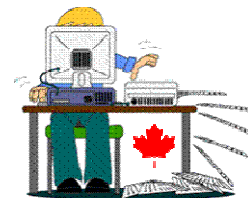


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

The gap between the kind of care people hope for at the end of life and what they receive: Scroll to [Specialist Publications](#) and 'Reinventing palliative care: Hospice in hospital' (p.11), in *Postgraduate Medical Journal*.

Canada

Palliative care workers should be psychologically screened: Poll

ALBERTA | *The Edmonton Journal* – 21 September 2016 – Palliative care (PC) workers should be subject to spot checks and undergo psychological screening for compassion and empathy, Canadians say in a new poll that calls on Ottawa to develop national standards for the services provided to dying patients.¹ The Ipsos survey was conducted for Palliative Care Matters, a national initiative led by Edmonton-based Covenant Health to improve end-of-life services around the country. Those who participated in the online poll were asked a variety of questions on the sensitive subject, including what services should be provided to palliative patients and caregivers, where access should be offered and who should pay. The results show Canadians have high expectations for the doctors, nurses and other health professionals who care for the dying. More than 85% of respondents said su-

pervisors should conduct regular spot checks of such providers, who should also be forced to obtain special certification and receive psychological screening to ensure they can exhibit adequate compassion. About 80% of respondents also supported the idea of mandatory annual training for PC staff. <https://goo.gl/aTJJkv>

Quotable Quotes

How far you go in life depends on your being tender with the young, compassionate with the aged, sympathetic with the striving and tolerant of the weak and strong. Because someday in your life you will have been all of these. **George Washington Carver (1864-1943)**

1. 'Canadians' Views of Palliative Care National Online Survey,' Palliative Care Matters, September 2016. <https://goo.gl/Sa6wVv>

Cont. next page

Selected articles on compassion and empathy in the context of end-of-life care

- *PALLIATIVE MEDICINE* | Online – 17 August 2016 – ‘**Sympathy, empathy, and compassion: A grounded theory study of palliative care patients’ understandings, experiences, and preferences.**’ Sympathy was described as an unwanted, pity-based response to a distressing situation, characterized by a lack of understanding and self-preservation of the observer. [Noted in Media Watch 22 August 2016, #476 (p.14)] <http://goo.gl/7vHa89>
- *JOURNAL OF MEDICAL ETHICS* | Online – 3 November 2015 – ‘**Smiling through clenched teeth: Why compassion cannot be written into the rules.**’ The discourse on the failings of the National Health System [in the U.K.] often cites lack of compassion as an important factor. This paper argues that compassion cannot be enforced by any rule. <https://goo.gl/A7tvMS>
- *INTERNATIONAL JOURNAL OF HEALTH POLICY & MANAGEMENT*, 2015;4(4):199-201. ‘**Why and how is compassion necessary to provide good quality healthcare?**’ While the link between high quality care and compassion is often taken for granted, it is less obvious how compassion – often originating in the individual’s emotional response – can become a moral sentiment and lead to developing a system of norms and values underpinning ethics of care. [Noted in Media Watch 30 March 2015, #403 (p.14)] <https://goo.gl/p0nNog>

How doctors are failing us in death

ONTARIO | *The Toronto Star* – 20 September 2016 – Like so many families who have had the difficult, but essential conversation with an aging parent around their end-of-life wishes, we had spoken with ... [my father-in-law] ... about his wishes. He was clear he did not want to be on life support. The eight doctors who treated my father-in-law all had different ideas about what those wishes meant, and how involved the family should be in making treatment decisions. This inconsistency – the waiting, the arguing, the feeling of powerlessness – was our family’s worst experience with a health care system of which we are so often proud. Some of the doctors acknowledged his wishes, but said life support was an essential part of the treatment plan; it was just a temporary measure to aid in his recovery. Others made very little effort to consult with us, and another outright refused! Another doctor assured us he would “bounce back,” though nurses told us this was increasingly unlikely and

that the doctor was prone to sugar-coating discussions with families. Because of this inconsistency, different members of my family were hearing different things – and that made it even more difficult for us to make a decision we all felt comfortable with. Finally, I pulled aside the latest doctor treating my father-in-law and asked him for an absolutely frank and direct discussion. Only then were we able to make an informed decision that respected my father-in-law’s wishes and provided as much comfort as possible to our family. <https://goo.gl/zTyGhK>

[Specialist Publications](#)

‘**A proposal for values-based law reform on unilateral withholding and withdrawal of potentially life-sustaining treatment**’ (p.5), in *Alberta Law Review*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 22 September 2016 – ‘**Ban conscientious objection by Canadian doctors, urge ethicists in volatile commentary.**’ Authorities should bar doctors from refusing to provide such services as abortion and assisted death on moral grounds, and screen out potential medical students who might impose their values on patients, leading Canadian and British bioethicists argue in a provocative new commentary.¹ They argue that physicians have no right to opt out of lawful medical services — from abortion to prescribing contraceptives – that are requested by a patient and in the person’s interest. <https://goo.gl/zAYZn9>

1. Doctors have no right to refuse medical assistance in dying, abortion or contraception,’ *Bioethics*, 22 September 2016. <https://goo.gl/QAMuRu>

U.S.A.

When should children take part in medical decisions?

THE NEW YORK TIMES | Online – 20 September 2016 – As children grow up, how can they, and how should they, begin to participate in making medical decisions? What if they disagree with their parents, or with their doctors? When do they get to decide whether to have elective surgery, whether to go on medication for attention deficit disorder, whether to undergo medical tests or treatments or just wait to see whether their symptoms clear up on their own? The American Academy of Pediatrics last month issued a new policy statement,¹ with an accompanying technical report,² analyzing the issue of informed consent by pediatric patients. It discusses the question of formal informed consent, but also the question of assent, suggesting that even a child as young as 7 can express an informed agreement with proposed medical treatment, and that if the child is properly informed and involved in the discussion, this can “foster the moral growth and development of autonomy in young patients.” <https://goo.gl/gBGHJj>

Extract from *The New York Times* article

When the stakes are high, and a child is not going to be allowed to refuse treatment, it's important to make that clear. Adults, of course, are allowed to refuse lifesaving treatments or surgeries and to ignore their doctors' advice. But they aren't generally allowed to do that on behalf of their children, and there is plenty of legal precedent for overruling religious preferences and mandating blood transfusions or medications for children even if parents would be able to refuse for themselves.

Specialist Publications

'Participation of children in medical decision-making: Challenges and potential solutions' (p.7), in *Journal of Bioethical Inquiry*.

1. 'Informed Consent in Decision Making in Pediatric Practice,' Policy Statement, American Academy of Pediatrics, August 2016. <https://goo.gl/2u400b>
2. 'Informed Consent in Decision Making in Pediatric Practice,' Policy Statement, American Academy of Pediatrics, August 2016. <https://goo.gl/2sY4F2>

Selected articles on decision making in pediatric palliative care

- *HEALTH PSYCHOLOGY*, 2015;34(4):446-452. '**The parents' ability to attend to the "voice of their child" with incurable cancer during the palliative phase.**' Whether or not the voice of children approaching the end-of-life is heard, often depends on their parents' ability to give them a voice. [Noted in Media Watch 27 April 2015, #407 (p.11)] <http://goo.gl/fSgXw5>
- *MEDICAL DECISION MAKING* | Online – 21 April 2015 – '**Evolution of pediatric chronic disease treatment decisions: A qualitative, longitudinal view of parents' decision-making process.**' In this study, decision making was an iterative process occurring in three distinct patterns. Understanding these and the varying elements of parents' decision processes is an essential step toward developing interventions that are appropriate to the setting and that capitalize on the skills families may develop as they gain experience with a chronic condition. [Noted in Media Watch 27 April 2015, #407 (p..11)] <http://goo.gl/SWRwE4>
- *PEDIATRICS* | Online – 5 January 2015 – '**Talking with parents about end-of-life decisions for their children.**' In this study, all physicians focused primarily on providing medical information, explaining their preferred course of action, and informing parents about the decision being reached by the team. Only in two cases were parents asked to share in the decision-making. [Noted in Media Watch 12 January 2015, #392 (pp.12-13)] <http://goo.gl/WL4uFJ>



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

International

End-of-life care in Australia

Funds fear for palliative care service

AUSTRALIA (Tasmania) | *The Mercury* (Hobart) – 20 September 2016 – Tasmania’s peak body for hospice and palliative care (PC) will be forced to close its Hobart office within the next two weeks unless it secures last-minute funding from the Federal Government, says the organisation’s general manager. Palliative Care Tasmania (PCT) has been federally funded for the past three years as part of the Better Access to Palliative Care in Tasmania Program. General manager Colleen Johnstone said although the organisation had “lobbied relentlessly,” it had not been able to secure any ongoing funding. “Without PCT, there will be a massive PC education void for the community, carers, volunteers and staff within the sector,” she said. “This means less people will have the knowledge to make choices about their end-of-life care and be supported in those choices. It will also be difficult for the sector in Tasmania to continue to grow and develop without an active PC peak body supporting it.” Ms. Johnstone said during the past three years, the group had educated more than 13,000 Tasmanians in the health care and community sectors. <https://goo.gl/9rfSV0>

Noted in Media Watch 5 September 2016, #478 (p.5):

- AUSTRALIA (Tasmania) | ABC News (Hobart) – 30 August 2016 – ‘**Push to keep palliative care education program to help Tasmanians die at home.**’ While Palliative Care Tasmania prepares to wind down the education program when its funding runs out at the end of September, the lobby to prevent its demise is gaining momentum. <http://goo.gl/YwBZ8h>

Person-centred care in Scotland: Palliative care

U.K. (Scotland) | *Holyrood* (Edinburgh) – 20 September 2016 – When it comes to putting the person in the centre of their care with shared decision making, are there lessons to be had from palliative care (PC) ... ? The Chief Medical Officer, Dr. Catherine Calderwood, thinks palliative discussions can reveal the “disconnect” between what a person wants towards the end of their life and what a clinician sometimes assumes the person wants. PC shows that sometimes in discussions about care a person might choose not to have an intervention. This was highlighted in the revised PC guidelines on resuscitation, which state patients should always be involved in the decision about whether to attempt to resuscitate them when their heart or breathing stops, unless they lack capacity to engage with the conversation. The changes to the national policy on Do Not Attempt Cardiopulmonary Resuscitation followed reviews by doctors and nursing unions as well as guidance

from the General Medical Council.¹ A report for the Scottish Parliament’s Health & Sport Committee last year revealed that in many cases, palliative conversations were not taking place until it was too late.² <https://goo.gl/WvWmWb>

A new publication is offering a comprehensive guide to end of life care facilities across Scotland

U.K. (Scotland | BBC News – 22 September 2016 – The ‘Scottish Atlas of Palliative Care’ has been compiled by academics based at the University of Glasgow’s Crichton campus in Dumfries.¹ It includes maps, tables, lists and diagrams showing which services are available, at what level, and where ... and contains previously-unavailable data on palliative care services across Scotland. <https://goo.gl/zgl68s>

1. ‘Scottish Atlas of Palliative Care,’ End of Life Studies Group, University of Glasgow. <https://goo.gl/Sf3DCy>

1. ‘Do Not Attempt Cardiopulmonary Resuscitation (DNACPR),’ Government of Scotland, August 2016. [Noted in Media Watch 5 September 2016, #478 (p.15)] <http://goo.gl/DO1q0m>
2. ‘International comparisons in palliative care provision: What can the indicators tell us?’ Health & Sport Committee, Health & Sport Committee, Scottish Parliament, September 2015. [Noted in Media Watch 21 September 2015, #428 (p.6)] <http://goo.gl/KhtqU>

End-of-life care in India

Palliative care centres hit by shortage of docs, morphine

INDIA (Maharashtra) | *The Hindu* (Mumbai) – 18 September 2016 – Two years after palliative care (PC) centres were set up in eight of Maharashtra's most backward districts to cater to patients with incurable medical conditions and acute pain, the project has hit a roadblock: six of these centres have been without doctors for six months now. While nurses and medical social workers are available, they are not PC specialists and, more importantly, cannot prescribe the pain-relieving morphine. Also, five of these centres hold the licence for morphine, but only three have it in stock. The centres, set up in 2014 as part of the National Palliative Care Policy, offer both in-patient and out-patient services. They were a boon for the 970 cancer patients registered with them, saving them the trip to the Tata Memorial Hospital in Mumbai for morphine. In all, 21,638 patients are registered with these centres at Amravati, Chandrapur, Gadchiroli,

Wardha, Nandurbar, Satara, Washim and Bhandara. PC doctors on contracts were posted at these centres until last year, but left due to a four-month delay in salaries, sources said. <https://goo.gl/ARPVOy>



World hospice &
palliative care day

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

8 October 2016

<http://goo.gl/iKZH4k>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND | *The New Zealand Herald* (Auckland) – 21 September 2016 – '**Assisted dying in New Zealand given orange light' by human rights watchdog.**' New Zealand's human rights watchdog has given the "orange light" to assisted dying, saying that the Government should proceed with caution and only if strict safeguards are in place. These safeguards should include a minimum age limit, a prognosis that a person will die within 12 months, and an opt-out clause for doctors who do not want to be part of the euthanasia process. The Human Rights Commission gave its position on the hugely contentious issue this morning before Parliament's Health Committee. <https://goo.gl/wD5JO3>

Specialist Publications

End-of-life in Canada

A proposal for values-based law reform on unilateral withholding and withdrawal of potentially life-sustaining treatment

ALBERTA LAW REVIEW | In Print – Accessed 23 September 2016 – As the legalization of assisted dying shifts from a project for law reform to one of implementation, the gaze for Canadian end-of-life law and policy academics and practitioners should be turned quickly to another pressing issue – the unilateral withholding and withdrawal of potentially life-sustaining treatment. What should happen when the health care team believes that treatment should not be provided and the patient's loved ones believe that it should? While the future of end-of-life law and policy no doubt includes many other issues, this is an urgent and immediate horizon issue for Canada as well as a number of other countries (e.g., the U.S., Australia, and New Zealand) and a more distant horizon (but inevitable) issue for many other countries as they move beyond the debate of whether to even withholding or withdrawal of potentially life-sustaining

Cont.

treatment (e.g., South Korea). In this paper, the authors attempt to take a step back from the drama and vitriol surrounding conflict that can arise when the health care team believes that treatment should not be provided and the patient's loved ones believe that it should. They suggest and model an approach to law and policy reform in this area. To that end, the authors begin with a review of what is known about what is going on in relation to unilateral withholding and withdrawal of treatment (without the consent or knowledge of the patient or patients substitute decision-maker) demonstrating that: it is happening; it is controversial; it is being challenged in courts; and, it is not being approached by the law in the same way in every country (or indeed, even in the same way within a country). They then present a process for pursuing law reform, exploring Canada as a case study, to provide a model strategy for approaching law reform in other countries and to advance the project of law reform in Canada. <https://goo.gl/8BcakN>

Related

- *JOURNAL OF MEDICAL ETHICS* | Online – 23 September 2016 – ‘**Causes and consequences of delays in treatment-withdrawal from permanent vegetative patients: A case study of *Cumbria National Health Service Clinical Commissioning Group v Miss S and Ors* [2016] EW COP 32.**’ Life-extending treatment, in the form of artificial nutrition and hydration, has often provided to people in permanent vegetative states (PVS) in England & Wales for many years, even when their family believes the patient would not want it and despite the fact that no court in the U.K. has ever found in favour of continuing such treatment for a patient with a confirmed PVS diagnosis. The first half of this article presents a close analysis of the recent case of *Cumbria NHS Clinical Commissioning Group v Miss S and Ors* [2016] EW COP 32. <https://goo.gl/sFmX1M>
- *PRACTICAL ETHICS* | Online – 23 September 2016 – ‘**Our special treatment of patients in a vegetative state is a form of cruel and unusual punishment.**’ Our Society has good reason to provide special treatment to people with severe brain injuries and their families. But our current “special treatment” for a group of the most severely affected people with brain injuries leads to devastating, agonising, protracted and totally preventable suffering. <https://goo.gl/lpkUxO>

Portrayal of brain death in film and television

AMERICAN JOURNAL OF TRANSPLANTATION | Online – 19 September 2016 – The authors sought to evaluate whether television and cinematic coverage of brain death is educational or misleading. They identified 24 accessible productions that addressed brain death using the archives of the Paley Center for Media (160,000 titles) and the Internet Movie Database (3.7 million titles). Productions were reviewed by two board-certified neurologists. Although 19 characters were pronounced brain dead, no productions demonstrated a complete examination to assess for brain death (6 included an assessment for coma, 9 included an evaluation of at least 1 brainstem reflex, but none included an assessment of every brainstem reflex, and 2 included an apnea test). Subjectively, both authors believed only a small fraction of productions ... provided the public a complete and accurate understanding of brain death. Organ donation was addressed in 17 productions (71%), but both reviewers felt that the discussions about organ donation were professional in a paucity of productions... <https://goo.gl/rx0lmb>

Barriers, enablers and challenges to initiating end-of-life care in an Australian intensive care unit context

AUSTRALIAN CRITICAL CARE | Online – 20 September 2016 – Five focus groups were conducted with 11 physicians and 17 nurses participating. Barriers include conflict between the ICU physicians and external medical teams, the availability of education and training, and environmental limitations. Enablers include collaboration and leadership during transitions of care. Challenges include communication and decision making, and expectations of the family. This study emphasised that positive communication, collaboration and culture are vital to achieving safe, high quality care at end of life. Greater use of collaborative discussions between ICU clinicians is important to facilitate improved decisions about end-of-life care (EOLC). Such collaborative discussions can assist in preparing patients and their families when transitioning from active treatment to initiation of EOLC. Another major recommendation is to implement EOLC leaders of nursing and medical backgrounds, and patient support coordinators, to encourage clinicians to communicate with other clinicians, and with family members about plans for EOLC. <https://goo.gl/otbjep>

Place of death in children and young people with cancer and implications for end-of-life care: A population-based study in England, 1993-2014

BMC CANCER | Online – 19 September 2016 – Hospitals and home were the main end-of-life care (EOLC) settings for children and young people (CYP) with cancer. Home death rates barely changed in the past two decades; deaths in hospitals remained the most common, but slightly shifted towards hospices. CYP with haematological malignancy or with co-morbid conditions had persistently high hospital deaths; these cases had an even lower chance of deaths in hospices (50%) than at home. There were deprivation- and area-related inequalities in place of death which may need service- and/or policy-level intervention. The findings highlight a need for CYP specific initiatives to enhance EOLC support and capacities both at home and in hospices. <https://goo.gl/Nx7iGW>

Palliative care nurse shortage sees declining respite options for sick children

NURSING PRACTICE | Online – 19 September 2016 – A shortage of palliative care nurses for children and young people in the U.K. is impacting the care provided to patients and their families. Together for Short Lives has said there are more than 50,000 children and young people in the U.K. who are expected to have short lives and the number is rising. However, two thirds of voluntary services surveyed by the charity reported that a shortage in nurses is resulting in a reduced offer of care to families: closing beds, reducing respite or affecting the continuity of care. <https://goo.gl/3aGH3c>

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

- *ARCHIVES OF DISEASE IN CHILDHOOD*, 2016;101(Suppl):A305-A306. '**Palliative care services for children and young people: Realist review of the literature.**' The delivery of palliative care services for children and young people in the U.K. is inconsistent, despite the development of guidance, recommendations and service standards. <http://goo.gl/W6g29j>

Related

- *HISPANIC HEALTH CARE INTERNATIONAL* | Online – 20 September 2016 – '**End-of-life care for Hispanic children: A study of California Medicaid beneficiaries.**' More than 8,000 Hispanic children die annually in the U.S. yet little is known about the end-of-life care utilized. The purpose of this study was to examine the children and family characteristics associated with end-of-life care for Hispanic children. <https://goo.gl/bbHpNS>
- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 21 September 2016 – '**Participation of children in medical decision-making: Challenges and potential solutions.**' Participation in healthcare decision-making is considered to be an important right of minors, and is highlighted in both international legislation and public policies. However, despite the legal recognition of children's rights to participation, and also the benefits that children experience by their involvement, there is evidence that legislation is not always translated into healthcare practice. <https://goo.gl/GJsShb>
- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 19 September 2016 – '**The day two talk: Early integration of palliative care principles in pediatric oncology.**' Since 2000, the number of hospital- and community-based pediatric palliative care (PPC) services, fellowship training programs, and educational opportunities for non-specialists has dramatically increased. With this growth, the importance of the early introduction of PPC, regardless of stage and prognosis, has been repeatedly demonstrated and has shown to substantially affect outcomes in multiple areas including patient symptoms and suffering. As models for early integration of PPC have emerged, so too has an understanding of the barriers to implementation, including still inadequate numbers of trained PPC specialists, the enduring perception that palliative care is synonymous with end-of-life care, and pediatric oncologists' lack of clarity about how and when to integrate palliative care and whether or not subspecialty services are available. Fifteen years later, the barriers remain significant enough that ... children dying as a result of cancer continue to suffer in significant numbers. <https://goo.gl/G2SZDI>

Rural residents' perspectives on the rural "good death": A scoping review

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 19 September 2016 – Twenty articles (for 17 studies and one systematic review) were identified... These papers revealed data collected from rural patients with a life-limiting illness and family caregivers, rural healthcare providers, the wider rural community, rural community leaders and rural health administrators and policy makers. Rural locations were heterogeneous. Residents from developed and developing countries believe a "good death" is one that is peaceful, free of pain and without suffering; however, this is subjective and priorities are based on personal, cultural, social and religious perspectives. Currently, there is insufficient data to generalise rural residents' perspectives and what it means for them to die well. <https://goo.gl/37rXhq>

N.B. Additional articles on end-of-life care in rural communities and remote regions noted in Media Watch 22 August 2016, #476 (p.11), 16 May 2016, #462 (p.18), and 18 April 2016, #459 (p.4).

The experience of family caregivers caring for a terminal patient at home: A research review

INTERNATIONAL JOURNAL OF NURSING STUDIES | Online – 14 September 2016 – This review shows that caring for a family member with advanced illness in the home has a great impact on the personal realm of the caregiver and in the relationship he or she maintains with the ill family member. Being involved in the process of dying translates into a prodigious physical and psychological effort, together with a substantial limitation on the normal development of their own life. Additionally, the caregiver must face and establish a new relationship with the family member, in accordance with the new ethos, without the help of a formal structure providing the necessary support. These results may help to focus attention on family caregiver needs and to develop the knowledge necessary to meet the current demands of end-of-life health care in the home. <https://goo.gl/YjskKn>

Related

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 19 September 2016 – '**Predictors of place of death of individuals in a home-based primary and palliative care program.**' Home-based primary and palliative care results in a high likelihood of nonhospital death, although certain demographic characteristics are strong predictors of death in the hospital. For Mount Sinai Visiting Doctors Program participants, home visits in the last month of life were not associated with death outside the hospital. <https://goo.gl/yJBIUU>

End-of-life care in Sweden

Feeling lonely in an unfamiliar place: Older people's experiences of life close to death in a nursing home

INTERNATIONAL JOURNAL OF OLDER PEOPLE NURSING | Online – 14 September 2016 – A move to and a life in a nursing home while being close to death is a reality for many older people in Sweden. Being able to express thoughts and feelings about death has been described as both crucial for sustaining personhood as well as for establishing a meaningful existence at the end of life. Important are the experiences of older people living in nursing homes who are approaching death. Feeling lonely in an unfamiliar place is based on three themes: 1) Waiting for death, with the sub-themes death as a release and thinking of oneself as dead; 2) Subordinate oneself to values and norms of the staff, with the sub-themes feeling offended and feeling trapped; and, 3) Keep the courage up. The older people's lives [i.e., those of the study participants] were characterised by feelings of aloneness in an unfamiliar place, which contributed to a sense of existential loneliness. They experienced few opportunities to discuss their thoughts of life and death, including preparations for passing away. It is of importance for professionals to be able to meet older people as they are and respect them as human beings in their transitions, before, during and after the move to a nursing home. It is important to find ways to support older people's wellbeing and identity near death. <https://goo.gl/Kt0QJi>

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Related

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 19 September 2016 – ‘**Palliative care consultations in nursing homes and reductions in acute care use and potentially burdensome end-of-life transitions.**’ Residents with consultations had lower rates of hospitalization than controls, with rates lowest when initial consultations were furthest from death. <https://goo.gl/ixl6in>

U.S. legal perspective on advance directives

Advance directives: A case of changing social norms and their legal implication

JOURNAL OF AGING, LONGEVITY & POLICY | Online – Accessed 20 September 2016 – With respect to care of the elderly, research has shown the end-of-life wishes of many Americans are not fulfilled due to the lack of clear communication to health care providers. This causes distrust of the medical profession, confusion among patients and their families over end-of-life care (EOLC), and a high economic and social burden in terms of medical costs and family caregiving. Rather than understanding the controversy over “death with dignity” and the “right to die” as that between the rights of the individual and the interests of the state it would be more fruitful to understand it as being between demanding greater patient autonomy on the one hand and avoiding violations of patient autonomy and that of the medical provider on the other. A shift in orientation would ameliorate the friction between patients and their caregivers, it could provide a more productive means for recognizing the underlying concerns that give rise to this tension, and it might give way to an approach to EOLC that finds a proper balance in protecting the rights of individuals. It may also promote shared decision-making between patients and health care providers, allowing for advance care planning rather than potentially ambiguous advance directives. <https://goo.gl/qcJ56S>

Related

- *HEALTH SOCIAL WORK* | Online – 13 September 2016 – ‘**Analysis of advance directive documentation to support palliative care activities in nursing homes.**’ At the initial phases of the intervention, 50% of the [1,877] records [analysed] contained an advance directive (AD). Of the ADs in the resident records, 55% designated a durable power of attorney for health care, most often a child (62%), other relative (14%), or spouse (13%). Financial power of attorney documents were sometimes found within the AD, even though these documents focused on financial decision making rather than health care decision making. Code status was the most prevalent health preference documented in the record at 97% of the records reviewed. <https://goo.gl/w6GYOz>

Care consistency with documented care preferences: Methodologic considerations for implementing the Measuring What Matters quality indicator

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 24 September 2016 – A basic tenet of palliative care is discerning patient treatment preferences and then honoring these preferences, reflected by the inclusion of “Care Consistency with Documented Care Preferences” as one of ten Measuring What Matters (MWM) quality indicators. MWM indicators are intended to serve as a foundation for quality measurement in health care settings. However, there are a number of logistic and practical issues to be considered in the application of this quality indicator to clinical practice. In this brief methodologic report, the authors describe how care consistency with documented care preferences has been measured in research on patients near the end of life. They outline methodological challenges in using this indicator in both research and practice, such as documentation, specificity and relevance, preference stability, and measuring non-events. Recommendations to strengthen the accuracy of measurement of this important quality marker in health care settings include consistent recording of preferences in the medical record, considerations for selection of treatment preferences for tracking, establishing a protocol for review of preferences, and adoption of a consistent measurement approach. <https://goo.gl/SyVpl1>

Cont.

Noted in Media Watch 23 November 2015, #437 (p.13):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 17 November 2015 – ‘**Feeling heard and understood: A patient-reported quality measure for the inpatient palliative care setting.**’ As endorsed by the palliative care (PC) ‘Measuring What Matters’ initiative,¹ capturing patients’ direct assessment of their care is essential for ongoing quality reporting and improvement. Fostering an environment where seriously ill patients feel heard and understood is of crucial importance to modern health care. <https://goo.gl/ZjvNsg>

1. ‘Measuring What Matters,’ American Academy of Hospice & Palliative Medicine and Hospice & Palliative Care Nurses Association: <https://goo.gl/xVWDiV>

The use of language in hospice care and the impact on patients and families

JOURNAL OF PALLIATIVE CARE | Online – Accessed 19 September 2016 – Whilst there is an expanding literature and a growing knowledge-base relating to patient and family experiences in hospice settings, there is a much more limited corpus reflecting the first-person perspective of patients and their families. These accounts can be helpful in highlighting perceived gaps between current practice and family needs. This narrative account reflects upon the perspective of a hospice patient’s family during her last week of life and notes how the actions and language of staff members and volunteers had a major impact on the overall experience and subsequent grieving processes of family members. <https://goo.gl/bt8aci>

N.B. The ownership of the journal is currently in the process of being transferred, but the journal is accepting manuscripts. Journal home page: <https://goo.gl/58TePW>

Fostering trusting relationships with older immigrants hospitalised for end-of-life care

NURSING ETHICS | Online – 21 September 2016 – This study has shown that while professional competencies are important to providing quality end-of-life care (EOLC) to older immigrant patients of non-English speaking backgrounds, it is a nurse’s moral commitment to fostering trust that may ultimately lay the foundations for a trusting quality care relationship to be established and sustained. This study has captured the processes used by nurses to foster trust as an essential element of quality EOLC in older immigrants. The characteristics of trust and the different factors influencing its expression in diverse cultural contexts are, however, under-researched. Accordingly, gaps remain in the knowledge and understanding of the specific cultural nuances and manifestations of trust across and within different cultures. This is an area that is germane to further cross-cultural and international collaborative scholarly inquiry and research. <https://goo.gl/NFlmw2>

Related

- *JOURNAL OF PATIENT EXPERIENCE* | Online – 14 September 2016 – ‘**Nursing strategies for engaging families of older immigrants hospitalized for end-of-life care: An Australian study.**’ Despite the recognized importance of family engagement when providing end-of-life care, the issue of ethnic minority family engagement has received little attention in the field. Five key strategies were identified: 1) Listening and understanding families; 2) Encouraging family members to speak first; 3) Dealing with angst; 4) Redressing naive views about the dying process; and, 5) Managing intergenerational differences. Underpinning these strategies was a profound “will to engage” with the families and their cultural worldviews. <https://goo.gl/N9ep9F>



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.13.

Grief and bereavement

Overload: A missing link in the dual process model?

OMEGA – JOURNAL OF DEATH & DYING | Online – 15 September 2016 – The Dual Process Model of Coping with Bereavement (DPM) was put forward as a framework to help understand reactions to the death of a loved person. Since its inception, there have been various developments and further specifications regarding the model's parameters. A number of researchers have assessed the model's contribution and put some of its parameters to empirical test. It has also been applied in clinical practice. Despite generally positive assessment among both scientific and applied communities, we recently discovered what we consider to be a major shortcoming. The concept of overload has been neglected. Incorporation of this feature helps explain the preponderance of mental and physical health problems beyond the previous DPM focus on complications of grief. In this article, the authors incorporate the phenomenon of overload within the original framework, illustrating its application, and they discuss broader implications for coping and adaptation to bereavement. <https://goo.gl/TtMyEF>

Cultural adaptation and validation of the Portuguese End-of-Life Spiritual Comfort Questionnaire in palliative care patients

PORTO BIOMEDICAL JOURNAL | Online – 17 September 2016 – This study opens new perspectives for the evaluation of comfort as a holistic outcome and suggests the need for more studies with larger samples. It also suggests the usefulness of shorter instruments, taking into account the clinical characteristics and conditions of the person suffering from a terminal illness. The Portuguese End-of-Life Spiritual Comfort Questionnaire represents a new approach to this important strategy of measuring a person's overall sense of wellbeing and meaningful life... Using this instrument in conjunction with a pain measure will give important insight into spiritual comfort and its potential to decrease the amount of pain meds necessary when the patient has more spiritual comfort. The instrument has good psychometric properties and is reliable, valid and sensitive to the study of spiritual comfort of the person in the final stages of life, particularly for research purposes. It is a strong supplement to measures of physical symptoms. <https://goo.gl/jV4qjD>

N.B. English language article.

Reinventing palliative care: Hospice in hospital

POSTGRADUATE MEDICAL JOURNAL, 2016;92(1089):426-428. There is still a large gap both in the U.K. and elsewhere between the kind of care people hope for at the end of life and what they receive. Only around a quarter of all deaths in England take place in hospices and at home. The majority still occur in hospital. Most hospitals now have a small, specialist team of palliative care doctors and nurses, who offer guidance to other staff. However, the services they provide are limited. In the U.K., only around 1 in 5 hospitals have access to face-to-face services 7 days a week. 24-hour services on site are uncommon. In theory, clinicians from other specialties should all be trained in good symptom control, but few hospitals follow the recommendation this should be mandatory, while some offer no training at all. A number of recent reports have shown that the care of people in hospital with terminal conditions is often beset by poor levels of staffing and equipment, a failure to recognise impending death, over-treatment in a futile attempt to defer this, insufficient pain relief and hydration, a lack of proper decision-making about resuscitation, and inadequate communication with patients and relatives. There is also a great deal of variation in the quality of care provided to patients across the geographical areas, as well as between different conditions. These facts are distressing, but in some ways not surprising. <https://goo.gl/sJP3me>



Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials.
<http://goo.gl/OTpc8l>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **MEDSCAPE** | Online – 20 September 2016 – ‘**Death With Dignity in Oregon: No evidence of abuse or misuse.**’ Oregon was the first state in the U.S. to enact a physician aid in dying law, known as Death With Dignity Act (DWD). Now, almost 20 years later, there is little evidence that it has been abused. Since the passage of the law in 1997, a total of 1,545 people have been written prescriptions under the DWD in Oregon, and 991 patients have died from ingesting the lethal medications. A majority of the patients had cancer, said Charles Blanke, MD, professor of medicine, Knight Cancer Institute, at Oregon Health & Sciences University in Portland. “Users are predominantly elderly, white, and well educated,” he added. “Almost all patients are in hospice, and almost all take the medications at home after telling loved ones of their decision,” said Dr Blanke, who provided an update on Oregon’s experience at the recent Palliative Care in Oncology Symposium 2016. It is relatively rare for patients to use DWD because they were suffering from inadequate pain palliation, he explained. The most common reasons were related to quality of life, autonomy, and dignity. <https://goo.gl/x9u4ch>

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.



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>

Worth Repeating

Distinguishing spiritual, psychological, and psychiatric issues in palliative care: Their overlap and differences

PROGRESS IN PALLIATIVE CARE, 2012;20(2):79-85. The authors present a four-step assessment for determining which perspective and which clinician may best aid a patient: 1) distinguish whether suffering is due to a normal syndrome of distress or to a psychiatric disorder; 2) Assess the potential efficacy of spiritual care, psychotherapy, or psychopharmacology for relieving distress of this type; 3) Determine probable effectiveness for spiritual care, psychotherapy, or psychopharmacology given limitations of clinician availability, clinicians' clinical competencies, and the treatment setting; and, 4) Learn whether the patient has a strong preference for a consultant with a secular (psychiatrist, psychotherapist) or religious (chaplain, clergy) professional identity. This assessment prioritizes patient preferences in its decision making, while evaluating the clinical problem, consultants' capabilities, and treatment setting so that recommendations hold promise for effectiveness. Spirituality, psychology, and psychiatry are each richly developed traditions of healing. The aim of care should be to provide the best from each towards reducing a patient's suffering. [Noted in Media Watch 30 July 2012, #264 (p.12)] <https://goo.gl/digEjc>

Media Watch: Online

International

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

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

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

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

Asia

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

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

Canada

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

Europe

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

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

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

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