, thereof) across the world. Among 80 countries included in the study, India came 67th. At one look, this may seem an improvement on the 2010 report, where India had ranked 40th out of 40 countries, below Uganda, which was at 39. However, closer study of the report would inform us that India escaped from being at the very bottom, not because of better quality of death, but because there is an atmosphere conducive to growth of palliative care (PC), as created by the formation of India's National Program in Palliative Care and the amendment of the Narcotic Drugs & Psychotropic Substances Act of India in 2014, though they are yet to be implemented. The Economist Intelligence Unit's report, while critical of the poor attention to the dying person in India, was appreciative of the developments in the State of Kerala. Kerala has more PC than in the rest of the country put together, though only 3% of India's population lives in this tiny state. More than 185 institutions in this state have a doctor and nurse with training in PC, stock and dispense oral morphine, and most dispense it free to patients in pain. At one glance, this would appear to be a heaven within a sea of suffering; but a closer look would tell us that Kerala has this exalted position only in comparison with the rest of the country. Things are not too rosy in Kerala, either. <http://goo.gl/FweNfk>

1. '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit (Commissioned by the Lien Foundation of Singapore), October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/JsSbW3>

N.B. Contents page to the current issue of the *Indian Journal of Palliative Care*: <http://goo.gl/8iffcc>

End-of-life care in Israel

Physician-facilitated designation of proxy decision maker

ISRAEL JOURNAL OF HEALTH POLICY RESEARCH | Online – 28 June 2016 – This article suggests that proxy decision-maker designation is only one aspect of end-of-life care; a challenging area littered with ethical and moral dilemmas. Without early, open and frank discussions with patients regarding their wishes at the end of life, proxy decision-makers may be in no better position than physicians or a court appointed proxy to make decisions in the patients' best interests/benefits. This commentary also touches upon the use of health and care passports being developed or in early phases in the U.K., and whether these may be utilised in the field of palliative care in Israel. <http://goo.gl/dm2QyX>

Media Watch: Searching Back Issues



The screenshot shows the IPCRC.NET website. On the left is the logo for The Institute for Palliative Medicine, featuring a sunburst design. The main content area includes a navigation menu with links for Home, About IPM, CIA, NCI, Partners, Contact, and Acknowledgements. Below the menu is the text 'GLOBAL PALLIATIVE CARE NEWS ARCHIVE' and 'MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE'. A search box with 'Google Custom Search' is visible. A sidebar on the right lists 'Media Watch Archives' with links for various years and months: 2016, Jan - Dec; 2016, July - December; 2014, January - June; 2013, July - December; 2013, January - June; 2012, July - December; 2012, January - June; 2011, July - December; 2011, January - June; and Current. A featured article snippet is also visible, titled 'MW 487: Compromised autonomy: When families pressure patients to change their wishes'.

Back issues of the weekly report can be downloaded at <http://goo.gl/frPgZ5>. Enter keyword/s in the search box. Links to back issues of Media Watch that include mention of the subject or topic of interest (among other links to information/resources on the IPCRC website) will be displayed.

Self-reported hearing in the last 2 years of life in older adults

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 24 June 2016 – Self-reported hearing loss increases during the last 2 years of life and is associated with physical and social vulnerability. Thirty-two percent ... of all participants and 60% ... of the 7% of participants who used hearing aids rated their hearing as fair or poor. The prevalence of fair or poor hearing was highest in participants interviewed closest to death... <http://goo.gl/iDI8pK>

N.B. Selected articles on hearing loss in the context of end-of-life care are noted in Media Watch of 4 April 2016, #456 (p.13).

Knowing death well: Intimate and contextual death competence among end-of-life labourers

JOURNAL OF CONTEMPORARY ETHNOGRAPHY | Online – 22 June 2016 – End-of-life (EOL) workers, regardless of occupational status, work against a transformed culture of death and dying. Against that backdrop of technological brinkmanship, segregation of aging and dying from other aspects of life, and a cultural denial of death's inevitability, EOL workers develop competence and expertise; however, that competence varies, shaped by the training and occupational status of its purveyors. Based on three years of participant observation and interviews with EOL labourers, the author identified two types of death competence – intimate and contextual – that develop at different levels of the occupational hierarchy. One situates death philosophically and morally, the other garners insight from the body to sustain elders' personhood in the face of diminishing capacities. These ways of knowing are valuable in a death-denying culture. <http://goo.gl/Nosl6>

Music therapy and spiritual care in end-of-life: A qualitative inquiry into ethics and training issues identified by chaplains and music therapists

JOURNAL OF MUSIC THERAPY | Online – 28 June 2016 – While it was clear that both chaplains and music therapists felt it was appropriate for music therapists to provide spiritual care as part of the hospice team, there is a need for formal and informal spiritual care training for music therapists doing this type of work. Training should potentially include information about comparative religions, cultural competence, scope of practice, and maintaining personal boundaries. <http://goo.gl/wgW6Ma>

The use of humour by caregivers: Is there a link with the confrontation with death?

MÉDECINE PALLIATIVE | Online – 30 June 2016 – The place of humour has been studied extensively in the caregiver-patient relationship; however, the authors did not find studies on the place of humour in the relationship between caregivers. This study focused on the frequency and type of humour... The authors also tried to answer the question: "Does one's choice to work in and be trained in palliative care (PC) influence humour?" They interviewed three categories of professionals (nurses, carers and hospital service agents) and compared three places of practice: PC units, surgical services, and residential facilities for dependent elderly people. The sample included a total of 342 caregivers. The authors did not find any significant relationship between the type of humour and the workplace, professions or service selection. However, the survey shows a link between the presence of humour and the workplace (less common in nursing homes) and occupation (more common among nurses than among hospital service agents). The type of humour also differs according to the profession and training in PC (more social-affiliative humour in people trained in PC). <http://goo.gl/3Y4qL8>

N.B. French language article.

Palliative care in hospital-at-home services in France: Nationwide study using administrative data

MÉDECINE PALLIATIVE | Online – 27 June 2016 – Hospital-at-home services increased the provision of palliative care (PC) between 2008 and 2014 (+61% increase in the number of home-based hospitalizations, accounting for 28,000 patients in 2014). PC now accounts for 23.6% of the total number of days of hospitalization. During the same period, the mean age of patients and their level of activity of daily living impairment increased. Cancer remains the most frequent diagnosis: the 30 most common tumor localizations are found in nearly 60% of the total case-mix. In 2014, almost 18,000 individuals died while being hospitalized at home (including 13,700 during a PC stay), the proportion of deaths in overall number of discharges rising from 7.2% in 2008 to 10.2% in 2014. However, the authors found considerable variation in the development of PC in hospital-at-home services across counties (from 0.5 to 87.5 PC home-based hospitalization per 1000 deaths). The provision of PC by hospital-at-home services remains insufficient compared with the needs for home-based PC in the general population. <http://goo.gl/APoJon>

N.B. French language article.

Related

- *FAMILY PRACTICE* | Online – 28 June 2016 – ‘**French general practitioners’ sense of isolation in the management of elderly cancer patients.**’ Although heavily involved in the care of their elderly patients living with cancer, the GPs who participated [in focus groups] reported feeling isolated in their role at each step during the course of the disease. The principal themes addressed were screening and diagnosis, therapeutic decisions, multidisciplinary consultation meetings, the announcement of the diagnosis and monitoring at home. <http://goo.gl/rsuKE7>
- *MÉDECINE PALLIATIVE* | Online – 27 June 2016 – ‘**Enclose the death between medicine and law?**’ The National Centre of Palliative Care and End of Life has been created in France... Financial support was obtained for a new plan for the development of palliative care... The authors’ analysis ... [concludes that] ... this new institution is not innovative in its missions ... because [it shares the same mission with] ... the National End of Life Observatory and the National Resource Centre of Palliative Care [which have been merged]... <http://goo.gl/0PKWJg>

N.B. French language article.

Palliative and end-of-life care for people living with dementia in care homes: Part 2

NURSING STANDARDS | Online – 29 June 2016 – This article, the second of two,¹ provides healthcare practitioners with an overview of best practice in palliative and end-of-life care, including nutrition, hydration, oral hygiene and pain management. Communication and spiritual care are discussed, as well as care after death. Providing support and education for families is an important aspect of palliative and end-of-life care. Care home nurses should ensure that the person living with dementia is at the centre of decision making, and provide care that is inclusive of their needs and wishes. The article is framed in a care home context; there is little research about how to optimise PC for people living with dementia in care homes. <https://goo.gl/p5rneq>

1. ‘Palliative and end-of-life care for people living with dementia in care homes: Part 1,’ *Nursing Standards*, 23 June 2016. [Noted in Media Watch, 27 June 2016, #468 (p.11)] <http://goo.gl/hJhYK0>

Noted in Media Watch, 28 March 2016, #455 (p.10):

- *INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY* | Online – 14 March 2016 – ‘**Perceived needs for support among care home staff providing end of life care for people with dementia: A qualitative study.**’ This study revealed rich and complex understandings of the practice dimensions of caring for people with dementia at the end of life and the impact these have on staff. There is a need to develop effective psychosocial interventions that focus on emotional support for care home staff. There will be challenges in providing this in employment settings that are generally low paid, low status, have high turnover and are reliant on temporary or migrant staff, where training is not rewarded, mandatory or culturally valued. <http://goo.gl/ti4aHU>

Cont.

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

- *BMC PALLIATIVE CARE* | Online – 4 November 2015 – ‘**Identification of the palliative phase in people with dementia: A variety of opinions between healthcare professionals.**’ Three different time points in the disease trajectory when people with dementia were considered to be eligible for palliative care (PC): 1) Early in the disease trajectory; 2) When signs and symptoms of advanced dementia are present; and, 3) From the time point that curative treatment of co-morbidities is futile. Yet, none of these time points was uniformly considered by the professional teams across Europe. In some cases, professionals working in the same nursing home didn’t even reach consensus when considering persons with dementia eligible for PC. <http://goo.gl/uj825G>

N.B. Additional articles on end-of-life care for people living with dementia are noted in Media Watch of 15 June 2015, #414 (pp.13-14),

A scoping review of bereavement service outcomes

PALLIATIVE & SUPPORTIVE CARE | Online – 29 June 2016 – No group of services or individual service was determined to yield clear and convincing evidence of effectiveness. Until high-quality research studies have repeatedly revealed evidence of effectiveness, it is possible that the positive outcomes of bereavement services will be largely based on bereaved people receiving helpful educational information and emotional support from organizations and people prepared to help them. This project outlines existing bereavement service types and the state of science in relation to determination of outcomes. It offers suggestions to advance the state of science to validate or refine bereavement services. It brings to light the issue that bereavement service outcomes need to be carefully researched so that evidence can drive service refinement and expansion. It also highlights the importance of effective bereavement services. <http://goo.gl/YTNjAz>

Cont. next page

Media Watch: Editorial Practice

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

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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.

Related

- *CANADIAN JOURNAL ON AGING*, 2016;35(2):273-278. **‘Bereavement programs and services in the province of Alberta (Canada): A mapping report.’** This 2014 mapping exercise sought to identify and describe all bereavement support programs and services in the province of Alberta, and compare these to those available four years previously. Although considerable (330%) growth, and more diversity in providers, programs, and services was evident, bereavement programs were no longer publicly funded. Instead, programs and services were now grassroots in origin, with individuals and community groups largely designing and providing bereavement support services. <https://goo.gl/i3g751>
- *MORTALITY* | Online – 30 June 2016 – **‘Coping with dying and deaths at home: How undocumented migrants in the U.S. experience the process of transnational grieving.’** The paper argues that the grieving process is unique for a group like this, where the undocumented status means that the migrants cannot go back home to help the dying, support the ones left behind, or receive consolation. The sadness and the guilt experienced in the process have particular characteristics when you are undocumented in a host country, and the mechanisms used to cope with the situation are different than if you are at home or away but are free to travel back and forth. One avenue for coping, for instance, is the use of communication technologies to create the illusion of “being there,” even when that is not an option. <http://goo.gl/g7y8n8>

N.B. Selected articles on undocumented immigrants in the U.S. are noted in Media Watch of 14 December 2015, #440 (p.9).

American Academy of Pediatrics

Guidelines for monitoring and management of pediatric patients before, during, and after sedation for diagnostic and therapeutic procedures: Update 2016

PEDIATRICS | Online – Accessed 27 June 2016 – The safe sedation of children for procedures requires a systematic approach that includes the following: no administration of sedating medication without the safety net of medical/dental supervision, careful pre-sedation evaluation for underlying medical or surgical conditions that would place the child at increased risk from sedating medications, appropriate fasting for elective procedures and a balance between the depth of sedation and risk for those who are unable to fast because of the urgent nature of the procedure, a focused airway examination for large (kissing) tonsils or anatomic airway abnormalities that might increase the potential for airway obstruction, a clear understanding of the medication’s pharmacokinetic and pharmacodynamic effects and drug interactions, appropriate training and skills in airway management to allow rescue of the patient, age- and size-appropriate equipment for airway management and venous access, appropriate medications and reversal agents, sufficient numbers of staff to both carry out the procedure and monitor the patient, appropriate physiologic monitoring during and after the procedure, a properly equipped and staffed recovery area, recovery to the pre-

sedation level of consciousness before discharge from medical/dental supervision, and appropriate discharge instructions. This report was developed through a collaborative effort of the American Academy of Pediatrics and the American Academy of Pediatric Dentistry to offer pediatric providers updated information and guidance in delivering safe sedation to children. <http://goo.gl/0aBGDG>

No child is an island: Ethical considerations in end-of-life care for children and their families

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 29 June 2016 – The focus of this review is on ethical issues unique to children and adolescents by nature of their dependence on their parents. Appreciation that child well-being is best promoted when care aligns with parental beliefs, values and culture has given rise to the practice of family-centred care, which the authors prefer to call “family-partnered” care. Occasionally, a family-partnered approach may challenge fundamental paediatric ethical principles, including best interests, developing autonomy, and the importance of honesty and truth-telling. <http://goo.gl/Mhhyuw>

Cont.

Noted in Media Watch, 4 June 2016, #443 (p.10):

- *MÉDECINE PALLIATIVE* | Online – 29 December 2015 – ‘**Palliative sedation in pediatric patients: Guidelines established by the pediatric palliative consultation service at Sainte-Justine hospital, Montréal, Québec.**’ Recommended criteria: 1) Ensure symptoms are really refractory; 2) Conduct an interdisciplinary meeting; 3) Conduct a meeting with the family (and patient if he/she is apt); and, 4) Decide on type and level of sedation. Adequate monitoring and comfort care should be provided at all times to the patient. Assistance and support of family is paramount throughout the decision-making process and course of sedation. Palliative sedation must be supervised by medical and pharmacological guidelines and an institutional policy. <http://goo.gl/B7XOFq>

N.B. French language article.

Noted in Media Watch, 12 October 2015, #431 (p.14):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 October 2015 – ‘**Pediatrician ambiguity in understanding palliative sedation at the end of life.**’ Pediatricians [i.e., survey respondents] were concerned with a decreased level of consciousness as the goal of palliative sedation (PS). They were split on whether they view PS as a distinct entity or as one broad continuum of care, equivalent to aggressive symptom management. Institutional-based policies are essential to clarify acceptable practice, enable open communication, promote further research. <http://goo.gl/7OZtA6>

Using a non-fit message helps to de-intensify negative reactions to tough advice

PERSONALITY & SOCIAL PSYCHOLOGY BULLETIN | Online – 27 June 2016 – Sometimes physicians need to provide patients with potentially upsetting advice. For example, physicians may recommend hospice for a terminally ill patient because it best meets their needs, but the patient and their family dislike this advised option. The authors explore whether regulatory non-fit could be used to improve these types of situations. Across five studies in which participants imagined receiving upsetting advice from a physician, they demonstrate that regulatory non-fit between the form of the physician’s advice (emphasizing gains vs. avoiding losses) and the participants’ motivational orientation (promotion vs. prevention) improves participants’ evaluation of an initially disliked option. Regulatory non-fit de-intensifies participants’ initial attitudes by making them less confident in their initial judgments and motivating them to think more thoroughly about the arguments presented. Furthermore, consistent with previous research on regulatory fit, the authors show that the mechanism of regulatory non-fit differs as a function of participants’ cognitive involvement in the evaluation of the option. <http://goo.gl/cqEi7g>

Related

- *PATIENT EDUCATION & COUNSELLING* | Online – 28 June 2016 – ‘**Clinicians’ strategies for managing their emotions during difficult healthcare conversations.**’ Understanding what strategies clinicians already employ to manage their emotions when holding difficult conversations has implications for educational planning and implementation. This study has potential to inform the development of education to support clinicians’ awareness of their emotions and to enhance the range and effectiveness of emotion management during difficult healthcare conversations. <http://goo.gl/MBcKMt>

Negotiation, mediation and communication between cultures: End-of-life care for South Asian immigrants in Canada from the perspective of family caregivers

SOCIAL WORK IN PUBLIC HEALTH | Online – 30 June 2016 – In the present study, the authors explore family caregivers’ experiences in providing end-of-life care (EOLC) for terminally ill South Asian immigrants. They employed qualitative methods and in-depth interviews were conducted with seven family caregivers living in Nova Scotia, Canada. Three major themes identified in the data illustrated 1) How South Asian caregivers experienced clashes between biomedical and ethno-cultural realms of care that led to cultural insensitivity; 2) How family members acted as mediators; and 3) How communication issues that challenged cultural sensitivity were handled. Findings provide directions for culturally sensitive EOLC planning. <http://goo.gl/kTJBaA>

Worth Repeating

Supporting the volunteer career of male hospice-palliative care volunteers

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online - 17 November 2010 – The author invited men to discuss their volunteer careers with hospice-palliative care (HPC) to better understand how to recruit and train, retain and support, and then successfully end their volunteer experience. They described a complex interplay of individual characteristics with the unique roles available to HPC volunteers. The men's recruitment experiences coalesced around both individually based and organizationally based themes. Results pertaining to retention revealed the interchange between their personalities, the perks and pitfalls of the unique experiences of an HPC volunteer, and the value of the organization's support for these volunteers. [Noted in Media Watch, 22 November 2010, #176 (p.8)] <http://goo.gl/8XS2mv>

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/hhrU3g>

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

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

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

Asia

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

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

Canada

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

Europe

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

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

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

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