

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.

19 September 2016 Edition | Issue #480



Compilation of Media Watch 2008-2016 ©

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Prognosis: Scroll down to [Specialist Publications](#) and 'A singular hope: How the discussion around cancer surgery sometimes fails' (p.7), in *Annals of Surgical Oncology*.

Canada

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 13 September 2016 – '**We can't debate the assisted dying law without data.**' How many legal assisted deaths have there been? No one is really saying – at least not officially. The closest we have to data is a CBC News survey of the provinces and territories that found at least 118 cases since Bill C-14 took effect 17 June.¹ That's just more than one a day. (To put that number in context, about 750 Canadians die on average each day.) The CBC found there were 49 assisted deaths in Ontario, 46 in British Columbia, 15 in Alberta, eight in Manitoba and "fewer than five" in Saskatchewan. Newfoundland & Labrador, Prince Edward Island, Northwest Territories and Nunavut recorded no cases. Quebec, New Brunswick and Nova Scotia refused to say how many assisted deaths were recorded. We know, however, from earlier reports ... that since Quebec's right-to-die law took effect last December, there have been 30 assisted deaths in that province, but the rate seems to have slowed since the federal law was adopted. (Quebec's law does have public reporting provisions, and a detailed report is expected to be published at the end of September.) This lack of public disclosure Canada-wide is troubling. <http://goo.gl/rZcsGd>

1. 'More than 100 Canadians have opted for assisted death since law passed,' CBC News, 2 September 2016. [Noted in Media Watch 5 September 2016, #478 (p.2)] <http://goo.gl/vqBILa>

U.S.A.

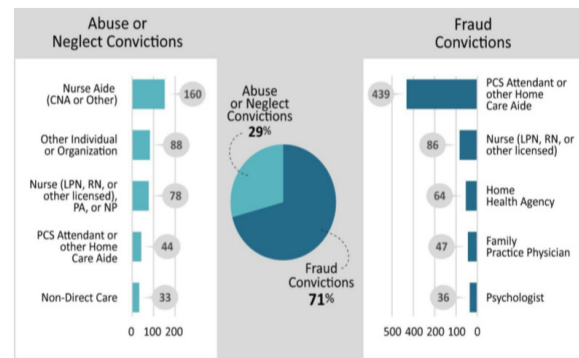
How tens of thousands of patients who weren't actually dying wound up on hospice care

THE WASHINGTON POST | Online – 15 September 2016 – Hospice patients are expected to die. The service, after all, is intended for the terminally ill. But over the past decade, as a 2014 *Washington Post* investigation found,¹ the number of patients who outlived hospice care in the U.S. has risen dramatically, in part because hospice companies earn more by recruiting patients who aren't actually dying. Now government inspectors have turned up information about how that happens. About one in three hospice patients were not given key information about what the choice of hospice entails at the time they enrolled,

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according to a report being released by the Office of Inspector General of the Department of Health & Human Services.² Government inspectors reviewed a random sample of the documentation that patients sign to indicate they want hospice care. In many cases, the patient was not informed that electing hospice meant that they intended to forgo a cure for their terminal illness – which investigators noted is a critical distinction between other health care. Hospices instead provide “palliative care” – that is, care focused on the prevention and alleviation of suffering of people nearing death. Moreover, in about 14% of cases reviewed, the physician who is supposed to approve the enrollment of a patient in hospice care paid only cursory attention to the matter. They provided scant information about the patient’s prognosis, and “appeared to have limited involvement in determining that the [patient] was appropriate for hospice care,” according to the report. <https://goo.gl/CaZqkT>

Provider Types with Most Convictions by Case Type



Specialist Publications

‘Who knew? Inpatient palliative care also saves money’ (p.12), in *MedScape*.

1. ‘The business of dying,’ *The Washington Post* [The 7-part series was noted in Media Watch through 2014] The series can be downloaded at: <http://goo.gl/FrTz89>
2. ‘Medicaid Fraud Control Units Fiscal Year 2015 Annual Report,’ Office of Inspector General, Department of Health & Human Services, September 2016. <https://goo.gl/3pdBoH>

Related

- WASHINGTON DC | *The Washington Examiner* – 12 September 2016 – **‘Medicare fraud rampant.’** Total fraud payments were \$43 billion. A leading cause of fraud is called “pay and chase,” in which the federal government pays a Medicare claim from a doctor or hospital before investigating whether it was a fraud. The agency relies “too heavily on investigating claims after the payments have been made rather than preventing them in the first place...” Lawmakers note the top Medicare services affected by fraud include home health and hospice care. <http://goo.gl/mX8Ms9>

Selected articles on Medicare fraud in the context of hospice care

- CALIFORNIA | My News (Los Angeles) – 20 June 2016 – **‘Medicare millionaire fraud: 8 years in prison as “dying” patients were just fine.’** Prosecutors said between March 2009 and June 2013, California Hospice submitted nearly \$9 million in fraudulent bills to Medicare and Medi-Cal for purportedly providing end-of-life care to patients who were, in fact, doing well. [Noted in Media Watch 27 June 2016, #468 (p.3)] <http://goo.gl/3CQtUA>
- PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 6 March 2016 – **‘Hospice fraud becoming a costly problem for Medicare.’** No one knows how big the problem of hospice fraud is ... but federal investigators prosecuted more than 60 cases in the last year alone, involving hundred of millions of dollars nationwide. [Noted in Media Watch 14 March 2016, #453 (p.5)] <http://goo.gl/qKILre>
- WASHINGTON DC | *The Washington Post* – 14 January 2015 – **‘How the drive for profits is shaping end-of-life care.’** Financial incentives provided by the Medicare payment system leads some hospices to target patients with easier to handle diagnoses because they are more profitable. Previous reports have focused on hospices that sign up patients in nursing homes and others that enroll patients who aren’t actually near death. [Noted in Media Watch 19 January 2015, #393 (p.2)] <http://goo.gl/iU8z2O>

New report finds lack of support for family caregivers

FORBES | Online – 13 September 2016 – Family caregivers for adults 65 and older are stressed, isolated and often suffering financially. With the aging of the boomer population, many more family members and friends will be needed to care for them in America in coming years. And yet fewer of those helpers will exist. Those are some of the troubling conclusions of the new report...¹ The 297-page study examines the challenges family caregivers currently face and what will be needed in the future. It also offers a number of public policy recommendations to address these concerning issues. Health care and social service systems have not been adequately prepared for the demographic shift that

will affect so many older adults and their caregivers, according to the report. And today's caregivers are often marginalized, left out of treatment decisions and untrained for complicated tasks. Yet, the report says, they are assumed to be available for a broad range of duties. <http://goo.gl/Cydllic>

[Specialist Publications](#)

'A valuable but demanding time: Family life during advanced cancer in an elderly family member' (p.7), in *Advances in Nursing Science*.

1. 'Families Caring for an Aging America,' National Academies of Sciences, Engineering & Medicine, September 2016. <http://goo.gl/UllOd2>

Recent articles on the role of the family caregiver in the context of health and social services

- *THE FISCAL TIMES* | Online – 21 June 2016 – '**Getting serious about home care for aging Americans.**' A new legislative effort comes alongside a new report which addresses the nations' elder caregiving crisis. ¹ The report highlights the growing importance of formal elder caregiving, needed even more as demographic and cultural changes increase the burdens on family caregivers. As the report states, Mobility is a feature of modern American life; it's time to incorporate that fact into a more reality-based elder caregiving model. [Noted in Media Watch 27 June 2016, #468 (p.4)] <http://goo.gl/KQA5lq>
- 1. 'Caring for America's Seniors; The Value of Home Care,' Home Care Association of America & Global Coalition on Aging, 2016. <https://goo.gl/Ma4ymo>
- *FORBES* | Online – 10 June 2016 – '**Can family caregivers reduce hospital costs?**' American Association of Retired Persons' figures the economic value of family care could be as much as \$470 billion annually. Here is another way to measure the value of family caregiving: by providing badly needed support for relatives living at home, can the care provided by family members cut health care costs by, say, reducing emergency room visits and hospitalizations? [Noted in Media Watch 13 June 2016 13 June 2016, #466 (p.3)] <http://goo.gl/wzkWeC>
- *THE WALL STREET JOURNAL* | Online – 3 June 2016 – '**Family caregivers become more crucial as elderly population grows.**' Strain on family caregivers is alarming many lawmakers and social-service providers. They are pushing for new ways to assist the vast unpaid workforce of people who are crucial in part because they allow more seniors to age in place and reduce reliance on public subsidies such as Medicaid, a major funder of institutional health care for older Americans. [Noted in Media Watch 6 June 2016, #465 (p.4)] <http://goo.gl/sLSflb>

[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>



International

Elder care in England

Elderly Britons bearing brunt of cuts to social care, report says

U.K. (England) | *The Guardian* – 15 September 2016 – Elderly people are bearing the brunt of cuts to social care, according to a report that warns of an increasing number of care homes going bust.¹ The study ... found that the care and support older people received depended on where they lived and how rich they were, rather than their level of need. Reductions in how much local authorities pay care homes, or below-inflation increases, mean that some are on the brink of collapse, leaving vulnerable people at risk. The cuts, combined with shortages of nurses and care workers, the introduction of the “national living wage” for staff and increasing reliance on people who can fund their own care, mean that many care homes are under unprecedented pressure, the report said. <https://goo.gl/81qrbe>

1. ‘Social care for older people: Home truths,’ The King’s Fund and the Nuffield Trust, September 2016. <https://goo.gl/VhRpQC>

End-of-life care in England

Doctors “routinely wrong” with predictions for when terminally ill will die

U.K. (England) | *The North-West Evening Mail* (Barrow-in-Furness, Cumbria) – 14 September 2016 – Doctors often get it wrong when predicting how long terminally ill people have left to live, new research suggests.¹ A review of more than 4,600 medical notes where doctors predicted survival showed a wide variation in errors, ranging from an underestimate of 86 days to an overestimate of 93 days. And it does not appear that more experienced or older doctors are any better at predicting when somebody will die than their younger counterparts. <https://goo.gl/9R4Wgh>

1. ‘A systematic review of predictions of survival in palliative care: How accurate are clinicians and who are the experts?’ *Plos One*, 25 August 2016. [Noted in Media Watch 29 August 2016, #477 (p.10)] <http://goo.gl/mUzCsH>

Cost of dying in the U.K.

The business of dying: Funeral costs soar

U.K. (England, Northern Ireland, Scotland & Wales) | *The Spectator* – 14 September 2016 – A new study out today reveals that U.K. funeral prices have soared by ten times the increase in the cost of living in just a year – a year! According to SunLife’s report,¹ the cost of dying is the fastest rising of any fixed cost in the U.K., increasing much quicker than rent, food, utilities, insurance and clothing. So, how much does the average person shell out for a funeral? When death-related expenditure such as probate, headstones and flowers are taken into account, in addition to the basic cost of a funeral, the figures stands at £8,802, an increase of 8.3% since

2015. The funeral itself – which makes up 44% of the cost of dying – has soared by 5.5% in a single year. The average funeral in the U.K. now costs £3,897 which is more than double the figure when SunLife first started tracking funeral prices in 2004. <https://goo.gl/05jFSZ>

Specialist Publications

‘Attending patient funerals: Practices and attitudes of Australian medical practitioners’ (p.9), in *Death Studies*.

1. ‘Cost of Dying 2016: A complete view of funeral costs over time’ (10th Edition), SunLife, September 2016. <https://goo.gl/mUPO4f>

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Noted in Media Watch 11 January 2016, #444 (p.4):

- U.K. | *The Daily Telegraph* – 8 January 2016 – ‘**British people donating bodies to science to avoid funeral costs.**’ Giving remains to anatomy departments can be seen as a way of avoiding the burden of funeral costs. However, science departments are not always able to take a person’s body because of disease or because there is simply no space. <http://goo.gl/aU7Ygf>

Noted in Media Watch 7 December 2015, #439 (p.7):

- U.K. | BBC News – 30 November 2015 – ‘‘**Paupers’ funerals” cost councils £1.7 million.**’ The cost to local councils of so-called “paupers’ funerals” has risen almost 30% to £1.7 million in the past four years. The number of these funerals has risen by 11%, a Freedom of Information request by BBC Local Radio revealed. <http://goo.gl/hYWfll>

End-of-life care in South Africa

On pain of death: The high price of overlooking palliative care

AFRICA (South Africa) | *The Daily Maverick* (Johannesburg) – 13 September 2016 – Palliative care (PC) has been described as “severely neglected” in South Africa, and there is a lack of access to it in public and private healthcare spheres alike. This is largely due to a lack of funds, but also a shortage of facilities and trained medical personnel. “Most people, because they are poor, die in pain and despair, without receiving the benefits of PC that would have prolonged their lives and allowed them to live with a measure of joy, peace and even productivity in their last days,” Rian Venter, director of West Gauteng Hospice, explains. Put simply, PC is often just not prioritised. In South Africa, government funding is already thin on the ground just trying to keep the country’s millions of patients alive. Hospices, where they exist, are generally privately funded. Beyond state healthcare, the situation is better, but not good enough. There are too few staff across the board, and according to Snyman, medical aid funding seldom adequately covers PC. There is good reason for concern over PC. Despite accounting for just 0.7% of the world’s population, South Africa houses 17% of HIV/Aids patients. <http://goo.gl/Ob94qe>

End-of-life care in Australia

Victorian Government to legalise future medical directives, stops short of euthanasia

AUSTRALIA (Victoria) | ABC News – 13 September 2016 – A bill to be introduced to State Parliament will allow Victorians to make legally binding decisions about their future medical treatment and end-of-life care, Victoria’s Health Minister Jill Hennessy says. The bill will allow Victorians to make advance care directives stating their preferences for future medical treatment, but does not legalise euthanasia. Ms. Hennessy said advance care directives would make patient choices clear to their medical practitioners. The law would apply to Victorians of all ages who were deemed able to make a decision, including children. <http://goo.gl/iKKF56>

End-of-life care in Northern Ireland

Palliative care is still largely misunderstood by the public

U.K. (Northern Ireland) | All Ireland Institute of Hospice & Palliative Care – 12 September 2016 – More than half of adults recently surveyed in Northern Ireland (51%) report that they have a basic or minimal understanding of what palliative care (PC) involves. Eighty-five percent of respondents did not believe that there is sufficient public understanding of PC. Among the 51% with a low level of understanding, 29% identified a basic understanding, 4% a low level and 18% said that they did not understand what PC involves at all. Young people (18-34) were more likely to know little about PC as 28% reporting no level of understanding compared to 13% among over 35s. <http://goo.gl/LU7c59>



All Ireland Institute of
Hospice and Palliative Care

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Noted in Media Watch 23 September 2013, #324 (p.9):

- *BMC PALLIATIVE CARE* | Online – 17 September 2013 – ‘**Public awareness and attitudes toward palliative care in Northern Ireland.**’ Public awareness of the concept of palliative care (PC) and of service availability remains insufficient for widespread effective and appropriate PC to be accepted as the norm. This has implications for PC service provision and policy. <http://goo.gl/cevN6g>

End-of-life care in India

Counsel terminally ill patients, experts say

INDIA (Jharkhand) | *The Times of India* (Ranchi) – 11 September 2016 – Family-related problems and health issues, which include terminal illness, are two prominent causes of suicide in the state. According to a detailed analysis of National Crime Records Bureau on suicide figures for 2014, of the 1,300 suicides in the state, 236 were related to family problems, with marriage-related issues topping the cause. Altogether 224 suicides had links with health issues, including 101 cases of simple illness, 38 cases of prolonged illness, 46 cases of insanity and 15 cases of those having diagnosed to be HIV-positive. While some of the non-government organiza-

tions have been extending help to the youth, counselling them against suicidal thoughts arising out of career related problems, unemployment, love affairs and failure in examination, those related to illness and terminal diseases often go unnoticed. <http://goo.gl/O0mXGg>

Specialist Publications

‘**Self-euthanasia, the Dutch experience: In search for the meaning of a good death or *eu thanatos***’ (p.13), in *Bioethics*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- DENMARK | *The Copenhagen Post* – 14 September 2016 – ‘**Half of Danes would assist their loved ones in dying.**’ A new Megafon poll has revealed that 50% of Danes would offer help to their terminally-ill family members and other relatives if they wished to die. On the other hand, 23% said they were against euthanasia and 14% were not sure how they would react. The debate on assisted suicide in Denmark reopened again when a court in Helsingør gave a 78-year-old man a 50-day suspended sentence for killing his ailing wife with sleeping pills. <https://goo.gl/zFAY8B>

Specialist Publications

Shared decision making to support the provision of palliative and end-of-life care in the emergency department: A consensus statement and research agenda

ACADEMIC EMERGENCY MEDICINE | Online – 9 September 2016 – Participants were identified based on expertise in emergency, palliative, or geriatrics care, policy, or patient-advocacy and spanned physician, nursing, social work, legal, and patient perspectives. Key research questions identified by the group related to which emergency department (ED) patients are likely to benefit from palliative care (PC), what interventions can most effectively promote PC in the ED, what outcomes are most appropriate to assess the impact of these interventions, what is the potential for initiating advance care planning in the ED to help patients define long-term goals of care, and what policies influence palliative and end-of-life care decision making in the ED. Answers to these questions have the potential to substantially improve the quality of care for ED patients with advanced illness. <http://goo.gl/Z8OS8b>

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Noted in Media Watch 2 May 2016, #460 (p.7):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 April 2016 – ‘**Effectiveness of emergency department based palliative care for adults with advanced disease: A systematic review.**’ Emergency departments (EDs) are seeing more patients with palliative care (PC) needs, but evidence on best practice is scarce. There is yet no evidence that ED-based PC affects patient outcomes except for indication from one study of no association with 90-day hospital readmission, but a possible reduction in length of stay if integrated PC is introduced early at ED rather than after hospital admission. <http://goo.gl/J18JG6>

N.B. Additional articles on end-of-life care in the emergency department noted in Media Watch 18 April 2016 issue of Media Watch (#458, p.10).

Death is a social justice issue: Perspectives on equity-informed palliative care

ADVANCES IN NURSING SCIENCE | Online – 7 September 2016 – All too often, palliative care (PC) services are not responsive to the needs of those who are doubly vulnerable, being that they are both in need of PC services and experiencing deficits in the social determinants of health that result in complex, intersecting health and social concerns. In this article, the authors argue for a reorientation of PC to explicitly integrate the premises of health equity. They articulate the philosophical, theoretical, and empirical scaffolding required for equity-informed PC and draw on a current study to illustrate such an approach to the care of people who experience structural vulnerabilities. <http://goo.gl/nOp89d>

A valuable, but demanding time: Family life during advanced cancer in an elderly family member

ADVANCES IN NURSING SCIENCE | Online – 9 September 2016 – This study explores experiences of elderly patients with cancer and their family members with regard to what is important and difficult in the family relationships during the palliative phase. Family group interviews were conducted with 26 families. Three themes emerged: 1) Ensuring a positive final time together; 2) Avoiding tension and conflict; and, 3) Concealing thoughts, feelings, and needs. The main theme, “a valuable but demanding time,” indicates that although families find this phase of life challenging, they emphasize the importance of ensuring that this time is spent together in a positive way as a family. <http://goo.gl/rsHBtZ>

Literature review

A singular hope: How the discussion around cancer surgery sometimes fails

ANNALS OF SURGICAL ONCOLOGY | Online – 9 September 2016 – Physicians tended not to dwell on prognosis in early discussions, instead emphasizing the uniqueness of individuals and the uncertainty of statistics. The treatment plan often became the dominant feature of the conversation and functioned to deflect attention from discussions of prognosis. Surgeons tended to understate possible complications and provided little detail regarding potential severity or long-term consequences. While most patients wished to be informed of their prognosis, only a subset actually received an estimate of life expectancy. Because optimism with respect to prognosis (often simplified as “hope”) has been largely considered essential for positivity and optimism – even a false or inappropriate optimism – many providers have created, tolerated, or enabled it. Several studies have emphasized, however, that hope can be maintained with truthful discussion, even if the topic is a bad prognosis or eventual death. <http://goo.gl/ZNu1XM>

N.B. Selected articles on prognosis noted in Media Watch 29 August 2016, #477 (pp.10-11).

Crash course in EPaCCS (Electronic Palliative Care Coordination Systems): 8 years of successes and failures in patient data sharing to learn from

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 13 September 2016 – EPaCCS are England's pre-eminent initiative in enabling advance care planning and improved communication and coordination at the end of life. EPaCCS have been under development for 8 years after being proposed, as Locality Registers, in the 2008 End of Life Care Strategy for England. EPaCCS are electronic registers or tools and processes for sharing data which aim to enable access to information about dying patients. Striking outcomes have been reported around EPaCCS, such as 77.8% of 'Coordinate My Care' patients dying in their preferred place. EPaCCS have, however, been extremely challenging to develop and implement, with many projects remaining continuously "under development" or folding. They also continue to be sub-optimally integrated with other data sharing initiatives. Rigorous research is non-existent. The authors discuss the current EPaCCS landscape and way forward. <https://goo.gl/ao50pL>

Caregiver activation and home hospice nurse communication in advanced cancer care

CANCER NURSING | Online – 14 September 2016 – Few studies have investigated nurse/caregiver communication in home hospice, and, to the authors' knowledge, no other studies focused on caregiver activation. Caregiver communication that reflected activation included demonstrating knowledge regarding the patient/care, describing care strategies, expressing opinions regarding care, requesting explanations of care, expressing concern about the patient, and redirecting the conversation toward the patient. Nurses [i.e., study participants] responded by providing education, reassessing the patient/care environment, validating communications, clarifying care issues, updating/revising care, and making recommendations for future care. Nurses prompted caregiver activation through focused care-specific questions, open-ended questions/statements, and personal questions. <https://goo.gl/QmjD5Z>

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

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Links to Sources

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4. Access to a complete article, in some cases, may require a subscription or one-time charge.
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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.

Attending patient funerals: Practices and attitudes of Australian medical practitioners

DEATH STUDIES | Online – 9 September 2016 – The appropriateness of attending a patient's funeral is a medical dilemma. This paper focuses on 437 doctors who participated in an online survey. Seventy-one percent of GPs, 67% of oncologists, 67% of psychiatrists, 63% of palliative medicine specialists, 52% of surgeons, and 22% of intensive care specialists had attended patient funerals. Significant differences in demographics and between specialties were identified in terms of barriers and benefits associated with attendance. While attendance is a personal decision, there is a need for open discussions in medical education and professional development concerning death and the role of doctors after a patient dies. <http://goo.gl/AxmtKV>

Noted in Media Watch 25 April 2011, #198 (p.8, under 'Worth Repeating'):

- *BRITISH MEDICAL JOURNAL* | Online – 27 July 2007 – '**Should doctors go to patients' funerals?**' It was heartening to receive many positive and supportive responses to both the published editorial and to the subsequent interviews performed.¹ We were privileged to hear personal stories from patients' relatives as well as learning about a range of practices doctors were undertaking to convey a gesture of respect and support following the death of a patient. These responses were instructive to us as authors and have left us with a more complete answer to our question: "Should doctors go to patients' funerals?" If possible and appropriate, yes. Should doctors have some method whereby they convey a gesture of acknowledgment, compassion and support? Absolutely. Dealing with the death of a patient is not something that appears to be a part of the medical school curriculum; however, it is a situation that we as doctors universally face. In terms of dealing with the external situation (personal coping with grief is a more complex issue) perhaps the only preparation that is necessary is an appreciation of how important our role can be following the death of a patient and some forethought as to what form that role may take. Attending the funeral is only one such option [see sidebar]. <http://goo.gl/Mk7iOY>

1. 'Should doctors go to patients funerals?' *British Medical Journal*, 21 June 2007. <http://goo.gl/9kG2Dr>

Acceptable options

- 1) Sending a condolence card or letter. This can be from the doctor with a personal message or thoughts appropriate to the particular patient or can be a collaborative effort with all the relevant staff adding their own personal message.
- 2) Having a practice meeting to "de-brief" after the patients' death to ensure everyone is coping and what the practice response will be. Someone other than the doctor may wish to attend the funeral, someone in the practice team may be aware of a particular need within the family that others are unaware of, worries or issues around the death can be aired and from this forum a card or letter may be able to be signed or flowers sent.
- 3) A telephone call to the next-of-kin or close relative following the death can express sympathy, check on family support, determine if any follow up is required and may be able to resolve any misunderstandings regarding medical care or the circumstances of death.
- 4) Arranging a family conference in the weeks following the death to review the patient illness or circumstances of death, to help answer any lingering questions and to ascertain how everyone is coping.



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.

The body of knowledge in thanatology: An outline

DEATH STUDIES | Online – 9 September 2016 – The Association for Death Education & Counseling has updated its articulation of the body of knowledge in the field of thanatology. In doing so it has relinquished the use of a matrix format in favor of a more serviceable outline... Accompanying the outline is a new commentary on the state of the field itself, along with an annotated bibliography of recent relevant publications. <http://goo.gl/gOLk1D>

Noted in Media Watch 26 December 2011, #233 (p.6):

- *JOURNAL OF DEATH & DYING*, 2012;64(2):157-169. ‘**The emergence of thanatology and current practice in death education.**’ This literature review aims to outline the history and evolution of thanatology in Western society, delineating the contextual circumstances that led to its origin and drawing special attention to current works on death education. <http://goo.gl/bLI7ij>

Factors associated with transition from community settings to hospital as place of death for adults aged 75 and older: A population-based mortality follow-back survey

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 9 September 2016 – There is an apparent reliance on hospitals to provide end of life (EoL) care for older people, particularly those living at home, who accounted for 71.9% of those who transitioned. Very few (4.7%) transitioned to an inpatient hospice unit at the EoL. Almost half (47.3%) who transitioned to the hospital were inpatients for several weeks to a month before death. Irrespective of their usual place of care, the likelihood of transition to the hospital was greater for people with respiratory and circulatory disease and with severe breathlessness. The likelihood of transition was lower for people who had discussed EoL care preferences with a health professional and those with an identified key healthcare professional. <http://goo.gl/6KVloz>

Paediatric palliative care in Australia

Pop Up: A new model of paediatric palliative care

JOURNAL OF PAEDIATRICS & CHILD HEALTH | Online – 9 September 2016 – This paper describes a model of paediatric palliative care (PPC) developed in the Australian context, to improve access to specialist PPC for children at home. The Paediatric Palliative Care Service at the Children’s Hospital at Westmead (CHW) is a multidisciplinary specialist team represented by medical, nursing, allied health and psychology. Approximately, 55 children a year are referred for specialist palliative care (SPC). The CHW SPCs’ catchment extends across metropolitan, rural and remote locations. Each year there is a small number of children who are approaching the end of their life in any particular community. The SPC team aims to provide a responsive, individualised and dynamic service to meet the needs of each child and their family and care givers. This requires a high level of engagement with local community care providers and adult-focused SPC services. A case study is described to illustrate this new model of care. <http://goo.gl/kFxrE7>

The challenges identified in providing specialist paediatric palliative care include:

Ensuring access to specialist support for each patient is available and equitable throughout an illness trajectory, irrespective of geographical location.

Engaging with local health services with limited community resources available.

Developing confidence and knowledge in local health services providing PPC (through the delivery of education when required that is individualised to each child and family’s needs).

Providing a responsive specialist service that is available for community providers when needed during a child’s illness.

Providing after hours support to clinicians caring for children with life limiting conditions and children requiring end of life care.

Cont.

Related

- *PEDIATRIC BLOOD & CANCER* | Online – 8 September 2016 – ‘**Going straight to the source: A pilot study of bereaved parent-facilitated communication training for pediatric subspecialty fellows.**’ The authors designed and implemented a pilot communication training seminar in which bereaved parent educators and faculty facilitators led small groups in interactive, role-play scenarios. Participants reported significant improvement in overall preparedness, breaking bad news to a patient and family, and including the adolescent or young adult patient in conversations. Additionally, participants reported a significant improvement in their ability to address a patient and family’s need for information, emotional suffering at the end of life (EOL), if and when a patient should be included in the conversation, and EOL care decisions. <http://goo.gl/KX1amY>

Cultural diversity calls for culture-sensitive health communication

MEDICAL DECISION MAKING, 2016;36(7):795-797. In the U.S., the immigrant population is estimated to be 13% of the whole population,¹ including refugees as well as permanent residents who were not born in the U.S. In addition, there is a large and increasing group of second-generation immigrants who were born in the U.S., but have at least one immigrant parent. These examples show that most societies deal with great variety in terms of cultural backgrounds of their citizens, cultural beliefs, and traditions. Such a cultural diversity is a challenge for health care that aspires and requires trustful

relationships between health care workers and the patient, as well as well-informed and committed patients. This special section of *Medical Decision Making* highlights effects of cultural diversity on medical decision making and health promotion. <https://goo.gl/yitYlr>

Worth Repeating

‘**Be a true listener, rather than a good conversationalist**’ (p.0), in *South Asian Journal of Cancer*.

1. 42.4 million of the total U.S. population of 318.9 million in 2014

N.B. Click on pdf icon to access full text of editorial. Journal Contents page: <https://goo.gl/pfxTBq>

Noted in Media Watch 18 April 2016, #458 (p.11):

- *JOURNAL OF INTERCULTURAL STUDIES*, 2016;37(2):103-117. ‘**The “other” in end-of-life care: Providers’ understandings of patients with migrant backgrounds.**’ The analysis brings to the fore three themes: 1) The expectation that the existence of difference and uncertainty is a given when caring for patients with migrant backgrounds; 2) The expectation that the extension of responsibility that difference entails creates a variety of dilemmas; and, 3) The expectation that difference will bring about misunderstandings and that patients’ needs can go unmet as a result of this. <http://goo.gl/35jYcU>

Noted in Media Watch 23 September 2013, #324 (p.2):

- U.S. | *The Philippine Daily Inquirer* (U.S. Bureau) | Online – 21 September 2013 – ‘**Immigrants rely on God, family, home in making end-of-life care decisions.**’ When it comes to making end-of-life health care decisions, religion, family and home are powerful influences on many terminally ill Filipino immigrants in America. This can pose a challenge to providers of palliative care who must deliver comfort care with sensitivity to seriously ill or dying Filipino patients. <https://goo.gl/96TkXP>



‘Living and dying in pain: It doesn’t have to happen’
8 October 2016
<http://goo.gl/iKZH4k>

Ethics at the end of life

MEDICINE | Online – 8 September 2016 – End-of-life care (EOLC) has always been prominent in discussions of clinical ethics. Almost 30% of hospital inpatients are in their last year of life. Doctors frequently encounter people with EOLC needs and should be equipped to respond. The bewildering array of what has been written about it leaves many doctors, other healthcare workers and the public uncertain and confused. What key things should doctors know and understand? The principles are the same as in any area of medicine, but they have to be applied in a different context. Some goals (e.g., long-term survival) can no longer be achieved, but new ones (e.g., new ways to improve quality of life) become available. This article briefly addresses key areas including why ethics matters in EOLC, how to apply familiar principles, how we can respond to some barriers to respect for autonomy, applying the doctrine of double effect and understanding the application of ethics in the last days of life. It also gives pointers to further detailed reading. <http://goo.gl/lzQD4Q>

Related

- *MEDICINE* | Online – 10 September 2016 – ‘**Discussing “do not attempt cardiopulmonary resuscitation” decisions with patients.**’ This article summarizes some of the key points for clinicians when making ‘do not attempt cardiopulmonary resuscitation’ (DNACPR) decisions, including when and how DNACPR discussions should take place. It also suggests examples and methods for how to approach conversations with patients and proxies. <http://goo.gl/iDDS88>

Who knew? Inpatient palliative care also saves money

MEDSCAPE | Online – 12 September 2016 – Researchers from Johns Hopkins Health System in Baltimore, Maryland, found in addition to improving quality of care and patient satisfaction, the combined inpatient and consultation palliative care (PC) programs contributed to substantially lower charges and costs per day. According to their analysis, the fiscal impact of an inpatient PC program could save them almost \$4 million a year. Over a 5-year period, they would be looking at savings of more than \$19 million. Researchers estimated the savings for an 11-bed PC unit based on the cost per day from fiscal year 2015 with a 6-bed unit (\$444 lower costs per day compared with hospital inpatient stay before transfer to the palliative unit). They then calculated the cost savings for an 11-bed unit operating at 80% occupancy and estimated the direct cost savings of consultations by using established methods. The estimated savings from the 11-bed PC unit was calculated out to \$1,336,000 per year or \$6.7 million over 5 years. For PC consultations, the total estimated savings in direct costs per case were \$2,530,000/year, or \$12,650,000 over 5 years. <http://goo.gl/9GM08c>

Selected articles on the economic benefits of palliative care

- *HEALTH AFFAIRS*, 2016;35(1):44-53. ‘**Palliative care teams’ cost-saving effect is larger for cancer patients with higher numbers of co-morbidities,**’ The receipt of a palliative care consultation within two days of [hospital] admission was associated with 22% lower costs for patients with a co-morbidity score of 2-3 and with 32% lower costs for those with a score of 4 or higher. [Noted in Media Watch 11 January 2016, #444 (p.3)] <http://goo.gl/WvU7mr>
- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 20 July 2015 – ‘**Economic benefits of palliative care consultation continue to unfold.**’ Benefits from palliative care intervention include the opportunity to reduce the frequency, intensity, and therefore cost of medical interventions at the end of life. [Noted in Media Watch 27 July 2015, #420 (p.14)] <http://goo.gl/YEQxCz>
- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 8 June 2015 – ‘**Prospective cohort study of hospital palliative care teams for inpatients with advanced cancer: Earlier consultation is associated with larger cost-saving effect.**’ Earlier palliative care (PC) consultation during hospital admission is associated with lower cost of hospital stay for patients admitted with an advanced cancer diagnosis. These findings are consistent with a growing body of research on quality and survival suggesting that early PC should be more widely implemented. [Noted in Media Watch 15 June 2015, #414 (p.5)] <http://goo.gl/3ZZHbU>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BIOETHICS* | Online – 15 September 2016 – ‘**Active and passive physician-assisted dying and the terminal disease requirement.**’ The view that voluntary active euthanasia and physician-assisted suicide should be made available for terminal patients only is typically warranted by reference to the risks that the procedures are seen to involve. Though they would appear to involve similar risks, the commonly endorsed end-of-life practices referred to as passive euthanasia are available also for non-terminal patients. The author assesses whether there is good reason to believe that the risks in question would be bigger in the case of voluntary active euthanasia and physician-assisted suicide than in that of passive euthanasia. <https://goo.gl/5zdLct>
- *BIOETHICS* | Online – 9 September 2016 – ‘**Self-euthanasia, the Dutch experience: In search for the meaning of a good death or *eu thanatos*.**’ The author takes as a point of departure the new notion of “self-euthanasia” and the corresponding practice that has evolved in The Netherlands in recent years. Both physician-euthanasia and self-euthanasia refer to an ideal process of a good death, the first being ultimately the physician’s responsibility, while the second is definitely the responsibility of the individual choosing to die. However, if we also accept the existence of a fundamental moral difference between ending another person’s life and ending your own life, and if we accept this moral difference to be also relevant to the normatively laden good death, then this difference represents a strong reason for preferring self-euthanasia to physician-euthanasia. <http://goo.gl/VyYNcU>
- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 12 September 2016 – ‘**Euthanasia in Belgium: Trends in reported cases between 2003 and 2013.**’ The authors undertook this study to describe trends in officially reported euthanasia cases in Belgium with regard to patients’ socio-demographic and clinical profiles, as well as decision-making and performance characteristics. Since legalization of euthanasia in Belgium, the number of reported cases has increased each year. Most of those receiving euthanasia were younger than 80 years and were dying of cancer. Given the increases observed among non-terminally ill and older patients, this analysis shows the importance of detailed monitoring of developments in euthanasia practice. <http://goo.gl/vEqY5LL>
- *THE LINACRE QUARTERLY*, 2016;83(3):246-257. ‘**Non-faith-based arguments against physician-assisted suicide and euthanasia.**’ Presented are four non-religious, reasonable arguments against physician-assisted suicide and euthanasia: 1) “It offends me,” suicide devalues human life; 2) Slippery slope, the limits on euthanasia gradually erode; 3) “Pain can be alleviated,” palliative care and modern therapeutics more and more adequately manage pain; and, 4) Physician integrity and patient trust, participating in suicide violates the integrity of the physician and undermines the trust patients place in physicians to heal and not to harm. <http://goo.gl/0aBhIH>
- *PALLIATIVE MEDICINE* | Online – 12 September 2016 – ‘**The European Association for Palliative Care White Paper on Euthanasia and Physician-Assisted Suicide: Dodging responsibility.**’ The White Paper of the European Association for Palliative Care (EAPC) on euthanasia and physician-assisted suicide in a previous issue is the result of a consensus-seeking process among representatives of the national palliative care organisations in Europe as well as the EAPC board members about the position statements that had been formulated in an earlier position paper in 2003.² With the aim of providing “a viewpoint from the palliative care perspective” and an overarching “normative ethical framework,” the authors end by reaffirming that “euthanasia is not a part of palliative care” despite noting strong dissent and a lack of consensus on pivotal statements. <http://goo.gl/mcHNT3>

Noted in Media Watch 23 November 2015, #437 (p.17):

- *PALLIATIVE MEDICINE* | Online – 19 November 2015 – ‘**Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care (EAPC).**’ The consensus process confirmed the 2003 EAPC white paper and its position on the relationship between PC and euthanasia and physician-assisted suicide. The EAPC feels it is important to contribute to informed public debates on these issues. Complete consensus seems to be unachievable due to incompatible normative frameworks that clash. <http://goo.gl/KLQ2tC>

Worth Repeating

Be a true listener, rather than a good conversationalist

SOUTH ASIAN JOURNAL OF CANCER, 2013;2(4):288-289. Oncology patient care is an ever evolving field both as a science and a clinical art. We evaluate, diagnose, and treat cancer patients daily. We break the bad and the good news to them. We are the hope on which their life and dreams hang on. We ... have to assess each patient as an intelligent observer. We have to devise our strategy to break heartbreaking news to them in a tailored and personalized fashion according to the physical, psychological, emotional, and social status of the patient. The process has to be gentle, perceptive, pragmatic, yet truthful. There needs to be reasonably good observational, listening, comprehending, and delivering potentials ... sharpened by experience and skills. [Noted in Media Watch 28 October 2013, #329 (p.11)] <http://goo.gl/l825rX>

Quotable Quotes

*One of our most difficult duties as human beings is to listen to the voices of those who suffer. The voices of the ill are easy to ignore ... most of us would rather forget our own vulnerability ... Listening is hard, but it is also a fundamental moral act. Arthur Frank, *The Wounded Story Teller: Body, Illness and Ethics* (University of Chicago Press, 1995).*

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/m98B1D>

IAHPC link updated 09.19.2016

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](http://goo.gl/JNHVMB)

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

Canada

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

Europe

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

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1l9K>

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



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