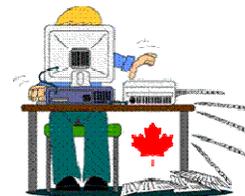


Media Watch...

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

Decision-making in “murky waters”: Scroll down to [Specialist Publications](#) and ‘Clarifying the best interests standard: The elaborative and enumerative strategies in public policy-making’ (p.13) in *Journal of Medical Ethics*.

Canada

Palliative care: The elephant in the room in the assisted dying debate

GLOBAL TV NEWS | Online – 6 June 2016 – A recent report from the Canadian Cancer Society paints a grim picture of access across the country.¹ With no federal guidelines, most provinces have developed their own strategies, leading to a patchwork of care. Despite many investments in recent years, the availability, accessibility and quality of care still depend on where you live. Quebec is the only province that has passed a law guaranteeing end-of-life care for the terminally ill. The consequence? The majority of gravely ill Canadians are dying in emergency rooms. With an aging population, experts say we simply can't afford the status quo. With politicians and pundits in Ottawa focussed on medically assisted dying legislation, there is frustration that the urgent need for palliative care (PC) is being ignored. Experts told a special parliamentary committee on assisted dying that Canadians can't make a true choice to end their lives without access to quality PC. The organization representing Canada's PC physicians is calling for a Palliative Care Secretariat and a National Palliative & End-of-Life Care Strategy,

as well as more research. While all three major political parties agree Canadians need access to quality PC no matter where they live, they have yet to work together to make it happen. <http://goo.gl/j8RgQz>



1. 'Right to Care: Palliative care for all Canadians,' Canadian Cancer Society, December 2015. [Noted in Media Watch, 18 January 2016, #445 (p.1)] <http://goo.gl/f3iFEB>

Cont.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC | Online – 11 June 2016 – ‘**Assisted dying legal gap leaves pharmacists, nurses in limbo.**’ As the Senate wrestles with new legislation around medically assisted death, physicians are protected against criminal prosecution, but the situation is less clear for the pharmacists and nurses they need to help them carry out the procedure. <http://goo.gl/ZOjl4>
- *THE ANGLICAN JOURNAL* | Online – 10 June 2016 – ‘**Church report accepts physician-assisted dying as new reality.**’ In a nod to changing times, the Anglican Church of Canada’s latest report on physician-assisted dying, rather than opposing the practice, recognizes it as a reality. The report offers reflections and resources around assisted dying and related issues, such as palliative care. <http://goo.gl/4TlkCf>
 1. ‘In Sure and Certain Hope Resources to Assist Pastoral and Theological Approaches to Physician Assisted Dying,’ The General Synod of the Anglican Church of Canada. <http://goo.gl/PHnbsK>
- *THE NATIONAL POST* | Online – 10 June 2016 – ‘**Strong majority of Canadians want assisted suicide bill to allow for “advance consent”:** poll.’ Canadians are strongly in support of both physician-assisted death and allowing people to request suicide before they become too ill to do so. A Forum Research survey ... defined advance consent as “when someone leaves explicit legal instructions for their assisted death in the event they become incompetent and can’t make their wishes known themselves.” <http://goo.gl/2LGKqH>
- ONTARIO | *The National Post* – 10 June 2016 – ‘**Ontario hospitals allowed to opt out of assisted dying, raising conscientious accommodation concerns.**’ Ontario will allow hospitals to opt out of providing assisted death within their walls, provoking charges from ethicists that conscientious accommodation has gone too far. <http://goo.gl/ccFHhp>
- ALBERTA | *The Globe & Mail* – 7 June 2016 – ‘**Alberta rules out prosecutions for assisted death medical teams.**’ Alberta has told prosecutors and police that no member of medical teams involved in an assisted death for mentally competent, severely ill adults will be prosecuted, the clearest attempt by any province to create certainty around the newly legalized practice. <http://goo.gl/qgw6vo>
- *THE HILL TIMES* (McGill University) | Online – 7 June 2016 – ‘**Without C-14 on the books, Canada will have the most open death hastening culture in the world.**’ Given how diverse and polarized the opinions are, trying to land on a perfect Bill – or as some have opined, “getting it right” – is like trying to achieve unison when everyone is singing from a different score. <http://goo.gl/fALS3>
- *THE CANADIAN PRESS* | Online – 6 June 2016 – ‘**In absence of federal law, a look at assisted-death guidelines across Canada.**’ The Colleges of Physicians & Surgeons in every province and one of three territories have issued guidelines that doctors must follow in providing medical assistance in dying. <http://goo.gl/4yGrmV>
- CTV NEWS | Online – 6 June 2016 – ‘**Provincial regulations insufficient on assisted dying.**’ Health Minister Jane Philpott is telling health care providers ... that provincial guidelines and regulations on doctor-assisted dying do not provide enough clarity and protection to those who may now be asked to help their patients die. <http://goo.gl/Pd5h0Y>
- *THE GLOBE & MAIL* | Online – 6 June 2016 – ‘**In absence of federal law, assisted dying enters era of uncertainty.**’ The legalization of assisted death enters a new era ... marked by conflicting approaches by provinces and uncertainty for patients and doctors that could take days or even months to resolve. <http://goo.gl/Tcj7Qj>
- ONTARIO | CBC News (Toronto) – 6 June 2016 – ‘**Ontario to create referral service, provide drugs at no cost for assisted dying.**’ Ontario’s health minister says the province will ensure that drugs for medically assisted dying will be available at no cost. Eric Hoskins also says the province will establish a referral service that will connect physicians unwilling or unable to provide medically assisted dying with those who are willing to complete a patient’s consultation and assessment on the matter. <http://goo.gl/fK4GMw>

U.S.A.

Can family caregivers reduce hospital costs?

FORBES | Online – 10 June 2016 – There are lots of ways to figure what caregiving is worth. For example, you could calculate what it would cost if all those family caregivers were paid market rates for the personal care they provide. American Association of Retired Persons' figures the economic value of family care could be as much as \$470 billion annually. Or you could try to calculate the lifetime financial sacrifice of a daughter who abandons her career to help a relative. By one estimate, the lifetime cost to a 50-something woman who quits her job to care for an aging parent can be as much \$300,000 in lost wages and retirement benefits. Here is another way to measure the value of family caregiving: By providing badly needed support for

relatives living at home, can the care provided by family members cut health care costs by, say, reducing emergency room visits and hospitalizations? If they could, they'd not only improve the well-being of those they are helping, but they may also save government a significant amount of health care dollars. <http://goo.gl/wzkWeC>

Specialist Publications

'Characteristics of decedents in Medicare Advantage and traditional Medicare' (p.13), in *JAMA Internal Medicine*.

Related

- *THE NEW YORK TIMES* | Online – 9 June 2016 – 'Finding ways to keep patients at home.' When we talk about advance directives (ADs) and reducing costly and unnecessary treatment at the end of life, we should also be talking about ways we can provide more support. Those sorts of discussions are essential, but they're not enough. We also need to revise the way we think about ADs. ADs help reduce health care costs at the end of life by avoiding aggressive treatment, but that's not the most compelling argument for them. It's not enough to reduce what we spend on aggressive treatment at the end of life; we also need to spend those resources in better ways. <http://goo.gl/hA7QS9>

The space between mourning and grief

THE ATLANTIC | Online – 8 June 2016 – The way people mourn online has been the subject of much cultural comment recently, particularly in the wake of mass tragedies and high-profile celebrity deaths... Some argue that the likes of Facebook and Twitter have opened up public space for displays of grief that had been restricted to private spheres of secular culture. But rather than reconstructing an outlet for public grief, social media often reproduces the worst cultural failings surrounding death, namely platitudes that help those on the periphery of a tragedy rationalize what has happened, but obscure the uncomfortable, messy reality of loss. Social media has increased the speed and ease of communication to an unprecedented degree, and yet sites like Facebook and Twitter are

poorly suited to grief's strangeness. By design, social media demands tidy conclusions, and dilutes tragedy so that it's comprehensible even to those only distantly aware of what has happened. <http://goo.gl/VMUX9p>

Specialist Publications

'Is pedagogy of mortality a good approach to bereavement care' (p.13), in *European Journal of Palliative Care*.

'Attachment, empathy and compassion in the care of the bereaved' (p.12), in *Grief Matters: The Australian Journal of Grief & Bereavement*.

Cont.

Noted in Media Watch, 3 November 2014, #382 (p.13):

- *JOURNAL OF SOCIAL & PERSONAL RELATIONSHIPS* | Online – 21 October 2014 – ‘**Death on Facebook: Examining the roles of social media communication for the bereaved.**’ This study examines the ways in which the social networking site Facebook was helpful and unhelpful to participants when someone they knew died. Analysis revealed three themes describing participants’ experiences during bereavement: 1) News dissemination; 2) Preservation; and, 3) Community. <http://goo.gl/l2itxA>

Food & Drug Administration moves to speed access to compassionate-use drugs

NATIONAL PUBLIC RADIO | Online – 8 June 2016 – The Food & Drug Administration (FDA) has reduced an obstacle from its compassionate use policy, streamlining paperwork that physicians must submit to obtain experimental drugs for patients with life-threatening illnesses. Doctors will now file an application for FDA approval that contains just 11 questions, 15 fewer than the old form. The new form is simpler because it was designed for individual patients, replacing an all-purpose format that had been used by doctors acting on behalf of individuals or groups of patients. The policy is intended to help patients with incurable diseases who have tried all standard therapies and hope to extend their lives by taking experimental drugs not yet approved by the FDA... <http://goo.gl/3bXhUx>

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. Although the issue of rapid access to investigational agents is not new, the pace of requests has increased. <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. 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://goo.gl/JWjfyu>

The comfort of a humane, caring end of life

OREGON | *The Oregonian* (Portland) – 7 June 2016 – In the past few years, the once-toxic subject of dying has gone mainstream. The disinformation campaign about “death panels” collapsed. Medicare has just begun to pay doctors for time spent having conversations about end-of-life wishes. At the same time in Oregon, the first state to pass a Death with Dignity Act, only one out of every 500 deaths comes from doctor-ordered medication. So why are we spending so much political energy to help the one rather than the 499? The debate reminds me of the way we attack issues these days – like food fights. We ramp up controversies with opponents on either side, hurling opinions at each other. <http://goo.gl/2LHWpU>



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>

Terminally ill minors should have the right to refuse life-sustaining medical treatment: Creating specialized health care courts

THE NATIONAL LAW REVIEW | Online – 6 June 2016 – The question of whether a competent, terminally ill minor should have the right to refuse life-sustaining medical treatment (LSMT) is perhaps the most intimate, personal, and difficult decision a person could possibly face. While the concepts of physician-assisted suicide and euthanasia are undoubtedly taboo and controversial, especially in the context of minors, they are nevertheless salient public health, legal, and ethical issues that need to be addressed to reconcile the patchwork of legal and medical doctrines that currently define this subject. Recent judicial rulings, legislative developments, and public policy polls suggest that the U.S. is prepared to hold a serious conversation surrounding a patient's right to refuse LSMT. State legislatures have made significant progress in the Death with Dignity movement; however, minimal progress, if any, has been made on whether competent, terminally ill minors should also have the right to refuse LSMT. In response to this topical issue, this article examines the statutory and constitutional landscape surrounding a minor's right to refuse LSMT, and promulgates that the best method to address this issue is by creating specialized health care courts. <http://goo.gl/tvAJck>

Noted in Media Watch, 30 March 2015, #403 (p.4):

- *THE NEW YORK TIMES* | Online – 28 March 2015 – **'Facing early death, on their terms.'** When patients are under 18 and do not have legal decision-making authority, doctors have traditionally asked anguished parents to make advanced care choices on their behalf. More recently, providers have begun approaching teenagers and young adults directly, giving them a voice in these difficult decisions, though parents retain legal authority for underage patients. Studies show they prefer to be involved and have not been harmed by any such involvement. There are no firm estimates of the number of young patients facing life-threatening diseases at any given time. Cancer, heart disease and congenital deformities together account for an estimated 11% of deaths among adolescents, about 1,700 per year. <http://goo.gl/IL3rVi>

U.K. perspective on decision-making in end-of-life care and minors living with a terminal illness

- *BRITISH MEDICAL JOURNAL* | Online – 24 March 2015 – **'Involve children with life-limiting conditions in decisions to stop treatment, says new guidance.'** The views of children who have incurable and life-limiting conditions should be actively sought and considered in decisions on whether to continue life-prolonging treatment, says new guidance from the Royal College of Paediatrics & Child Health.¹ <http://goo.gl/eRIYhz>

1. 'Very sick children: Treatment at any cost? New framework to help doctors make tough decisions on end-of-life care,' The Royal College of Paediatrics & Child Health, March 2015. <http://goo.gl/tqoYQv>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | *The Los Angeles Times* – 9 June 2016 – **'What we know about physician-assisted death from Oregon, by the numbers.'** Oregon was the first state to allow patients with terminal illnesses to request medications that would end their lives. Though other states have since adopted similar laws, Oregon remains the best guide for what to expect in California when physician-assisted death becomes legal in the state... Here are some statistics about who has taken advantage of Oregon's aid-in-dying law since it took effect in 1998... <http://goo.gl/yuwrEi>

[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.17.

International

End-of-life care in Australia

Parliament of Victoria inquiry into end-of-life choices

AUSTRALIA (Victoria) | Palliative Care Victoria – 9 June 2016 – The 440-page report of the Legal & Social Issues Committee of the Victorian Legislative Council conveys the complexity of the issues under consideration. The report outlines 12 core values for end-of-life care (EOLC). These include: the value of every human life, open discussion about death and dying, the right to make informed choices, person-centred EOLC, alleviation of pain and suffering, addressing the needs of families and carers, palliative care (PC) is an invaluable and life-enhancing part of EOLC, high quality EOLC should be available in all settings, non-discrimination in access to care, support and protection of vulnerable people, coherent and transparent law, and law should be followed and enforced. Forty-nine recommendations are presented in the report, which covers three main sections: 1) Towards a community based approach to PC; 2) Improving advance care planning; and, 3) Legalising assisted dying. The report recognises the value of PC and makes 28 specific recommendations to strengthen PC and EOLC across Victoria. <http://goo.gl/XDOvF5>



Specialist Publications

'The role of advance care planning in end-of-life care for residents of aged care facilities' (p.9), in *Australian Journal of Advance Nursing*.

Noted in Media Watch, 20 April 2015, #406 (p.5):

- AUSTRALIA (Victoria) | *The Sydney Morning Herald* – 15 April 2015 – **'Palliative care services in Victoria overwhelmed: Auditor-General report finds.'** Dying people in Victoria are facing waiting lists of up to six weeks for specialist care to relieve their pain and suffering and many who want to die at home are not able to because palliative care services are overwhelmed, an audit has revealed.¹ <http://goo.gl/q3ZJd3>

1. 'Palliative Care,' Victorian Auditor-General Report, April 2015. <http://goo.gl/XAcDmQ>

Noted in Media Watch, 6 October 2014, #378 (p.7):

- AUSTRALIA (Victoria) | Grattan Institute (Melbourne) – September 2014 – **'Dying well.'** Despite widespread assumptions about the cost of end-of-life care, only about \$5-billion a year is spent on the last year of life for older people in a health budget of \$100-billion. But only about \$100-million is spent on helping people to die at home. <http://goo.gl/oGsqgT>

Lesbian, gay, bisexual and transgender people face “significant barriers” in end-of-life care, report finds

U.K. | *The Daily Mail* – 9 June 2016 – Some lesbian, gay, bisexual and transgender (LGBT) people fear they will be discriminated against by healthcare workers...¹ These fears are “not unwarranted,” the authors said, as they outlined cases of discrimination including one instance where a doctor would not treat a lesbian without a chaperone. They also outlined other issues such as dying people having to “come out”

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to each new healthcare worker they met. The report highlights a small poll of 237 LGBT people which found three-quarters were not confident that health and social care services provide them sensitive end-of-life care. One in four said they had experienced discrimination from health and social care professionals at some point in their lifetime. As a result, many people delay accessing the care they need and are more likely to experience unmanaged symptoms and pain at the end of their lives. <http://goo.gl/FjpsYN>

1. 'Hiding Who I Am,' Marie Curie, June 2016. <https://goo.gl/s7tMFq>

End-of-life care in Singapore

Almost 8 in 10 Singaporeans wish to die at home: Survey

SINGAPORE | AsiaOne – 8 June 2016 – A new study, commissioned by Lien Foundation, found that 77% of Singaporeans wish to die at home, but only 27% of Singaporeans do so. Of those who want to die at home, most said they would still choose to do so even if there was insufficient support from family, friends or medical professionals. The study, which polled more than 1,000 people for their views towards death and dying, also found that they wish to die affordably and not leave financial burdens behind. And it would help to have well-trained doctors and nurses guide them about hospice palliative care (HPC). They also want a platform to talk about death in the community, such as national conversations and public education on HPC to discuss issues on death and dying. <http://goo.gl/ob8fek>

Noted in Media Watch, 21 September 2015, #428 (p.12):

- **HEALTH POLICY** | Online – 11 September 2015 – **'Preferences for end-of-life care among community-dwelling older adults and patients with advanced cancer: A discrete choice experiment.'** Singapore is in the midst of several healthcare reforms in efforts to finance and deliver health services for a rapidly aging population. The primary focus of these reforms is to make healthcare services, including those at the end of life (EOL), affordable. Given the increasingly high health care costs at the EOL, policy makers need to consider how best to allocate resources. <http://goo.gl/N01Bof>

Noted in Media Watch, 29 June 2015, #416 (pp.5-6):

- SINGAPORE | AsiaOne – 25 June 2015 – **'Manpower crunch poses challenges for home hospice.'** There are 51 accredited specialists in palliative medicine in Singapore, but only an estimated 34 of them work full-time. This works out to less than one full-time palliative consultant per 100,000 people – less than half the ratio recommended by Palliative Care Australia. Adding to the strain is the distribution of resources... Most palliative care nurses and doctors are based in the hospitals or inpatient facilities. <http://goo.gl/PO7cNR>

It is cheaper and more compassionate to care for the dying out of hospital

U.K. | *The Daily Telegraph* – 7 June 2016 – It seems hardly a week goes by without the publication of a report into end-of-life care (EOLC) which makes for tough reading. The latest example of this growing trend, by the Care Quality Commission,¹ paints a grim picture of some of this country's most vulnerable people, such as those with dementia and learning difficulties, not being able to access good quality EOLC, with some being admitted to hospital wards against their wishes. Once there, it is increasingly difficult for them to leave – a new report from the National Audit Office found the number of vulnerable pensioners trapped in hospital beds had risen by a third in the past two years.² People dying in hospital when they would rather be at home is an enduring problem. Too many currently end their days in hospital because they are unable to receive the care they need at home, where the vast majority of people would prefer to die. This is partly happening because dying people's care is often not properly coordinated, with various parts of the National Health Service and social services lacking a common record of a dying person's needs and wishes. <http://goo.gl/91HVSj>

1. 'A Different Ending: Addressing Inequalities in End-of-Life Care,' Care Quality Commission, May 2016. [Noted in Media Watch, 16 May 2016, #462 (p.5)] <http://goo.gl/qbOL09>
2. 'Discharging older patients from hospital,' National Audit Office, May 2016. <https://goo.gl/Ki6puJ>

End-of-life care in Ireland

Palliative care patient “was left groaning in pain before death”

IRELAND | *The Journal* (Dublin) – 6 June 2016 – A new report has found that some patients in palliative care (PC) are being left in pain, while one family said trying to find out what services are available is like “dealing with the mafia.” The ... [report¹] ... found that 52% of PC users said they felt frustrated or helpless during the process. The survey includes the experiences of 528 PC service users and carers from across the island (419 in the Republic of Ireland and 109 in Northern Ireland). One woman described how her 63-year-old sister was left groaning in pain the night before she died as the doctor-on-call refused to call out to the hospice with the extra pain relief medicine required. Another carer described sitting with a patient for almost an hour during which there was a very strong smell of excrement as she had soiled herself, but not cleaned up. About 51% of respondents to the survey said their emotional and psychological needs were not met and 42% wanted better co-ordination of care or treatment. <http://goo.gl/hWtCi9>

1. ‘Let’s Talk About Palliative Care Survey Report,’ All Ireland Institute of Hospice & Palliative Care, April 2016. <http://goo.gl/5wz47l>

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

End-of-life care in Australia

The role of advance care planning in end-of-life care for residents of aged care facilities

AUSTRALIAN JOURNAL OF ADVANCE NURSING, 2016;33(4):26-34. This case study highlights the fact that advance care planning (ACP) is not routinely discussed with residents upon their entry to residential aged care facility (RACFs), and that this omission may, in consequence, have detrimental effects on the quality of life, and death, of the residents. The barriers to such discussions are becoming clear, and it would be beneficial to address these by investigating solutions to the obstacles, and requirements for further education and support of staff in RACFs in relation to ACP, its discussion, documentation, and implementation. Generally, alignment between the States/Territories’ requirements and documentation may resolve discrepancies. This, together with ready access to standardised procedural information and documents from a central source, is likely to reduce the confusion and uncertainty surrounding ACP expressed by professionals and patients alike. A systematic method for the practice of ACP, particularly in RACFs, is required for person centred

care to ensure the residents’ wishes are known and respected. This should include education for staff on initiating discussions with residents and their families, and the subsequent documentation of decisions reached. Furthermore, the development and implementation of a standardised form, including a forcing function, across these facilities would enhance this process. Support from professionals experienced in the practice of ACP, for example a clinical nurse consultant, may prove useful in initiating and reinforcing these practices. The feasibility of a designated expert employed in the community sector to regularly visit RACFs should therefore be investigated. <http://goo.gl/VtACuf>

Worth Repeating

‘Using the values-based history to fine-tune advance care planning for oncology patients’ (p.16), in *Journal of Cancer Education*.

Noted in Media Watch, 23 November 2015, #437 (p.8):

- *AUSTRALIAN HEALTH REVIEW* | Online – 16 November 2015 – ‘**Advance care planning in Australia: What does the law say?**’ 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. <http://goo.gl/Y1X5vl>

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Related

- *PALLIATIVE MEDICINE* | Online – 6 June 2016 – ‘**Process and impact of an advance care planning intervention evaluated by bereaved surrogate decision-makers of dialysis patients.**’ Two themes related to the process of Sharing Patient’s Illness Representations to Increase Trust (SPIRIT) were: 1) SPIRIT provided a welcome opportunity to think about and discuss topics that had been avoided, and 2) SPIRIT helped patients and surrogates to share their feelings. Four themes of the SPIRIT’s impact were as follows: 1) SPIRIT was an eye-opening experience, acquiring knowledge and understanding of the patient’s illness and end-of-life care; 2) SPIRIT helped strengthen relationships between patients and surrogates; 3) SPIRIT helped surrogates feel prepared during the time leading up to end-of-life decision-making; and, 4) SPIRIT helped surrogates have peace of mind during and after actual end-of-life decision-making. <http://goo.gl/M5huUJ>

Necessary but not yet sufficient: A survey of aged residential care staff perceptions of palliative care communication, education and delivery

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 10 June 2016 – The study reveals an ongoing need for staff palliative care (PC) education. Results suggest the development of an integrated model of care which draws on both hospice and aged residential care (ARC) staff expertise. A survey of clinical staff in 52 ARC facilities in 1 urban district health board was conducted... Only 199 (46.2%) of staff participants reported undertaking PC education. Nurses were more likely to have engaged in PC education in comparison with healthcare assistants... Participants who wanted further education preferred an interactive, hands-on applied education (13.9%) in comparison to short topic-specific sessions/seminars (6.5%) or lecture-based courses (7.7%). <http://goo.gl/emWMrq>

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 June 2016 – ‘**Assessment of a state-wide palliative care team training course: COMFORT communication for palliative care teams.**’ Interprofessional, hospital-based palliative care team members were competitively selected to participate in a two-day training using the COMFORT™ SM (Communication, Orientation and options, Mindful communication, Family, Openings, Relating, Team) Communication for Palliative Care Teams curriculum. Participants reported moderate communication effectiveness in their institutions, with the weakest areas being during bereavement and survivorship care. Participants taught an additional 962 providers and initiated institution-wide training for clinical staff, new hires, and volunteers. Team member training improved communication processes and increased attention to communication with family caregivers. <http://goo.gl/mUPBFF>

Palliative care in multiple sclerosis

CONTINUUM (American Academy of Neurology), 2016;22(3):943-946. Collaboration between the neurologist and palliative care team in the care of patients with severe demyelinating disease can result in improved patient care, and discussion of the complex ethical issues that arise when a patient expresses a wish to die may be rewarding for both patients and caregivers. <http://goo.gl/4qapkN>

N.B. Selected articles on the palliative care needs of people living with a neurodegenerative disorder are noted in the issue of Media Watch of 16 May 2016, #462 (p.8).

“The talk”: Discussing hospice care

CURRENT ONCOLOGY REPORTS | Online – 7 June 2016 – Referral of advanced cancer patients for hospice care is of growing importance for oncologists. Hospice care is high quality and high value care that can benefit the patient and family’s experience of living and dying with terminal cancer. We are challenged to become a part of the shift from hospice meaning “giving up” to hospice meaning “giving more, but differently.” The purpose of this report is to frame a communication approach that any oncologist can incorporate into his or her practice that will facilitate the timely referral of appropriate patients for hospice care. <http://goo.gl/UxHp4L>

Cont.

Related

- *CONTEMPORARY CLINICAL TRIALS* | Online – 1 June 2016 – ‘**The family communication study: A randomized trial of prospective pediatric palliative care consultation, study methodology and perceptions of participation burden.**’ 380 family members of 220 children ... were recruited... Most family participants were parents (86% control; 92% intervention) and female (66% both groups). Comments suggest that participation was beneficial by promoting reflection and self-awareness about stress, coping and resilience, and feeling cared for because the intervention and questionnaires focused on their own well-being. <http://goo.gl/NZhZbZ>

Approaches to end-of-life care: A comparison between the U.K. and Albania

FUTURE HOSPITAL JOURNAL (Royal College of Physicians), 2016;3(2):134-135. Changing the culture around how palliative care (PC) is viewed by patients and family members in Albania will take time. Education is needed for both health professionals and the general public if the philosophy of good PC, as seen in the U.K., is to be embedded within Albanian society. There is a low awareness of health issues in Albania and people do not have regular check-ups – only seeking help when they have a problem – and they often have to pay, as the public healthcare provision is limited. The PC services in Albania face enormous challenges if they are to embrace a philosophy of care that is truly person centred. Some of these challenges are being addressed... Clearly, there is a need for massive investment in the infrastructure of the health service in Albania and hopefully PC will feature as a priority in the country’s future health strategy. Albania can pride itself on the kind of family support and family values that are less common in the U.K., but on the other hand their attitudes towards terminal illnesses need to adapt to embrace the philosophy of PC as we know it in the U.K. <http://goo.gl/N77fqf>



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

Noted in Media Watch, 5 November 2012, #278 (p.10):

- *ADVANCES IN PALLIATIVE MEDICINE*, 2012;11(1):1-5. ‘**Perception and attitude toward end of life in Albania.**’ Most of the patients relatives, general public and health professionals [i.e., study participants] defined easy end of life as: 1) To be treated with dignity and respect; 2) Being auto-sufficient; 3) Living in a family environment; 4) Being close with friends and family members; and, 5) Living without pain and suffering. Most of physician don’t tell the truth to the cancer patients asserting that: 1) Families don’t allow them; 2) The low health culture among population affects their perception and attitude on this topic; 3) Communication issue have not been part of curricula; and, 4) Most of them are not trained on how to tell the truth. <https://goo.gl/eqXd0z>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 7 June 2016 – ‘**Ranking of palliative care development in the countries of the European Union.**’ The U.K. achieved the highest level of development (86% of the maximum possible score), followed by Belgium and The Netherlands (81%), and Sweden (80%). In the domain resources, Luxembourg, the U.K. and Belgium were leading. The top countries in vitality were Germany and the U.K. In comparison to 2007, The Netherlands, Malta and Portugal showed the biggest improvements, whereas the positions of Spain, France and Greece deteriorated. The ranking method permitted a comparison of palliative care development between countries and shows changes over time. Recommendations for improving the ranking include improvements to the methodology and greater explanation of the levels and changes it reveals. <http://goo.gl/B3G4Ya>

Cont.

- *PALLIATIVE MEDICINE* | Online – 8 June 2016 – ‘**Lay and professional stakeholder involvement in scoping palliative care issues: Methods used in seven European countries.**’ Different stakeholder involvement methods were used successfully to identify key issues in palliative care. A total of 23 issues common to three or more countries informed decisions about the intervention and comparator of interest, sub-questions and specific assessments within the health technology assessment. <http://goo.gl/y2p2Ky>

Relatives’ presence during cardiopulmonary resuscitation

GLOBAL HEART | Online – 3 June 2016 – A total of 1,286 Argentine physicians and 1,848 physicians from other countries responded to this voluntary survey. The survey found that 23% (296) of Argentine and 20% of other respondents favor the presence of family members during cardiopulmonary resuscitation. This practice was more common among physicians treating pediatric and neonatal patients than among those who treat adults. The most commonly reported reason (21.8%) for avoiding the presence of relatives was concerns that physicians, communications, and medical practices might be misunderstood or misinterpreted. <http://goo.gl/RHyyKE>

Related

- *PLOS ONE* | Online – 2 June 2016 – ‘**Family presence during resuscitation: A qualitative analysis from a national multicenter randomized clinical trial.**’ Family presence can help to ameliorate the pain of the death through the feeling of having helped to support the patient during the passage from life to death and of having participated in this important moment. The authors’ results showed the central role of communication between the family and the emergency care team in facilitating the acceptance of the reality of death. <http://goo.gl/oqpMpk>

Selected articles on relatives’ presence during cardiopulmonary resuscitation

- *CIRCULATION: CARDIOVASCULAR QUALITY & OUTCOMES* | Online – 24 March 2015 – ‘**Policies allowing family presence during resuscitation and patterns of care during in-hospital cardiac arrest,**’ Hospitals with an family presence during resuscitation policy generally have no statistically significant differences in outcomes and processes of care as hospitals without this policy... [Noted in Media Watch, 30 March 2015, #403 (p.6)] <http://goo.gl/WfiveSs>
- *YALE JOURNAL OF BIOLOGY & MEDICINE*, 2014;87(1):63-72. ‘**Family presence during resuscitation: Attitudes of Yale-New Haven hospital staff.**’ One topic that should be affected by the patient- and family-centered care paradigm is family presence during resuscitation, which continues to be a highly debatable topic with no widespread implementation. [Noted in Media Watch, 17 March 2014, #349 (p.16)] <http://goo.gl/tHvl59>
- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 March 2013 – ‘**Family presence during cardiopulmonary resuscitation.**’ Family-witnessed CPR did not affect resuscitation characteristics, patient survival, or the level of emotional stress in the medical team, and also did not result in medico-legal claims. [Noted in Media Watch, 18 March 2013, #297 (p.4)] <http://goo.gl/o6tNL7>

Attachment, empathy and compassion in the care of the bereaved

GRIEF MATTERS: THE AUSTRALIAN JOURNAL OF GRIEF & BEREAVEMENT, 2016;19(1):20-25. Neuroscience research has extended our understanding of how early attachment experiences effect brain development and may become reactivated in times of challenge, such as illness and bereavement. Professional caregivers have their own early childhood attachment experiences, which may also become activated. Empathy and compassion are crucial in professional caregivers. Neuroscience research has helped with understanding the difference between empathy and compassion in the brain. It has been suggested that what is called compassion fatigue is in fact empathic distress. This article questions whether the early and later attachment experiences of professional caregivers may leave them more open to empathic strain and empathic distress in the care of the bereaved and discusses interventions that are proving to be of help in developing compassionate practitioners. <https://goo.gl/82sfG3>

Cont.

Related

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(3):146-148. **'Is pedagogy of mortality a good approach to bereavement care.'** There are various theories of grief informing different models of good bereavement care and what it should be aiming for. Pedagogy of mortality suggests that the aim of bereavement care could be to support grievors in developing a meaningful sense of need for active preparation for future deaths, including one's own.

N.B. Access to this article requires a subscription to the journal. Contents page: <http://goo.gl/XfHTo0>

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

Characteristics of decedents in Medicare Advantage and traditional Medicare

JAMA INTERNAL MEDICINE | Online – 6 June 2016 – Approximately 25% of all Medicare expenditures are for care received in the last year of life. Much research has been done to understand cost and utilization patterns for Medicare beneficiaries at the end of life (EOL). However, when assessing EOL costs, most studies focus on decedents with traditional fee-for-service (FFS) Medicare owing to the lack of cost and utilization data for the 30% of Medicare beneficiaries in Medicare Advantage (MA) plans. This gap is a cause for concern because utilization and quality of care may differ between MA and FFS beneficiaries. The authors sought to examine differences in characteristics of decedents in MA and FFS Medicare based on detailed survey data. <http://goo.gl/9oqPAi>

Developing a typology for peer education and peer support delivered by prisoners

JOURNAL OF CORRECTIONAL HEALTH CARE | Online – 7 June 2016 – Peer interventions delivered for prisoners by prisoners offer a means to improve health and reduce risk factors for this population. This paper presents a typology developed as part of a systematic review of peer interventions in prison settings. Peer interventions are grouped into four modes: 1) Peer education; 2) Peer support; 3) Peer mentoring; and, 4) Bridging roles, with the addition of a number of specific interventions identified through the review process. The paper discusses the different modes of peer delivery with reference to a wider health promotion literature on the value of social influence and support. In conclusion, the typology offers a framework for

developing the evidence base across a diverse field of practice in correctional health care. <http://goo.gl/t7ddro>

Extract from *Journal of Correctional Health Care* article

Prison hospices were described as being based on a concept of providing a “decent prison,” which entailed maintaining terminally ill prisoners’ humanity and dignity. Prison hospice volunteers worked within a wider multi-disciplinary team to provide companionship, practical assistance, and social and emotional support to terminally ill patients.

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of the articles, reports, etc., noted in past issues of the weekly report can be downloaded at the Palliative Care Community Network website: <http://goo.gl/qgd4hp>

Clarifying the best interests standard: The elaborative and enumerative strategies in public policy-making

JOURNAL OF MEDICAL ETHICS | Online – 6 June 2016 – One recurring criticism of the best interests standard concerns its vagueness, and thus the inadequate guidance it offers to care providers. The lack of an agreed definition of “best interests,” together with the fact that several suggested considerations adopted in legislation or professional guidelines for doctors do not obviously apply across different groups of persons, result in decisions being made in murky waters. In response, bioethicists have attempted to specify the best interests standard, to reduce the indeterminacy surrounding medical decisions. In this paper, the authors discuss the bioethicists’ response in relation to the state’s possible role in clarifying the best interests standard. <http://goo.gl/UDkLPt>

Cont.

Selected articles on determining patient “best interests” in the context of end-of-life care

- *JOURNAL OF MEDICAL ETHICS* | Online – 16 June 2015 – ‘**Patients, doctors and the good life (for the patient).**’ An earlier acceptance of the physician as the decision-maker at the bedside relied on the premise that, among those at the bedside, the physician was most likely to be a person of practical wisdom. The premise was that, in the welter of medical and non-medical considerations, the doctor was the most likely to pick out the best available option for the patient, the option that would best advance the patient’s interests. [Noted in Media Watch, 22 June 2015, #415 (p.11)] <http://goo.gl/DF9Vy4>
- *END OF LIFE JOURNAL* | Online – 10 April 2015 – ‘**Assessing best interests in end-of-life care for a patient in a minimally conscious state.**’ This article discusses the case of *Aintree University Hospitals National Health Service Foundation Trust (Respondent) vs. James (Appellant)* [2013] and the approach taken by the Court of Protection and the Court of Appeal in applying the Mental Capacity Act 2005 when assessing whether withholding life-sustaining treatment is ever in a person’s best interests. [Noted in Media Watch, 13 April 2015, #405 (p.8)] <http://goo.gl/yNlkmC>
- *DISABILITIES STUDY QUARTERLY*, 2014;34(4). ‘**Determining “best interests” in end-of-life decisions for the developmentally disabled: Minnesota state guardians and wards.**’ The authors review the legal cases, legislative statutes, and professional standards that guide public guardians in deciding whether to begin, continue, or withdraw or withhold life-sustaining medical treatment from their wards. [Noted in Media Watch, 26 January 2015, #394 (p.10)] <http://goo.gl/4dHs36>

How well do we understand health care professionals’ perceptions and needs in the provision of palliative care? A mixed methods study

JOURNAL OF PALLIATIVE MEDICINE | Online – 10 June 2016 – Despite palliative care (PC) being standard for patients with chronic and/or life-limiting conditions, a perceived lack of clarity regarding the definition and scope of PC persists. Although critical care health care professionals (HCPs) scored symptom management and patient/family interaction items more highly compared with other HCPs, mean scores for both groups (surveyed) indicated participants lacked confidence to perform this aspect of care independently. Critical care HCPs were more comfortable caring for dying patients and talking to families about death. Ward HCPs were more supportive of early referral to PC. Cancer diagnoses were overestimated as common causes of death. Education needs focused on ethical issues, end-of-life communication skills, dealing with delirium, and use of the Liverpool Care Pathway. Key themes identified from the four focus groups were: 1) Delays or non-referral to PC created considerable stress and feelings of inadequacy despite a perceived understanding of the broader definition of PC; and, 2) HCPs commonly focused on end-of-life care. Ambiguity regarding the meaning and delivery of PC persists in the acute care setting across disciplines. Results confirmed that innovative approaches to education and upskilling HCPs in PC and referral pathways is warranted. <http://goo.gl/Nft2QU>

Which public health approach to palliative care? An integrative literature review

PROGRESS IN PALLIATIVE CARE | Online – 9 June 2016 – Public health and palliative care (PC) are both broad disciplines with blurred boundaries. There is growing support for an alignment of PC to public health. Given the novel nature of this alignment and the ambiguity of the parent definitions, there is an understandable lack of clarity around this merged model. The aim of this study is to describe the theoretical features of the public health approach to PC as articulated in the current research literature. The search identified 18 studies. A thematic synthesis of these studies identified three different paradigms of a public health approach to PC within the current empirical research. These were defined as a health-promotion approach focused on empowerment at community level, a World Health Organisation approach which focused on systems at country level, and a population-based approach which typically viewed PC issues from an epidemiological perspective. This review highlights that the public health approach to PC is understood in various ways. It is important that future research studies clarify which public health approach they are referring to. <http://goo.gl/4EGYB0>

Cont.

Selected articles on a public health approach to end-of-life care

- *PROGRESS IN PALLIATIVE CARE* | Online – 6 July 2016 – ‘**Public health approaches to palliative care: The progress so far.**’ This article discusses four broad questions often asked about the public health approach to palliative care (PC): 1) What is the evidence for the effectiveness of the approach?; 2) Will this approach embedded inside PC services deliver the kinds of social changes needed to address the social epidemiology of living with life-limiting illness, long term caregiving and grief and bereavement?; 3) Is recent interest in this approach simply all about cost-savings for governments?; and, 4) Will an emphasis on health promotion and community development subtract from efforts to increase or maintain clinical supports at the end of life? [Noted in Media Watch, 11 January 2016, #444 (p.13)] <http://goo.gl/OQmVbh>
- *PALLIATIVE MEDICINE* | Online – 12 August 2015 – ‘**The impact of a new public health approach to end-of-life care: A systematic review.**’ Interest is building regarding the application of a public health approach to those facing the end of life, their families and communities. Three themes emerged: 1) Making a practical difference; 2) Individual learning and personal growth; and, 3) Developing community capacity. [Noted in Media Watch, 17 August 2015, #423 (p.17)] <http://goo.gl/Yqtvds>
- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 22 February 2013 – ‘**Public health approaches to end-of-life care in the U.K.: An online survey of palliative care services.**’ Of those providers [i.e., respondents] 60% indicated that public health approaches to death, dying and loss were a current priority for their organisation. The findings demonstrate the relevance of a public health approach for palliative care services and how they are currently engaging with the communities they serve. [Noted in Media Watch, 4 March 2013, #295 (p.11)] <http://goo.gl/x38FN7>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BMJ OPEN* | Online – 7 June 2016 – ‘**Research priorities relating to the debate on assisted dying: What do we still need to know? Results of a modified Delphi technique.**’ This consultation revealed a number of important uncertainties around the debate on assisted dying and end-of-life issues more broadly. Eighty-five unique research questions were suggested by a broad range of interested parties with high levels of topic expertise. Research questions with the highest levels of consensus were predominantly concerned with understanding how and why people make end-of-life decisions, and which factors influence those decisions. Dissemination of these findings alongside a focused examination of the existing literature may be the most effective way to bring objective research evidence into the ongoing debate around assisted dying. <http://goo.gl/CSyANW>
- *JOURNAL OF THE ASSOCIATION OF PHYSICIANS IN INDIA*, 2016;64:44-47. ‘**Doctor’s attitudes towards euthanasia: A cross-sectional study.**’ Euthanasia will never be easy, but the attitude of the major stakeholders becomes important when the nation is yet to formulate policy guidelines in the matter. The present study reveals that despite euthanasia being illegal in the country, there is a section of doctors who view it to be justified in the face of intractable suffering and terminal illness. However, the majority of them have reservations regarding its misuse if legalized. The fact that they have been asked for euthanasia by the patients or relatives also indicates that the public are also getting aware and finding the concept acceptable. <http://goo.gl/kiYvsl>

N.B. A recent issue of the *Indian Journal of Medical Ethics*, noted in Media Watch of 8 February 2016, #448 (p.14), includes several articles which offer insights into the complexities of end-of-life care in India from an ethical, legal and medical perspective against the backdrop of the country’s healthcare system and the inequities in access to healthcare. Contents page (scroll down to ‘Theme: Healing & Dying with Dignity’): <http://goo.gl/O2k0pa>

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 June 2016 – ‘**Multi-ethnic attitudes toward physician-assisted death in California and Hawaii.**’ As aid-in-dying laws are gaining more public acceptance and support, it is important to understand diverse perceptions toward physician-assisted death (PAD). The authors compare attitudes of residents from California and Hawaii to identify variables that may predict attitudes toward PAD. This study shows that in the ethnically diverse states of California and Hawaii, faith/religion/spirituality and age are major influencers of attitudes toward PAD and not ethnicity and gender. Even in the subgroups least supportive of PAD, the majority supports PAD. <http://goo.gl/SjUwzV>

Worth Repeating

Using the values-based history to fine-tune advance care planning for oncology patients

JOURNAL OF CANCER EDUCATION | Online – 16 January 2010 – One approach to discussing advanced care planning (ACP) involves the use of a values history (VH). The VH focuses on questions related to overall health, personal relationships, and independence, as well as symptoms and facilitates communication with the patient and allows the patient to express their view. This approach is less threatening to patients and does not force the patient into thinking that they need the right answer. Values-based directives are less intrusive on a doctor's skill in making appropriate clinical decisions. They ask questions that require no technical skill and are easily done by other members of the health-care team. Compared to medicalized advance directives (ADs), VH are less subject to the objections of not being clearly established at the time of their writing, or applicable in the circumstances that subsequently arise as in this case. They can help to validate preferences about treatment and indicate appropriate courses of action that were not, or could not, be covered by traditional ADs alone. <http://goo.gl/D6tOcl>

N.B. Sample values history form (Health Sciences Center Institute for Ethics, University of New Mexico): <http://goo.gl/33UQSm>

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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2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Media Watch: Palliative Care Network-e Website

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

[Media Watch: Online](#)

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/hhrU3g>

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

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

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

Asia

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

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

Canada

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

Europe

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

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

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

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