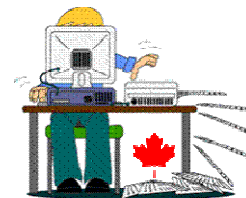


Media Watch...

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

In the last stages of life: Scroll down to [Specialist Publications](#) and 'Managing risk during care transitions when approaching end of life: A qualitative study of patients' and health care professionals' decision making' (p.15), in *Palliative Medicine*.

Canada

The death of Patient X and the failure of the system

BRITISH COLUMBIA | CBC News (Vancouver) – 15 October 2016 – We'll call him Patient X – an 88-year-old man suffering from kidney failure, bladder cancer and dementia. His longtime physician tells him nothing more can be done. The man confirms his wish for palliative care (PC). The doctor phones the patient's wife. He later described her as "relieved." But what follows is not the calm, peaceful ending Patient X wanted. Instead, he wound up back in hospital, the advice of his personal physician ignored, his family given false hope in a mire of miscommunication. Patient X died one week later. "He spent his final days being poked and prodded with unnecessary and futile treatment," his physician would later complain. Patient X's story is told in a decision posted ... by B.C.'s Health Professions Review Board,¹ a kind of appeal court for people unsatisfied with the outcomes to complaints to the bodies which govern medical professions. "He could have spent his final days in peace and comfort with the focus on PC and symptom control in the hospice house." The case went to the

board after the man's physician complained to the [province's] College of Registered Nurses about the PC coordinator – a nurse – at a hospice. The decision to put Patient X back in hospital with the hope of extending his life was made at the hospice, overruling the family doctor. <https://goo.gl/uyLmAo>

Improving end-of-life care for British Columbians

BRITISH COLUMBIA | Legislative Assembly (Select Standing Committee on Health) – Accessed 19 May 2016 –The Committee supports moving toward a more integrated palliative model of care and recommends that patients be referred to palliative care earlier in the course of their illness; an integrated and interdisciplinary palliative model of care be applied across the health service continuum to reflect a patient-centred approach to cultural practices and sensitivities regarding end-of-life care; (Noted in Media Watch 23 May 2016, #463 (p.1) <http://goo.gl/jBmTS>

1. Decision No. 2015-HPA-056(a) In the matter of an application (the "Application") under section 50.6 of the Health Professions Act, R.S.B.C. 1996, c. 183, as amended, (the "Act") for review of a complaint disposition made by, or considered to be a disposition by, an inquiry committee. British Columbia's Health Professions Review Board <https://goo.gl/iQs4j2>

Report finds “significant” gaps in Ontario healthcare

ONTARIO | *The Toronto Star* – 13 October 2016 – As a mental health advocate, Alicja Raimundo says it is not uncommon for those with complex health issues to be spending hundreds of dollars a month on their prescriptions, or for them to go off meds they can't afford. Inequity creates these holes in health care coverage, according to a report from Health Quality Ontario...¹ The report looks at a range of complex points-of-access and the performance of the province's public health care system. It paints the picture of a province divided by geography and class, noting “significant gaps” in coverage for low income families, new Canadians, and for those living in poor and remote areas. <https://goo.gl/8g1YME>

1. 'Measuring Up 2016: A Yearly Report on How Ontario's Health System is Performing,' Health Quality Ontario, October 2016. <https://goo.gl/7hOfk4>

Noted in Media Watch 4 July 2016, #469 (p.2):

- ONTARIO | Health Quality Ontario – 28 June 2016 – ‘**Ontarians are talking about end-of-life care, yet for many, palliative care may begin too late or not at all, new report finds.**’ Almost 60% of people in Ontario who die receive palliative care (PC) services, according to a new report by Health Quality Ontario.¹ And among those who have a record of receiving PC, about half begin to receive it in their last month of life. <http://goo.gl/4iQXTu>

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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 9 October 2016 – ‘**Catholics hoping for a funeral after assisted death face different answers from different churches.**’ A proper funeral is far more than an end-of-life celebration for practising Catholics, who believe last rites cleanse the soul of sin in preparation for eternal life in heaven. But for the faithful questioning whether those final sacraments are available to a loved one who has chosen a medically assisted death, the answer may depend on whom in the church they ask. Catholic doctrine is unequivocal in its opposition to any form of suicide, but Canadian bishops have taken different positions on whether churchgoers who choose an assisted death should be barred from having an official funeral. <https://goo.gl/x7HD8R>
- *THE GLOBE & MAIL* | Online – 7 October 2016 – ‘**Catholic hospitals have no right to refuse assisted dying.**’ Canadians are grappling with one of the most difficult legal issues we have faced in decades: our collective responsibility to facilitate medically assisted death for those who choose it and satisfy the legal criteria. Since the Supreme Court decided in 2015 that Canadians have a Charter-protected right to a dignified death of their choosing, governments, doctors, hospitals and citizens have struggled to accept and move forward with a workable regime. One of the biggest impediments, however, is institutional resistance. Hospitals that claim a right to conscientious objection may well prove the Achilles heel in government efforts to breathe life into a right to die. <https://goo.gl/gPrMPF>

Extract from Health Quality Ontario report

Nearly two-thirds (64.9%) of patients who received palliative care (PC) die in hospital, despite the fact that surveys of patients and caregivers have shown repeatedly that most people would prefer to die at home.

Nearly two-thirds (62.7%) of patients who received PC had an unplanned emergency department visit in their last month of life. Although some unplanned emergency department visits may be unavoidable and appropriate, these can be a sign that people are not receiving enough supports at home or elsewhere in the community.

N.B. A new chapter on palliative care begins on p.96 of the report.

[Specialist Publications](#)

‘**Suffering and medicalization at the end of life: The case of physician-assisted dying**’ (p.17), in *Social Science & Medicine*.

U.S.A.

Caregiving is forcing women 50+ to leave the workforce

FORBES | Online – 10 October 2016 – When employers force their employees with caregiving duties to choose between work and family, everyone loses. This can be particularly true for women, who still make up 60% of the family caregiver population (though men are increasingly shouldering the responsibility). Two out of every five adults – tens of millions of Americans – are family caregivers of loved ones. Most of the people caring for someone at home are also working full- or part-time jobs. But increasingly, working women over 50 are leaving their jobs in order to provide the necessary care. <https://goo.gl/GpglJJ>

Federal ruling may end nursing homes' no-lawsuit agreements

OKLAHOMA | *Enid News & Eagle* – 5 October 2016 – A new federal ruling could settle a long-disputed question of whether Oklahoma nursing homes can force patients or their families to sign away their rights to sue in court as a condition for admission. The Centers for Medicare & Medicaid Services announced a final rule last week that blocks nursing homes that receive federal funds from using pre-dispute binding arbitration agreements. Almost all nursing homes get federal funds. Over the years, the controversial practice has been used by dozens of nursing homes and assisted living centers in the state as part of their admission contracts. The agreements require disputes to be settled by an arbitrator instead of by a judge or jury as part of a lawsuit. <https://goo.gl/PD0gVH>

Study: Medicaid abuse persistent as boomers retire

CBS ('This Morning') | Online – 4 October 2016 – Investigators from the Department of Health & Human Services Office of Inspector General (OIG) are once again criticizing Medicaid for not cracking down in this area, saying the government needs better regulations to prevent patient neglect and fraud cases. Estimates of questionable billing since 2012 total more than \$600 million... [David Ceron, a special agent with the OIG, said] there are no consistent standards for personal care workers nationwide, which is why the Inspector General's office is recommending "minimum federal qualifications and screening standards" for workers. That includes background checks, state registers for all attendants and better tracking of services provided. <https://goo.gl/LR4A9v>

Specialist Publications

'Medicare hospice spending hit \$15.8 billion in 2015, varied by locale, diagnosis' (p.12), in *Health Affairs*.

Young boy's struggle to survive sparked push for drugs for terminally ill

KAISER HEALTH NEWS | Online – 3 October 2016 – Josh Hardy's story – and the plight of thousands of others facing life-threatening diseases with no government approved therapies – has inspired multiple, sometimes conflicting efforts by government, industry and activists to make experimental medications more widely available. The Food & Drug Administration (FDA) ... has reduced the time that doctors spend requesting an unapproved drug to just forty-five minutes. Nonetheless, some patient advocates are leading a drive to provide access to experimental drugs without the FDA's help. Thirty-two states have passed laws designed to give patients the "right to try" an unapproved medication, by protecting doctors who provide such therapies from losing their state medical licenses. <https://goo.gl/qGkUjZ>

Specialist Publications

'Children with complex medical conditions: An under-recognized driver of the pediatric cost crisis' (p.12), in *Current Treatment Options in Pediatrics*.

Cont.

Noted in Media Watch 22 February 2016, #450 (p.12):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 11 February 2016 – ‘**The ethical challenges of compassionate use.**’ Granting access to drugs, vaccines, biologics, and devices not yet approved by governmental regulatory authorities is a growing challenge for physicians, public officials, patient advocacy groups, institutional review boards, and patients. <http://goo.gl/Llu1iO>

Noted in Media Watch 5 October 2015, #430 (p.7):

- *ANNALS OF INTERNAL MEDICINE* | Online – 29 September 2015 – ‘**Right-to-try laws: Hope, hype, and unintended consequences.**’ Most “right-to-try” laws do not set qualifications for either the health care provider making attestation of terminal illness or the physician recommending experimental treatment. <http://goo.gl/JWifuy>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NEW YORK TIMES* | Online – 10 October 2016 – ‘**Aid in dying movement advances.**’ New York, Colorado and the District of Columbia may soon join the handful of states where doctors are allowed to help terminally ill patients die by prescribing a lethal dose of painkillers. A proposal to allow physician-assisted dying will be on the ballot in Colorado next month. In the District of Columbia, the District Council’s Health & Human Services Committee last week approved a physician-assisted dying bill that the full council could vote on before the end of the year. New York lawmakers, meanwhile, are hopeful that support in the Legislature for aid-in-dying bills will soon overcome opposition from religious leaders and some medical groups. Victories in the three jurisdictions would galvanize a movement that seeks to give terminally ill Americans a dignified alternative to the dismal choices they face in most of the country. <https://goo.gl/TTnchZ>

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.

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1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
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6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

International

Social care cuts take English service to tipping point, regulator warns

U.K. (England) | *The Guardian* – 13 October 2016 – A&E (Accident & Emergency) units are struggling to cope because social care services that help elderly people have been cut so much that they are reaching a “tipping point,” England’s care regulator is to warn. The Care Quality Commission (CQC) warns that elderly and disabled care sector as a whole is at risk as providers pull out over rising costs and cuts to council budgets. Hospitals are ending up dangerously full and have seen “bed-blocking” hit record levels because of a widespread failure to give elderly people enough support to keep them healthy at home, says the CQC. A worsening lack of at-home care services and beds in care homes are forcing hospitals to admit more patients as emergencies, which deepens their already serious financial problems. Figures contained in the commission’s annual report show that the number of hospital bed days lost through patients being unable to leave because social care was not available to allow them to be discharged safely soared from 108,482 in April 2012 to 184,199 in July this year – a 70% rise.¹
<https://goo.gl/xSp2Kd>

1. ‘The State of Health Care & Adult Social Care in England, 2015-2016,’ Care Quality Commission, 12 October 2016.
<https://goo.gl/mJIFqB>

Extract from Care Quality Commission report (p.135)

Equality-led approach to end-of-life care commissioning

In ‘A different ending,’ Central Manchester Clinical Commissioning Group (CCG) stood out as an example of good practice in commissioning to meet the needs of the local population. The CCG has made equality a central part of its approach to end of life care.

Specialist Publications

‘U.K. end-of-life care services in dementia, initiatives and sustainability: Results of a national online survey’ (p.9), in *BMJ Supportive & Palliative Care*.

‘Palliative care education for medical students: Differences in course evolution, organisation, evaluation and funding: A survey of all U.K. medical schools’ (p.15), in *Palliative Medicine*.

‘GPs to do weekly care home rounds under new National Health Service England plan’ (p.16), in *Pulse*.

Palliative care: Keeping hope alive for the terminally ill

AFRICA (Rwanda) | *The New Times* (Kigali) – 10 October 2016 – When terminal illness sets in, it takes a toll on the loved ones of the patient both financially and psychologically. Some are lucky to manage while others give up along the way when resources can no longer permit. As a result, desperate family members literally abandon their loved ones in hospitals with hope that the hospital would offer help. Health experts say the problem has been exacerbated by lack of knowledge about palliative care (PC) and shortage of PC professionals in the country. However, the Ministry of Health and other stakeholders say they are working hard to train more PC professionals in the sector. <https://goo.gl/gCEK7K>

Silver tsunami incoming: Australians facing death with little support, says palliative doctor

AUSTRALIA | *The Sydney Morning Herald* – 8 October 2016 – Australia is confronted with a “silver tsunami” of people facing death with little infrastructure in place to cope with such a seismic shift in population, according to a leading American palliative care doctor. Dr. B. J. Miller said there was a huge workforce of largely ignored potential carers who could be reimbursed, trained and supported to keep people out of hospitals and hospices and die at home. “Hospitals are no place to live and die, that’s not what they were designed for,” he said. “There is a distinction between a disease-centred and a patient-centred model of care ... where caring can become both creative and less expensive. <https://goo.gl/eFgFD4>

Cont.

Noted in Media Watch 5 September 2011, #200 (p.1):

- CANADA (British Columbia) | CBC News – 29 August 2011 – **‘Cost of aging population on health care “overblown.”**’ Fears Canada’s aging population could lead to soaring health-care costs may be greatly exaggerated, say researchers, who suggest that the predicted “grey tsunami” may turn out to be more like a “grey glacier.” <https://goo.gl/LGsbMP>

More Chinese committed to end-of-life care

CHINA | *New China* (Beijing) – 8 October 2016 – More than 1,000 people have joined the Changsha Shifangyuan Elderly Hospice & Mind Care Center since it opened two years ago. Changsha Shifangyuan, now has 40 hospices in more than 20 cities, with over 10,000 volunteers working there. Li Zan, director general of Changsha Shifangyuan, said that of 200 million Chinese aged over 60, more than 40 million are critically ill. Most of them are disabled, blind, or suffering from conditions like Alzheimer’s and aphasia. Most patients in Changsha hospices have a life expectancy of 10 months to three years. Currently, only a small proportion of patients can access hospice care, as the waiting list comes mainly from nursing homes and community health centers, while experienced hospice workers are hard to come by. <https://goo.gl/fGsDOI>

N.B. China was ranked 71st 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/nuPWII>

Trust introduces dignity bags as permanent part of end of life care after successful trial

U.K. (England) | *Brentwood Today* – 7 October 2016 – A National Health Services (NHS) trust is offering dignity bags to people suffering bereavements following a successful trial. Barking, Havering and Redbridge University Hospitals NHS Trust decided to make the bags a permanent feature of its hospitals’ end-of-life care programme. They have been distributed to all wards across Queens’ Hospital in Romford and King George Hospital in Goodmayes... They are designed to be a personal carrier bag into which grieving families can put the possessions of their loved ones. <https://goo.gl/bNZ5pz>

End-of-life care in Scotland

Quality of life can be worth more than extending life at all costs

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 7 October 2016 – There is never a more important time to get someone’s care needs right than when they are at the end of life – you only get one chance. Ensuring that care and support is built around the needs of the patient and their wishes is absolutely vital to that. It’s about what matters to them. The passion of Dr. Catherine Calderwood, the Chief Medical Officer, for an approach to realistic medicine in Scotland sits perfectly with care for people living with a terminal illness and approaching the end of life. Often, particularly at this time, people might receive treatment and medical interventions that are of little or no benefit, may make them worse, and be in complete contrast to their wishes. Sometimes the clinician’s mindset is still focused on curative approaches and extending life at all costs and they can lose sight of the quality aspect of life, which for many patients is what they want. <https://goo.gl/jB2nfb>

Related

- U.K. (Scotland) | *The Herald* (Glasgow) – 14 October 2016 – **‘£30 million pledged to children’s charity to increase palliative care.’** A charity that helps terminally ill children and their families is to benefit from £30 million of Scottish Government cash. Health Secretary Shona Robison said the Children’s Hospice Association Scotland will receive the funds over the next five years. The money will help fund its hospices in Kinross, Perthshire and Balloch, West Dunbartonshire... <https://goo.gl/j3iv32>

Why doctors aren't good at predicting how long patients have left

U.K. | *The Spectator* (London) – 6 October 2016 – Predicting survival is notoriously difficult to do. A recent review of research conducted over the last four decades has demonstrated the extent of prognostic inaccuracy in all healthcare professionals.¹ It is important to stress that these findings only relate to professionals' predictions about how long patients with a known terminal illness are likely to survive. It does not imply that patients are being misdiagnosed or that they are being incorrectly advised that they are terminally ill when they are in fact curable (or vice versa). <https://goo.gl/Au7jql>

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

Home care in the U.K.

Frail and disabled elderly are still only seeing carers for 15 minutes a day

U.K. (England, Northern Ireland, Scotland & Wales) | *The Daily Express* (London) – 2 October 2016 – Thousands of elderly and vulnerable patients are still enduring 15-minute "flying care" visits, two years after they were supposed to have stopped. More than a dozen councils across Britain have continued the practice despite Government warnings that they are an "assault on dignity." Last year 93,442 care visits lasted 15 minutes or less and so far this year two councils, Dundee and Comhairle nan Eilean Siar in Scotland, have commissioned more than 7,000 visits lasting less than a quarter-of-an-hour. The figures emerged after the Liberal Democrats submitted Freedom of Information requests to all local authorities responsible for social care. <https://goo.gl/GEjZ7j>

Noted in Media Watch 1 February 2016, #447 (p.4):

- U.K. (England) | BBC News – 29 January 2016 – '**Short home care visits "plague system."**' Unacceptably short 15-minute home care visits to elderly and disabled people are still plaguing the care system in England, a report suggests.¹ <http://goo.gl/PZm4qE>
 1. 'Delivering Personal Care and Practical Support to Older People Living in Their Own Homes,' National Institute for Health & Care Excellence, September 2015. [Noted in Media Watch, 28 September 2015, #429 (p.8)] <https://goo.gl/kEQM0z>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SWITZERLAND | Swiss Broadcasting Company (Bern) – 11 October 2016 – '**Assisted suicides increase in Switzerland.**' The Federal Statistical Office reports that in 2014 Switzerland saw 742 cases of assisted suicide, more than 2.5 times as many as five years previously. In the latest statistics, assisted suicide accounted for 1.2% of all deaths in Switzerland that year. Men and women were nearly equally represented in the assisted suicide numbers, with ten out of 100,000 men and nine out of 100,000 women choosing to die in that way when spread out over Switzerland's resident population. In 42% of cases, assisted suicides followed illnesses caused by cancer. Neurodegenerative disorders led to 14% of assisted suicides, followed by cardiovascular illnesses at 11% and musculoskeletal maladies at 10%. <https://goo.gl/B0esUS>
- SWITZERLAND | Swiss Broadcasting Company (Bern) – 6 October 2016 – '**Salvation Army ordered to permit assisted suicide.**' A Christian nursing home in the French-speaking part of Switzerland must allow assisted suicide – per order of the Federal Court. Located in canton Neuchâtel, the old age home belongs to the Salvation Army, an international Christian church and charitable organisation. According to a cantonal law in effect since 1 January 2015, recognised charitable institutions – which receive subsidies – must respect a patient's wish for assisted suicide on their premises; non-recognised institutions need only explain their position on assisted suicide. <https://goo.gl/faYg5k>

Specialist Publications

Aboriginal grief and loss: A review of the literature

AUSTRALIAN INDIGENOUS HEALTH BULLETIN | Online – 13 October 2016 – The review reinforces the need that has long been articulated for training, resources and support for New South Wales Aboriginal Mental Health & Wellbeing Workers in grief and loss. Addressing the high mortality rates and high rate of traumatic deaths in aboriginal communities needs to underpin this support, in order to reduce the number of losses through bereavement. In addition, extensive systemic and policy change needs to be implemented, with particular reference to the development and practice of cultural competency in non-aboriginal staff and managers. Attention needs to be focused on understanding the specific grief-related needs of workers for their own social and emotional wellbeing as well as building the resilience of the communities they live and work in. It is important all organisations who employ aboriginal staff provide or give access to support which may take different forms including supervision, self-care, or “heal the healer” programs. <https://goo.gl/Pf9p7j>

Related: From England

- *CHILD: CARE, HEALTH & DEVELOPMENT* | In Press – Accessed 15 October 2016 – ‘**Siblings of children with life-limiting conditions: Psychological adjustment and sibling relationships.**’ Children with life-limiting conditions (LLCs) siblings presented significantly higher levels of emotional and behavioral difficulties, and lower quality of life than population norms. Their difficulties were at levels comparable to siblings of children with autistic spectrum disorder (ASD). Family socio-economic position, time since diagnosis, employment and accessing hospice care were factors associated with better psychological adjustment. <https://goo.gl/PQaWq4>

Related: From Sweden

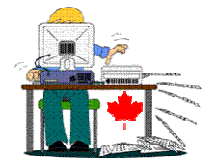
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 3 October 2016 – ‘**How to support teenagers who are losing a parent to cancer: Bereaved young adults’ advice to healthcare professionals – A nationwide survey.**’ Four themes emerged: 1) To be seen and acknowledged; 2) To understand and prepare for illness, treatment, and the impending death; 3) To spend time with the ill parent; and, 4) To receive support tailored to the individual teenager’s needs. This study contributes hands-on suggestions to healthcare staff regarding attitudes, communication, and support from the perspective of young adults who, in their teenage years, lost a parent to cancer. <https://goo.gl/ZqeiCB>

Related: From the U.S.

- *PEDIATRICS* | Online – 10 October 2016 – ‘**The American Academy of Pediatrics Resilience in the Face of Grief & Loss Curriculum.**’ The roles of pediatricians merge the intellectual and emotional aspects of patient care. Although the pediatrician’s responsibilities and roles can be rewarding, they can also be challenging. This role demands self-reflection, including the ability to deal with change, empathize with patients and families, and accept fallibility. To maintain resilience, it is essential to have exposure to strategies to recognize these risks and incorporate programmatic and individual strategies for wellness. <https://goo.gl/AUgmS9>

Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I’ve been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I’ve applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://goo.gl/5CHoAG>



International changes in end-of-life practices over time: A systematic review

BMC HEALTH SERVICES RESEARCH | Online – 3 October 2016 – End-of-life policies are hotly debated in many countries, with international evidence frequently used to support or oppose legal reforms. Existing reviews are limited by their focus on specific practices or selected jurisdictions. Among 8,183 references, 39 jurisdiction-wide surveys conducted between 1990 and 2010 were identified. Of those, 22 surveys used sufficiently similar research methods to allow further statistical analysis. Significant differences were found across surveys in the frequency of treatment withdrawal, use of opiates or sedatives and the intentional use of lethal drugs. Analyses showed increased use of opiates and sedatives over time, which could reflect more intense symptom management at the end of life, or increase in these drugs to intentionally cause

patients' death. Better distinction between practices with different legal status is required to properly interpret the policy significance of these changes. Research on the effects of public policies should take a comprehensive look at trends in end-of-life practice patterns and their associations with policy changes. <https://goo.gl/KJKxN5>

Authors' affiliation

Advisory Committee, Canadian Medical Association, College of Family Physicians of Canada, Canadian Bar Association, Ministère de la santé et des services sociaux du Québec, Réseau des soins palliatifs du Québec, and Commissaire à la santé et au bien-être du Québec.

Related: From the U.S.

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 11 October 2016 – '**End-of-life care patterns at a community hospital...**' Seventy-nine percent [of the patient population studied] arrived to the hospital with no requested limitations in the extent of resuscitative efforts, even though 98% of all patients had major or extreme severity of illness and risk of mortality scores. The presence of an advance directive requesting a limitation of resuscitative efforts modestly impacted resources and procedures... Among the 21% of patients with pre-existing limits, 21% requested more aggressive support during their course. Critical care unit utilization was seen in 69% of patients for a median of 48 hours. A request for palliative care (PC) consultation was received in 44% of patients but only occurred in 30% of all patients due to the short period between the consultation request and patient death (median 37 hours). Among this group of dying patients, engagement of the PC team came too late in the course of many patients, suggesting that automated tools embedded in the electronic medical record might be helpful in the identification of appropriate patients earlier. <https://goo.gl/Bqafyx>

U.K. end-of-life care services in dementia, initiatives and sustainability: Results of a national online survey

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 14 October 2016 – Fifteen services responded. They engaged in a wide range of activities predominately providing direct care (80%) and workforce development/advisory or educational activities (87%). Results suggest that sustainability of services is reliant on clinicians with a leadership role and wider system support through funding mechanisms and a minimum level of integration within normal service provision. Recent initiatives are largely built on the expertise of the nursing profession (with or without input from medical consultants), and driven mainly by the charity and hospice sector. This has generated a potential new model of care provision in end of life dementia care, 'Hospice-enabled Dementia Care.'¹ <https://goo.gl/ij0LYm>

1. 'Hospice enabled dementia care – the first steps,' Dementia UK, March 2015. <https://goo.gl/mT9fE3>

Cont. next page

Related

- *DEMENTIA* | In Press – Accessed 13 October 2016 – ‘**End-of-life care: A scoping review of experiences of advance care planning for people with dementia.**’ Despite increasing attention given to dementia by international governments and policy makers the focus of end-of-life care (EOLC) has been on the dying trajectory of malignant disease. People with severe dementia have complex physical and psychological needs, yet, the disease is not always recognised as terminal. Advance care planning (ACP) involving people with dementia and their families can provide opportunities to discuss and later, initiate timely palliative care. Twenty five eligible studies reported on ACP and EOLC decisions for individuals with dementia. <https://goo.gl/0z98Ed>

Noted in Media Watch 3 October 2016, #482 (p.4):

- U.K. (England) | *The Sun* – 30 September 2016 – ‘**Number of people dying with dementia more than doubles in past decade.**’ One in six deaths in 2014 had dementia on the certificate, against one in 15 in 2001. Victims are less likely to die at home than people with cancer, circulatory or respiratory illnesses. Two-thirds of adults want to see their days out in familiar surroundings and 21% aged 65-plus do. That falls to eight per cent for dementia patients. A report by Public Health England says the condition is “not routinely identified as a terminal illness,” meaning patients have less access to end-of-life-care. <https://goo.gl/pSZeAJ>

1. ‘Dying with dementia,’ Public Health England, September 2016. goo.gl/eK1ewa

Noted in Media Watch 22 August 2016, #476 (p.7):

- U.K. (England) | *The Guardian* – 16 August 2016 – ‘**New “dementia atlas” reveals disparity in care across England.**’ An interactive “dementia atlas”¹ ... exposes wide differentials in aspects of dementia care: while in some parts of England, 85.8% dementia patients have their care looked at every year, in others just 49.3% receive the same service. <https://goo.gl/1pJhHe>

1. Interactive Dementia Map, Department of Health, August 2016. <https://goo.gl/3gVqag>

Discordance between patients’ stated values and treatment preferences for end-of-life care: Results of a multicentre survey

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 6 October 2016 –With few exceptions, participants’ [i.e., study participants] expressed values were not associated with expected corresponding treatment preferences. Of the 109 (40%) patients and 95 (42%) family members who had made decisions about use of life-supports, 68 (56%) patients and 60 (59%) family members had decisional conflict. Decision-making regarding medical treatments at the EOL is inadequate. To reduce decisional conflict, patients and their families need more support to clarify their values and ensure that their preferences are grounded in adequate understanding of their illness and treatment options. <https://goo.gl/hZ5Mff>

Pediatric palliative care in Canada in 2012: A cross-sectional descriptive study

CANADIAN MEDICAL ASSOCIATION JOURNAL OPEN | Online – 11 October 2016 – All 13 programs identified, including 3 with a free-standing hospice, agreed to take part in the study. Of the 1401 children who received care, 508 (36.2%) were under 1 year of age, and 504 (36.0%) had a congenital illness or condition originating in the perinatal period. Of the 431 children who died in 2012, 105 (24.4%) died in a critical care setting. Programs with a hospice provided care to 517 children (36.9%). Children in this group tended to be older, more often had a neurologic illness and received care for a longer time than those who received care from programs without a hospice. Overall, 18.6% ... of deceased children who might have benefitted from specialized pediatric palliative care (PC) based on diagnosis received such care, with 110 (25.2%) receiving care for less than 8 days. Program growth and changes in patients’ demographic and clinical characteristics indicate improved reach of programs. However, barriers remain that prevent most children with life-threatening conditions from receiving specialized pediatric PC services. <https://goo.gl/HaZMWk>

Cont.

Related: From Brazil

- *REVISTA BRASILEIRA DE TERAPIA INTENSIVA*, 2016;28(3):335-340. **‘Health professionals’ perceptions about the decision-making process in the care of pediatric patients.’** This study demonstrates a perceived lack of opportunity to express an opinion during the care decision-making process using a validated instrument, the Voice Scale, to report on cases involving the end-of-life care of children. In the three professional categories studied, physicians expressed less of a perceived lack of opportunity to express their opinions compared to nurses and nursing technicians. <https://goo.gl/uBZiXz>

N.B. Portuguese language article. Additional articles on the “child’s voice” in end-of-life care noted in Media Watch 26 Media Watch 2016, #481 (p.3, p.7).

Related: From Romania

- *JOURNAL OF MEDICAL ETHICS* | Online – 3 September 2016 – **‘Cancer care in Romania: Challenges and pitfalls of children’s and adolescents’ multifaceted involvement.’** Interviews with participants discussed 18 patient cases. Different facets of patient participation were identified: 1) Restricting; 2) Widening; and, 3) Enhancing involvement. A fourth category, unintentional involvement, occurred for all patients due to children’s observations during long-term hospitalisations and access to the Internet. Uncertainty overarched parental attitudes regarding the extent to which children should be included. Physicians usually complied with parental wishes to limit involvement, but together with parents involved patients at least in a practical way. Adults’ protective attitude may backfire, as adolescents’ online searches often expose patients to worse-case scenarios. <https://goo.gl/xyXO2x>

N.B. Additional articles on decision making in pediatric palliative care noted in Media Watch 26 September 2016, #481 (pp.3,7).

Related: From Scotland

- *ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 28 September 2016 – **‘How many children and young people with life-limiting conditions are clinically unstable? A national data linkage study.’** Over 2,200 children and young people (CYP) with life-limiting conditions (LLCs) in Scotland were unstable, deteriorating or dying in each year. Compared with 1- to 5-year-olds, children under 1 year of age had the highest risk of instability; all older age groups had lower risk. Girls were more likely to be unstable than boys. CYP of South Asian, Black and Other ethnicity were more likely to experience instability than White CYP. The large number of CYP with LLCs who are unstable, deteriorating or dying may benefit from input from specialist paediatric palliative care. <https://goo.gl/mnqKHD>

Related: From the U.K.

- *NURSING CHILDREN & YOUNG PEOPLE* | Online – 7 October 2016 – **‘Draft guidelines address regional variations, but there are worries over terminology, the needs of family members and implementation.’** The death of a child is a comparatively rare event in the U.K. Even so, more than 3,000 infant and 2,000 children and young people age 1-19 years died in England and Wales in 2012. <https://goo.gl/HNI3sE>

Related: From the U.S.

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 11 October 2016 – **‘Baby O and the withdrawal of life-sustaining medical treatment in the devastated neonate: A review of clinical, ethical, and legal issues.’** Definitive clinical guidelines are lacking, clinical research is limited, ethical disagreement is commonplace, and while case and statutory law provide legal underpinning for the practice in defined circumstances, uncertainty in this realm likely influences clinical practice. The authors use the case of a neurologically devastated neonate to highlight and review these arenas and show how, using available legal, ethical, and clinical standards and practice, the case of Baby O was resolved, and to underline the need for further research in neonatal palliative care. <https://goo.gl/1Xcphf>

Cont.

- *CURRENT TREATMENT OPTIONS IN PEDIATRICS* | Online – 7 October 2016 – ‘**Children with complex medical conditions: An under-recognized driver of the pediatric cost crisis.**’ Children with medical complexity (CMC) represent less than 1% of all U.S. children, but account for more than 30% of total pediatric healthcare costs. They are a rapidly growing population of children with the highest levels of medical fragility and intensive healthcare needs that drive them in and out of inpatient settings, particularly intensive care units, at astounding frequencies. CMC account for 34% (\$1.6 billion) of all Medicaid pediatric healthcare expenditures, 47% of Medicaid’s total spending on pediatric hospital care, and for 71% of the 30-day unplanned hospital readmissions. <https://goo.gl/ynlxSI>

Palliative care in progressive multiple sclerosis

EXPERT REVIEW OF NEUROTHERAPEUTICS | Online – 8 October 2016 – Multiple sclerosis (MS) is a progressive disease of the central nervous system with unknown etiology. It could be associated with severe disability and losses of physical, psychological and social role functioning over time. People with MS share experiences in common with people affected by diseases with a shorter and clearer terminal phase. Therefore, it is appropriate to offer a palliative care (PC) approach to people with severe MS and their caregivers. Benefits for severe MS patients and their caregivers were shown when PC was included in their care. However, many neurologists show no interest toward PC services for people with severe MS. Misunderstandings about the services of PC are still prevalent. <https://goo.gl/8yuvUG>

Noted in Media Watch 1 August 2016, #473 (p.16):

- *PLOS ONE* | Online – 21 July 2016 – ‘**Progressive dwindling in multiple sclerosis: An opportunity to improve care.**’ This study aimed to identify factors associated with progressive dwindling and found that early disease milestones such as age at onset, progression and wheelchair use can be used as potential predictors, thus allowing timely discussions, a vital step towards providing formative care to those who need it. The results from this study provide a frame work on which to base subsequent care strategies, and to target those who might benefit most from formative care. <http://goo.gl/Jmo5yK>

Noted in Media Watch 20 June 2016, #467 (p.14):

- *NEUROLOGICAL SCIENCES* (Italian Neurological Society) | Online – 14 June 2016 – ‘**Need for palliative care for neurological diseases.**’ The realization of an effective palliative approach to neurological diseases requires specific skills and expertise to adapt the concept of palliation to the peculiarities of these diseases; this approach should be realized through the cooperation of different services and the action of a multidisciplinary team in which the neurologist should play a central role to identify and face the patient’s needs. <http://goo.gl/kOQ9z7>

Medicare hospice spending hit \$15.8 billion in 2015, varied by locale, diagnosis

HEALTH AFFAIRS, 2016;35(10):1902-1907. Between 2007 and 2015, Medicare hospice spending rose by 52%, from \$10.4 billion to \$15.8 billion, driven primarily by an increase in the number of patients in hospice care. Medicare spending on hospice care was \$642 million, 4.2%, higher in 2015 than it was in 2014. Spending and spending growth varied by geographic region and diagnosis. <https://goo.gl/h4SUiG>

The role of spirituality in coping with chronic illness: What health care providers need to know for advance directive decision making

JOURNAL OF DOCTORAL NURSING PRACTICE, 2016;9(2):194-198. Volume 9, Number 2, 2016, Spirituality is recognized by health care providers as having a significant influence on an individual’s ability to cope. The role of spirituality in coping with chronic illness as well as what providers need to know about spirituality in advance directive decision making, however, are poorly understood phenomena. With the growing population of people with chronic illness combined with escalating costs and disease burden, providers must understand and use the role of spirituality in the care of their patients who have demanding states of health and illness. Research has demonstrated the power of spirituality in managing chronic illness as well as the importance of spirituality during end-of-life care planning. <https://goo.gl/HBszkz>

Cont.

Related

- *OPEN JOURNAL OF NURSING* | Online – Accessed 13 October 2016 – ‘**The hole in holistic patient care.**’ Many nurses do not feel comfortable with the “spiritual” element of care and are uncertain about their professional role in the assessment and delivery of spiritual care. Contributing factors to the “hole in holistic patient care” include: 1) Blurring of boundaries in the language and definitions of “spirituality” and “religion”; 2) Insufficient attention to definitions of spirituality and spiritual distress; 3) Confusion and role conflict with professional identity among disciplines related to responsibility for spiritual care; and, 4) Insufficient education and skill development for nurses and other healthcare professionals in the assessment, intervention and appropriate referral of patients experiencing spiritual distress. <https://goo.gl/yjggcO>

N.B. Additional articles on “spiritual care” in the context of end-of-life care noted in Media Watch 12 September 2016, #479 (p.12).

Feasibility of conducting prospective observational research on critically ill, dying patients in the intensive care unit

JOURNAL OF MEDICAL ETHICS | Online – 13 September 2016 – Studying patients during the end of life is important, as it has the potential to lead to improvements in care for the dying. For patients who die after a controlled withdrawal of life-sustaining therapies in the intensive care unit, information about the natural history of death and the process of removing life support has additionally led to advances in practice for deceased organ donation. However, this unique population of severely critically ill and imminently dying patients has been difficult to study, largely due to assumptions made by research teams and ethics boards alike about the logistical difficulties of obtaining consent and completing research procedures before or during the process of withdrawal of life-sustaining therapies. The authors describe the ethics sub-study of the first prospective observational research study in Canada to obtain consent and collect clinical data on patients during the process of withdrawal of life-sustaining therapies in the intensive care unit. They describe in detail the process of protocol development, review by five institutional research ethics boards and bedside staff satisfaction with the study. <https://goo.gl/OJB1KN>

Psychosocial assessment by hospice social workers: A content review of instruments from a national sample

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 13 October 2016 – Participating hospices were largely freestanding (65%), non-profit (60%), and either medium (39%) or small (37%) in terms of average daily census. Over 60% of the sample assessments included content on: financial resources; family structure; coping resources; bereavement risk; past losses; caregiver depression; religiosity/spirituality; patient anxiety, patient depression; and, advance directives. However, most assessments did not include items evaluating: patient physical/functional status; preferences for treatment/care; awareness of diagnosis, prognosis, or disease progression; communication and literacy issues; changes in relationship intimacy/sexuality; and, cultural values, beliefs and customs. Hospice social workers should consider modifying their assessment practices to include a comprehensive array of assessment topics pertinent to patients and families. An accurate, comprehensive assessment that contributes to a holistic, interdisciplinary approach will likely lead to better clinical outcomes. <https://goo.gl/ZF2O4k>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 15 October 2016 – ‘**Psychosocial care provided by physicians and nurses in palliative care: A mixed methods study.**’ Qualitative results revealed three themes: 1) The contents of psychosocial care included not only disease-related events, but also emotional and family support; 2) Providing psychosocial care was a dynamic process including assessment, interventions, and evaluation; and, 3) There were difficulties from the participants themselves, patients and families, and the system. Quantitative results showed that the most common psychosocial care was discussion about the progress of the disease and future care plan; the difficulty was the long-term problems in families; and the psychosocial care professionals most needed were social workers and clinical/counseling psychologists. <https://goo.gl/gHSdxF>

Cont.

Noted in Media Watch 15 August 2016, #475 (p.9):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 9 August 2016 – ‘**Family relationships and psychosocial dysfunction among family caregivers of patients with advanced cancer.**’ Classification of family types has been shown to identify patients at risk of poor psychosocial function. However, little is known about how family relationships affect caregiver psychosocial function. Three family types emerged [in this study]: low-expressive; detached; and, supportive. <http://goo.gl/tFNpD8>

Employing imaginative rationality: Using metaphor when discussing death

MEDICAL HUMANITIES | Online – 5 October 2016 – In a qualitative study exploring expectations of longevity, the authors observed repeated recourse to the imaginative rationality provided by metaphors to express perspectives on longevity and death. Bafflement, acceptance, uncertainty and distress were conveyed through metaphors, providing valuable insight into the internal healthcare frameworks of participants. Skilful use of imaginative rationality in the healthcare setting may illuminate the elusive and often eschewed topic of death in a way that fosters clarity and new understandings, and pave the way towards a better life, and death for patients. By becoming aware of the nuances contained within patients’ – as well as their own – metaphors, clinicians may enhance patients’ overall healthcare experience and avert unintended miscommunication. <https://goo.gl/FIWROc>

N.B. Additional articles on the use of metaphors in the context of end-of-life care noted in Media Watch 29 June 2015, #416 (p.11).

Voluntary stopping eating and drinking: Death with dignity or without?

NARRATIVE INQUIRY IN BIOETHICS, 2016;6(2):109-113. Conceivably, in an ideal world, all patients with a life-limiting illness would receive optimal hospice and palliative care (PC) so that no one would ever wish to hasten their own death. The reality, however, is that despite provision of optimal hospice and PC, individuals with terminal illness experience suffering, loss of meaning, or deterioration in quality of life to the extent where they express the desire to expedite the dying process. While there has been extensive discussion surrounding physician-assisted death (PAD), there has been less attention paid to the practice of voluntary stopping eating and drinking (VSED) near the end of life. Twelve compelling narratives [in this issue of Narrative Inquiry in Bioethics] represent a dramatic groundswell of attention to the practice of VSED.¹ In a review of these narratives, numerous statements of significance emerged along with common ethical themes which bring to light matters that might otherwise remain idle. As such, integrity and autonomy become paramount while, unfortunately, logical fallacies like that of the slippery slope argument are asserted. <https://goo.gl/sTN2h9>

1. Journal contents page: <https://goo.gl/4JWuve>

Noted in Media Watch 21 September 2015, #428 (p.16):

- *ANNALS OF FAMILY MEDICINE*, 2015;13(5):408-409. ‘**Voluntary stopping of eating and drinking (VSED), physician-assisted death (PAD), or neither in the last stage of life? Both should be available as a last resort.**’ When a suffering patient requests VSED or PAD, the first steps should always be a careful evaluation to understand why, to ensure the adequacy of palliative care (PC), and to assess the patient’s decision-making capacity. While a patient’s values and preference remain in the center of decision making, evaluating clinicians must also take into account legal limits and their personal values. VSED can be an important option for some suffering patients who wish an earlier death, but the meaning attached to this practice can vary considerably from a welcomed, patient-controlled escape to an absurd end that adds to suffering as much or more than alleviating it. Furthermore, VSED also takes too long to adequately respond to overwhelming, immediate physical suffering. The comparative risks, benefits and burdens of these last resort practices continue to be debated among well-intended, sophisticated, experienced PC practitioners as well as the broader society as we try to find better ways to respond to those infrequent but very troubling patients who suffer unacceptably despite receiving state of the science PC. <https://goo.gl/5cTZW1>

Cont.

- *ANNALS OF FAMILY MEDICINE*, 2015;13(5):410-411. ‘**Voluntary stopping of eating and drinking (VSED), physician-assisted suicide (PAS), or neither in the last stage of life? PAS: No; VSED: It depends.**’ An adequate answer to the question is neither clear nor straightforward. The author’s position is that if one has reservations about PAS, as she does, then one ought to have some reservations about VSED as well. The ethical permissibility of PAS continues to be an issue of ongoing ethical dispute. This much is obvious. What is much less obvious is the idea that the ethical permissibility of PAS and VSED are linked. The ethical permissibility of the latter depends in part on the ethical permissibility of the former. <https://goo.gl/f8MfPb>

Managing risk during care transitions when approaching end of life: A qualitative study of patients’ and health care professionals’ decision making

PALLIATIVE MEDICINE | Online – 7 October 2016 – When making decisions about transitions in care, an important consideration is the risks of remaining in/transferring back to home, and how these risks are managed. Patients and health care professionals use the presence of community and carer services to inform decisions about risk and possible transfer to a different care setting. Patients and health care professionals take different approaches in managing risk: patients prefer to make choices about how to cope with risk, while decisions made in hospital are risk-adverse. This study highlights how the concept of risk is used in decision making about transitions in care, raising the importance of more open dialogue between the patients and health care staff on discussing patient choice in this area of decision making. Further research is needed to understand how community-based staff and allied health professionals can be better integrated into decision making in this area. <https://goo.gl/4eUm7x>



Improving the Last Stages of Life

The Commission recently released three new research papers in this series, including ‘Improved Care Setting Transitions in the Last Year of Life.’ <http://goo.gl/anPJz>

Noted in Media Watch 3 October 2016, #482 (p.14):

- *JOURNAL OF PUBLIC HEALTH* | Online – 21 September 2016 – ‘**Final transitions to place of death: Patients and families wishes.**’ In this four-country study (Belgium, The Netherlands, Italy and Spain) ... hospital death from home (25-55%) and home death from hospital (16-30%) were the most frequent types of final transitions in all countries. Patients’ or families’ wishes were mentioned as a reason for a final transition in 5-27% and 10-22% across countries. Hospital deaths from home is the most prevalent final transition in three of four countries studied, in a significant minority of cases because of patient/family wishes. <https://goo.gl/f9wefd>

Palliative care education for medical students: Differences in course evolution, organisation, evaluation and funding: A survey of all U.K. medical schools

PALLIATIVE MEDICINE | Online – 7 October 2016 – Information is limited regarding the current organisation of palliative care (PC) teaching across U.K. medical schools. Development, organisation, course evaluation and funding for PC teaching at UK medical schools are variable. The PC course was established through active planning (13/30, 43%), *ad hoc* development (10, 33%) or combination of approaches (7, 23%). The place of PC teaching within the curriculum varied. A student-selected PC component was offered by 29/30 (97%). All medical schools sought student feedback. The course was reviewed in 26/30 (87%) but not in 4. Similarly, a course organiser was responsible for the PC programme in 26/30 but not in 4. A total of 22 respondents spent a mean of 3.9 h (median 2.5)/week in supporting/ delivering PC education... In all, 17/29 (59%) had attended a teaching course or shared duties with a colleague who had done so. Course organisers received titular recognition in 18/27 (67%; no title 9 (33%); unknown 3 (11%)). An academic department of palliative medicine existed in 12/30 (40%) medical schools. Funding was not universally transparent. PC teaching was associated with some form of funding in 20/30 (66%). <https://goo.gl/9SRWwZ>

Anticipatory prescribing for end-of-life care

PRESCRIBER | Online – Accessed 14 October 2016 – In patients receiving end-of-life care at home, anticipatory prescribing can provide a back-up for when urgent symptom control is needed. This article discusses the practicalities surrounding anticipatory prescribing, including the use of “just in case” boxes, the role of family members, and how to handle difficult conversations with patients. <https://goo.gl/LDWcbM>

GPs to do weekly care home rounds under new National Health Service England plan

PULSE | Online – 30 September 2016 – GP practices around the country will be paired with care homes with the expectation of carrying out a weekly round, National Health Service (NHS) England has said. A report ... on a new “enhanced health in care homes” model, says care home residents “are not having their needs properly assessed and addressed.” It says there should be one-to-one mapping of GP practices to care homes, with each resident having a named GP, across the whole of England. GP leaders are warning that there are not enough GPs to carry out this level of enhanced care, and it will remove the concept of patient choice. NHS England say that six areas are currently piloting the model, and are “seeing early results” of enhanced primary care support, including “a reduction in falls, prescribing costs, reduced ambulance conveyances and fewer avoidable [hospital] admissions.” <https://goo.gl/x776P7>

Palliative care in lung cancer: A review

SEMINARS IN RESPIRATORY & CRITICAL CARE MEDICINE, 2016;37(05):750-759. Lung cancer patients are at high risk of suffering due to severe and refractory symptoms, concomitant respiratory comorbidity, frequent disease progression, and treatment that can worsen and compromise quality of life. Palliative care (PC) has shown multiple benefits to cancer patients such as better quality of life, higher patient and family satisfaction, improved disease understanding, less symptom burden, fewer depressive symptoms, less aggressive end of life care, and even improved survival with early implementation. For these reasons, multiple societies have recognized PC as an essential component of lung cancer care, and early PC is recommended for patients with metastatic disease or refractory symptoms. Unfortunately, utilization of PC is both low and often near the end of life, increasing risk for suffering. Misconceptions about PC often underlie delayed referral to PC. <https://goo.gl/lueGMp>

N.B. Additional articles on end-of-life care for patients living with lung cancer noted in Media Watch 12 September 2016, #479 (p.15).

Death with dignity from the Confucian perspective

THEORETICAL MEDICINE & BIOETHICS | Online – 5 October 2016 – The authors attempt to reconstruct Confucian views on human dignity and the dignity of death and, based on those views, to analyze the following issues: the relationship between the dignity of death and biological life, the relationship between the dignity of death and suffering, the relationship between the dignity of death and the autonomy of human beings, and the relationship between the dignity of death and social justice. This article will also compare the Confucian views on these issues with the views of Western philosophers. Confucian ethics can offer distinct answers to the above issues and help resolve some confusions concerning concepts and theories in Western research on the dignity of death. <https://goo.gl/pvQZz6>



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.18.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *JAMA ONCOLOGY* | Online – 6 October 2016 – ‘**Drug price inflation and the cost of assisted death for terminally ill patients – death with indignity.**’ Since 2009, the number of Death with Dignity (DWD) prescriptions dispensed in Washington State has steadily increased, and the majority of patients (approximately 75% with cancer diagnoses) to whom the medications are dispensed will ingest them. The DWD program has generally been considered successful and patients have reported feeling grateful to have an option for physician-assisted death. Today, however, patients and their families are raising new concerns about the high cost of DWD medication and the unaffordability of ending their lives in this way. <https://goo.gl/C5RtP8>
- *JOURNAL OF MEDICAL LAW AND ETHICS*, 2016;4(2):127-140. ‘**Advance directives requesting euthanasia in The Netherlands: do they enable euthanasia for patients who lack mental capacity?**’ With the Termination of Life on Request & Assisted Suicide (Review Procedures) Act, which came into force in 2002 in The Netherlands, euthanasia, although a criminal act, is justified if performed by a physician complying with specified due care requirements. These requirements are largely based on jurisprudence. New in the Act is article 2.2, which allows physicians to carry out euthanasia on patients lacking mental capacity based on 1) A written advance directive requesting euthanasia; and, 2) Fulfilment of the due care requirements “to the extent allowed for by the actual situation.” Uncertainty exists about the interpretation of the wording. In addition, the professional code prescribed by the Royal Dutch Medical Association is stricter than the law, resulting in further ambiguity regarding the significance of advance directives. <https://goo.gl/2nLcJw>
- *SOCIAL SCIENCE & MEDICINE* | Online – 12 October 2016 – ‘**Suffering and medicalization at the end of life: The case of physician-assisted dying.**’ The authors ask how proponents of physician-assisted dying (PAD) articulate suffering with the role of medicine at the end of life within the context of a decriminalization and legalization debate. They draw upon empirical data from their study of *Carter v. Canada*, the landmark court case that decriminalized PAD in Canada in 2015. The authors conducted in-depth interviews with 42 key participants of the case and collected over 4,000 pages of legal documents generated by the case. They show the different ways proponents construct relationships between suffering, mainstream curative medicine, palliative care, and assisted dying. Proponents see curative medicine as complicit in the production of suffering at the end of life; they lament a cultural context wherein life-prolongation is the moral imperative of physicians who are paternalistic and death-denying. Proponents further limit palliative care’s ability to alleviate suffering at the end of life and even go so far as to claim that in some instances, palliative care produces suffering. Proponents’ articulation of suffering with both mainstream medicine and palliative care might suggest an outright rejection of a place for medicine at the end of life. <https://goo.gl/gYoOEq>



Closing the Gap Between Knowledge & Technology

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



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

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/aNcShR>

IAHPC link updated 10.17.2016

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

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

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

Asia

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

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

IAHPC link updated 10.17.2016

Canada

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

Europe

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

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

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

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