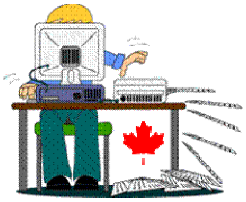
Media Watch...

*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.*

6 November 2017 Edition | Issue #537



Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to Specialist Publications and 'Physicians' opinions on engaging patients' religious and spiritual concerns: A U.S. national survey' (p.10), in *Journal of Pain & Symptom Management*.

Canada

Orthodox Jewish family wants brain dead son's death certificate rescinded because faith won't accept he's deceased

ONTARIO | *The National Post* (Toronto) – 1 November 2017 – Doctors say Shalom Ouanounou is brain-dead, and has been for over a month after suffering a cardiac arrest. His family, devout Orthodox Jews who do not believe that neurological demise equals death, insist the 25-year-old is still alive. The Toronto residents launched an unprecedented court case against a hospital, doctors and coroners that could overturn the way end of life is handled in Canada. Citing the Charter of Rights & Freedoms, they are pressing for an exemption from the brain-death declaration for patients whose religion does not accept the concept. That would mean keeping Shalom on life support until his heart stops permanently and the coroner's office tearing up the death certificate it issued. Justice Glenn Hainey issued a temporary injunction preventing Humber River Hospital from taking Ouanounou off life support while the case is ongoing. https://goo.gl/ksLQvv

The landscape of scientific research is changing

Contributing factors include the evolution in recent years of what is widely-termed "predatory journals." Running parallel with this development is the rising number of retractions in the scientific literature. **Journal Watch** (p.13) will be an occasional feature of this weekly report, alerting recipients of Media Watch to trends in publishing that have the potential to negatively impact on evidence-based practice and, in turn, undermine the trust and confidence of the general public in scientific research. ***BRA***

Noted in Media Watch 23 January 2017 (#496, p.13):

- *JOURNAL OF RELIGION & HEALTH* | Online – 19 January 2017 – **'The care of the Ultra-Orthodox Jewish patient.'** The authors describe some of the unique challenges that stem from the encounter between modern medical practice and the Ultra-Orthodox world. Through examples of clinical and ethical scenarios ranging from prenatal care to end-of-life decisions, they illustrate problems related to observance of age-old practices in a modern hospital setting. **Abstract:** https://goo.gl/cgsJPY

N.B. See 'Do the "brain dead" merely appear to be alive?' *Journal of Medical Ethics*, 2017;43(11):747-753 (first published online 28 August 2017. [Noted in Media Watch 4 September 2017 (#528, p.9)] **Full text:** https://goo.gl/LhrX3f

U.S.A.

Poll: Americans avoid planning for serious illness

KAISER FAMILY FOUNDATION | Online – 2 November 2017 – Americans are generally aware that most people die after a period of worsening health rather than suddenly and think that problems affording medical care and support services are common for people in late life. People say a number of different aspects of life are important to them to maintain a good quality of life in older age, including making sure their medical wishes are followed, but more than half say they do not have a document that describes their wishes for care or names a person they would want to make medical decisions on their behalf. In fact, one-third say they have a written document outlining their wishes and four in ten say they have a written document designating someone to make medical decisions on their behalf. Discussions of these issues with family members are reportedly much more common than written documentation. Most say they have not talked with a doctor or health care provider about their wishes, including among older adults and adults that report being in fair or poor health. For those that have written documents, few report sharing them with their doctors or other health care providers, leaving open the potential for uncertainty or confusion about what a person would want if seriously ill, even though they have gone to the effort of documenting their wishes. https://goo.gl/ertU2E

Specialist Publications

'Physicians' opinions on engaging patients' religious and spiritual concerns: A U.S. national survey' (p.10), in *Journal of Pain & Symptom Management.*

'Factors associated with opinions about hospice among older adults: Race, familiarity with hospice, and attitudes matter' (p.9), in *Journal of Palliative Care.*

Related

- *HARVARD BUSINESS REVIEW* | Online – 2 November 2017 – **'How health care providers can ensure patients' end-of-life wishes are known.'** Advance care planning (ACP) is widely recognized as something that should be a central element of the way that patients, their physicians, and their families together decide which end-of-life care to provide. Efforts to boost participation in these conversations include the introduction of new billing codes to financially incentivize primary care physicians to discuss ACP, as well as grassroots advocacy efforts to highlight the importance of discussing end-of-life wishes. And yet these efforts to popularize the creation of advance care documents do not address a key issue: access to them. https://goo.gl/QN32N7

Palliative care and hospice: Case managers face haunting challenges

MINNESOTA | *RAC Monitor* (St. Paul) – 2 November 2017 – There are many staffing models for case managers. A number of years ago, the trend leaned toward combining the activities of discharge planning and utilization instead of employing two individuals to look at the same chart. Recently, the pendulum appears to be swinging back with many health systems identifying that often the duties associated with helping patients and families prepare for discharge from the hospital are hindered by the often-difficult conversations regarding utilization management. Regardless of the model used, hospital case managers charged with assisting patients and families as they navigate down the harrowing road of deciding "what's next?" face multiple challenges themselves. One critical challenge comes from the collaboration (or lack thereof) with the patient's provider. While case managers are having conversations with patients about expectations and wishes for their care, these same discussions may take a very different form when they involve the patient and physician. In fact, some might not be "discussions" at all. Whether due to physician misunderstanding of palliative care and hospice, reluctance to have such a conversation with the patient and family (at times due to a perception of "giving up" on the patient), or uncertainty about continuity of care by adding another provider into the mix, the topic of palliative care can be quickly glossed over – or never brought up at all. https://goo.gl/ukNb4X

End-of-life care is the third rail of health-care debates

THE NATIONAL REVIEW | Online – 2 November 2017 – About 1% of the U.S. population accounts for roughly 20 to 30% of health spending, and 5% for more than 50%, a finding that holds over time. These patients tend to be either newborns with catastrophic issues or the elderly. A 2004 study found that 10% of Medicare spending happens in the last trimester of life, and 30% in the last year of life. Since then, there has been a lot of gesticulation about doing less aggressive medicine in the last year of life, but "pull up the curtain on these statistics, and the drama that unfolds tells a very different story," a 2013 summary by *Kaiser Health News* argued.[1] "End-of-life care (EoLC) continues to be characterized by aggressive medical intervention and runaway costs." And, in the policy debates over health care, *KHN* noted, EoLC is the "third rail." And how else could it be? Of course, the Left believes that everyone is entitled to an essentially infinite quantity of care. Meanwhile, the Right, understandably, is afraid of anything that smacks of "death panels," for libertarian reasons, or religious fears of euthanasia, or both. But political coalitions are responsive to voters, so end-of-life healthcare issues are only a signal of the underlying cultural problem. The limitless American pragmatism, with its faith in the possibility of technical solutions for every problem, is a powerful spur to heroic medicine when combined with fear of death. https://goo.gl/Qvi3tP

[1] 'End-of-life care: A challenge in terms of costs and quality,' *Kaiser Health News* (Morning Briefing), 4 June 2013. https://goo.gl/8ZAfjC

Vitas hospice scrutinized by *Post* reaches record Department of Justice settlement

FLORIDA | *The Palm Beach Post* – 31 October 2017 – Federal officials are calling a $75 million settlement with South Florida-based hospice provider Vitas the industry's biggest ever under the False Claims Act, resolving allegations the company inflated charges and overbilled taxpayers. "Today's resolution represents the largest amount ever recovered under the False Claims Act from a provider of hospice services," Acting Assistant Attorney General Chad A. Readler of the U.S. Justice Department's civil division said in a statement... In 2012, *The Palm Beach Post* reported for-profit Vitas, based in Miami, billed the government for patient stays in Palm Beach County that averaged 40% longer than those of non-profit competitors. The newspaper also showed hospice services were marketed at assisted-living facilities as a service for people who might not necessarily die – or even get better – though federal law required a diagnosis of six months or less to live. A year later, the Justice Department filed a 51-page complaint under the False Claims Act alleging Vitas bilked Medicare in South Florida and elsewhere by charging for people who were not terminally ill and sending "crisis care" bills for patients that nurses said were at church, bingo or the beauty parlor. https://goo.gl/5q4Ntf

Noted in Media Watch 26 May 2014 (#359, p.3):

- *THE NATIONAL LAW REVIEW* | Online – 20 May 2014 – **'All eyes on hospice care**.' In 2013, the Department of Justice and the Office of Inspector General charged the nation's largest for-profit hospice chain, Vitas Innovative Hospice Care, with false Medicare billings, inappropriately admitting patients with "aggressive marketing tactics," and misleading patients and families about Medicare hospice benefits. This suit is just one of many recently filed against hospice providers, indicating that they are being watched keenly by enforcement authorities and government agencies. https://goo.gl/m7sLvA

Noted in Media Watch 9 January 2012 (#235, p.3):

- FLORIDA | *The Palm Beach Post* – 7 January 2012 – **'Hospice for profit: Business of dying is booming.'** Three decades after becoming a Medicare benefit, hospice care has emerged as its fastest-growing cost – and more than one federal investigation is targeting the nation's largest provider. Vitas Healthcare, the only for-profit hospice licensed in Palm Beach County, denies wrongdoing. But its local patients average 40% longer stays on government-reimbursed care than those at non-profit competitors, records analyzed by the *Palm Beach Post* show. https://goo.gl/pHw6iL

International

End-of-life in Japan

Lonely deaths/unattended death estimate tops 40,000

JAPAN | *The Japan News* (Tokyo) – 4 November 2017 – More than 17,000 people who were living alone died unattended at home across 19 prefectures and Tokyo's 23 wards in 2016, according to research by *The Yomiuri Shimbun* [newspaper], a finding that suggests the national figure was greater than 40,000. In its research, the *Yomiuri* contacted all 47 prefectural police headquarters and the Medical Examiner's Office of the Tokyo metropolitan government. There is no legal definition of an unattended death, and the government does not conduct a nationwide survey regarding the matter. https://goo.gl/KCAykb

End-of-life care in Australia

We have to get better at supporting patients right to the end of life

AUSTRALIA | *The Guardian* (Surry Hills, New South Wales) – 3 November 2017 – There are three issues that continually are raised at the national level ... with regards to end-of-life care and dying in Australia. One, the fact that there is without a doubt inequitable access to palliative care (PC) across the country. The social determinants of health play out in this space. Health inequities result from social inequalities. Two, dying is stigmatised in this country. Most people avoid talking about death and dying – it's a barbecue stopper. Death will never happen to us, you see, and it's always someone else's problem, not mine, because I'm going to live forever. We spend a lot of time preparing for the birth of children. We develop birth plans, host baby showers, and attend health services for prenatal checks. But we spend comparatively little time preparing for our own deaths. And three, the health workforce is under-equipped to deal with end-of-life issues. We know aged care services struggle to meet the needs of dying residents, general practitioners can't give the time required to provide holistic care, and as for specialist PC doctors, there are only 213. 181 of those work in major cities and 32 across the rest of the country. It can't all be left to them, that would equate to one doctor per 704 deaths each year. We need a comprehensive workforce strategy that addresses these shortfalls given the projected doubling of deaths by 2050. The current debate about voluntary assisted dying provides an opportunity for action to address these inequities, help to dispel the fear of death and to better support the health workforce to deliver high-quality care for those facing the end of their lives. https://goo.gl/mMe2N7

THE CONVERSATION

What is palliative care? A patient's journey through the system

AUSTRALIA | The Conversation (Melbourne, Victoria) – 29 October 2017 – Palliative care (PC) involves a team of doctors, nurses, allied health and other volunteers who work together to provide an extra layer of support to the person and their family. PC teams are commonly involved with illnesses such as heart, lung or kidney disease, cancer or advanced dementia. Involving PC allows for better control of symptoms and an improved sense of quality of life. It also helps the family of the person who is ill. With better symptom control and support, this frequently translates to less time spent in hospital. A number of studies have even shown early involvement of PC can lead to improved survival. PC doctors are specialist physicians skilled in treating symptoms associated with serious illnesses such as pain, nausea, fatigue and appetite problems. A key component of their role is facilitating difficult discussions about prognosis, stopping various treatments and exploring the medical decisions a person would want at different stages of their illness. https://goo.gl/TJYpsK

N.B. This is the first article in a series on demystifying palliative care, where experts explain the process of end-of-life care in Australia. The Conversation is "an independent source of news and views, from the academic and research community, delivered direct to the public": https://goo.gl/p74D2h

Day of the Dead offers brave new perspective and celebrates lives

AUSTRALIA (Victoria) | ABC News (Melbourne) – 2 November 2017 – Mourning the death of a loved one is often done privately among family and close friends, but a Mexican tradition is a direct challenge to how we grieve. Dia de los Muertos, or Day of the Dead, celebrated annually across Mexico on 2 November, is a way to honour deceased family and friends with vibrant parades, elaborate artwork, and ornate decorations. Altars called "ofrendas" are laid out with offerings of special food in the belief that the spirits of those who have died will sense the aromas and be welcomed home. Dr. Colleen Nordstrom of the Palliative Care Unit at La Trobe University has been researching Day of the Dead since witnessing the event in Mexico five years ago. She said the celebration's strength was its ability to transfer grief from a private, individual, experience into a shared, communal space. "It's about honouring what it is to be human and to love people," Dr. Nordstrom said. "It allows expression – when you're coming together with other people who are also sharing their grief, it makes you realise you're not alone in this." In her work advising nurses and paramedics, Dr. Nordstrom said many lessons could be taken from the Mexican view of death, which sees the process as a part of everyday life. https://goo.gl/BwkWwd

A second class ending: End-of-life care for people who are homeless

U.K. (England) | Care Quality Commission – 31 October 2017 – There is huge variation in the quality of care that people receive at the end of their life. Homeless people face significant health inequalities: the average age of death is just 47 years. Their end-of-life care (EoLC) needs and preferences also differ considerably from the rest of the population. The Commission worked closely with the Faculty for Homeless & Inclusion Health and draw on their research findings to co-produce this discussion paper...[1] It follows up from its 2016 report.[2] When the Commission published 'A different ending,' it also produced 10 short briefing papers on EoLC for specific groups. This included a short paper looking at EoLC for homeless people.[3] https://goo.gl/LoAGGv

1. 'A second class ending: Exploring the barriers and championing outstanding end-of-life care for people who are homeless,' Care Quality Commission, November 2017. https://goo.gl/5aygwT
2. 'A different ending: End-of-life care review,' Care Quality Commission, May 2016. [Noted in Media Watch 16 May 2016 (#462, p.5)] https://goo.gl/DEJQa2
3. 'People who are homeless' (A different ending: Addressing inequalities in end-of-life care), Care Quality Commission, May 2016. https://goo.gl/rtF4a1

N.B. The Faculty for Homeless & Inclusion Health is an independent, multi-disciplinary network for nurses, doctors, allied medical professionals, social workers, public health experts, health advocates and support workers, commissioners, and researchers. https://goo.gl/a9uZpE

Noted in Media Watch 10 July 2017 (#520, p.5):

- U.K. (England) | *The Evening Standard* (London) – 4 July 2017 – **'London's homeless "dying in hostels rather than hospices."'** Homeless people in London who are terminally ill face the distressing process of dying in hostels rather than hospices due to a lack of community support, a study has suggested.[1] Hostel staff often end up caring for some of the sickest homeless people, despite not having palliative care training. https://goo.gl/MSZUbw
    1. 'End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care,' *Palliative Medicine*, published online 3 July 2017. **Full text:** https://goo.gl/b3eQ42

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.14.

Palliative and end-of-life care in England

National Health Service palliative care delays mean thousands of terminally ill patients risk dying in hospital rather than at home

U.K. (England) | *The Independent* (London) – 31 October 2017 – Thousands of terminally ill patients risk dying in hospital when they could be at home because of "unacceptable" delays accessing urgent care support and funding, according to a study.[1] The report ... estimates 57,000 patients who are terminally ill, or progressing to a terminal stage of their illness, are not receiving timely home terminal-care support. Fewer than a third (28%) of National Health Service clinical commissioning groups (CCGs) hit national targets on providing fast-track continuing healthcare support within 48 hours. Of the two thirds missing the target, a third (32%) of CCGs reported patients waited more than a week, with some areas even reporting two week waits for this support. The report received responses from around half of CCGs for the year 2015-2016 and calculated that across England this amounts to 57,000 people waiting beyond the recommended 48 hours. Twenty-five thousand patients waited longer than a week and the report warns there are "no second chances" for patients who are not granted their wish to die at home. https://goo.gl/PvPdkR

Specialist Publications

'Developing the methods and questionnaire for a national retrospective mortality follow-back survey of palliative and end-of-life care in England' (p.7), in *BMJ Supportive & Palliative Care*.

1. 'Concerns over delays in fast-track care for thousands of dying patients,' Marie Curie, 31 October 2017. **Download/view additional background information at:** https://goo.gl/mr8B8s

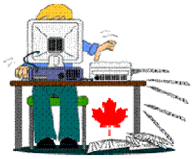
Noted in Media Watch 27 February 2017 (#501, p.4):

- U.K. (England, Northern Ireland, Scotland & Wales) | *The Daily Telegraph* (London) – 22 February 2017 – **'Dying patients forced to spend last days in hospital amid funding wrangles.'** Research found that more than nine in 10 nurses had witnessed cases where dying patients remained needlessly in hospital because of delays agreeing funding to pay for their care. A poll of almost 1,000 nurses found 94% were aware of cases where delays in funding and community provision of care meant dying patients were forced to remain in hospital. https://goo.gl/jpqj6U

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Victoria) | Special Broadcasting Service (Melbourne) – 3 November 2017 – **'Victoria's euthanasia bill passes the Upper House in second reading.'** Victoria's euthanasia bill has passed the Upper House 22 votes to 18 in its second reading after robust debate over the controversial proposal. Extra palliative care for regional Victoria will be considered as Labor tries to win the support of key Liberal MPs in a bid to pass controversial assisted dying laws. https://goo.gl/azTuw4



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

Specialist Publications

National Survey of Bereaved People

Developing the methods and questionnaire for a national retrospective mortality follow-back survey of palliative and end-of-life care in England

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 3 November 2017 – The National Survey of Bereaved People was conducted by the Office for National Statistics on behalf of National Health Service England for the first time in 2011, and repeated annually thereafter. It is thought to be the first time that nationally representative data have been collected annually on the experiences of all people who have died, regardless of cause and setting, and made publicly available informing palliative and end-of-life policy, service provision and development, and practice. This paper describes the development of the questionnaire used in the survey (VOICES-SF), a short-form of the VOICES (**V**iews **O**f **I**nformal **C**arers – **E**valuation of **S**ervices) questionnaire, adapted specifically to address the aims of the national survey. The pilot study to refine methods for the national survey is also described. The paper also reports on the development of the retrospective, after-death or mortality follow-back method in palliative and end-of-life care, and reviews its strengths and weaknesses. **Abstract:** https://goo.gl/Ncjj7A

The value of embedding: Integrated palliative care for patients with metastatic breast cancer

BREAST CANCER RESEARCH & TREATMENT | Online – 30 October 2017 – The American Society of Clinical Oncology recommends concurrent palliative care (PC) for patients with metastatic cancer.[1] Recent data show benefits of early PC (at least 90 days before death). However, little is known about PC among patients who die from metastatic breast cancer. In the 18-month study period, oncologists referred for PC 105 of their 515 (20.4%) patients; 59 (11.5%) patients were seen by the PC physician. Of the 38 referred patients who died, 23 (60.5%) were seen by embedded PC and all 23 received PC within 90 days of death... Embedded PC was well-received by patients and oncologists, increased early PC referrals, and improved end-of-life (EoL) care. Avoidable, unnecessary health care utilization at the EoL, such as ICU stays in the last month of life, represent an important potential reduction in patient suffering and system costs. **Abstract:** https://goo.gl/TVuk7L

1. 'American Society of Clinical Oncology provisional clinical opinion: the integration of palliative care into standard oncology care,' *Journal of Clinical Oncology*, 2012;30(8):880-887 (first published online 7 February 2012). [Noted in Media Watch 13 February 2012, #240.] **Full text:** https://goo.gl/4NXMvR

Related

- *MEDICAL CLINICS*, 2017;101(6):1181-1196. **'Palliative care for cancer survivors.'** The palliative care approach begins with comprehensive assessment of communication and advance care planning (ACP) needs and the physical, psychological and psychiatric, social, spiritual and religious, and cultural domains. Communication and decision-making about difficult issues should include responding to emotions, planning for future communication needs, and considering reasons for miscommunication. Key palliative approaches to symptom management include addressing physical and psychosocial concerns, and using non-pharmacologic approaches first or together with medications. Physicians should address ACP in older cancer survivors and those at significant risk of recurrence and mortality, ideally through ongoing conversations in a longitudinal care relationship. **Abstract:** https://goo.gl/fCrvqM

Updated 11.01.2017

Palliative Care Network Community

Prison Hospice: Backgrounder

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

Palliative and end-of-life care of people with diabetes: Issues, challenges and strategies

DIABETES RESEARCH & CLINICAL PRACTICE | Online – 30 October 2017 – Palliative and end-of-life care are essential, but largely overlooked, aspects of comprehensive, personalised diabetes care. Life expectancy is lower in people with diabetes than in the general population due to complications and comorbidities, especially those associated with obesity such as cardiovascular disease, frailty and cancer. This paper makes the case for early initiation of palliative care (PC) and proactive planning for end of life. Early use of PC improves symptom management, comfort and quality of life, and often improves function. Significantly, it reduces disease burden and unnecessary treatment. Prognostication is challenging, but tools such as the Gold Standard Framework[1] and diabetes-related indicators of reduced life expectancy can help identify those at high risk one year mortality. Skilled conversations, underpinned by an evidence-based framework, are a critical component in helping people with diabetes, and their families, discuss these complex issues and make appropriate advance care plans based on their values and preferences. **Abstract:** https://goo.gl/wEJfNE

1. 'Going for gold: The Gold Standards Framework programme and accreditation in primary care,' *End of Life Journal*, published online 9 December 2016. [Noted in Media Watch 12 December 2016 (#491, p.9)] **Abstract:** https://goo.gl/61tEoP

Noted in Media Watch 3 October 2016 (#482, p.8):

- *CURRENT DIABETES REPORTS* | Online – 22 September 2016 – **'Caring for people with diabetes at the end of life.'** While general end-of-life care (EoLC) guidelines apply to diabetes, there are some diabetes-specific issues that need to be considered. These include the usual long trajectory to EoLC that enables clinicians and people with diabetes to proactively discuss when to change the focus of care from preventing diabetes complications (tight control) to a palliative approach. The aim of this paper is to discuss common disease trajectories and their relationship to diabetes care, outline strategies for proactively discussing these issues and suggest indications that palliative care is warranted. **Abstract:** https://goo.gl/S23le5

Noted in Media Watch 1 February 2016 (#447, p.10):

- *DIABETES CARE*, 2016;39(2):308-318. **'Management of diabetes in long-term care and skilled nursing facilities: A position statement of the American Diabetes Association.'** The authors address diabetes management at end of life and in those receiving palliative and hospice care. The integration of diabetes management into long-term care facilities is important and requires an interprofessional team approach. To facilitate this approach, acceptance by administrative personnel is needed, as are protocols and possibly system changes. It is important for clinicians to understand the characteristics, challenges, and barriers related to the older population living in LTC facilities as well as the proper functioning of the facilities themselves. **Full text:** http://goo.gl/e5k80D

Palliative and end-of-life care in the U.S.

The value of palliative care

HEALTH PROGRESS, 2017;November-December:59-60. Only a few hospitals have (PC) care programs well integrated in their service. The lack of PC programs is a failure on the part of medicine and society to attend to the needs of advanced and terminal patients, to relieve the pain and suffering. The challenge is not "helping to die," in the perspective of physician-assisted suicide or euthanasia, but helping to live until the end of life, offering care and accompaniment. The holistic approach of PC has been demonstrated to be effective in bolstering the dignity of dying patients, addressing their suffering and reducing requests for hastened death. The Pontifical Academy for Life has been committed to PC advocacy for years. It was a partner of the Maruzza Lefebvre D'Ovidio Onlus Foundation in the creation of the "Religions of the World Charter for Children's Palliative Care," by which leaders from several religions, patients and families, PC experts and human rights activists advocate for children's PC. The 'Religions of the World Charter: Palliative Care for Older People,' an interfaith charter promoting PC for the elderly across the world, was

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launched in 2017 to support and share the universal right to PC as the best solution to guarantee dignity and a better quality of life to older people with advanced chronic conditions or who are approaching the end of life. The Pontifical Academy for Life has dedicated two General Assemblies to PC, 'Aging & Disability' in 2014 and 'Assisting the Elderly & Palliative Care' in 2015, and is now sponsoring an international project, to be known as PAL-LIFE, to improve clinical and spiritual care for the dying, with particular attention to the development of PC. The academy's principal goal through this project is to make ecclesial institutions more aware of the need to develop effective PC around the world, together with bringing PC to the attention of all social and cultural organizations and promoting dialogue and cooperation in practical initiatives among stakeholders at all levels. **Full text:** https://goo.gl/TmQRS5

> **N.B.** This issue of the Journal of the Catholic Health Association of the United States includes several articles focused on or related to end of life and end-of-life care. Journal contents page: https://goo.gl/6rHSmC

Related

- *JOURNAL OF PALLIATIVE CARE* | Online – 30 October 2017 – **'Factors associated with opinions about hospice among older adults: Race, familiarity with hospice, and attitudes matter.'** This study identified predictors of opinions about hospice (OAH) among older adults. Results showed race of the respondent was the strongest predictor of one's OAH. Predictors of positive opinions of hospice included being of Caucasian race, non-Hispanic ethnicity, better health, greater familiarity with hospice, a high importance of pain control, the importance of fulfilling personal goals, a desire to have healthcare professionals involved in one's care, and having engaged in advance care planning. **Abstract:** https://goo.gl/qZ3XAR

Palliative and end-of-life care in rural U.S.

Palliative and supportive interventions to improve patient-reported outcomes in rural residents with cancer

JOURNAL OF COMMUNITY & SUPPORTIVE ONCOLOGY, 2017;15(5):e248-e255. Palliative care (PC) and supportive oncology are designed to increase the quality of life and other important patient-reported outcomes for people with advanced cancer. People living in rural areas have limited access to these supportive services and the impact of PC and supportive oncology on this population is not well studied. The objective of this systematic review is to identify publications that evaluated effects of PC and supportive oncology interventions on various patient-reported outcomes (PRO) in people with advanced cancer in rural areas. Eight studies were included in this systematic review. The studies identified consisted primarily of small sample sizes, single-group designs, and were not powered to detect impact on PRO. However, these studies did provide preliminary evidence that PC and supportive oncology interventions may have a positive effect on physical and emotional symptoms as well as overall quality of life in this population. In addition, these interventions were positively viewed by participants and have the potential to positively impact financial outcomes for the individuals and the society. **Abstract:** https://goo.gl/GWY34i

> **N.B.** Click on pdf icon to access **full text**. Additional articles on the provision and delivery of palliative and end-of-life care in rural and remote regions of the U.S. are noted in the 2 October 2017 issue of Media Watch (#532, pp.3-4).

Defining palliative care in cystic fibrosis: A Delphi study

JOURNAL OF CYSTIC FIBROSIS | Online – 30 October 2017 – A working group of 36 cystic fibrosis (CF) care providers, researchers, palliative care (PC) providers, quality improvement experts, individuals with CF, and CF caregivers completed a series of questionnaires to rate the value of each of 22 attributes of PC, rank top attributes to construct definitions of PC, and then rate proposed definitions. Many identified overlaps in routine CF care and PC and highlighted the importance of a definition that feels relevant across the lifespan. Modified Delphi methodology was used to define PC in CF. The definition will be used as the foundation for development of CF-specific PC guidelines. **Abstract:** https://goo.gl/z4bZmn

Cont.

Noted in Media Watch 25 September 2017 (#531, p.13):

- *JOURNAL OF CYSTIC FIBROSIS* | Online – 13 September 2017 – **'End-of-life practice patterns at U.S. adult cystic fibrosis care centers: A national retrospective chart review.'** The authors reviewed 248 deaths from 71 cystic fibrosis (CF) care centers. While median FEV1 was in the severe lung disease category ... 38% had mild or moderate lung disease in the year preceding death. The most common location of death was the intensive care unit ... and 12% of decedents were listed for lung transplant. Fewer of those dying in the ICU personally participated in advance care planning (ACP) or utilized hospice or palliative care (PC) services. **Abstract:** https://goo.gl/iWo9DB

N.B. Additional articles on end-of-life care for people living with cystic fibrosis are noted in the 10 July 2017 issue of Media Watch (#520, p.11).

Do-not-attempt-resuscitation orders: Understanding and interpretation of their use in the hospitalised patient in Ireland. A brief report

JOURNAL OF MEDICAL ETHICS | Online – 3 November 2017 – Alarmingly, the authors' results demonstrate that 26.8% of staff nurses and 30% of primary care physicians surveyed believed that a patient with a do-not-attempt resuscitation (DNAR) order could not receive any/at least one of a list of simple treatments including antibiotics, physiotherapy, intravenous fluids, pain relief, oxygen, nasogastric feeding or airway suctioning, which were higher percentages compared to the other hospital doctors and experienced nurses groups with statistically significant differences. Furthermore, a higher percentage of staff nurses (26.8%) and primary care physicians (22.5%) believed that a patient with a DNAR order could not be referred to hospital from home/a nursing home, when compared with other healthcare groups. These findings highlight continued misunderstanding and over-interpretation of DNAR orders. **Abstract:** https://goo.gl/8hCJ1z

Noted in Media Watch 29 May 2017 (#514, p.7):

- *IRISH JOURNAL OF MEDICAL SCIENCE* | Online – 16 May 2017 – **'Doctors' attitudes towards the introduction and clinical operation of do not resuscitate orders in Ireland.'** A substantial proportion of hospital doctors surveyed demonstrated an incomplete understanding of do-not-resuscitate orders and their clinical operation. However, the overwhelming majority believed that domestic guidelines are needed on the matter. **Abstract:** https://goo.gl/E9XEti

Physicians' opinions on engaging patients' religious and spiritual concerns: A U.S. national survey

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 31 October 2017 – There has been a sustained debate in the medical literature over whether or not physicians should engage with patients' religious and spiritual concerns. In 2010, a questionnaire was mailed to 2,016 U.S. physicians with survey items querying about the relative importance of addressing patients' spiritual concerns at the end of life (EoL) and the appropriateness of interventions in addressing those concerns. The survey also contained an experimental vignette to assess physicians' willingness, if asked by patients, to participate in prayer. The majority of physicians (65%) believe that it is essential to good practice for physicians to address patients' spiritual concerns at the EoL. Physicians who were more religious were more likely to believe that spiritual care is essential to good medical practice ... and believe it is appropriate to always encourage patients to talk to a chaplain... A majority of the physicians (55%) stated that, if asked, they would join the family and patient in prayer. Physicians' willingness to join ranged from 67% when there was concordance between the physician's and the patient's religious affiliation and 51% when there was discordance. The majority of U.S. physicians endorse a limited role in the provision of spiritual care, though opinions varied based on physicians' religious characteristics. **Abstract:** https://goo.gl/9Px6DN

N.B. Additional articles on spirituality in the context of end-of-life care (EoLC) are noted in the 16 October 2017 issue of Media Watch (#534, p.15). Articles of related interest: on addressing a patient's hope for a miracle noted in the 16 October 2017 (#534, p.12); and, the role of chaplains in EoLC noted in the 17 July 2017 issue of Media Watch (#521, pp.3-4).

Measuring patient-centeredness of care for seriously ill individuals: Challenges and opportunities for accountability initiatives

JOURNAL OF PALLIATIVE MEDICINE | Online – 1 November 2017 – The authors describe methodological challenges of using measures of patient- and family-centeredness in accountability initiatives such as public reporting and pay for performance. They begin with background on measuring patient- and family-centered care using standardized surveys, describe evidence of the use of these measures for quality improvement, and highlight methodological challenges in the development and implementation of these measures for use in accountability. To ensure that patient- and family-centeredness is the cornerstone of public and private accountability initiatives designed to promote high-quality care to seriously ill patients, the authors recommend development of: 1) A nationally endorsed survey instrument that assesses patient and family experiences of serious illness care across the full range of patient trajectories and care settings in which this care is provided; 2) Administrative data infrastructure that allows for identification and outreach to the most knowledgeable respondents for the survey, regardless of the patient's setting of care; and, 3) A broad toolkit of quality improvement approaches to ensure that as the emphasis on accountability grows, providers across settings have access to tools that can help them improve patient- and family-centeredness of care for the seriously ill. **Full text:** https://goo.gl/eQVVKU

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 November 2017 – '**A person-centered, registry-based learning health system for palliative care: A path to Co-producing better outcomes, experience, value, and science.**' A learning health system that includes patients and families partnering with clinicians and care teams is directly linked to a registry to support networks for improvement and research, and offers an ideal framework for measuring what matters to a range of stakeholders interested in improving care for this population. The authors describe an approach to co-designing and implementing a palliative care registry that functions as a learning health system by combining patient and family inputs and clinical data to support person-centered care, quality improvement, accountability, transparency, and scientific research. **Abstract:** https://goo.gl/NRREEo
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 November 2017 – '**Achieving goal-concordant care: A conceptual model and approach to measuring serious illness communication and its impact.**' The authors conceptual model describes the relationship between communication, goal-concordant care, and other relevant outcomes. Measures to assess the quality of serious illness communication and care include: 1) The timing and setting of serious illness communication; 2) Patient experience of communication and care; and, 3) Caregiver bereavement surveys that include assessment of perceived goal concordance of care. Future measurement priorities include direct assessment of communication quality, prospective patient or family assessment of care concordance with goals, and assessment of the bereaved caregiver experience. **Full text:** https://goo.gl/f5ebLr

Psychosocial care models for families of critically ill children in pediatric emergency department settings: A scoping review

JOURNAL OF PEDIATRIC NURSING, 2018;38(1):46-52. Due to individual family diversity and needs, in combination with health setting demands and socio-cultural factors, it is unlikely that there will ever be a definitive "one size fits all" care model or intervention that works universally. Family care models must be therapeutic and tailored to individual family needs. The articles reviewed have developed models relevant to their individual service contexts, but translational ability is uncertain. This review adds valuable information to the limited pool of literature currently available, providing suggestions for clinical practice and improved care of families, decreasing both short and long term negative impacts of these unavoidable experiences, and promote improved coping capacity and resilience in families and staff. This review is also helpful to clinicians looking to develop clinical practice guidelines within their own health services, and to researchers wanting to evaluate them. Once developed, testing any models and interventions in single sites and across broader health services is vital, filling the gap in research and practice that currently exists for therapeutic interventions that begin the moment the family enters the hospital system. **Full text:** https://goo.gl/apW731

Cont.

Related

- *JOURNAL OF CHILD HEALTH CARE* | Online – 26 October 2017 – **'The possibilities and challenges in providing pediatric spiritual care.'** Based on the literature, this article presents an overview of spiritual care (SC) in pediatric settings highlighting the assessment of spirituality, expected outcomes, and the corresponding nursing interventions. SC provided to children and adolescents should take into account all aspects of the developmental stage, life experiences, and familiar and socio-cultural contexts. Different approaches can be used to perform SC. However, lack of knowledge and time are highlighted as the main challenges in integrating SC into the clinical practice. **Abstract:** https://goo.gl/HEkjG6

No choice without care: Palliative care as a relational matter, the case of Ireland

SOUNDINGS: AN INTERDISCIPLINARY JOURNAL, 2017;100(4):353-374. In recent years, choice and autonomy have been prioritized as key quality indicators in palliative care (PC) services. This article examines current PC discourses with respect to patient choice. While recognizing the importance of personal autonomy ... this article explores how a discourse on choice can contribute to inequalities in PC because it fails to take account of pre-existing structural inequalities, human relationality, and bodily decline. **Abstract:** https://goo.gl/BCz3sQ

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BRITISH JOURNAL OF GENERAL PRACTICE*, 2017;67(664):515. **'Access to medical records for assisted death: clarifying the guidance.'** Noel Conway recently lost his appeal at the High Court calling for a judicial review into the blanket ban on assisted dying and stated his intention to seek permission to appeal to the Supreme Court. Regardless of outcome, uncertainty remains surrounding the practice of access to medical records when a patient seeks an assisted death abroad. The numbers of British citizens dying in Switzerland is increasing year on year. As part of the request for assistance to die in Switzerland a patient must provide medical verification of their condition. It is this that patients approach their doctors for in the U.K. to provide in the form of a written report or a copy of their medical records. Following the Nicklinson, Lamb, and Martin case in 2013, the General Medical Council clarified guidance on this issue by stating that doctors should be prepared to listen to and to discuss the reasons for the patient's request. **Full text:** https://goo.gl/Qr3R1D

  Noted in Media Watch 9 October 2017 (#533, p.8):

  - U.K. (England) | *The Daily Telegraph* (London) – 5 October 2017 – **'Terminally-ill man loses High Court challenge against the law on assisted dying.'** A man who is terminally ill with motor neurone disease has lost his High Court challenge against the law on assisted dying. Retired college lecturer Noel Conway took his case to the Court of Appeal after he was refused permission to bring a judicial review over the blanket ban on providing a person with assistance to die. In March a panel of High Court judges rejected his bid to change the law, saying it would be "institutionally inappropriate" for the court to challenge the decision of Parliament. MPs debated changing the law in September 2015, but the proposals were voted down by a 212 majority. https://goo.gl/jrTHzV

PALLIMED
A HOSPICE & PALLIATIVE MEDICINE BLOG

Media Watch: Behind the Scenes
http://goo.gl/XDjHxz

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

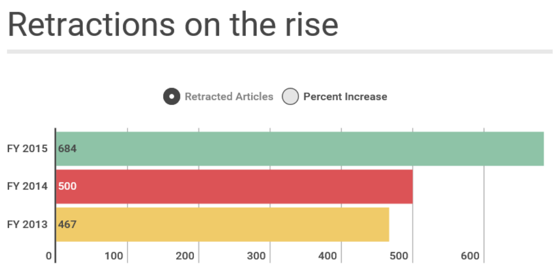
http://goo.gl/OTpc8I

Journal Watch

Many academics are eager to publish in worthless journals

U.S. | *The New York Times* – 30 October 2017 – Call it a classic case of supply meeting demand. Universities, colleges, even community colleges insist that faculty publish scholarly research, and the more papers the better. Academics and the schools they teach at rely on these publications to bolster their reputations, and with an oversupply of PhD's vying for jobs, careers hang in the balance. Competition is fierce to get published in leading journals. But what about the overworked professors at less prestigious schools and community colleges, without big grants and state-of-the-art labs? How do they get ahead? As it turns out, many of their articles are appearing in "journals" that will publish almost anything, for fees that can range into the hundreds of dollars per paper. These publications often are called predatory journals, on the assumption that well-meaning academics are duped into working with them – tricked by flattering emails from the journals inviting them to submit a paper or fooled by a name that sounded like a journal they knew. But it's increasingly clear that many academics know exactly what they're getting into, which explains why these journals have proliferated despite wide criticism. The relationship is less predator and prey, some experts say, than a new and ugly symbiosis. https://goo.gl/wbh42J

37% Increase in Retractions in 2015



Retraction Watch https://goo.gl/JZE525

Retraction Watch home page: https://goo.gl/tAiZdr

Noted in Media Watch 9 October 2017 (#533, p.1):

- CANADA | CTV News (Toronto, Ontario) – 7 October 2017 – **'Predatory publishing a growing problem, warn scientists.'** One study[1] ... looked at more than 1,900 studies published in suspected predatory journals and found the majority of them didn't meet the basic information requirements to be published by a legitimate journal. The Ottawa researchers found that more than 90% of studies claiming to be randomized controlled trials, a gold standard of scientific research, failed to describe how patients were assigned to different treatment groups. They also found that less than one-quarter noted whether patients and assessors were blind-controlled or not. https://goo.gl/GahLFy

    1. 'Stop this waste of people, animals and money,' *Nature*, published online 6 September 2017. **Full text:** https://goo.gl/CXLDMC

Noted in the 14 August 2017 issue of Media Watch (#525, p.16)

- *SOUTH AFRICAN JOURNAL OF SCIENCE*, 2017;113(7/8):1-9. **'The extent of South African authored articles in predatory journals.'** The authors present a first estimate of the extent of predatory publishing amongst South African academics based on an analysis of all South African authored papers that qualified for subsidy over the period 2005 to 2014. The analysis shows that 4,246 South African papers were published in 48 journals which the authors re-classified (refining Beall's classification[1]) as either being probably or possibly predatory. A breakdown of these papers by year shows that the greatest increase in predatory publishing has occurred since 2011. **Full text:** https://goo.gl/pJazoq

    1. 'What I learned from predatory publishers,' *Biochemia Medica*, 2017;27(2):273-279. [Noted in Media Watch 19 June 2017, #517 (p.7)] **Full text:** https://goo.gl/TknXDS

N.B. The issue of *Biochemia Medica* cited includes several articles on predatory journals (journal contents page: https://goo.gl/GZLYvu). Additional articles on predatory journals are noted in the 5 June and 19 June 2017 issues of Media Watch (#515, p.6 and #517, p.7, respectively).

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.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/3oecYD

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 'Media Watch by Barry Ashpole']

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: https://goo.gl/IXO4mD

SINGAPORE | Centre for Biomedical Ethics (CENTRES): https://goo.gl/JL3j3C

Canada

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: https://goo.gl/BLgxy2
[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): https://goo.gl/wGi7BD
[Scroll down to 'Additional Resources']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): https://goo.gl/lOSNC7

ONTARIO | Mississauga Halton Palliative Care Network: https://goo.gl/ds5wYC
[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

Cont.

Europe

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

HUNGARY | Magyar Hospice Alapítvány: http://goo.gl/5d1l9K

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

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