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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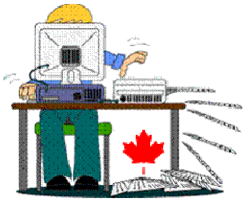

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Compiled & Annotated by Barry R. Ashpole

Prognosis: Scroll down to U.S.A. and 'Discussions of life expectancy and changes in illness understanding in patients with advanced cancer' (p.3), published in the *Journal of Oncology* and reported in Cornell University's *Cornell Chronicle.*

Canada

Caregivers at high risk of depression finds Hamilton study

ONTARIO | *The Hamilton Spectator* – 27 May 2016 – Family and friends caring for recovering loved ones at home are at high risk for clinical depression, flags a study involving Hamilton caregivers.[1] Two-thirds of caregivers suffer major depressive symptoms in the first week after patients leave the hospital, found the research done in part by McMaster University and St. Joseph's Healthcare. A year later, more than 40% still show signs of clinical depression, warns the study... "It was pretty daunting to us because these are the people the patients are relying on in their recovery," said study researcher Dr. Jill Rudkowski, who specializes in internal medicine and critical care. The study of 280 caregivers including 30 from Hamilton was led by Toronto's University Health Network. It's significant considering 3.3 million Ontario men and women are family caregivers and their unpaid work is essential to the sustainability of North American health-care systems, saving Canada an estimated $27 billion a year. If caregivers needs aren't met, you go from having "one patient to having two," points out Smith, who was one of the authors of a 2015 report to the Ontario government making recommendations to improve community care.[2] http://goo.gl/JRjpnT

Palliative care for families: Remembering the hidden patients

CANADIAN JOURNAL OF PSYCHIATRY, 2004; 49(6):359-365. The illness experience profoundly affects family members' psychological and physical health; recognition of this has coined the term "hidden patients." The authors define the family, emphasizing a systems approach to family care. They describe the impact of the illness on the family in terms of family members' health, family communication issues, psychological issues, needs for information, physical care demands, and family costs of caring. [Noted in Media Watch, 7 September 2015, #426 (p.18, under 'Worth Repeating')] https://goo.gl/UsZ8FL

1. 'One-year outcomes in caregivers of critically ill patients,' *New England Journal of Medicine*, 2016; 374(21):1831-1841. http://goo.gl/ums18m
2. 'Bringing Care Home,' Report of the Expert Group on Home & Community Care,' March 2015. [Noted in Media Watch, 16 March 2015, #401 (pp.12)] http://goo.gl/PVAUwG

Canada’s health-care system favours the cradle and ignores the grave

THE GLOBE & MAIL | Online OpEd – 26 May 2016 – While our parliamentarians and media pundits focus on the narrow machinations of Bill C-14 that deal with medical assistance in dying, palliative care (PC) physicians continue to try to give birth to a long-overdue national discussion on holistic and compassionate end-of-life care for all Canadians. Each day we face desperately ill patients and their anguished families, who literally beg us for help – with their pain, their nausea, their mental torment and the financial burden of their illness. The agony of suffering ravages their bodies and often saddles their families with immense guilt born of helplessness and a sense of isolation. This is a national failure to address dying with dignity from an ethical, funding and continuum-of-care perspective. This failure must be acknowledged and corrected in the current discussions around a new health accord between Ottawa, the provinces and territories and our indigenous peoples. As a country, our public policy and health system choices have favoured our collective cradle, but eschewed our inevitable grave. Pre-birth programs, newborn immunizations and early childhood interventions across our health-care, social-welfare and education systems are laudable and should be expanded. This same dedication of resources must also underpin our approaches to better pain and symptom management and a range of PC options for us, our loved ones and friends as we bravely face our own mortality. http://goo.gl/35yKR8

Extract from *The Globe & Mail* OpEd

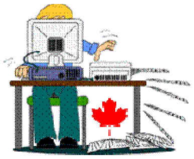
While Bill C-14 is in the process of becoming law, PC units in Ontario are closing due to funding cuts, and there is no law on the table about the right to PC. Tragically, many people die at home, with no access to PC supports such as home care nursing or visits from a family doctor or, when needed, a PC team.

N.B. Healthiest Babies Possible Programs exist on most Canadian provinces and territories. ***BRA***

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE CANADIAN PRESS | Online – 25 May 2016 – **‘All provinces have assisted death guidelines.’** The Colleges of Physicians & Surgeons in every province and one of three territories have issued guidelines that doctors must follow in providing medical assistance in dying (MAID). With the exception of Quebec, they all rely heavily on the eligibility criteria set out by the Supreme Court last year in a landmark ruling which concluded that MAID should be available to clearly consenting adults with “grievous and irremediable” medical conditions who are enduring suffering that they find intolerable. Some offer interpretations or definitions of the terms used by the court. http://goo.gl/SnkyJm



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

U.S.A.

Center for Research on End-of-Life Care

Oncologists need to better discuss patient life expectancy

STATE OF NEW YORK | *Cornell Chronicle* (Cornell University) – 23 May 2016 – Despite their nearness to death, a sizeable proportion of advanced cancer patients remain unaware of basic information about their illness or its treatment, researchers from Weill Cornell Medicine report.[1] Reviewing test results with their oncologist not only improves patients' understanding of the fatal nature of their illness, but also helps to inform their decisions about care. The study ... compared patients' under-standing of their illness before and after undergoing scans that staged their cancer, and before and after discussing results with their oncologist. Before their scans, nine of the 178 patients [i.e., study participants] acknowledged being at the end stage of incurable cancer with just months to live. "We were astonished to learn that only 5% of this sample had sufficient knowledge about their illness to make informed decisions about their care," said [lead author] Dr. Holly G. Prigerson ... [of] ... the Center for Research on End-of-Life Care at Weill Cornell Medicine. Delivering sensitive information to dying patients is difficult for many oncologists and many avoid such discussions; 38% of the patients had never discussed their prognoses with their oncologist. http://goo.gl/kUu82J

Specialist Publications

'Palliative care for patients with end-stage cardiovascular disease and devices: A report from the Palliative Care Working Group of the Geriatrics Section of the American College of Cardiology' (p.10), in *JAMA Internal Medicine*.

'Cost analysis and policy implications of a pediatric palliative care program' (p.11), in *Journal of Pain & Symptom Management.*

'Gap between recommendations and practice of palliative care and hospice in cancer patients' (p.12), in *Journal of Palliative Medicine.*

1. 'Discussions of life expectancy and changes in illness understanding in patients with advanced cancer,' *Journal of Oncology*, 23 May 2016. http://goo.gl/K2szxn

Selected articles on discussions of prognosis and goals of care

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 3 February 2016 – **'Do patients with lung cancer recall physician-initiated discussions about planning for end-of-life care following disclosure of a terminal prognosis?'** Participants in this study had little or no recall of physicians initiating discussions about their concerns or goals of care, and did not perceive that they had been provided with either information about or opportunities to engage in advance care planning. [Noted in Media Watch, 8 February 2016, #448 (p.6)] http://goo.gl/qfvBkn

- *CLINICAL ONCOLOGY* | Online – 14 December 2015 – **'Prognosis, treatment benefit and goals of care: What do oncologists discuss with patients who have incurable cancer?'** The authors describe documentation of prognosis, treatment benefit and goals of care discussions in outpatients with advanced cancer. There was substantial variation in the frequency of discussing prognosis (range 33-90%), treatment intent (range 55-100%), and goals of care (range 0-17%). [Noted in Media Watch, 11 January 2016, #444 (p.9)] http://goo.gl/W7iooz

- *Journal of Clinical Oncology* | Online – 5 October 2015 – **'Outcomes of prognostic disclosure: Associations with prognostic understanding, distress, and relationship with physician among patients with advanced cancer,'** Prognostic disclosures are associated with more realistic patient expectations of life expectancy, without decrements to their emotional well-being or the patient-physician relationship. [Noted in Media Watch, 12 October 2015, #431 (p.4)] \http://goo.gl/nBNHhh

Long-term care in America: Expectations and preferences for care and caregiving

ASSOCIATED PRESS-NORC CENTER FOR PUBLIC AFFAIRS RESEARCH | Online – 22 May 2016 – The 2016 Long-Term Care (LTC) trends poll finds many people expect to rely on Medicare and Social Security to pay for their LTC needs as they age, although these programs generally do not cover most LTC services or costs. Additionally, support is high for policies that help Americans save for LTC and for those that defray the costs of caregiving. As the American population ages, the need for LTC services and supports to assist seniors with activities of daily living will exponentially increase. http://goo.gl/bxa9U3

N.B. Selected articles on long-term care in the U.S. are noted in Media Watch of 23 May 2016, #463 (pp.5,6).

Related

- *FORBES* | Online – 24 May 2016 – **'Are women as caregivers getting a raw deal?'** 15.5 million caregivers provided an estimated 17.7 billion hours of unpaid care for aging family with dementia, valued at more than $220 billion in 2013. It's probably more now. Most of these caregivers for aging loved ones are the daughters and daughters-in-law. http://goo.gl/JzUlbA

Advance directives

Making end-of-life care more scientific

PENNSYLVANIA | *The Inquirer* (Philadelphia) – 22 May 2016 – Two Penn Medicine patients are part of a clinical trial analyzing how the wording of advance directives changes patient choices and outcomes. It is among the portfolio of studies overseen by the ... FIELDS (Fostering Improvement in End-of-life Decision Science) program, an effort to look at how we die in a more scientific way.[1] "Everyone recognizes the problems that pervade end-of-life care and, be-cause of that broad recognition, everyone is interested in a solution," said Scott Halpern, a critical care medicine doctor and director of FIELDS. The problem, he said, is lots of people have jumped in with well-intended, intuitively appealing programs that may not work. Those could crowd out opportunities for more effective approaches. Among his targets are Five Wishes, Respecting Choices and The Conversation Project, popular programs meant to help people make end-of-life choices. "None of these are backed by much evidence," said Halpern... While there is scientific support for outpatient palliative care programs, the evidence is weaker for the burgeoning number of inpatient programs, he said. He is most critical of POLST (Physician Orders for Life-Sustaining Treatment) programs because they are inflexible and illness is unpredictable. http://goo.gl/5Aajw0

Extract from *The Inquirer* article

Halpern made his case recently ... for funding more of the kind of research he does.[1] He argued that growing political acceptance of end-of-life planning, including the government's new willingness to pay physicians for talking with patients about it, calls for evidence on what actually helps patients get the kind of care they want while minimizing trauma to families.

1. 'Toward evidence-based end-of-life care,' *New England Journal of Medicine*, 2015;373(21);2001-2003. [Noted in Media Watch, 19 October 2015, #432 (p.14)] http://goo.gl/R86dkt

Extract from *New England Journal of Medicine* article

But one of the most sobering facts is that no current policy or practice designed to improve care for millions of dying Americans is backed by a fraction of the evidence that the Food & Drug Administration would require to approve even a relatively innocuous drug.

1. 'Fostering Improvement in End-of-life Decision Science,' Perelman School of Medicine, University of Pennsylvania. http://goo.gl/Ub18fn

Cont.

Noted in Media Watch, 23 May 2016, #463 (p.15):

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 5 May 2016 – **'The near-failure of advance directives: Why they should not be abandoned altogether, but their role radically reconsidered.'** Advance directives are fraught with tensions and this is the reason why they are both important and deeply problematic. The authors outline six such tensions, and conclude with some positive suggestions about how to better promote patients' autonomy in end-of-life decision. http://goo.gl/RxuyVt

Noted in Media Watch, 2 May 2016, #460 (p.10):

- *PALLIATIVE MEDICINE*, 2016;30(5): 421-422. **'Advance care planning: Not a panacea.'** There is a need for a broader base of evidence demonstrating the extent of effectiveness of different models of advance care planning (ACP). Whereas studies have shown beneficial effects, ACP is a complex intervention and we lack insight into which elements bring these beneficial effects about and what their potential drawbacks are. http://goo.gl/Iq1LtU

Specialist Publications

'Adversaries at the bedside: Advance care plans and future welfare' (p.9), in *Bioethics*.

See Worth Repeating (p.15)

When Doctors and Daughters Disagree:
Twenty-two Days and Two Blinks of an Eye.

Related

- CALIFORNIA | *The Los Angeles Times* – 22 May 2016 – **'The patient is Code 3 critical. Her frail, 90-year-old body is failing. How much should I do to save her life?'** Here's the thing about advance directives: They are guidelines. They do not have the force of law. This is a good thing. Despite what many of us think, we can't truly anticipate how we will feel when we are about to die. Advance directives are especially valuable when someone has a terminal disease or a stroke, and they want to tell doctors what to do when they can no longer decide for themselves. But with a patient such as mine, who was alert despite her distress, it's much more complicated. The human will to live is powerful. Most of the time when patients truly face death, they insist we do what we can to keep them alive. http://goo.gl/cJjA0o

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Please feel free to share this weekly report with your colleagues.
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MW 452: Dying better, even if it means sooner

Download the complete issue (PDF 275 KB)

U.S. REPORT & WORLDS NEWS | *Online – 29 February 2016* | Defying and delaying death often remains the focus of many care providers even when patients reach their 80s, 90s and 100s. These individual decisions add up to the single greatest expenditure in the national health system: care in the last 12 months of life accounts for over 25% of total expenditures for both Medicare and Medicaid. **read more...**

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International

End-of-life care in Australia

Listening to patients at the end of their lives is crucial – so why don't doctors do it?

AUSTRALIA | *The Guardian* (U.K.) – 25 May 2016 – The timeless business of dying has never had a higher profile, which is why the results of a recent survey by the Royal Australasian College of Physicians (RACP) make for sobering reading.[1] The RACP end-of-life working party, of which I was a member, surveyed more than 1,500 physicians to identify their knowledge and practice of advance care planning and end-of-life care (EOLC). Unsurprisingly, the majority reported routinely caring for patients who were likely to die within 12 months. On a weekly basis, one third of doctors observed provision of treatments inconsistent with known patient wishes and one-third observed treatment with little chance of benefit. And while doctors overwhelmingly agreed that discussing EOLC was important, only a minority actually translated the intention into action. Barriers included a lack of time, but just under half of the physicians felt insufficiently trained to undertake what is easily one of the most consequential conversations in the doctor-patient relationship. As a result, a dismal 17% of physicians expressed confidence in knowing the end of life preferences of their patients. http://goo.gl/EDQpWi

Diagnosis/progression of life-limiting illness

- Acknowledgment of uncertainty of prognosis
- Begin advance care planning process in the community, outpatient setting or hospital
- Care coordination and liaison with community services (e.g. general practice, home-based and residential aged care services)
- Ongoing active treatment ± palliative approach for symptom management and psychosocial support

Likely to die soon (medium term but timing may be uncertain)

- Goal setting and advance care planning
- Palliative approach for symptom management, and psychosocial and family support (treating team ± specialist team)
- Clear management planning (including limitations of medical treatment) on admission and/or after episodes of acute deterioration
- Care coordination and liaison with community services (e.g. home-based and residential aged care services)
- Medication review

Dying (short term but timing may be uncertain)

- Review by senior clinician
- Goal setting and advance care planning
- Clear management planning (including limitations of medical treatment) on admission and/or after episodes of acute deterioration
- Interventions for symptom control, meeting spiritual and cultural needs, family support, etc.
- Medication review
- Provision of terminal care
- Bereavement care for family

Figure 2: Opportunities for end-of-life care interventions. Reproduced from Australian Commission on Safety and Quality in Health Care (2015).[28]

1. 'Improving Care at the End of Life: Our Roles & Responsibilities,' Royal Australasian College of Physicians, May 2016. https://goo.gl/N4O4bS [Word search website for survey findings. ***BRA***]

Related

- AUSTRALIA | ABC News – 24 May 2016 – **'Ageing population blamed for 80% increase in palliative care spending.'** In 2013-2014, $5.3 million in palliative care (PC) medicine services was paid from the Medicare Benefits Schedule, up from $3 million five years prior [according to a new report by the Australian Institute of Health and Welfare (AIHW).[1]] Spending remained relatively steady in 2014-2015, at just over $5.3 million. The report also revealed a nation-wide increase in the number of people admitted to both private and public hospitals to receive PC. But in all states and territories public hospitals were responsible for the majority of palliative care patients. http://goo.gl/odQDIK

  1. 'Palliative Care Services in Australia 2016,' Australian Institute of Health & Welfare, May 2016. http://goo.gl/aA60BK

Care "has improved for 12,000 in homes" in England

U.K. (England) BBC News – 25 May 2016 – More than 12,000 people in England are now safer and being looked after better in care homes than they were two years ago, the Care Quality Commission (CQWC) says.[1] The watchdog said nearly three-quarters of 372 care homes rated inadequate in 2014 and still operating had improved. Of those, 205 had moved from an inadequate rating to requiring improvement, 68 were now rated good, and 99 did not have their rating changed. Thirty four others rated inadequate in 2014 have since closed. There are more than 11,000 homes providing care for people who are older or disabled in England. The CQC introduced a tougher inspection system for care homes in October 2014. http://goo.gl/YVoLKJ

1. 'Inspections Reveal Care Home Improvement,' Care Quality Commission, 2016. http://goo.gl/lPAC8L. To view slide deck, click on...

   Care home improvement slide deck
   PPTX | 157.47 KB

Civil society report: Update on implementation of the 2014 World Health Assembly resolution on palliative care[1]

WORLDWIDE HOSPICE PALLIATIVE CARE ALLIANCE | Online – 23 May 2016 – The [WHO] adoption of the palliative care (PC) resolution has given a clear boost to PC as dozens of countries have begun implementing its recommendations and the WHO secretariat has increased its technical support and policy development. Yet, much remains to be done even in some developed countries PC needs higher priority. Availability of PC remains very limited in much of the world; many countries have yet to embark on a comprehensive effort to implement the resolution's recommendations; and donor countries have not made adequate resources available to allow the WHO or individual countries to facilitate this process. As a result, millions continue to face severe and needless suffering at the end of life. http://goo.gl/TUkySC

Progress integrating PC into health policy

South Africa has a draft policy framework for integration of PC into the country's health system. The **Ethiopian** government announced in 2016 that it has made PC a priority area for development. In **India** a national PC policy has been drafted, but not yet implemented by government. **Colombia** passed a national law on PC in 2014. In 2016, Hospis **Malaysia** published a needs analysis for PC that is intended to assist in the formulation of a national plan for PC. **Romania** included PC in its 2016 National Comprehensive Cancer Plan, and approved specialization for PC. **Mexico** integrated PC into its universal health coverage program Seguro Popular in 2016.

1. 'Strengthening of Palliative Care as a Component of Integrated Treatment Within the Continuum of Care,' World Health Assembly, May 2014. http://goo.gl/P6YNE6

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

We doctors can't prescribe a "good death"

U.K. | *The Guardian* – 22 May 2016 – Each new month seems to bring with it another well-intentioned report on death and end-of-life care. So far in 2016 we have had the 'End of Life Care Audit: Dying in Hospital' from the Royal College of Physicians, a report from the British Medical Association ('End-of-Life Care and Physician-Assisted Dying'), and a review from the Care Quality Commission ('A Different Ending: End of Life Care').[1,2,3] Western ideas about death are informed by secularism and individualism. The current discussion on death and dying, however, has been hijacked by the extremists on both sides. In the barren and neglected middle ground are truths that we have conveniently ignored. As contemporary issues, assisted suicide and advance directives are both a symptom of a deeper malaise (namely the obsession with personal autonomy and control) and a distraction. They are a distraction because the real issues are elsewhere. Death, we are constantly told, has become "medicalised." Roughly half of all people dying in Britain or Ireland do so in a general hospital. Just over 20% die at home, and only 5% in a hospice. Large general hospitals are the best place to be when you are very sick, but are ill-equipped to meet the needs of the dying. The Liverpool Care Pathway, a rather quixotic, tick-boxy attempt to give hospice-type care to people dying in general hospitals, was an abject failure.[4] Acute hospitals are criticised, with some justification, for failing to care properly for the dying, yet society has handed over most of the responsibility for such care to these institutions. http://goo.gl/UUmzhP

Specialist Publications

'In defence of the "tick-box approach": Why end-of-life care is no exception' (p.9), in *British Journal of General Practice.*

1. 'End of Life Care Audit – Dying in Hospital National Report for England 2016,' Royal College of Physicians, May 2016. [Noted in Media Watch, 9 May 2016, #461 (p.6)] https://goo.gl/x2qSih

Cont.

2. ‘End-of-Life Care and Physician-Assisted Dying,’ British Medical Association, January 2016. (Scroll down to ‘Reflections & Recommendations,’ Volume 3) [Noted in Media Watch, 18 January 2016, #445 (p.4)] http://goo.gl/N4Cldm

3. ‘A Different Ending: Addressing Inequalities in End-of-Life Care,’ Care Quality Commission, May 2016. [Noted in Media Watch, 16 May 2016, #462 (p.5)] http://goo.gl/qbOL09

4. ‘Review of Liverpool Care Pathway for Dying Patients,’ Department of Health, July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] https://goo.gl/ujDKOT

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Victoria) | The Age – 28 May 2016 – **‘Dying with dignity: Coroners Court weighs in to euthanasia debate ahead of historic report.’** According to figures sent to the committee last week, the Coroners Court identified 240 suicides across the state between 2009 and 2013 involving people who were experiencing “irreversible decline” in their physical health due to diseases (such as cancer or Parkinson’s) or injury (such as road or workplace accidents). Poisoning was the method of death in a third of all cases, typically with drugs that had been prescribed to treat the person’s health condition. Hanging was the second most common option – taking place in a quarter of suicides linked to irreversible decline – while firearms were involved in about 14%. And in terms of age and gender, men represented the biggest cohort – 180 of the 240 suicides – mostly involving people aged over 55. It’s the kind of information that many would rather ignore – shocking, sad, hard to fathom – but in the context of an inquiry into end-of-life choices, it’s the kind of data you just can’t avoid. For the past 10 months, Parliament’s Legal & Social Issues Committee has been investigating the vexed question of how we die, receiving more than 1,000 submissions and hearing from more than 100 witnesses: some in favour of law reform; others vehemently against it. http://goo.gl/CuxMJq

- AUSTRALIA | ABC News – 26 May 2016 – **‘Voluntary euthanasia policy up for discussion by Australian Medical Association.’** Almost 4,000 members of the AMA responded to a survey on voluntary euthanasia. The exact findings have not been made clear, but representatives of the organisation have said it is considering a change to its policy position, which would be released by the end of the year. Currently, the AMA has a policy that medical practitioners should not be involved in interventions “that have as their primary intention the ending of a person’s life,” excluding the discontinuation of futile treatment. http://goo.gl/3Z0wX0

Specialist Publications (e.g., in-print and online journal articles, reports, etc.)

Anthroposophy and integrative care at the end of life

ALTERNATIVE & COMPLEMENTARY THERAPIES | Online – 19 May 2016 – The aim of this descriptive study is to present anthroposophic know-how in relation to end-of-life care (EOLC) and draw parallels between the anthroposophic paradigm and the good-death model of the modern hospice movement. Anthroposophic therapies applied in EOLC, engaging care professionals in patient and family reception and the environment and integrative work between the various actors, can contribute toward the quality of life of these patients, helping them in the process of dying and the bereavement phase. There are significant similarities between the good-death model of the hospice movement and anthroposophic EOLC. Care professionals who work with patients with progressive, advanced, and terminal illness may encounter substantial elements in the anthroposophic paradigm to help these patients and their families, while learning about new forms of care and approaches to the process of dying. http://goo.gl/Qqn5v8

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. Listing p.15.

Performance of DSM-5 persistent complex bereavement disorder criteria in a community sample of bereaved military family members

AMERICAN JOURNAL OF PSYCHIATRY | Online – 24 May 2016 – The authors examined the accuracy of the *Diagnostic & Statistical Manual of Mental Disorders*, 5th Edition (DSM-5) proposed criteria for persistent complex bereavement disorder in identifying putative cases of clinically impairing grief and in excluding non-clinical cases. Performance of criteria sets for prolonged grief disorder and complicated grief were similarly assessed. The DSM-5 persistent complex bereavement disorder criteria accurately exclude non-clinical, normative grief, but also exclude nearly half of clinical cases, whereas complicated grief criteria exclude non-clinical cases while identifying more than 90% of clinical cases. The authors conclude that significant modification is needed to improve case identification by DSM-5 persistent complex bereavement disorder diagnostic criteria. http://goo.gl/nEEXiI

Noted in Media Watch, 27 April 2015, #407 (p.10):

- *DEATH STUDIES* | Online – 23 April 2015 – **'The medicalization of bereavement: (Ab)normal grief in the *DSM-5*.'** This article first considers the removal of the bereavement exclusion and then examines the macro level and micro level consequences of this medicalization of grief, including over diagnosis and overtreatment, a potential expanded market for pharmaceutical companies, and the loss of traditional and cultural methods of adapting to the loss of a loved one. http://goo.gl/Cz8s2T

Adversaries at the bedside: Advance care plans and future welfare

BIOETHICS | Online – 23 May 2016 – Some have argued that advance care plans (ACPs) often fail to be normatively binding on caretakers because those plans do not reflect the interests of patients once they enter an incompetent state. The authors argue that when the core medical ethical principles of respect for patient autonomy, honest and adequate disclosure of information, institutional transparency, and concern for patient welfare are upheld, a policy that would allow for the disregard of ACPs is self-defeating. This is because when the four principles are upheld, a patient's willingness to undergo treatment depends critically on the willingness of her caretakers to honor the wishes she has outlined in her ACP. A patient who fears that her caretakers will not honor her wishes may choose to avoid medical care so as to limit the influence of her caretakers in the future, which may lead to worse medical outcomes than if she had undergone care. http://goo.gl/g1SdNY

In defence of the "tick-box approach": Why end-of-life care is no exception

BRITISH JOURNAL OF GENERAL PRACTICE, 2016;66(647):290-291. The need for better training in palliative care is undeniable, and initiatives such as the General Medical Council's recently launched educational campaign around end-of-life care (EOLC) are extremely welcome.[1] However, improved training does not negate the need for accessible real-time guidance for practising clinicians. Examples such as the North of England Cancer Network's excellent 'Palliative and End-of-Life Care Guidelines for Cancer and Non-Cancer Patients' demonstrate that concise and specific, yet broad-reaching advice applicable to patients of varying diagnoses is indeed possible.[2] Documents such as these have the capacity to empower junior clinicians to give excellent care and indeed the Royal College of Physicians audit found that virtually all trusts had guidance on prescribing for the commonest end-of-life symptoms.[3] However a national discourse which is actively distancing itself from specific advice risks driving these useful resources further into the closet. Conversely, this sort of guidance needs to be given greater prominence, arguably by direct incorporation into clinical documentation, and to be standardised nationally to give consistent, quick access for junior doctors who move frequently between places of work: a set-up which begins to look rather similar to the former Liverpool Care Pathway (LCP). The LCP has gone, and nothing is gained in continuing to lament its passing. However, if it is true that it wasn't really broken in the first place, then trying to fix its perceived problems is likely to cause more harm than good. Rather than causing any recently documented improvements, the removal of protocols and tick-boxes from EOLC may have impeded even greater progress, where high standards can spread even to where expert support is sparse. http://goo.gl/MV5ext

Cont.

1. ‘End-of-Life Care – Support, Work, Learn Together,’ General Medical Council, February 2016. http://goo.gl/1zNZEi
2. ‘Palliative and End-of-Life Care Guidelines for Cancer and Non-Cancer Patients,’ National Health Service North of England Cancer Network, 2012. http://goo.gl/PN35hi
3. ‘End of Life Care Audit – Dying in Hospital National Report for England 2016,’ Royal College of Physicians, May 2016. [Noted in Media Watch, 9 May 2016, #461 (p.6)] https://goo.gl/x2qSih

Related

- *JOURNAL OF MULTIDISCIPLINARY HEALTHCARE*, 2016; (9):219-226**. ‘Opportunities to maximize value with integrated palliative care.’** One common misconception about palliative care (PC), and supportive care in general, is that it amounts to “doing nothing” or “giving up” on aggressive treatments for patients. Rather, PC involves very aggressive care, targeted at patient symptoms, quality-of-life, psychosocial needs, family needs, and others. Integrating PC into the care plan for individuals with advanced diseases does not necessarily imply that a patient must forego other treatment options, including those aimed at a cure, prolonging of life, or palliation. https://goo.gl/4kkJzq

Doctors raise concerns about India’s draft bill to regulate life support withdrawal

BRITISH MEDICAL JOURNAL | Online – 23 May 2016 – India’s first draft bill to regulate decisions to withhold or withdraw life support and medical treatment to terminally ill patients has worried doctors who believe that the proposed rules may involve the courts in medical decisions. The bill, released by the Indian health ministry last week for public responses, would allow terminally ill people or their families to decline treatment and doctors receiving such requests to withhold or withdraw support without the threat of legal consequences. Members of the Indian Society for Critical Care Medicine and the Indian Association of Palliative Care have been urging the health ministry to regulate issues relating to end-of-life care. Many doctors believe that an inadequate legal framework and a reticence in the community to discuss death have unnecessarily prolonged the experience of terminally ill patients as well as the wasteful use of private and public resources. http://goo.gl/TJxaYz

Palliative care for patients with end-stage cardiovascular disease and devices: A report from the Palliative Care Working Group of the Geriatrics Section of the American College of Cardiology

JAMA INTERNAL MEDICINE | Online – 23 May 2016 – Palliative care (PC) has not traditionally been seen as applicable to patients who are candidates for device-based therapies, including transcatheter aortic valve replacement (TAVR) and ventricular assist devices (VADs). However, although improvements in technology, expertise at implanting devices, and patient selection have been made, these devices come with a risk of morbid complications that can be particularly deleterious in elderly patients with pre-existing co-morbidities and impaired baseline functional and/or cognitive status. Therefore, working group designed a survey of clinicians (physicians, nurses, and advanced practice practitioners) to assess attitudes toward and current status of PC in the approach to patients undergoing TAVR and VAD implantation procedures. http://goo.gl/KiSlAJ

N.B. Selected articles on implantable cardioverter-defibrillators at end of life are noted in Media Watch of 1 February 2016, #447 (p.11).

Media Watch: Palliative Care Network-e Website

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. http://goo.gl/8JyLmE

Taking a stand against predatory publishers

JOURNAL OF ADVANCED NURSING | Online – 18 May 2016 – There is a blight ... academic credibility and the value of our scholarship, the blight of "predatory publishing" (Beall 2012, Pickler *et al* 2015, Simpson 2016). This is a more modern and more malign equivalent of the embarrassing phenomena of "vanity publishing." Once, if you were convinced of your literary talents but could find no reputable publisher who shared your rosy self-assessment, you could find a vanity publisher who would print a few hundred copies of your treasured poems or great first novel, in hidebound leather, with gold lettering. At last, you were now a published author, at least in your own mind. That may have been appropriate for some, or sad and harmless for others, but there is nothing either appropriate or harmless about today's predatory publishers. Latest estimates show there are over 10,000 predatory journals churning out over 400,000 articles per year and netting the predators over US$74 million (Shen & Björk 2015). Finances aside, the potential effect on scholarship and on the trustworthiness of what we consult and respect as "the literature" or "evidence" could be catastrophic. http://goo.gl/HNFn4Q

Noted in Media Watch, 11 April 2016, #457 (p.7):

- *ANNALS OF THE ROYAL COLLEGE OF SURGEONS OF ENGLAND*, 2016;98(2):77-79. **'Best practices for scholarly authors in the age of predatory journals.'** The growth of open access (pushed by institutions, grant bodies and governments as a means of improving human health and knowledge) has come with some unforeseen consequences. http://goo.gl/8EanhK

N.B. Recent articles on predatory journals are noted in Media Watch of 11 April 2016, #457 (p.7), 29 February 2016, #451 (p.9), and 8 February 2016, #448 (p.9).

Cost analysis and policy implications of a pediatric palliative care program

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 24 May 2016 – In 2010, California launched Partners for Children (PFC), a pediatric palliative care (PC) pilot program offering hospice-like services for children eligible for full-scope Medicaid delivered concurrently with curative care, regardless of the child's life expectancy. The average per enrolee per month (PEPM) health care costs of program enrollees decreased by $3,331 from prior to their participation in PFC to the enrolled period, driven by a reduction in inpatient costs of $4,897 PEPM. PFC enrollees experienced a nearly 50% reduction in the average number of inpatient days per month, from 4.2 to 2.3. Average length of stay per hospitalization dropped from an average of 16.7 days prior to enrollment to 6.5 days while in the program. Through the provision of home-based therapeutic services, 24/7 access to medical advice, and enhanced, personally tailored care coordination, PFC demonstrated an effective way to reduce costs for children with life-limiting conditions by moving from costly inpatient care to more coordinated and less expensive outpatient care. http://goo.gl/83nGDu

End-of-life care in Spain

The Catalonia WHO Demonstration Project of Palliative Care: Results at 25 years (1990-2015)

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 24 May 2016 – The present report describes the achievements and progress made through this project. Numerous innovations have been made with regard to the palliative care (PC) model, organization, and policy. As the concept of PC has expanded to include individuals with advanced chronic conditions, new needs in diverse domains have been identified. The Catalan Department of Health, together with key institutions, developed a new program in 2011 to promote comprehensive and integrated PC approach strategies for individuals with advanced chronic conditions. The program included epidemiological research to describe the population with progressive and life-limiting illnesses. One key outcome was the development of a specific tool (NECPAL CCOMS-ICO©) to identify individuals in the community in need of PC. http://goo.gl/scZw18

N.B. Spain was ranked 23rd of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://goo.gl/nuPWll

Gap between recommendations and practice of palliative care and hospice in cancer patients

JOURNAL OF PALLIATIVE MEDICINE | Online – 26 May 2016 – There remains a gap between recommended timing of supportive services and real-world practice of care. Results [of this study] suggest that difficulties in prognosticating death are not fully responsible for underexposure to hospice. Most veterans received hospice care (71%), whereas fewer received palliative care (PC) (52%). Among all cancer decedents, 59% received hospice care for their last three days of life. Patients who received hospice care did so a median of 20 days before death... Patients who received PC did so a median of 38 days before death... http://goo.gl/IOpdjd

Sibling supporters' experiences of giving support to siblings who have a brother or a sister with cancer

JOURNAL OF PEDIATRIC ONCOLOGY NURSING | Online – 19 May 2016 – This study confirms sibling supporters should be a part of the health care team that treat and support the family when a child has cancer. All 12 sibling supporters currently working in Sweden participated in this study from which five categories emerged, showing they supported siblings from diagnosis until possible death. They enabled siblings who were in the same situation to meet each other and arranged activities suited to their ages, as well as offering an encouraging environment. To help the siblings, the sibling supporters found it necessary to interact with both the parents and the ward staff. They felt their support was important and necessary in helping siblings promote their own health both when the sick child was alive and also after his or her death. Their experience was that they listened to the siblings' stories and met them when they were in their crisis. http://goo.gl/Zt6GWI

Supporting bereaved or grieving children

CANADIAN
Virtual Hospice
Information and support on palliative
and end-of-life care, loss and grief.

http://goo.gl/ydHfq9

Related

- *JOURNAL OF PEDIATRICS* | Online – 27 May 2016 – **'Parents' experiences and wishes at end of life in children with spinal muscular atrophy Types I and II.'** Parents' communication with the physician about their wishes and concerns regarding their child's end-of-life care and preferred location of death (LoD) contributed to their wishes being fulfilled. The wish of hospital death was fulfilled more often than the wish of home deaths. Thirty-six of the study participants (75%) reported that their child had siblings: 12 reported that the sibling was too young for professional psychological support, and only 4 of the remaining 24 siblings received such support after the death of their brother or sister. http://goo.gl/BKA1ZR

  N.B. To access full text click on PDF icon.

Noted in Media Watch, 28 December 2015, #442 (p.9):

- *JOURNAL OF PEDIATRIC ONCOLOGY NURSING* | Online – 14 December 2015 – **'Bereaved siblings' advice to health care professionals working with children with cancer and their families.'** The most common advice, suggested by 56% of siblings [surveyed], related to their own support. One third suggested giving better medical information to siblings. Some wanted to be practically involved in their brother's or sister's care and suggested health care professionals (HCPs) should give parents guidance on how to involve siblings. Other advice related to psychosocial aspects, such as the siblings' wish for HCPs to mediate hope, yet also realism, and the importance of asking the ill child about what care they wanted. http://goo.gl/4vEOrz

End-of-life care in England

End-of-life care for people with chronic kidney disease: Cause of death, place of death and hospital costs

NEPHROLOGY DIALYSIS TRANSPLANTATION | Online – 19 May 2016 – People with chronic kidney disease (CKD) are less likely to die at home than those without CKD. The authors estimate causes and place of death, and cost of hospital care for people with CKD in England in the final 3 years of life. The proportion of deaths at home was 10.7% in people with CKD and 17.2% in the age- and gender-matched non-CKD group. CKD was associated with an increase in hospital costs of £3,380 in the last 12 months of life, holding constant place of death, co-morbidities and other variables. Home death was associated with a reduction in hospital costs of £2,811 in the 12 months before death. The most commonly recorded cause of death in people with CKD was heart disease. CKD was not mentioned on the death certificate in two-thirds of deaths in people with the condition. http://goo.gl/EtWjGv

> **N.B.** Selected articles on end-of-life care for people living with kidney disease are noted in Media Watch of 14 March 2016 issue of Media Watch, #453 (p.10).

End-of-life care in Pakistan

Barriers and perceptions regarding code status discussion with families of critically ill patients in a tertiary care hospital of a developing country: A cross-sectional study

PALLIATIVE MEDICINE | Online – 25 May 2016 – In Asian societies, including Pakistan, a complex background of illiteracy, different familial dynamics, lack of patient's autonomy, religious beliefs, and financial constraints give new dimensions to code status discussion. A total of 77 (57.4%) physicians responded [to a survey]. Family-related barriers were found to be the most common. They include family denial (74.0%), level of education of family (66.2%), and conflict between individual family members (66.2%). Lack of knowledge regarding prognosis (44.1%), personal discomfort in discussing death (29.8%), and fear of legal consequences (28.5%) were the top most personal barriers. In hospital-related barriers, time constraint (57.1%), lack of hospital administration support (48.0%), and suboptimal nursing care after do not resuscitate (48.0%) were the most frequent. There were significant differences among opinions of trainees when compared to those of attending physicians. Family-related barriers are the most frequent roadblocks in the end-of-life care (EOLC) discussions for physicians in Pakistan. Strengthening communication skills of physicians and family education are the potential strategies to improve EOLC. Large multi-center studies are needed to better understand the barriers of code status discussion in developing countries. http://goo.gl/q2m6oq

Hospice and palliative social workers' experiences with clients at risk of suicide

PALLIATIVE & SUPPORTIVE CARE | Online – 23 May 2016 – The study results suggest that suicide-related competencies are important in the practice of hospice and palliative social work. Most [survey] respondents reported having worked with patients, family caregivers, or other clients who had exhibited warning signs of suicide during the previous year. Fewer respondents indicated that they had worked with patients and family members who had attempted or died by suicide. While the majority of respondents believed they possessed sufficient knowledge and skills to intervene effectively with individuals at risk of suicide, they indicated that additional education on this topic would be valuable for their professional practice. http://goo.gl/cqO19m

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 April 2016 – '**A survey of home hospice staff knowledge of suicide risk factors, evaluation, and management.**' No abstract available. Access requires a subscription. Alternatively, a college or university library may be able to gain access depending on the conditions and terms of its licensing agreement. http://goo.gl/QUQ8fv

Cont.

Noted in Media Watch, 24 March 2014, #350 (p.13):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2014;10(1):95-105. **'Suicide prevention training program for gatekeepers working in community hospice settings.'** This study evaluated a promising, evidence-based suicide prevention program. Satisfaction and need for additional time for suicide prevention training were highly rated by study participants. http://goo.gl/xmLgx0

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *MEDICAL DAILY* | Online – 25 May 2016 – **'Suicide tourism: Traveling for the right to die, and the ethical and legal dilemmas that come with it.'** As the idea of assisted suicide becomes more acceptable around the world, many patients have grown critical of restrictive laws in their states and countries. For those with a progressive or terminal disease, making the effort of campaigning for change with a local government is unappealing... For most patients hoping to end their lives, traveling to a region that allows assisted suicide is much easier than changing the law at home. Thus suicide tourism was born. The phenomenon has only grown and will continue to do so unabated, according to one team of Swiss researchers.[1] They found that, between 2008 and 2012, 611 visitors came to Switzerland for the sole purpose of ending their lives. These people came from 31 different countries, but most hailed from Germany and the U.K.. The study authors write that "in the U.K., at least, "going to Switzerland" has become a euphemism for assisted suicide." Suicide tourism is not confined to Europe. http://goo.gl/nEFrWI

    1. 'Suicide tourism: A pilot study on the Swiss phenomenon,' *Journal of Medical Ethics*, 20 August 2014. [Noted in Media Watch, 25 August 2014, #372 (p.2)] http://goo.gl/Sf6dfB

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

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
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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.

Worth Repeating

When doctors and daughters disagree: Twenty-two days and two blinks of an eye

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY, 2011;59(12):2337-2340. A cornerstone of American medical ethics is the right to say, “Keep your hands off of me,” to decline medical treatment. A central problem is how to decide about individuals who have become incapacitated and can no longer request or refuse potentially life-sustaining treatment. An advance directive (AD) is a formal attempt to protect people’s right to autonomy when they are no longer autonomous. As such, it assumes that previously expressed wishes are precise and immutable, but many families make decisions together, and individuals may negotiate, compromise, and modify their genuine preferences, especially when novel threats arise, and the stakes are high. The current article describes a case in which two daughters overruled a patient’s explicit preference to refuse life-sustaining treatment, leading to burdensome illness before death. In the end, the mother seemed to understand her children’s needs and seemed willing, at least in retrospect, to have met those needs. After the death of this individual, the authors continued to talk with the daughters and videotaped an interview in which they shared their perspectives on the case. The daughters consented to be videotaped and to share the video with the medical community.[1] Their forceful devotion to their mother and their search in retrospect for what could have been done differently has completely changed the authors understanding of events. They believe that the daughters’ behavior is not the indefensible breach of respect for person that it seemed to be. Their mother’s true wishes might well have included a desire to help her children during her own dying. Family members’ preferences are likely to be important considerations for many people, although the possibility of coercion has to be acknowledged as well. Accommodating this level of decision-making complexity is highly problematic for our understanding of AD. [Noted in Media Watch, 21 November 2011, #228 (p.8)] http://goo.gl/lj5RFn


When Doctors and Daughters Disagree:
Twenty-two Days and Two Blinks of an Eye.

1. Videotape of the interview with the daughters in which they shared their perspectives on the case. http://goo.gl/aM4izO

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://goo.gl/0Q1Mh4

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]

Europe

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

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

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