

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

Evidence-based practice in end-of-life care: Scroll down to [Specialist Publications](#) and ‘A systematic review of reasons for gatekeeping in palliative care research’ (p.15), in *Palliative Medicine*.

Canada

Quebec promises more palliative care

QUEBEC | *The Montreal Gazette* – 16 November 2015 – The [Philippe] Couillard government responded to critics on and presented its 2015-2020 plan for more palliative care (PC) in the province. Health Minister Gaétan Barrette began by describing the level of service currently offered as inadequate. “Elements are dysfunctional,” he said. “The people who provide PC in Quebec, they’re involved and they give great quality services. But policies are random in Quebec, the implementation of policies is random ... I would say, politely, that it’s not uniform.” Barrette cited Montreal’s east end as an example of where services are lacking. He said his government will invest at least \$10 million a year over the next five years to help people die in dignity. The number of PC beds in the province will increase to 873 from 825, Barrette said. Half a million dollars has been earmarked for the training of orderlies, and starting April 1 next year, \$4.5 million will go to family caregivers to help them look after their loved one. That will translate into envelopes of \$1,000 for each family that needs respite. Barrette said medical staff will be in charge of evaluating a patient’s need for professional help at home, for such things as bathing. Ultimately, the goal is to have more

people dying at home, Barrette continued. Of the 62,000 Quebecers who die every year, only 6,600 fulfill their wish to die at home, he said. <http://montrealgazette.com/health/quebec-promises-more-palliative-care>

Extract on end-of-life care from the Quebec Ombudsman report (pp.83-84)

The Ombudsman noticed in several regions and numerous institutions that access to – and the quality of – palliative care is wanting. In 2013, the Ombudsman presented a brief to the Committee on Health & Social Services as part of the public hearings on Bill 52, the Act respecting end-of-life care (EOLC). On this occasion it recommended that the EOLC policy be updated and an action plan be drawn up in the short term to improve the service offering in every region that requires it. These recommendations stemmed from the Quebec Ombudsman’s findings to the effect that some professionals do not have the required skills for providing EOLC and services. In the past year, the Quebec Ombudsman has had to remind institutions about their responsibilities in this regard. [Noted in Media Watch, 21 September 2015, #428 (p.1)] <http://www.myvirtualpaper.com/doc/protecteur-du-citoyen/2015-annual-report/2015090301/#0>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE CANADIAN PRESS | Online – 14 November 2015 – **‘Government says assisted-death panel won’t give advice for legislation.’** A federal panel created in the wake of the Supreme Court ruling on assisted death will no longer be asked to make recommendations to the government and will now simply report on its consultations on the issue. Justice Minister Jody Wilson-Raybould and Health Minister Jane Philpott say in a statement that along with the modified mandate, the date for the panel to make its report has been extended by a month to 15 December. In July, the Conservative government established the panel to solicit attitudes and opinions of Canadians and key stakeholders after the Supreme Court of Canada recognized the right of clearly consenting adults who endure intolerable physical or mental suffering to end their lives with a physician’s help. <http://medicinehatnews.com/news/national-news/2015/11/14/government-says-assisteddeath-panel-wont-give-advice-for-legislation/>

U.S.A.

End of “death panels” myth brings new end-of-life challenges

THE NEW YORK TIMES | Online – 20 November 2015 – Any emergency room physician or intensive care unit social worker can tell harrowing tales of frantically trying to locate a relative, a neighbor, a document – any clue to what an incapacitated older adult wants when she can’t speak for herself. Medicare reimbursement, alas, will not magically solve that problem. A lot has to happen first. Somehow patients must learn that they can have extended discussions about life and death decisions with a doctor if they want to. Somehow, too, doctors must learn how to broach and explore very tender subjects. The prospect makes them hesitant and anxious, said Dr. Diane Meier, who leads the Center to Advance Palliative Care at Mount Sinai Hospital in New York. “The great majority of providers ... have had no training in effective communication about what’s most important to people with a serious illness,” Dr. Meier said. “People are not born knowing how to have these conversations any more than they’re born knowing how to do an appendectomy.” Before health care profes-

sionals can pose unnerving what-if questions, truly listen to people’s answers, and help frame a plan, “communication skills need to be practiced and drilled and rehearsed,” Dr. Meier added. http://www.nytimes.com/2015/11/24/health/end-of-death-panels-myth-brings-new-end-of-life-challenges.html?_r=0

Specialist Publications

‘Critical care implications of the Affordable Care Act’ (p.10), in *Critical Care Medicine*.

‘Avoiding spending while meeting patients’ wishes: A model of community-based palliative care uptake in California from 2014-2022’ (p.10), in *Journal of Palliative Medicine*.

‘Patient-reported barriers to high-quality, end-of-life care: A multiethnic, multilingual, mixed-methods study’ (p.13), in *Journal of Palliative Medicine*.

Noted in Media Watch, 2 November 2015, #434 (p.4):

- THE NEW YORK TIMES | Online – 30 October 2015 – **‘New Medicare rule authorizes “end-of-life” consultations.’** Six years after legislation to encourage end-of-life planning touched off a furor ... the Obama administration issued a final rule [effective January 2016] that authorizes Medicare to pay doctors for consultations with patients on how they would like to be cared for as they are dying. http://www.nytimes.com/2015/10/31/us/new-medicare-rule-authorizes-end-of-life-consultations.html?_r=0

War on drugs means millions are needlessly dying in pain

CNN NEWS | Online – 17 November 2015 – Millions of people are dying in pain because of the repressive stance the world has taken on drugs. That's because states are obsessed by the fear that people will use controlled medicines such as morphine as recreational drugs, thereby neglecting their important medical uses. Where you live determines whether you will be able to access to controlled medicines, particularly opiates, when confronting an acute terminal, chronic or painful illness. 92% of the world's morphine is consumed by only 17% of the world's population, primarily the U.S. and Europe. Seventy-five percent of the world's people in need do not have access to pain relieving medicine. In other words, most of the global population, outside the affluent countries in the North, dying in pain, including from terminal cancers, do so in the absence of dignified palliative care. Essential medicines such as morphine, taken for granted as the standard relief of severe pain in the global North, do not enjoy the same status in the global South. <http://www.cnn.com/2015/11/17/opinions/controlled-medicines-access-gcdp/index.html>

Selected articles on availability and accessibility of opioids

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 20 October 2015 – ‘**Identification of challenges to the availability and accessibility of opioids in twelve European Countries: Conclusions from two Access to Opioid Medication in Europe six-country workshops.**’ A number of challenges in participating countries were identified in the domains of knowledge and education, regulatory, legislative, as well as public awareness, and training barriers that limit opioid prescription. [Noted in Media Watch, 26 October 2015, #433 (p.12)] <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0051>
- *THE LANCET* | Online – 8 March 2015 – ‘**The Harvard Global Equity Initiative: Lancet Commission on global access to pain control and palliative care.**’ In low-income and middle-income countries regulations hampering opioid accessibility, combined with the scarcity of trained doctors and other health professionals, has stymied delivery of pain treatment and palliative care. [Noted in Media Watch, 23 March 2015, #402 (p.9)] [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(15\)60289-6/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)60289-6/fulltext)
- *ANNALS OF ONCOLOGY*, 2013;24(suppl11):xi7-xi13. ‘**The Global Opioid Policy Initiative project to evaluate the availability and accessibility of opioids for the management of cancer pain in Africa, Asia, Latin America and the Caribbean, and the Middle East: Introduction and methodology.**’ Data provided highlight issues in formulary inadequacy, problems with cost to consumer and actual availability of medication, and the extent of regulatory barriers... [Noted in Media Watch, 20 January 2014, #341 (p.9)] http://annonc.oxfordjournals.org/content/24/suppl_11/xi7.full.pdf+html

N.B. See ‘Availability of Opioid Painkillers,’ 2015 Quality of Death Index (Figure 5.2, p.42), Economist Intelligence Unit, October 2015. [Noted in Media Watch, 26 October 2015, #433 (p.12)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Kansas “Right to Try” bill would ease access to trial drugs but some see peril

KANSAS | KCUR News (Kansas City) – 16 November 2015 – House Bill 2004 seeks to give Kansans with terminal illnesses access to drugs in the early phases of Federal Drug Administration (FDA) clinical trials. It's based on model legislation from the Goldwater Institute, a small-government advocacy think tank. The bill did not get a House vote last year. But Kansas is in the middle of a two-year legislative cycle ... which means the bill remains eligible for a vote after the Legislature reconvenes in January. Kansas lawmakers are promoting bills at the state and federal level intended to streamline the FDA approval process or let people ... bypass portions of it and access experimental drugs sooner. But some fear those efforts could allow profit-seeking drug companies and medical device manufacturers to rush products to market before anyone knows the potential risks or side effects. <http://kcur.org/post/kansas-right-try-bill-would-ease-access-trial-drugs-some-see-peril#stream/0>

Cont.

Noted in Media Watch, 19 October 2015, #432 (p.4):

- CALIFORNIA | *The Washington Free Beacon* (Washington DC) – 12 October 2015 – ‘**California Governor denies terminally ill access to potentially life-saving drugs.**’ Californians who are terminally ill will not be able to access drugs with the potential to save or prolong their lives as a result of Governor Jerry Brown’s veto of the Right to Try Act, AB 159, the California Right to Try Act, passed the state assembly and senate with overwhelming bipartisan support. <http://freebeacon.com/issues/california-governor-denies-terminally-ill-access-to-potentially-life-saving-drugs/>

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. Worse, the door is left open for the unscrupulous or inept to prey on desperately ill patients and their families. Further, the laws absolve companies and physicians from legal liability should be the experimental product cause harm. <http://annals.org/article.aspx?articleid=2443961>

N.B. Selected articles on right-to-try laws noted in past issues of Media Watch are listed in this issue of the weekly report.

In caring for sickest babies, doctors now tap parents for tough calls

NATIONAL PUBLIC RADIO | Online – 16 November 2015 – One of the most difficult parts of [Dr. William] Benitz’s job [at Lucile Packard Children’s Hospital at Stanford University] is determining how much treatment to give babies like these, and figuring out when it’s time to let them go. More and more, doctors like Benitz are looking to parents to help make these decisions, based on the parents’ values and preferences. The American Academy of Pediatrics recently advised that parents should be given wide latitude in deciding how aggressive doctors should be with treatment in cases where their child is at high risk of death or serious disability. In practice, this means parents willing to raise a child with severe disabilities might elect to pursue more aggressive care than parents who do not want to take on that risk. That’s a big change. When Benitz first started at Stanford in 1973, doctors were considered the absolute authorities in life-and-death decisions, he says. They consulted with colleagues and decided how much intensive care to give, based on what they thought was the likeliest outcome. Often these doctors didn’t even tell the parents of the decision before taking action. “It never occurred to anyone that that might be a reasonable conversation to have,” Benitz says. “We were in unexplored territory.” <http://www.npr.org/sections/health-shots/2015/11/16/455641133/in-caring-for-sickest-babies-doctors-now-tap-parents-for-tough-calls>

Related:

- KAISER HEALTH NEWS | Online – 16 November 2015 – ‘**A sick newborn, a loving family, and a litany of wrenching choices.**’ As doctors and families consider how far to push medical care, a chasm can open between the parents’ hopes and what providers consider realistic. Studies suggest that providers do tend to have a different view of quality of life than parents. There’s often a lag between when health care providers and parents sense a child isn’t going to make it. Researchers found, for instance, that oncologists realized children were going to die months before the parents. <http://khn.org/news/a-sick-newborn-a-loving-family-and-a-litany-of-wrenching-choices/>

Noted in Media Watch, 26 October 2015, #433 (p.14):

- *JOURNAL OF PERINATOLOGY* | Online – 22 October 2015 – ‘**Primary palliative care in the delivery room: Patients’ and medical personnel’s perspectives.**’ Most delivery room staff do not report relevant signs of distress in dying neonates and providing palliative care (PC) was not named as a relevant care-related source of distress by medical personnel. Half of the study participants reported high degrees of caregiver’s emotional distress in primary PC situations, identifying insecurity of how to communicate with parents and to provide emotional support as the most common source of distress. <http://www.nature.com/jp/journal/vaop/ncurrent/full/jp2015127a.html>

N.B. Selected articles on perinatal palliative care noted in past issues of Media Watch are listed in this issue of the weekly report.

Salt Lake City's homeless deserve hospice care

UTAH | *Desert News* (Salt Lake City) – 16 November 2015 – Is Salt Lake City a city of compassion or a city of abandonment? About 50 homeless people die here annually. Death is a natural process; since the dawn of humanity, people have been dying at home. But where do homeless people go to die? The shelters are not equipped to deal with the end of life, hospitals can't keep these patients for weeks or months on end, and most lack insurance to pay for a skilled nursing facility. Without a stable place to live, they end up in and out of the emergency room, straining our city's fire, police and hospital resources, and eventually dying on the streets or in parks. <http://www.deseretnews.com/article/865641596/Salt-Lake-Citys-homeless-deserve-hospice-care.html>

Specialist Publications

'Minding the gap: Access to palliative care and the homeless' (p.9), in *BMC Palliative Care*.

International

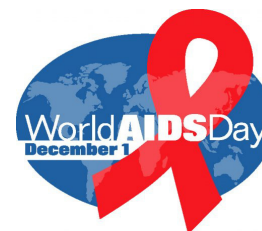
End-of-life issues in England

Court approves withdrawal of treatment in landmark end-of-life case

U.K. (England) | Family Law – 20 November 2015 – The Court of Protection yesterday ... authorised the withdrawal of treatment from a 68-year-old woman who is at the end stages of multiple sclerosis – the first time such a decision has been made to withdraw life-sustaining treatment from a person in a “minimally conscious state.” A judge was asked to decide whether doctors could stop providing treatment by the woman's daughter and family who say that the treatment is prolonging an existence without dignity or quality of life. The woman, who is being treated in the North of England but cannot be identified for legal reasons, was diagnosed with multiple sclerosis in 1991, and for around the past 8 years has been provided with nutrition, fluids and medication through a tube. At the Court of Protection, Mr. Justice Hayden ruled that treatment could now be stopped after hearing evidence from medical experts as well as the family of the woman. The woman's interests were represented by the Office of the Official Solicitor, which acts for people without mental capacity to make decisions themselves. The Official Solicitor indicated during the course of the hearing that he supported the application to withdraw life-sustaining treatment, meaning that by the end of the case the application was not opposed by any of the parties involved. http://www.familylaw.co.uk/news_and_comment/court-approves-withdrawal-of-treatment-in-landmark-end-of-life-case#.Vk9yaDZdHyQ

Noted in Media Watch, 26 October 2015, #433 (p.16):

- *JOURNAL OF MEDICAL ETHICS* | Online – 20 October 2015 – ‘**Court applications for withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state: Family experiences.**’ Withdrawal of artificially delivered nutrition and hydration (ANH) from patients in a permanent vegetative state (PVS) requires judicial approval in England & Wales, even when families and healthcare professionals agree withdrawal is in the patient's best interests. Part of the rationale underpinning the original recommendation for such court approval was the reassurance of patients' families, but there has been no research as to whether or not family members are reassured by the requirement for court proceedings or how they experience the process. The authors' analysis of family experience supports arguments grounded in economic and legal analysis that court approval should no longer be required. <http://jme.bmj.com/content/early/2015/09/30/medethics-2015-102777.full.pdf+html>



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.16.

How to help children cope with the death of a parent

U.K. (England) | *The Daily Telegraph* – 18 November 2015 – “When a parent dies suddenly, the first reaction in a child is usually numbness and shock,” says Shelley Gilbert, a psychotherapist and founder of Grief Encounter, a charity which provides help to bereaved children... “That’s necessary as it helps the child get through the initial trauma. A child will then replay the visual images over and over in their heads of what they think happened,” she explains adding that while most adults are preoccupied with what to tell children, listening is important too. Though there needs to be more research done, Gilbert says, recent studies have found that those who lose a parent in childhood and don’t process the event can experience more depression, anxiety and low self-esteem in adulthood. In England, there are currently 261,000 bereaved 5-16 year olds¹ ...and, for every classroom of 29 kids, one will have lost a parent, brother or sister...² <http://www.telegraph.co.uk/women/family/how-to-help-children-cope-with-the-death-of-a-parent/>

1. Childhood Bereavement Network, county-by-county statistics:
<http://www.childhoodbereavementnetwork.org.uk/research/local-statistics.aspx>
2. Selected articles on discussing dying and death in the classroom noted in past issues of of Media Watch are listed in the issue of Media Watch, 16 November 2015, #436 (p.3).

N.B. Resource: ‘Support Services for Grieving or Bereaved Children: Needs Assessment – Literature Search,’ <file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/G9UWWHL9/ChildrenandYouthCollaborativeFinalLiteratureSearch.pdf>; Supplement to the literature search on helplines, online support, and social media. file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/UPG4XG0C/SupplementChildYouthGriefCollaborativeROPFINAL_2015_20150514162617.pdf Both undertaken for the ‘Children’s Anticipatory Grief & Bereavement Collaborative,’ Region of Peel (Ontario, Canada), March 2015.


End-of-life care in Viet Nam

Palliative care eases burden on healthcare system

VIET NAM | *Việt Nam News* (Ha Noi) – 18 November 2015 – In Viet Nam, about 150,000 diagnoses of cancer occur annually with 70% of them in the last stage, according to Viet Nam Cancer Society. Of the 40 million people worldwide who could benefit from palliative care (PC) because of cancer and other chronic diseases, only 14% receive such care. The proportion is even lower in Viet Nam, a developing country with rapid urbanisation and increasingly unhealthy lifestyles. The Ministry of Health tried to encourage the practice by issuing PC guidelines for cancer and AIDS patients in 2006, but so far only 13 hospitals have PC wards or have implemented programmes. Viet Nam ranks 58th on end-of-life care on the Economist Intelligence Unit’s 2015 Quality of Death Index, which ranks PC across the world.¹ <http://vietnamnews.vn/society/278694/palliative-care-eases-burden-on-healthcare-system.html>

1. ‘2015 Quality of Death Index,’ Economist Intelligence Unit, October 2015. Commissioned by the Lien Foundation of Singapore [Noted in Media Watch, 2 November 2015, #434 (p.15)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

[Media Watch: Back Issues](#)



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Please feel free to share this weekly report with your colleagues.
Barry R. Ashpole, Oshawa, Ontario, CANADA
519-523-9084 | barry@ipcrc.net

MW 400: Palliative care in advanced lung disease: The challenge of integrating palliation into oncology care

Download the complete issue (PDF 450 KB)

QUEST | Online – 0 March 2015 | The tendency toward “ethics” pushing palliative care or comfort in traditional biomedical care paradigms does little to optimize care in advancing chronic illness. Calls for improved palliation in chronic lung disease mandate a new view of related care gaps and current clinical practices. [read more...](#)

Media Watch Archives

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<http://www.ipcrc.net/archive-global-palliative-care-news.php>

End-of-life care in Australia

To die at home or in hospital? Aussies want one but we fund the other

AUSTRALIA | *The Conversation* – 16 November 2015 – Where do you want to die? Provided symptoms can be controlled, most people at the end of life prefer to die at home. However, just over half of Australians who died in 2011-12 died in hospital. In the same year, about A\$2.4 billion was spent on hospital care for people aged 65 or older in their last year of life. But only a small fraction of that amount is spent supporting people to die at home. Public money is being wasted on ineffective and inefficient treatments and health services which do not meet patients' and families' needs and wishes at the end of life. This money would be better spent on palliative care services. Among other benefits, these more than double the chance of dying at home through the provision of home-based support services such as nursing. Health funds spent on

treatments and health services of negligible and questionable value, such as chemotherapy at the end of life, should be reallocated to palliative care services. This would improve our chances of dying well and in accordance with our wishes. <http://theconversation.com/to-die-at-home-or-in-hospital-aussies-want-one-but-we-fund-the-other-47773>

Specialist Publications

'Advance care planning in Australia: What does the law say?' (p.8), in *Australian Health Review*.

'Routine integration of palliative care: What will it take?' (p.14), in *Medical Journal of Australia*.

Elder care in England

New home care team for elderly formed in Bradford to help reduce hospital pressures

U.K. (England) | *The Telegraph & Argus* (Bradford) – 16 November 2015 – As well as helping older people stay in their homes longer, the service has been set up to cut the number of needless emergency admissions to hospital which should then leave more beds for the most critically ill. The hub is a joint effort by community, health and social services to make a single access point for GPs and other professionals needing to refer patients for immediate care ... to get it in their homes rather than be admitted to hospital. http://www.thetelegraphandargus.co.uk/news/14033518.New_home_care_team_for_elderly_formed_in_Bradford_to_help_reduce_hospital_pressures/

End-of-life care in Scotland

Hospitals begin to think more about palliative care

U.K. (Scotland) | *The Sunday Herald* (Glasgow) – 15 November 2015 – When Professor David Clark and his team at Glasgow University researched the prevalence of death among hospital patients, theirs was the first study of its kind in the world. It told us something many people may have realised on a subconscious level, but which is rarely stated: A key part of the business of hospitals is death. His 2010 study implied that nearly a third of those in hospital in Scotland at any one time will die within a year. Around one in ten of those in hospital on a given day will die during that hospital admission. Speaking recently about the extensive snapshot research carried out on a single day five years ago Professor Clark revealed the existence of a follow up study, in 2013, which repeated the experiment, with almost exactly the same findings. This may not tally with our modern ideas of a hospital as a hi-tech environment, where lives are routinely saved. But should hospitals do more to discuss death with patients? If they don't, who will? If we should, how do we make the time for hard pressed National Health Service staff, especially when new hospitals such as the new Dumfries General Hospital are geared to ensuring most patients spend as little time there as possible? <http://www.heraldscotland.com/opinion/14033232.display/>

Cont.

Noted in Media Watch, 24 March 2014, #350 (p.5):

- U.K. (Scotland) | *The Herald* (Edinburgh) – 18 March 2014 – ‘**One-third of hospital patients “die within 12 months.”**’ Researchers from the University of Glasgow who followed the progress of patients at 25 hospitals across Scotland found 28.8% died within a year. Professor David Clark, head of the school of interdisciplinary studies at the university, said the research showed there was a need for hospitals to adopt a more vigorous approach to identifying patients entering the last year of their lives.¹
<http://www.heraldscotland.com/news/home-news/one-third-of-hospital-patients-die-within-12-months.23732974>

1. ‘Imminence of death among hospital inpatients: Prevalent cohort study,’ *Palliative Medicine*, 17 March 2014. <http://pmj.sagepub.com/content/early/2014/03/17/0269216314526443.abstract>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (England) | *Breaking News.ie* (Blackpool, Cork, Ireland) – 16 November 2015 – ‘**Assisted suicide campaigners take fight to High Court in England.**’ Disability rights campaigners go to the High Court in England to challenge the prosecution policy in relation to the law on assisted suicide. Three judges in London will hear the case brought against Director of Public Prosecutions (DPP) Alison Saunders. The U.K.’s Suicide Act 1961 makes it a criminal offence to assist or encourage suicide. The DPP has discretion on whether to prosecute according to the published policy. In October last year, the DPP amended the policy, making the prosecution of healthcare professionals in assisted suicide cases less likely. Earlier this year, Nikki and Merv Kenward were given permission to challenge the DPP’s actions, arguing that the DPP had in fact “changed” the policy and made it more “liberal.”
<http://www.breakingnews.ie/world/assisted-suicide-campaigners-take-fight-to-high-court-in-england-705887.html>

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

End-of-life care in Australia

Advance care planning in Australia: What does the law say?

AUSTRALIAN HEALTH REVIEW | Online – 16 November 2015 – Formal documentation of wishes increases the chances that a person’s wishes will be known and followed. However, one of the biggest impediments for doctors following the person’s wishes is uncertainty surrounding the law, which is complicated and varies between the states and territories of Australia. Substitute decision maker (SDM) legislation varies regarding who can be appointed, how they are appointed, the powers that an SDM can be given and the decision-making principles that the SDM needs to follow. In circumstances where an SDM has not been appointed, the hierarchy for determining the default SDM for a person also varies between states. Although many states have legislated advance directive (ACD) forms allowing for documentation of a person’s health care wishes, these forms allow for different things to be documented and have different requirements to be valid. The Australian population is mobile, with patients frequently moving between states. The status of ACP documentation created in a state other than the state in which a patient requires treatment also varies, with some states recognising interstate ACDs whereas others do not.
<http://www.publish.csiro.au/nid/270/paper/AH15120.htm>

Noted in Media Watch, 20 January 2014, #341 (p.6):

- *AUSTRALIAN AGEING AGENDA* | Online – 17 January 2014 – ‘**Doctors unclear on advance care planning laws,**’ Many doctors are confused about the legality of advance care directives and the authority of substitute decision-makers, leaving them open to possible legal action, research has found.¹
<http://www.australianageingagenda.com.au/2014/01/17/doctors-unclear-advance-care-planning-laws/>

1. ‘Medical practitioners’ knowledge and self-reported practices of substitute decision-making and implementation of advance care plans,’ *Internal Medicine Journal*, 24 December 2013.
<http://onlinelibrary.wiley.com/doi/10.1111/imj.12354/citedby>

Nurses respond to patients' psychosocial needs by dealing, ducking, diverting and deferring: An observational study of a hospice ward

BMC NURSING | Online – 17 November 2015 – During the 8-month period of observation, 227 encounters within 38 episodes of care were observed among 38 nurses and 47 patients. Within these encounters, 330 psychosocial needs (PNs) were expressed. Nurses were observed immediately responding to expressed PNs in one of four ways: 1) Dealing (44.2 %); 2) Deferring (14.8 %); 3) Diverting (10.3 %); and, 4) Ducking (30.7 %). However, it is rare that one type of PN was clearly expressed on its own: many were expressed at the same time and usually while the patient was interacting with the nurse for another reason, thus making the provision of psychosocial support challenging. The nurses' response patterns varied little according to type of need. This study has allowed an exploration of the actual PNs of patients in a hospice setting, the way in which they were expressed, and how nurses responded to them. The nurses faced the challenge of responding to PNs whilst carrying out the other duties of their shift, and the fact that nurses can provide psychosocial support as an inherent component of practice was verified. <file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/UPG4XG0C/s12912-015-0112-8.pdf>

Related:

- *CONTEMPORARY SOCIAL SCIENCE* | Online – 17 November 2015 – '**Social death in end-of-life care policy.**' Social death denotes a loss of personhood. The concept is engaged with in English end-of-life care policy that sees social death before physical death as a problem. Policy-makers posit that dying persons are likely to be subject to a social death prior to their physical death unless they play an active and aware role in planning their death, facilitated through communication and access to services. <http://www.tandfonline.com/doi/abs/10.1080/21582041.2015.1109799?journalCode=rsoc21>

Noted in Media Watch, 12 May 2014, #357 (p.13):

- *PALLIATIVE MEDICINE & HOSPICE CARE OPEN*, 2014;1(1):1-3. '**Importance of psychological research in palliative care: Barriers in its development.**' The analysis of the psychosocial aspects in patients with advanced illness or at the end of life has a number of characteristics difficult to study. Barriers to research identified in this study were related to: 1) Psychological issues are subjective, variables or constructs are complex and difficult to operationalize; 2) Psychological variables are difficult to measure; 3) The patients are fragile, their condition (physical and psychological) is mediated by the progress of the disease and the presence of impending death; 4) Health professionals have limited time to conduct assessments or research; and, 5) There is a lack of validated clinical tools. <http://openventio.org/PalliativeMedicineandHospiceCareOpenJournal/ImportanceofPsychologicalResearchinPalliativeCareBarriersinitsDevelopment-PMHCOJ-1-101.pdf>

Minding the gap: Access to palliative care and the homeless

BMC PALLIATIVE CARE | Online – 18 November 2015 – The history of palliative care (PC) is one of a movement that grew from an initial call to advocate on behalf of dying patients whose needs were not being met by the conventional medical system of its day. It was a response to the abandonment patients and families experienced and a recognized need for dignity to be infused into this most sacred and final act of our existence. This value was and remains its core mission. However, PC has become more recognized by mainstream medicine and perhaps more medicalized as a result of that encounter. In truth, our current PC delivery system requires a degree of monetary, in-person, and infrastructure support that often creates barriers for the homeless population; barriers they simply cannot overcome. This reality affects access to quality PC, not only at the end of life but also along the trajectory of a disease where recent evidence supports its use. Current PC services are glaringly unequipped to properly meet the needs of the homeless. McNeil *et al* have called for the creation of initiatives that cater to the needs of the poor by adopting flexible, low-threshold strategies, partnering with local community agencies, and by strengthening the training on end-of-life care issues amongst those who care for the homeless population.¹ <file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/87XQHXCX/art%253A10.1186%252Fs12904-015-0059-2.pdf>

Cont.

1. 'Recommendations for improving the end-of-life care system for homeless populations: A qualitative study of the views of Canadian health and social services professionals,' *BMC Palliative Care*, 15 September 2012. [Noted in Media Watch, 17 September 2012, #271 (p.7)]
<http://www.biomedcentral.com/content/pdf/1472-684X-11-14.pdf>

Noted in Media Watch, 16 February 2015, #397 (p.10):

- *DEATH STUDIES* | Online – 12 February 2015 – '**What constitutes a good and bad death? Perspectives of homeless older adults.**' In this study the themes identified for a good death were: 1) Dying peacefully; 2) Not suffering; 3) Experiencing spiritual connection; and, 4) Making amends with significant others. Themes for a bad death were: 1) Experiencing death by accident or violence; 2) Prolonging life with life supports; 3) Becoming dependent while entering a dying trajectory; and, 4) Dying alone. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2014.958629>

N.B. Selected articles on end-of-life care for the homeless noted in past issues of Media Watch are listed in the issue of the weekly report of 3 February 2014, #343 (p.4).

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

Critical care implications of the Affordable Care Act

CRITICAL CARE MEDICINE | Online – 12 November 2015 – The Affordable Care Act (ACA) represents the furthest reaching regulatory changes in the U.S. healthcare system since the 1965 Medicare and Medicaid provisions of the Social Security Act. The aim is to expand health insurance coverage to millions of Americans and place an emphasis on quality and cost-effectiveness of care. From models which link pay and performance to those which center on episodic care, the Act outlines sweeping changes to health systems, reimbursement structures, and delivery of critical care. Staffing models that include daily rounding by an intensivist, palliative care integration, and expansion of the role of telemedicine in areas where intensivists are inaccessible are potential strategies that may improve quality and profitability of ICU care in the post-ACA era. The authors describe strategies that may help health systems and providers effectively adapt to the changes...
http://journals.lww.com/ccmjournal/Abstract/publishahead/Critical_Care_Implications_of_the_Affordable_Care.97071.aspx

Avoiding spending while meeting patients' wishes: A model of community-based palliative care uptake in California from 2014-2022

JOURNAL OF PALLIATIVE MEDICINE | Online – 19 November 2015 – If Californians participated in Community-based palliative care (CBPC) in the numbers envisioned, in 2014 there would have been a \$72 million reduction in intensive hospital based care, while still respecting patients' wishes, and nearly \$1.1 billion in spending could be avoided in 2022. Overall hospital spending would be reduced by more than \$5.5 billion through 2022. Existing CBPC programs have the potential to provide care that is both in alignment with patients' wishes and avoids substantial amounts of unnecessary hospital-based spending.
<http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0046>

Noted in Media Watch, 26 September 2011, #220 (p.7):

- *THE MILBANK QUARTERLY*, 2011;89(3):343-380. '**Increased access to palliative care and hospice services: Opportunities to improve value in health care.**' The evolution and growth of palliative care (PC) and hospice in the U.S. have resulted from the combined investments of both the public and the private sectors. The twenty-five-year-old Medicare hospice benefit exemplifies the role and impact of PC at the end of life and the new delivery and payment models encouraged by the Affordable Care Act and aimed at a high-risk high-need target population have the potential to strengthen PC capacity in the acute, post acute, and long-term care settings for seriously ill patients who are not dying.
http://www.researchgate.net/publication/51657167_Increased_Access_to_Palliative_Care_and_Hospice_Services_Opportunities_to_Improve_Value_in_Health_Care

Predatory journals and the breakdown of research cultures

INFORMATION DEVELOPMENT, 2015;31(5): 473-476. Research cultures are passed down from one generation of scholars to the next. The advent of predatory journals and conferences is damaging existing research cultures. Predatory publishers and conferences carry out a fake or incomplete peer review that allows low-quality, unvetted research to become a part of the scholarly record. This article examines predatory publishers and conferences within the framework of the five functions of scholarly communication. Academic institutions need to revise their

evaluation policies based on the realities predatory journals and conferences have created. <http://idv.sagepub.com/content/31/5/473.short>

Post publication peer review

PubPeer allows academics to engage in post-publication peer review of scientific research. The website has highlighted shortcomings in several high-profile papers. <https://pubpeer.com/>

Noted in Media Watch, 12 January 2015, #392 (p.1):

- *THE GLOBE & MAIL* | (Toronto, Canada) – 3 January 2015 – ‘**Predatory journals take a bite out of scholarship.**’ The academic imperative “publish or perish” is so well known people with no intention of entering scholarly life are familiar with it – no tenure for you, my friend, without at least a handful of citations. The journals should be reputable and selective, as all the best ones are, but in the crunch quantity might just trump quality. Alas, now comes this new storm on the horizon of university careerists: predatory journals. <http://www.theglobeandmail.com/globe-debate/predatory-journals-take-a-bite-out-of-scholarship/article22275403/>

Noted in Media Watch, 13 October 2014, #379 (p.9):

- *JOURNAL OF THE ROYAL SOCIETY OF MEDICINE*, 2014;107(10):384-385. ‘**Science for sale: The rise of predatory journals.**’ A new threat has emerged to the integrity of academic publishing: predatory journals. These unscrupulous publishers are exploiting the open-access model by corrupting the peer-review process, which is often absent or minimal. Their motivation is the procurement of evaluation and publication fees, which in the absence of traditional subscription rates are necessary to cover operating costs. Some claim to assess submissions within seventy-two hours and digitally publish them upon acceptance and receipt of the fee. <http://jrs.sagepub.com/content/107/10/384.full>



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://www.ipcrc.net/barry-r-ashpole.php>

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://www.pcn-e.com/community/pg/file/owner/MediaWatch>

Provision of palliative care in low- and middle-income countries: Overcoming obstacles for effective treatment delivery

JOURNAL OF CLINICAL ONCOLOGY | Online – 17 November 2015 – Despite being declared a basic human right, access to adult and pediatric palliative care (PC) for millions of individuals in need in low- and middle-income countries (LMICs) continues to be limited or absent. The requirement to make PC available to patients with cancer is increasingly urgent because global cancer case prevalence is anticipated to double over the next two decades. Fifty-percent of these cancers are expected to occur in LMICs, where mortality figures are disproportionately greater as a result of late detection of disease and insufficient access to appropriate treatment options. Notable initiatives in many LMICs have greatly improved access to PC. These can serve as development models for service scale-up in these regions, based on rigorous evaluation in the context of specific health systems. However, a multipronged public health approach is needed to fulfill the humane and ethical obligation to make PC universally available. This includes health policy that supports the integration of PC and investment in systems of health care delivery; changes in legislation and regulation that inappropriately restrict access to opioid medications for individuals with life-limiting illnesses; education and training of

health professionals; development of a methodologically rigorous data and research base specific to LMICs that encompasses health systems and clinical care; and shifts in societal and health professional attitudes to palliative and end-of-life care. International partnerships are valuable to achieve these goals, particularly in education and research. Leadership and health systems stewardship within LMICs are critical factors that will drive and implement change. <http://jco.ascopubs.org/content/early/2015/11/16/JCO.2015.62.1615.abstract>



The Economist Intelligence Unit
An Economic Intelligence Unit study, commissioned by the Lin Foundation

THE 2015 QUALITY OF DEATH INDEX
RANKING PALLIATIVE CARE ACROSS THE WORLD
KEY FINDINGS INFOGRAPHIC

<file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/87XQHXCX/2015%20Quality%20of%20Death%20Index%20Infographic.pdf>

N.B. Full report noted in Media Watch, 12 October 2015, #431 (pp.1,6,15,19): http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Noted in Media Watch, 22 September 2014, #376 (p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 September 2014 – **‘Reported availability and gaps of pediatric palliative care in low- and middle-income countries: A systematic review of published data.’** The majority of young people in need of palliative care (PC) live in low- and middle-income countries, where curative treatment is less available. The most pervasive gaps were in national health system support (unavailable in 7 of 17 countries with programs reporting), specialized education (unavailable in 7 of 19 countries with programs reporting), and comprehensive opioid access (unavailable in 14 of 21 countries with programs reporting). Comprehensive pediatric PC provision is possible even in markedly impoverished settings. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0095>

Noted in Media Watch, 15 September 2014, #375 (p.11):

- *HEALTH AFFAIRS*, 2014;33(9):1612-1619. **‘Innovation can improve and expand aspects of end-of-life care in low- and middle-income countries.’** Provision for end-of-life care (EOLC) around the world is widely variable and often poor, which leads to millions of deaths each year among people without access to essential aspects of care. However, some low- and middle-income countries have improved specific aspects of EOLC using innovative strategies and approaches such as international partnerships, community-based programs, and philanthropic initiatives. The authors recommend actions that policy makers and individuals can take to improve EOLC, regardless of the income level in a country. <http://content.healthaffairs.org/content/33/9/1612.short>

Feeling heard and understood: A patient-reported quality measure for the inpatient palliative care setting

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 17 November 2015 – As endorsed by the palliative care (PC) ‘Measuring What Matters’ initiative,¹ capturing patients’ direct assessment of their care is essential for ongoing quality reporting and improvement. Fostering an environment where seriously ill patients feel heard and understood is of crucial importance to modern health care. As part of a larger ongoing cohort study of inpatient PC, the authors developed and administered the following point-of-care item: “Over the past two days, how much have you felt heard and understood by the doctors, nurses and hospital staff?” (completely, quite a bit, moderately, slightly, not at all). Participants completed the measure before and the day following PC consultation. For the post-consultation version, we changed the time frame from “past two days” to “today.” One hundred sixty patients with advanced cancer completed the pre-consultation assessment and 87% of them completed the post-consultation version. Responses encompassed full use of the ordinal scale, did not exhibit ceiling or floor effects, and showed improvement from pre- to post-assessments. The item was quick to administer and easy for patients to complete. The “Heard & Understood” item is a promising self-report quality measure for the inpatient PC setting. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00607-7/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00607-7/abstract)

1. ‘Measuring What Matters,’ American Academy of Hospice & Palliative Medicine and Hospice & Palliative Care Nurses association: <http://aahpm.org/quality/measuring-what-matters>

Patient-reported barriers to high-quality, end-of-life care: A multiethnic, multilingual, mixed-methods study

JOURNAL OF PALLIATIVE MEDICINE | Online – 17 November 2015 – This study in Burmese, English, Hindi, Mandarin, Tagalog, Spanish, and Vietnamese was held in multiethnic community centers in five California cities. Primary patient-reported barriers were: 1) Finance/health insurance barriers; 2) Doctor behaviors; 3) Communication chasm between doctors and patients; 4) Family beliefs/behaviors; 5) Health system barriers; and, 6) Cultural/religious barriers. Multiethnic patients report that high-quality end-of-life care (EOLC) is important to them; but unfortunately, a majority state that they have encountered barriers to receiving such care. Efforts must be made to rapidly improve access to culturally competent EOLC for diverse populations. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0403>

Noted in Media Watch, 27 April 2015, #407 (p.4):

- U.S. | *The Washington Post* – 22 April 2015 – ‘**Ethnicity complicates patient-doctor discussion of death.**’ A new study has found that difficulty discussing end-of-life medical treatments is complicated further when there are ethnic differences that can create subtle barriers between the doctor and patient.¹ A survey of more than 1,000 medical professionals found that virtually all of them encountered difficulties holding end-of-life discussions with their patients magnified by cultural and ethnic differences that hindered discussion about end-of-life treatment, with 86% rating them as “challenging.” <http://www.washingtonpost.com/news/local/wp/2015/04/22/ethnicity-complicates-patient-doctor-discussion-of-death/>
1. ‘No easy talk: A mixed methods study of doctor reported barriers to conducting effective end-of-life conversations with diverse patients,’ *Plos One*, 22 April 2015. The biggest doctor-reported barriers: 1) Language, medical interpretation; 2) Patient/family religio-spiritual beliefs about death, dying; 3) Doctors’ ignorance of patients’ cultural beliefs, values, practices; 4) Patient/family’s cultural differences in truth handling, decision making; 5) Patients’ limited health literacy; and, 6) Patients’ mistrust of doctors, the health care system. <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0122321>

N.B. The *Journal of Palliative Medicine* and the *Plos One* articles are by the same authors, the former from a patient perspective, the latter from a physician perspective.

Routine integration of palliative care: What will it take?

MEDICAL JOURNAL OF AUSTRALIA | Online – 16 November 2015 – A whole-of-system approach has been advocated, involving quality-improvement strategies that identify and respond to specific gaps in care, coupled with measures of achievement and accountability. Yet, even in systems without barriers to PC, there remain two clinical tasks that appear critical to its successful integration: 1) Recognition of the possibility (and need) for PC; and, 2) Sensitive communication. A number of prompts have been proposed to ensure the task of recognition occurs. These include disease specific prognostic tools, measures of need both symptomatic and psychosocial, and clinical prompts such as “would I be surprised if this patient died in the next 6 months?” An alternative approach based on service use, such as increasing frequency of admissions, or the development of a nominated disease complication such as metastatic disease, may offer an administrative prompt that occurs routinely and requires a response, rather than initiation, by the physician. Once recognised, there remains the task of communicating with the patient and family around issues of worsening disease, disability and death. Yet, our society determinedly avoids discourse around dying, focusing instead on “staying positive” and “fighting hard.” The media reinforces this language and focus, offering few stories of those whose illness progresses. This silence is also

present in the clinic, and so instead we frequently find it easier to offer a further round of treatment rather than discuss the implications of failure of the last. By failing to engage patients and their families in such discussion until death is imminent, we limit opportunities of patients to realise choices in the final phase of life. <https://www.mja.com.au/journal/2015/203/10/routine-integration-palliative-care-what-will-it-take>

Early integration of palliative care for children with high-risk cancer and their families

PEDIATRIC BLOOD & CANCER | Online – 18 November 2015 – Despite increasing data to support pediatric palliative care (PPC) as an integral component of high-quality care for children with life-threatening conditions and their families, timely integration of PPC is offered inconsistently to children with high-risk cancer. The authors summarize the growing body of literature in support of early integration of PPC for children with high-risk cancer and their families, advocating that PPC principles and resources are imperative to holistic cancer-directed care and rooted in evidence-based medicine. They offer possible strategies for optimizing integration of PPC into holistic cancer care for children and families. <http://onlinelibrary.wiley.com/doi/10.1002/pbc.25848/abstract>

Parents’ perspectives on the important aspects of care in children dying from life-limiting conditions: A qualitative study

MEDICAL JOURNAL OF MALAYSIA, 2015;70(5):295-299. Generally children with malignant disease appear to have a precocious understanding of the concepts of death. Their experiences during treatment might include the deaths of other patients, and they can sense the extraordinary stress of their parents and doctors when death is imminent, as well as feel tremendous isolation if they are not given permission to talk openly about their illness and impending death. Whilst knowledge of the developmental understanding of death and timing is critical when it comes to communicating with children, it is also important to be receptive to when the child is initiating a conversation. “Teachable moments” may be fleeting, and healthcare workers need to be trained and tuned to these moments, so that it can be capitalized with an immediate response. Parents who wish but do not know how to break the news to their child are offered assistance by trained staff. The practice of collusion and mutual pretence seems to be commonly adopted by Malaysian families. Asian cultural practices and beliefs may influence the degree of open communication that takes place. An individual is not autonomous but lives in the context of a family and community. In the case of minors and elders, healthcare decisions are often made by the family. As parents are the final arbiters on decisions and assent a collaborative disclosure process taking into account the family’s wishes within the context of its culture will likely offer greater benefit overall, than would overriding and undermining the parents’ role in promoting the long term autonomy and well being of their children. <http://www.e-mjm.org/2015/v70n5/paediatric-palliative-care.pdf>

Cont.

N.B. For a global perspective: 'Children's Palliative Care,' 2015 Quality of Death Index (p.44), Economist Intelligence Unit, October 2015. [Noted in Media Watch, 2 November 2015, #434 (p.15)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Noted in Media Watch, 3 August 2015, #421 (p.11):

- *JOURNAL OF PEDIATRIC ONCOLOGY NURSING* | Online – 27 July 2015 – '**Experiences of pediatric oncology patients and their parents at end of life: A systematic review.**' The child and parent experience provides valuable information to guide how health care professionals can improve the transition to end of life and the care provided to children and families during the vulnerable period. Analysis of the evidence revealed five themes: 1) Symptom prevalence and symptom management; 2) Parent and child perspectives of care; 3) Patterns of care; 4) Decision making; and, 5) Parent and child outcomes of care. <http://jpo.sagepub.com/content/early/2015/07/23/1043454215589715.abstract>

Noted in Media Watch, 9 December 2013, #335 (p.5):

- *ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 5 December 2013 – '**What parents want from doctors in end-of-life decision-making for children.**' The majority of parents [i.e., study participants] found their child's doctor enabled them to be the ultimate decision maker for their child, which was what they very clearly wanted to be, and consequently enabled them to exercise their parental autonomy. Parents found it problematic when doctors took over decision-making. A less frequently reported, yet significant role for doctors was to affirm decisions after they had been made by parents. <http://adc.bmj.com/content/early/2013/12/05/archdischild-2013-304249.abstract>

A systematic review of reasons for gatekeeping in palliative care research

PALLIATIVE MEDICINE | Online – 17 November 2015 – When healthcare professionals or other involved parties prevent eligible patients from entering a trial as a research subject, they are gatekeeping. This phenomenon is a persistent problem in palliative care (PC) research and thought to be responsible for the failure of many studies. Thirty papers on gatekeeping in PC research were included in this review. Five groups of potential gatekeepers were identified: 1) Healthcare professionals; 2) Research ethics committees; 3) Management; 4) Relatives; and, 5) Researchers. The fear of burdening vulnerable patients was the most reported reason for gatekeeping. Other reasons included "difficulty with disclosure of health status," "fear of burdening the patient's relatives," "doubts about the importance or quality of the study," "reticent attitude towards research and (research) expertise," and, "logistics." In hospice and homecare settings, the pursuit of comfort care may trigger a protective attitude. Gatekeeping is also rooted in a (perceived) lack of skills to recruit patients with advanced illness. Gatekeeping is motivated by the general assumption of vulnerability of patients, coupled with an emphasis on the duty to protect patients. Research is easily perceived as a threat to patient well-being, and the benefits appear to be overlooked. <http://pmj.sagepub.com/content/early/2015/11/12/0269216315616759.abstract>

Noted in Media Watch, 19 October 2015, #432 (p.14):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 October 2015 – '**Toward evidence-based end-of-life care.**' The disquieting patterns of end-of-life care in the U.S. have been well documented. In the last month of life, one in two Medicare beneficiaries [in the U.S.] visits an emergency department, one in three is admitted to an intensive care unit, and one in five has inpatient surgery. 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 the Food & Drug Administration would require to approve even a relatively innocuous drug. <http://www.nejm.org/doi/full/10.1056/NEJMp1509664>

Noted in Media Watch, 5 October 2015, #430 (p.10):

- *CANCER BIOLOGY & MEDICINE*, 2015;12(3):193-200. '**Reality of evidence-based practice in palliative care.**' The complex multi-morbidity of end-of-life care involves considerations of the patient's physical, psychological, social and spiritual needs. In addition, the field of palliative care (PC) covers a heterogeneous group of chronic and incurable diseases no longer limited to cancer. Adequate sample sizes can be difficult to achieve, reducing the power of studies, and high attrition rates can result in inadequate follow up periods. <http://www.cancerbiomed.org/index.php/cocr/article/view/871>

End-of-life care in Wales

Two-thirds of palliative care patients are not on GP registers

PULSE | Online – 17 November 2015 – Two thirds of people with end-of-life care needs in Wales are not on a GP palliative care (PC) register – reducing the chances of them getting comprehensive co-ordinated PC... The statistics emerged in a Welsh Government annual analysis of end-of-life care, which shows the numbers of patients on GPs' PC registers in the country almost tripled between 2008/2009 and 2013/2014.¹ However, it found practices are still only registering about a third of those who are in the final year of their lives. The report estimates about 24,000 people a year require PC overall, but there are only 8,272 on a PC register. <http://www.pulsetoday.co.uk/clinical/more-clinical-areas/elderly-care/two-thirds-of-palliative-care-patients-are-not-on-gp-lists/20030432.article>

1. 'Together for Health End of Life Care: Annual Report 2015,' National Health Service Wales, November 2015. There has been a 15.7% increase in the number of people registered on a primary care palliative register over the last 12 months. [Noted in Media Watch, 16 November 2015, #436 (p.4)] <file:///C:/Users/admin/AppData/Local/Microsoft/Windows/NetCache/IE/11673N6U/151113endofliferepor t15en.pdf>

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/publications/newsletter/2015/11/media-watch/>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

PALLIATIVE CARE NETWORK COMMUNITY: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

PALLIMED (Hospice & Palliative Medicine Blog): <http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://aphn.org/category/media-watch/>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/updates/international-palliative-care-resource-center-media-watch/>

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> [Scroll down to 'International Websites' and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report]

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://www.eapcnet.eu/Themes/Organization/Links.aspx> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes>

U.K. | Omega, the National Association for End-of-Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **BMC PALLIATIVE CARE** | Online – 14 November 2015 – ‘**Palliative care professionals’ willingness to perform euthanasia or physician assisted suicide.**’ This is the first German study to ask about the willingness of professionals to take action as regards euthanasia and physician assisted suicide (PAS) without biased phrasing. Results demonstrate a profound problem in the actual discussion about PAS in Germany: if PAS were allowed, who should perform it. General practitioners are not trained to perform any form of life-ending procedures. This has been documented extensively by studies from Belgium and The Netherlands, where false drugs were selected, euthanasia was mistaken for palliative sedation and *vice versa*. On the other hand, palliative care physicians are reluctant to perform euthanasia or PAS. So far public debate has disregarded the central question: Who should train doctors to perform PAS correctly. <http://link.springer.com/article/10.1186/s12904-015-0058-3>

Noted in Media Watch, 31 August 2015, #425 (p.3):

- **CANADA** | CTV News – 25 August 2015 – ‘**Doctors group looking at intensive course to train willing MDs in assisted death.**’ Doctors who are willing to assist in a patient’s death once the act becomes legal early next year will need to be trained because they’ve never been taught the procedures for ending a life, the Canadian Medical Association (CMA) says. The 80,000-member doctors’ organization is considering an intensive two-day course for physicians “who have never had to learn this, who have not taken it in medical school or residency.” <http://www.ctvnews.ca/health/doctors-group-looking-at-intensive-course-to-train-willing-mds-in-assisted-death-1.2532609>
- **PALLIATIVE MEDICINE** | Online – 19 November 2015 – ‘**Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care.**’ In recognition of the ongoing discussion on euthanasia and physician-assisted suicide, the Board of Directors of the European Association for Palliative Care (EAPC) commissioned this white paper from the palliative care (PC) perspective. This white paper aims to provide an ethical framework for PC professionals on euthanasia and physician-assisted suicide. It also aims to provide an overview on the available evidence as well as a discourse of ethical principles related to these issues. Starting from a 2003 EAPC position paper, 21 statements were drafted and submitted to a five-round Delphi process. A panel with 17 experts commented on the paper in round 1. Board members of national PC or hospice associations that are collective members of EAPC were invited to an online survey in rounds 2 and 3. The expert panel and the EAPC board members participated in rounds 4 and 5. This final version was adopted as an official position paper of the EAPC in April 2015. Main topics of the white paper are concepts and definitions of PC, its values and philosophy, euthanasia and physician-assisted suicide, key issues on the patient and the organizational level. The consensus process confirmed the 2003 EAPC white paper and its position on the relationship between PC and euthanasia and physician-assisted suicide.¹ The EAPC feels it is important to contribute to informed public debates on these issues. Complete consensus seems to be unachievable due to incompatible normative frameworks that clash. <http://pmj.sagepub.com/content/early/2015/11/18/0269216315616524.abstract>
- 1. ‘The euthanasia debate and a new position paper from a Task Force of the European Association for Palliative Care: A helpful reappraisal or a retreat into obfuscation?’ *Palliative Medicine*, 2003;17(2):92-93. <http://pmj.sagepub.com/content/17/2/92.full.pdf+html>
- **PATIENT EDUCATION & COUNSELING** | Online – 16 November 2015 – ‘**Nursing staff and euthanasia in The Netherlands: A nation-wide survey on attitudes and involvement in decision making and the performance of euthanasia.**’ The majority [of respondents] (83%) state that physicians have to discuss the decision about euthanasia with the nurses involved. Besides, 69% state that a physician should discuss a euthanasia request with nurses who have regular contact with a patient. Nursing staff who have religious or other beliefs that they consider important for their attitude towards end-of-life decisions, and staff working in a hospital or home care, are most likely to have this opinion. Being present during the euthanasia is quite unusual: only a small group (7%) report that this has ever been the case in their entire working life. Seven % (incorrectly) think they are allowed to administer the lethal drugs. [http://www.pec-journal.com/article/S0738-3991\(15\)30121-X/abstract](http://www.pec-journal.com/article/S0738-3991(15)30121-X/abstract)

Cont.

- *PSYCHOLOGY, PUBLIC POLICY & LAW*, 2015;21(4):420-431. **‘What patient and psychologist characteristics are important in competency for physician-assisted suicide evaluations?’** In an effort to identify important characteristics of patients and clinicians involved in evaluations of competence to request physician-assisted suicide (PAS), 216 licensed psychologists from Oregon and Montana were surveyed regarding their attitudes toward PAS and their personal and professional experiences with suicide. Cognitive ability, as indicated by a question regarding the importance of cognitive ability and components of competence that rely on reasoning skills, was the only patient factor that significantly predicted competence decisions. Results also suggested that personal characteristics of clinicians, particularly whether someone in their personal life had ever attempted suicide and their willingness to support a family member’s choice of PAS, influence their decision regarding the competence of the patient. Exploratory analyses also revealed that clinicians consider perceived burdensomeness to be of little importance when conducting a competence evaluation for PAS. <http://psycnet.apa.org/journals/law/21/4/420/>

Media Watch: Editorial Practice

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Something Missed or Overlooked?

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

Barry R. Ashpole
Guelph, Ontario CANADA

‘phone: 519.837.8936
e-mail: barryashpole@bell.net