

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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Goals of care: Scroll down to [Specialist Publications](#) and 'Patient self-defined goals: Essentials of person-centered care for serious illness' (p.6), in *American Journal of Hospice & Palliative Medicine*.

Canada

Gladu's private member's bill set for third reading...

ONTARIO | *The Sarnia Observer* – 22 March 2017 – A private member's bill [C-277] introduced in [the federal] Parliament by Sarnia-Lambton [Conservative] MP Marilyn Gladu took another step this week to becoming a law.¹ A House of Commons committee voted to support the bill providing for development of a national framework for palliative care (PC). It is expected to return to the House in April for third reading. If the bill passes third reading in the House, and is then adopted by the Senate, it will become law. According to Health Canada, PC provides patients who have life-threatening or serious illness with care that can improve quality of life, reduce or relieve physical and psychological symptoms, have a more peaceful and dignified death, while also supporting their family and

those who cared for them. The bill should provide "some clarity about what services the government is prepared to fund, across the country, and to figure out how to get access for those," Gladu said. It will also look at collecting data on PC. <https://goo.gl/eVunV5>

[Specialist Publications](#)

'Levels of intervention: How are they used in Quebec hospitals?' (p.10), in *Journal of Bioethical Inquiry*.

'Healthcare and end-of-life needs of lesbian, gay, bisexual, and transgender older adults: A scoping review' (p.8), in *Geriatrics*.

1. Bill C-277, 'Framework on palliative care in Canada.' <https://goo.gl/9cnCNk>

Related

- ONTARIO | My West Nipissing (Sturgeon Falls) – 23 March 2017 – **'Hughes lobbies for better hospice palliative care coverage.'** There's a push in the House of Commons to have the Canada Health Act cover hospice palliative care (PC). Carol Hughes, who represents Algoma-Manitoulin-Kapuskasing, is making the pitch for the wider coverage. Hughes says people in PC have to deal with a lot as they get closer to death. She says their loved ones also have a lot on their plate. The New Democrat says the wider coverage would make matters a little easier for everyone involved. The request to include hospice PC under the health act is in a petition Hughes gave fellow MPs. <https://goo.gl/sxuDAr>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | *The Toronto Star* (Quebec Bureau) – 24 March 2017 – ‘**Quebec considers assisted death for dementia patients**’ Quebec’s health minister says the province will consider allowing people to make advance requests for assisted suicide, which would allow people with Alzheimer’s disease and dementia to access to the medical procedure. Gaetan Barrette told reporters that he is forming an expert group to consider expanding the criteria under Quebec’s pioneering euthanasia law, which came into force in December 2015. The province will also ask the courts to clarify a section of the federal assisted suicide law, which states that the procedure should only be available to those whose deaths are “reasonably foreseeable.” Barrette said the lack of definition around this term poses a “major problem” for health professionals asked to administer the procedure by patients. <https://goo.gl/P4IAQi>

Noted in Media Watch 22 February 2016, #450 (p.2):

- *THE GLOBE & MAIL* | Online – 16 February 2016 – ‘**A dignified death for dementia patients: Who makes that call?**’ The idea [to allow for people diagnosed with dementia to make a request for assisted death ahead of time] is compelling, at least superficially. After all, no one relishes the thought of gradually losing their memory, their intellect, their ability to function independently. Shouldn’t we be able to end it all? Practically though, letting someone choose to die at some undetermined future date is perilous, both legally and ethically. <http://goo.gl/Z57M5z>
- *THE NATIONAL POST* | Online – 20 March 2017 – ‘**Doctors harvesting organs from Canadian patients who underwent medically assisted death.**’ Doctors have already harvested organs from dozens of Canadians who underwent medically assisted death, a practice supporters say expands the pool of desperately needed organs, but ethicists worry could make it harder for euthanasia patients to voice a last-minute change of heart. In Ontario, 26 people who died by lethal injection have donated tissue or organs since the federal law decriminalizing medical assistance in dying, or MAiD, came into effect last June... A total of 338 have died by medical assistance in the province. Most of the 26 were tissue donors, which usually involves eyes, skin, heart valves, bones and tendons. Bioethicists and transplant experts say people who qualify for assisted dying deserve to be offered the chance to donate their organs. <https://goo.gl/9By6xt>

U.S.A.

Palliative care linked to fewer repeat hospitalizations

FOX NEWS | Online – 24 March 2017 – Comfort care for advanced cancer patients is associated with fewer repeat hospitalizations and more hospice referrals, according to a study highlighting how this approach may offer chronically sick or terminally ill people a better quality of life.¹ Researchers focused on terminal cancer patients who often end up receiving a lot of care during their final months of life; all were already hospitalized for serious medical issues. The study team tested what happened to these patients before and after the start of a new palliative care (PC) consultation program in the hospital. PC aims to improve quality of life for seriously ill patients by relieving their symptoms and easing their stress. <https://goo.gl/zbvqS7>

1. ‘Standardized criteria for palliative care consultation on a solid tumor oncology service reduces downstream health care use,’ *Journal of Oncology Practice*, published online 17 March 2017. [Noted in Media Watch 20 March 2017, #504 (p.11)] <https://goo.gl/i9Ah1U>

Level of hospice care equal across types of facilities

UNITED PRESS INTERNATIONAL | Online – 23 March 2017 – A study found only slight differences in the intensity of hospice services between nursing homes, assisted living centers and in-home care.¹ Researchers from the Indiana University Center for Aging Research and the Regenstrief Institute analyzed data from more than 32,600 men and women in 18 states who received routine hospice care between 2009 and 2015. “It has been a concern that patients who live in nursing homes or assisted living facilities may be getting potentially less hospice care than people receiving hospice care at home,” Dr. Kathleen Unroe, assistant professor of medicine at the IU School of Medicine, said. “We found that not to be the case. However, while the intensity of hospice services across settings was quite similar, people living at home were more likely to get more hospice nurse care, while those living in nursing homes or in assisted living facilities received more hospice aide care across hospice episode.” <https://goo.gl/u83MWv>

1. ‘Variation in hospice services by location of care: Nursing home versus assisted living facility versus home,’ *Journal of the American Geriatrics Society*, published online 14 March 2017. [Noted in Media Watch 20 May 2017 #504 (p.10)] <https://goo.gl/PWewbN>

Center for end-of-life care experiences record year

WEST VIRGINIA | *The Intelligencer* (Wheeling) – 21 March 2017 – The West Virginia Center for End-of-Life Care experienced a record year in 2016, with more than 80,000 advance directive and medical order forms distributed and more than 20% of those dying in the state having a form filed with the center. Data show that for 2016, nearly half of people who participated in the registry died at home, compared to 36% of all deaths in the state. For those who participated in the registry the percentage of individuals dying in the hospital was half that of those who did not... <https://goo.gl/lpiy5C>

Yale study: End-of-life planning often not well communicated

CONNECTICUT | *The New Haven Register* – 20 March 2017 – Older adults are not doing a good job of letting their loved ones know of their end-of-life (EoL) wishes, according to a Yale School of Medicine study.¹ The study found both that too many people fail to make plans for EoL medical treatment and fail to communicate their wishes clearly. In the best circumstances, a person making decisions about what kind of medical treatment he or she would prefer as they approach death would choose a surrogate to make sure those wishes are carried out. However, too often, even when advance plans are made, they are not communicated well to the surrogate. The survey found that more than 40% of the veterans and their surrogates [who were interviewed] agreed that advanced care planning either had not been done, through a living will or health care proxy, or that the surrogates were not clear

about the veterans’ wishes. And only 20% of surrogates could say what the veteran’s EoL decisions were. <https://goo.gl/IMDtE1>

Specialist Publications

‘Speaking a different language: A qualitative analysis comparing language of palliative care and pediatric intensive care unit physicians’ (p.6), in *American Journal of Hospice & Palliative Medicine*.

‘Specific words and experience matter to surrogates when making end-of-life decisions’ (p.7) in *Health Communications*.

‘New penalties for ignoring advance directives and do-not-resuscitate orders’ (p.10), in *Journal of Clinical Ethics*.

1. ‘Engagement in advance care planning and surrogates’ knowledge of patients’ treatment goals,’ *Journal of the American Geriatrics Society*, published online 20 March 2017. <https://goo.gl/F38hEH>

Cont.

Selected articles on surrogate decision makers in the context of end-of-life care

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2016;316(1):35-37. **‘Strategies to support surrogate decision makers of patients with chronic critical illness: The search continues.** Surrogate decision makers for patients with chronic critical illness face challenging decisions about whether to continue life-prolonging treatments given uncertain outcomes. A growing body of research indicates that surrogates often experience symptoms of depression, anxiety, and post-traumatic stress in the months following the intensive care unit admission of a family member. [Noted in Media Watch 11 July 2016, #470 (p.15)] <http://goo.gl/NuAyQh>
- *ANNALS OF AMERICAN THORACIC SOCIETY* | Online – 4 August 2015 – **‘Prior advance care planning is associated with less decisional conflict in surrogates for the critically ill.’** In this study moderate or high levels of decisional conflict were present in 48% of the 471 surrogates representing 257 patients. Surrogates who had engaged in prior advance care planning (ACP) conversations had significantly lower levels of decisional conflict compared to those who had not. This suggests the scope of benefit of ACP may extend beyond respecting patients’ wishes to also ameliorate the burden placed on patients’ loved ones who act as surrogates. [Noted in Media Watch 10 August 2015, #422 (p.11)] <https://goo.gl/7GP4Wy>
- *CRITICAL CARE MEDICINE* | Online – 6 January 2015 – **‘How clinicians discuss critically ill patients’ preferences and values with surrogates: An empirical analysis.’** In a third of 71 intensive care unit (ICU) family conferences recorded for patients at high risk of death, neither clinicians nor surrogates discussed patients’ preferences or values about end-of-life (EoL) decision making. In less than 12% of family conferences did participants address the values of high importance to most patients.. Interventions are needed to ensure patients’ values and preferences are elicited and integrated into EoL decisions in ICUs. [Noted in Media Watch 19 January 2015, #393 (p.9)] <https://goo.gl/32a8a6>

Changing demographics

More grandparents than ever

THE NEW YORK TIMES | Online – 20 March 17 – The number of grandparents in the U.S. rose to 69.5 million in 2014, up from 65.1 million in 2009...¹ The youngest baby boomers turned 50 in 2014, and the country’s 75.4 million boomers make up an exceptionally large pool of potential grandparents. The number of grandparents has grown by 24% since 2001. In 2001, there were an estimated 56.1 million grandparents. <https://goo.gl/f6xkcn>

1. ‘Current Population Report,’ U.S. Census Bureau, March 2017. (Scroll down to ‘Fertility Research Brief - census.gov.’) <https://goo.gl/k6zPN6>

Many seniors age without support system

OKLAHOMA | *Enid News* – 19 March 2017 – A recent study has raised awareness about the growing population of seniors who are aging without the benefit of a family support system. Increasing numbers of Americans are choosing to remain single and childless, creating new challenges for a health care system already stretched thin by the aging baby boomer population. Maria Toroella Carney, chief of geriatric and palliative medicine at North Shore-LIJ Health System, recently presented evidence ... that nearly one-quarter of Americans, age 65 or older, are in danger of becoming “elder orphans.” That estimate may be on the rise. According to U.S. Census data, approximately one-third of American adults age 45 to 63 are single, illustrating an increase of 50% since 1980. In a research article [published last year],¹ Carney introduces a series of questions designed to help physicians and other health care professionals screen patient populations and help identify those patients most at risk for falling into the category of elder orphan. <https://goo.gl/nBqUxI>

1. ‘Elder orphans, hiding in plain sight: A growing vulnerable population,’ *Current Gerontology & Geriatrics Research*, published online 12 July 2016. <https://goo.gl/6Nb8Db>

Cont.

Noted in Media Watch 12 December 2016, #491 (p.3):

- PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 2 December 2016 – ‘**Alone and aging: Creating a safety net for isolated seniors.**’ Phyllis Krantzman represents a universe that’s come to be known among geriatric specialists as “elder orphans” – seniors with no relatives to help them deal with physical and mental health challenges. Their rising numbers prompted the American Geriatrics Society this week to unveil guidelines for a segment of these older adults who can no longer make their own medical decisions and have no designated surrogates.¹ <https://goo.gl/Nlv5yG>

1. ‘Making medical treatment decisions for unbefriended older adults,’ *Journal of the American Geriatric Society*, published online 22 November 2016. [Noted in Medias Watch 28 November 2016, #489 (p.11)] <https://goo.gl/68dZQy>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- HAWAII | Associated Press (Honolulu) – 23 March 2017 – ‘**Hawaii lawmakers kill bill to offer medical aid in dying.**’ A bill to give terminally ill Hawaii residents medical help to end their lives has died. The House Committee on Health decided not to advance the proposal... Some lawmakers say the bill is flawed and there isn’t enough time to fix it before the legislative session ends in May. Hundreds testified for and against the measure. Supporters including cancer patients and those who saw loved ones suffer through drawn-out deaths say they want to have options to die peacefully. Critics raised concerns that ill people might choose suicide to relieve family burdens or choose death when there’s a chance of survival. <https://goo.gl/yPZkGH>
- ARIZONA | *Arizona Daily Sun* (Phoenix) – 21 March 2017 – ‘**Legislation would make it illegal to force health care entity to euthanize.**’ State lawmakers sent legislation ... to Governor Doug Ducey that proponents say will give additional protection to medical professionals and hospitals from having to help people die. SB 1439, approved by the House on a 32-24 margin, spells out it is illegal to discriminate against any health care entity because it does not provide or facilitate in providing any service that results in the death of the individual. That includes assisted suicide, euthanasia and mercy killing. The Senate already has approved the identical language. <https://goo.gl/U85GiW>

[Specialist Publications](#)

‘**Aid-in-dying laws and the physician’s duty to inform**’ (p.15), in *Journal of Medical Ethics*.

[International](#)

U.K. home care industry “on the brink of collapse,” says report

U.K. | *The Financial Times* – 20 March 2017 – The U.K.’s home care industry is “on the brink of collapse” with companies either going bankrupt or pulling out of contracts, according to a joint report by the Local Government Information Unit and one of the country’s biggest providers.¹ The industry has been hit by cuts to local authority budgets and the fees they pay, rises in the minimum wage, a shortage of trained nurses, and tougher immigration rules. The funding crisis is also causing problems in hospitals, with elderly patients occupying beds because they cannot be discharged for lack of social care. The report ... says the £2 billion of extra funding for social care over the next three years announced in the budget in March falls short of the much needed “wider systemic shift in the way home care is commissioned and delivered.” Home nursing care for the elderly and disabled was almost all managed and paid for by the state until the 1970s when it became one of the first parts of the healthcare service to be handed to the private sector. <https://goo.gl/1BQQTE>

1. ‘Paying for it: the human cost of cut-price care,’ Local Government Information Unit, March 2017. <https://goo.gl/qSI02u>

Cont.

Related

- U.K. | BBC News – 20 March 2017 – **‘Lack of money prompts care firms to end council contracts.’** Care firms have cancelled contracts with 95 U.K. councils, saying they cannot deliver services for the amount they are being paid... The Local Government Association said it was the result of “historic under-funding” and an ageing population. The figure for the number of cancelled contracts comes from a Freedom of Information request... <https://goo.gl/4ctEbN>

Noted in Media Watch 6 June 2016, #465 (pp.6-7):

- U.K. | *The Guardian* – 31 May 2016 – **‘Two years ago we called for reform in care homes. We’re still waiting.’** Last year, [Secretary of State for Health] Jeremy Hunt told a local government audience families should take more responsibility for the care of their loved ones. It was a statement that offended many and a recent Carers UK report makes plain why: the price paid, physically, psychologically and financially, is huge. Will there be enough good quality care to support those without families in their old age? One in four care homes could go bust within three years. Care home leaders lobbied the Department of Health about the continued squeeze on fees and warned the national living wage would lead to many care businesses struggling with cash flow and facing bankruptcy. <http://goo.gl/iyOqtO>

Specialist Publications

Patient self-defined goals: Essentials of person-centered care for serious illness

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 23 March 2017 – Movement from problem-oriented disease-specific care implying a desire to be fixed toward goal-oriented care based upon individual desires of health within all aspects of whole person has potential to improve or maintain quality of life when physical decline is inevitable. Research results demonstrate that patients express a diverse range of goals related to global aspirations and many facets of the whole person, which patients identify nonmedical goals as often as medical goals. Identification and consideration of medical, non-medical, multiple, and global goals of serious illness presents an opportunity to individualize assessments and care planning processes. Whole-person assessments realign disease-specific goals with views of well-being beyond physical health that have been shown to support broader psychosocial needs. Care planning and goals of care discussions including self-defined goals can assist in individualizing and setting context to established disease-specific guidelines and assist decision-making that more fully reflect current health status and psychosocial spiritual aspects of patients’ lives. Integrating nonmedical day-to-day living goals is especially relevant for serious illness to sustain a sense of hope and healing when physical decline, cure, or controlling a disease is no longer possible. <https://goo.gl/z7J2ew>

Speaking a different language: A qualitative analysis comparing language of palliative care and pediatric intensive care unit physicians

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 21 March 2017 – Family conferences in the pediatric intensive care unit (ICU) often include palliative care (PC) providers. We do not know how ICU communication differs when the PC team is present. Nine ICU physicians and 4 PC providers participated in 18 audio-recorded family conferences. Of the 9 transcripts without the PC team, the authors identified 526 ICU physician statements, generating 10 thematic categories. The most common themes were giving medical information and discussing medical options. Themes unique to ICU physicians included statements of hopelessness, insensitivity, and “health-care provider challenges.” Among the 9 transcripts with the PC team, there were 280 statements, generating 10 thematic categories. Most commonly, the PC team offered statements of support, giving medical information, and quality of life. Both teams promoted family engagement by soliciting questions; however, the PC team was more likely to use open-ended questions, offer support, and discuss quality of life. <https://goo.gl/yjiQnJ>

Cont.

Related

- *CARDIOVASCULAR BUSINESS* | Online – 22 March 2017 – ‘**Palliative care’s sobering question: Quality vs. quantity of life for heart failure patients.**’ Explaining to a patient with end-stage heart failure why palliative care (PC) may be a better option than curative or life-prolonging treatment is a conversation that even the most experienced cardiologists may dread. A survey of International Society of Heart Failure & Transplant members found that only 17% of clinicians felt they were “really well trained” to discuss the complexities of PC with their heart failure patients. <https://goo.gl/WX0uTT>
- *HEALTH COMMUNICATIONS* | Online – 17 February 2017 – ‘**Specific words and experience matter to surrogates when making end-of-life decisions.**’ This study investigated the relationship between end-of-life terminologies and decisional conflict ... in surrogate decision makers. Researchers simulated a situation in which people were asked to decide whether to provide or withhold cardiopulmonary resuscitation as end-of-life care for a loved one. Divided into two randomized groups, study participants received a survey packet that varied only in the phrases “Do Not Resuscitate (DNR)” and “Allow Natural Death (AND).” While the results revealed no difference in decisional conflict ... AND respondents perceived their decision as good and were eight times more likely to sign the document than DNR participants. <https://goo.gl/3iRq6Q>
- *JOURNAL OF HEALTH PSYCHOLOGY* | Online – 20 March 2017 – ‘**Patients with limited communication in end-of-life situations: Initial psychometric properties of a discomfort observation scale.**’ This work presents an observational scale which takes into account different observable indicators of discomfort of patients in end-of-life situations with difficulties in communicating due to cognitive impairment, fatigue or sedation and provides details of its validation. This study provides data regarding the properties of a discomfort assessment scale. Such a scale is needed and could be very useful for the evaluation of such patients and thus to attend to their needs. <https://goo.gl/4kZalp>

Potential predatory and legitimate biomedical journals: Can you tell the difference? A cross-sectional comparison

BMC MEDICINE | Online – 16 March 2017 – The Internet has transformed scholarly publishing, most notably, by the introduction of open access publishing. Recently, there has been a rise of online journals characterized as “predatory,” which actively solicit manuscripts and charge publications fees without providing robust peer review and editorial services. The authors carried out a cross-sectional comparison of characteristics of potential predatory, legitimate open access, and legitimate subscription-based biomedical journals. They identify 13 evidence-based characteristics by which predatory journals may potentially be distinguished from presumed legitimate journals. These may be useful for authors who are assessing journals for possible submission or for others, such as universities evaluating candidates’ publications as part of the hiring process. <https://goo.gl/OtwrGV>



N.B. Additional articles on “predatory journals” are noted in past issues of Media Watch, e.g., 30 January 2017, #497 (p.14); 23 January 2017, #496 (p.1); 9 January 2017, #494 (p.7); 19 December 2016, #492 (p.6); 5 December 2016, #490 (p.2); 5 September 2016, #478 (p.14); 30 May 2016, #464 (p.11); and, 11 April 2016, #457 (p.7).



[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>

End-of-life care in Germany

Critical attitudes and beliefs towards guidelines amongst palliative care professionals: Results from a national survey

BMC PALLIATIVE CARE | Online – 21 March 2017 – Little is known about palliative care (PC) professionals' attitudes towards guidelines. In 2015, the German Association for Palliative Medicine published an evidence based guideline for PC in adults with incurable cancer. Before publication the authors conducted a national survey among members of the association to detect possible barriers and facilitators for its implementation. The aim of the present publication is to evaluate critical attitudes and beliefs which could hinder the effective implementation of the new guideline and to evaluate differences within professional groups and medical specialisations. The person-centred and individual approach of PC does not seem to contradict the acceptance of guidelines. PC professionals' attitudes towards guidelines are similar to other medical disciplines. Main barriers were related to scepticism regarding the quality of guidelines and doubts about the implementation of guidelines in general. High quality of the PC guideline will be achieved through evidence and consensus based recommendations and a thorough development process as recommended by the Guidance for Guideline Development of the Association of the Scientific Medical Societies in Germany. The implementation of the PC guideline needs to be a multi-stage approach with publications, presentations, courses, use of quality indicators and discussions with relevant stake holders. <https://goo.gl/UeiNra>

Healthcare and end-of-life needs of lesbian, gay, bisexual, and transgender older adults: A scoping review

GERIATRICS | Online – 16 March 2017 – To some extent, our ability to draw inferences about the experience of lesbian, gay, bisexual, and transgender (LGBT) older adults across jurisdictions is limited given the current state of the literature. Continued research in this area is particularly timely given that several countries are experiencing a demographic shift and a movement towards inclusivity. This shift is noted through reports on LGBT aging and end of life released in the U.K. and Australia. Taking a life course perspective necessitates an understanding of the personal histories and historical context in which LGBT older adults are situated. In Canada, for example, major historical milestones aiming to guarantee equal civil liberties members of the LGBT community include the decriminalization of homosexuality in 1969 as well as the Civil Marriage Act in 2005, which allowed same-sex couples access to marriage. It is similarly important to note that the rights of trans individuals in Canada continue to lag behind those of other members of the LGBT community and vary considerably depending on jurisdiction. Undeniably, the experience of Canadian older LGBT individuals is unique relative to LGBT individuals residing in countries around the world. Thus, there is a gap in the literature on LGBT aging in Canada and, more precisely, the last stages of life. In order to better understand the experiences of LGBT older adults with respect to the last stages of life, more jurisdiction-specific research is needed as is a focus on the needs of the transgender community at the end of their lives. <https://goo.gl/VEyPch>

Noted in Media Watch 24 October 2016, #484 (p.7):

BMJ SUPPORTIVE & SUPPORTIVE CARE, 2016;6(3):388. **“What makes it worth the investment to say it?” – Care experiences of lesbian, gay, bisexual and/or trans people facing life-limiting illness: A qualitative interview study.** Five main themes emerged: 1) Palliative care needs that may require additional or different consideration for LGBT people; 2) Communicative or service level barriers and stressors, including heteronormative assumptions, and homophobic/transphobic behaviours; 3) Internalised or invisible barriers and stressors, including fears, or experiences, of discrimination; 4) Which shape individuals' preferences for disclosure and exploration of identity; and, 5) Communicative or service level facilitators to accessing care and support. <https://goo.gl/OELqVf>

N.B. Additional articles on end-of-life care for LGBT communities noted in Media Watch 23 May 2016, #463 (p.3) and 8 February 2016, #448 (p.16).

Mandatory basic life support training: Why NOT in India; Mandatory end-of-life care policy: Why NOT in India; Mandatory medical research requirements: Why SO in India!

INDIAN JOURNAL OF COMMUNITY HEALTH, 2017;1(1);1-3. – In the world of things and doings, mandatory is a human invention for the times when optional and free-will do NOT get things done. When quality of life gains momentum to catch on with the age-old run for quantity of life, the medical education, medical decision-making and medical policy-making do NOT leave an option for medical practitioners but to follow the mandate as required and warranted by society they cater for. The author reviews and discusses some of those potential mandates for practitioners of medicine from the perspective of a) a person who can be in the hot seat of a patient himself, b) a physician who can be caught in the dubious scenarios of treating patients similar to himself, and, c) a medical teacher-researcher who till recently as an inquisitive medical student was himself delving with similar questions for the system. In a nutshell, this is the author's perspective from my limited understanding that basic life support training and end-of-life care policy are in need for mandate to being made mandatory whereas medical research requirements are in need to be made optional without covert-overt penalties. <https://goo.gl/zRWp0w>

End-of-life care in Ireland

Funding provided for end-of-life sanctuaries

IRISH HEALTH | Online – 22 March 2017 – Eight hospitals around the country have received funding to create end-of-life (EoL) sanctuaries for patients and their families. The aim of this is to provide space and sanctuary to families as they go through very difficult times within the hospital setting. The eight hospitals have been granted almost €650,000 funding as part of the Irish Hospice Foundation and Health Services Executive's Design & Dignity Grants Scheme. Each hospital is also adding their own contribution, bringing the total investment to €1.07 million. The Design & Dignity project has been running since 2007 and its aim is to have an EoL sanctuary in every public hospital nationwide by 2021. <https://goo.gl/mOkte1>



N.B. The Design & Dignity project, Irish Hospice Foundation. <https://goo.gl/TeppDD>

Maintaining family life balance while facing a child's imminent death: A mixed methods study

JOURNAL OF ADVANCE NURSING | Online – 22 March 2017 – Parents [study participants] created an intimate lifeworld and a sense of normality for the child at home. They constantly balanced the family's lifeworld with the requirements and challenges posed by the outside world. This work exhausted parents. Parental "readiness" and social support drove end-of-life (EoL) care for children at home. Parents needed practical help with housekeeping and had negative experiences when dealing with insurance. In only 34.8% of cases was a child's EoL home care supported by a paediatric palliative care team. Paediatric EoL care at home is only feasible if parents make extraordinary efforts. If family-centred EoL home care is provided by a hospital-based paediatric palliative home care team, which includes paid housekeeping help and psychological support, parents needs could be better met. <https://goo.gl/V5NKTg>

Royal College of Nursing backs call for ringfenced child palliative care funds

NURSING TIMES | Online – 23 March 2017 – All elements of children's palliative care should be eligible for ring-fenced state funding, according to a charity.¹ The Royal College of Nursing backed the call from the charity that provides specialist emotional and practical support to families with children with a life threatening or terminal illness. The Rainbow Trust Children's Charity estimated it was saving public services at least £2 million every year through its work. However, the Trust noted that it only received 3% of its funding from the state – enough to fund only 11 days of support in a year. <https://goo.gl/JJ8d7E>

1. 'Hidden Savings: How Rainbow Children's Charity Saves Money for the Health and Social Care System,' Rainbow Trust Children's Charity, March 2017. <https://goo.gl/YiqZDe>

Levels of intervention: How are they used in Quebec hospitals?

JOURNAL OF BIOETHICAL INQUIRY | Online – 21 March 2017 – In order to promote better practices and communication around end-of-life (EoL) decision-making, several Canadian hospitals in the province of Quebec have developed a tool called “Levels of Intervention” (LOI). No work to date has been published demonstrating improvement since these forms were implemented. A retrospective study was undertaken of 299 charts of patients who had died in three Quebec hospitals with a LOI ordered. High compliance with the level of intervention ordered at the time of death was recorded, as well as high involvement of patient and/or family, demonstrating the efficiency of LOI in promoting respect for autonomy. Other results show delays in EoL care discussions in the course of the hospitalization. Only a small proportion of patients who died had a palliative care consultation, which may reflect equity issues in access to care. This study highlights the importance of the LOI in Quebec and the role it is playing in respect for EoL preferences as well as in the involvement of patients and families in the decision-making process. Training specific to EoL decision-making conversations would help support the LOI form’s use, as would developing provincial or national guidelines on the use of LOI to standardize organizational policies and practice around EoL care. <https://goo.gl/EineQG>

New penalties for ignoring advance directives and do-not-resuscitate orders

JOURNAL OF CLINICAL ETHICS, 2017;28(1). Patients in the U.S. have been subject to an ever-growing “avalanche” of unwanted medical treatment. This is economically, ethically, and legally wrong. As one advocacy campaign puts it: “Patients should receive the medical treatments they want. Nothing less. Nothing more.” First, unwanted medical treatment constitutes waste (and often fraud or abuse) of scarce healthcare resources. Second, it is a serious violation of patients’ autonomy and self-determination. Third, but for a few rare exceptions, administering unwanted medical treatment contravenes settled legal rules and principles. This legal briefing describes a central and growing role for the law. Specifically, courts and agencies have increasingly imposed penalties on healthcare providers who deliberately or negligently disregard advance directives and do-not-resuscitate orders. <https://goo.gl/eeEnyt>

Complicated grief: A evolving theoretical landscape

JOURNAL OF COUNSELING & DEVELOPMENT | Online – 16 March 2017 – The bereavement literature has proliferated in recent decades, generating a shift from conceptualizing grief as a stepwise, uniform process to an idiosyncratic experience that varies among individuals. Among the most notable developments is the empirical exploration of complicated grief – a protracted, debilitating, sometimes life-threatening response to the death of a loved one – and the testing of novel interventions to treat it. This article provides counselors with recommendations for identifying and treating complicated grief. <https://goo.gl/dWy9bu>

Noted in Media Watch 3 October 2016, #482 (p.11):

- *WORLD PSYCHIATRY*, 2016;15(3):266-275. “**Prolonged grief disorder**” and “**persistent complex bereavement disorder**,” but not “**complicated grief**,” are one and the same diagnostic entity: An analysis of data from the Yale Bereavement Study.’ There exists a general consensus that prolonged grief disorder, or some variant of, represents a distinct mental disorder worthy of diagnosis and treatment. Nevertheless, confusion remains over whether different names and proposed symptom criteria for this disorder identify the same or different diagnostic entities. <https://goo.gl/GksBNx>

Noted in Media Watch 23 February 2015, #398 (p.3):

- U.S.A. | *The New York Times* – 16 February 2015 – ‘**When grief won’t relent.**’ Most often, within six months of a death, survivors adjust and are more or less able to resume usual activities, experience joy, and remember their loved ones without intense pain. But sometimes, even when the loss is neither sudden nor unexpected survivors close to the deceased can experience extremely disruptive grief reactions that persist far longer. In a recently published report Dr. Katherine Shear presents a composite portrait of what is known as complicated grief.¹ <http://goo.gl/4xXSZs>

1. ‘Complicated grief,’ *The New England Journal of Medicine*, 2015;372(2):153-160. <http://goo.gl/HT35IP>

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

Factors driving live discharge from hospice: Provider perspectives

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 18 March 2017 – The proportion of patients disenrolling from hospice prior to death has increased over the decade with significant variations across hospice types and regions. Such trends have raised concerns about live disenrollment's effect on care quality. Live disenrollment may be driven by factors other than patient preference and may create discontinuities in care, disrupting ongoing patient-provider relationships. The objective of this study was to ascertain provider perspectives on key drivers of live discharge from the Medicare hospice program. Analysis [of semi-structured telephone interviews] generated four themes: 1) Difficulty estimating patient prognosis; 2) Fear of Centers for Medicare & Medicaid Services audits; 3) Rising market competition; and, 4) Challenges with inpatient contracting. Participants emphasized challenges underlying each decision to discharge patients alive, stressing there often exists a grey line between "appropriate" and "inappropriate" discharges. Discussions also focused on scenarios in which financial motivations drive enrollment and disenrollment practices. <https://goo.gl/x3Fa8J>

Noted in Media Watch 5 December 2016, #490 (p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 November 2016 – '**Events leading to hospital-related disenrollment of home hospice patients: A study of primary caregivers' perspectives.**' Approximately 25% of hospice disenrollments in the U.S. occur as the result of hospitalization, which can lead to burdensome transitions and undesired care. Four major themes contributing to hospitalization emerged: 1) Distressing/difficult-to-witness signs and symptoms; 2) Needing palliative interventions not deliverable in the home setting; 3) Preference to be cared for by non-hospice physicians or at a local hospital; and, 4) Caregivers not comfortable with the death of their care recipient at home. <https://goo.gl/4qWXhA>

Related

- *CARING FOR THE AGES*, 2017;18(3):20. '**Dying for dollars.**' The headline read, 'How tens of thousands of patients who weren't actually dying wound up on hospice care.'¹ The reason, according to this article, was that "hospice companies earn more by recruiting patients who aren't actually dying." As a result of this revelation, the Office of Inspector General "has investigated and is investigating hundreds of hospice fraud schemes."² I must ask: What is the purpose here? To raise concerns in the public mind about whether palliative medical care and the hospice movement are a sham? To create doubt that they are just another way the medical-industrial complex has found to squeeze money from dying patients – who are not, after all, really dying? During my early years in medicine, optimal end-of-life care – palliative medicine and hospice – was not routinely available. It is instructive to briefly review the history of such care, something our legislators and regulators probably haven't taken the time to do. <https://goo.gl/HJCxeX>

1. 'How tens of thousands of patients who weren't actually dying wound up on hospice care,' The Washington Post, 15 September 2016. <https://goo.gl/CaZqkT> [Noted in Media Watch 19 September 2016, #480 (p.1).
2. 'Medicaid Fraud Control Units Fiscal Year 2015 Annual Report,' Office of Inspector General, Department of Health & Human Services, September 2016. [Noted in Media Watch 19 September 2016, #480 (p.1). <https://goo.gl/3pdBoH>



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.

Hospice and palliative care policy in Korea

KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE, 2017;20(1):8-17. Korea has implemented a hospice and palliative care (HPC) policy as part of a cancer policy under the 10 year plan to conquer cancer and a comprehensive measure for national cancer management. A legal ground for the HPC policy was laid by the Cancer Control Act passed in 2003. Currently in the process is legislation of a law on the decision for life-sustaining treatment for HPC and terminally-ill patients. The relevant law has expanded the policy-affected disease group from terminal cancer to cancer, human immunodeficiency virus/acquired immune deficiency syndrome, chronic obstructive pulmonary disease and chronic liver disease/liver cirrhosis. Since 2015, the National Health Insurance (NHI) scheme reimburses for HPC with a combination of the daily fixed sum and the fee for service systems. By the provision type, the HPC is classified into hospitalization, consultation, and home-based treatment. Also in place is the system that designates, evaluates and supports facilities specializing in HPC, and such facilities are funded by the NHI fund and government subsidy. Also needed along with the legal system are consensus reached by people affected by the policy and more realistic fee levels for HPC. The public and private domains should also cooperate to set HPC standards, train professional caregivers, control quality and establish an evaluation system. A stable funding system should be prepared by utilizing the long-term care insurance fund and hospice care fund. <https://goo.gl/A3NrEL>

N.B. Journal contents page: <https://goo.gl/enhK2F>

N.B. South Korea was ranked 18th of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015. Commissioned by the Lien Foundation of Singapore. [Noted in Media Watch 12 October 2015, #431 (p.6)] <http://goo.gl/bT3PV5>

Using social exchange theory to understand non-terminal palliative care referral practices for Parkinson's disease patients

PALLIATIVE MEDICINE | Online – 22 March 2017 – A palliative approach is recommended in the care of Parkinson's disease patients; however, many patients only receive this care in the form of hospice at the end of life. Physician attitudes about palliative care (PC) have been shown to influence referrals for patients with chronic disease, and negative physician perceptions may affect early palliative referrals for Parkinson's disease patients. Participants [in this cross-sectional survey study of neurologists] reported significantly stronger endorsement of the rewards ... of PC referrals than the costs... Physicians may be more likely to refer patients to non-terminal PC if 1) They work in interdisciplinary settings and/or 2) previous personal or patient experience with PC was positive. They may be less likely to refer if 1) they fear a loss of autonomy in patient care, 2) they are unaware of available programs, and/or 3) they believe they address palliative needs. Initiatives to educate neurologists on the benefits and availability of non-terminal palliative services could improve patient access to this care. <https://goo.gl/f9l0ic>

Noted in Media Watch 27 February 2017, #501 (p.8):

- *JOURNAL OF PARKINSONISM & RESTLESS LEGS SYNDROME* | Online – 20 February 2017 – 'Palliative care for patients with Parkinson's disease: An interdisciplinary review and next step model.' The complex and extensive patient and caregiver needs warrant a dedicated clinic to provide the necessary interdisciplinary care. In contrast to a typical model where the neurology clinician refers the patient to various ancillary treatment groups resulting in multiple separate clinic visits, the interdisciplinary model supports direct communication between the different disciplines during the clinic visit, allowing for a more coordinated response that takes into account multiple perspectives. Such an interdisciplinary model has been utilized in neurologic disorders with complex end-stage disease needs, such as amyotrophic lateral sclerosis with notable improvement in quality of life and survival. <https://goo.gl/ZiCMJm>

N.B. Click on [Download Article \[PDF\]](#) to access complete text. Additional articles on palliative care for people living with Parkinson's disease are noted in past issues of Media Watch, e.g., 28 November 2016, #489 (p.6); and, 11 April 2016, #457 (p.12).

End-of-life care in Croatia

Development of palliative medicine in Pozesko-Slavonska County

RADOVI ZAVODA ZA ZNANSTVENI I UMJETNIČKI RAD U POŽEGI | Online – Accessed 21 March 2017

– Although the first hospice department in Croatia was founded in Požega in 1991, there has been no real development of palliative care (PC) and medicine since. Apart from insufficient funds, the geographic specificity and isolation of the Požega-Slavonia County, and the deficit of medical doctors and other trained health professionals are additional problematic issues concerning the development of PC in this County. The County has entered demographic aging, with indications of further aging. For an adequate development of PC, a positive policy of the Ministry of Health and maximal involvement of the local policy makers are needed. Therefore, a County Commission for Palliative Care has been formed. The Commission should as soon as possible adopt a strategic plan for the development of PC and coordinating centres for PC, mobile teams and outpatient ambulances, and counselling centres for PC, without overloading the County budget. The Church, as an institution playing an important role in the life and society of the Požega-Slavonia County, should be integrated in this development process, with both its experience and its capacities. It is further necessary to sensitise and involve the civil sector and nongovernmental organizations, which are essential for the development of PC. During this process, it is obligatory to educate and supervise the implementation of the activities of the civil sector, and to respect the scientific and professionally-based multidisciplinary standards in the implementation. Sustainable development and permanent financing will certainly depend on the capabilities of the local community, yet humanitarian collecting of the funds and sustainable long-term project funding by the European Union are also needed. The overall goal is the realization of equal development and the implementation of equal access to health services in all parts of the Republic of Croatia. <https://goo.gl/3TPZA0>



N.B. Croatian language article.

Noted in Media Watch 26 January 2015, #394 (p.7):

- *WELFARE SOCIETY TERRITORY* | Online – 19 January 2015 – **‘Where the terminally ill die without palliative care.’** For the terminally ill in Croatia, there is no public healthcare. The situation is so bad that some patients are left without food or water in their homes, dying in excruciating pain. This is the dramatic reality denounced by the Croatian Association for Palliative Medicine, which is calling for a drastic sea change. <https://goo.gl/0YFQdn>

Noted in Media Watch 16 July 2012, #262 (p.11):

- *MEDICINA FLUMINENSIS*, 2012;48(2):131-141. **‘Palliative care in Croatia on the threshold of entering the European Union: Medical-legal and medical-ethical review.’** Recommendations from the European Association for Palliative Care prove the flaw in the Croatian system of palliative care (PC), with special emphasis on the need to prompt establishment of a national health policy of PC. <https://goo.gl/tDJLb7>



Closing the Gap Between Knowledge & Technology

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

End-of-life care in Singapore

Death among elderly patients in the emergency department: A needs assessment for end-of-life care

SINGAPORE MEDICAL JOURNAL, 2017;58(3):129-133. Elderly patients with serious chronic diseases often present to the emergency department (ED) in the last moments of their life, many with identifiable trajectories of dying: organ failure, advanced cancer and chronic frailty. These patients and their families may benefit more from good end-of-life care (EoLC) provision than the standard resuscitative approach. This study aimed to determine the incidence and nature of death among patients aged ≥ 65 years in an ED, and characterise their trajectories of dying. In one year, 197 patients aged ≥ 65 years died in the ED, 51.3% of whom suffered from serious chronic illnesses, with identifiable trajectories of dying. Of these patients, 46.5% had pre-morbid functional limitation with KPS scores of 0-40. However, only 14.9% of patients had a pre-existing resuscitation status and 74.3% received aggressive resuscitative measures. There is a significant burden of EoLC needs among elderly patients in the ED. Many of these patients have chronic illness trajectories of dying. This study underscores the need for improvement in EoLC provision for dying patients and their families in the ED. <https://goo.gl/KRe4eM>

Noted in Media Watch 13 February 2017, #499 (p.6):

- *ANNALS OF EMERGENCY MEDICINE* | Online – 3 February 2017 – ‘**The association of community-based palliative care with reduced emergency department visits in the last year of life varies by patient factors.**’ Emergency department (ED) use increases significantly toward the end of life. Numerous studies have reported that community (home)-based palliative care (PC) for people with life-limiting conditions is associated with reduced use of acute care health services. Although multidisciplinary PC has been demonstrated to reduce acute care service use, not all use of the ED is unwarranted. <https://goo.gl/C296Ey>

Noted in Media Watch 5 December 2016, #490 (p.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 30 November 2016 – ‘**“They shouldn’t be coming to the ED, should they?”: A descriptive service evaluation of why patients with palliative care needs present to the emergency department.**’ There is no international agreement on which patients are best cared for in the emergency department (ED), compared to the primary care setting or direct admission to the hospital. Findings of this single centre study challenge the misconception that patients known to a palliative care team should be cared for outside the ED. <https://goo.gl/qQL7qS>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BIOETHICS UPDATE* | Online – 20 March 2017 – ‘**A proposal for a shared care plan at the end of life: The Natural Death Protocol.**’ Recent evidence has highlighted that many patients still receive overtreatment or inappropriate support to face dying in all its complexity. These scenarios may increase thoughts of death that often occur during the course of terminal illnesses requiring prompt and adequate interpretations and interventions. This suggests the need for a change in treating dying patients along with a clear understanding of the root causes of requests for euthanasia. The authors propose a protocol for a shared end-of-life care plan aimed at ensuring a quality accompaniment toward natural death. <https://goo.gl/pY31IG>
- *EUROPEAN JOURNAL OF INTERNAL MEDICINE* | Online – 20 March 2017 – ‘**Commitment to life and the right to die.**’ Repeated polling by Gallup has found since 1973 majorities in favor of legal doctor-assisted dying, with widespread preference for state regulation and disfavor for any patient/doctor’s private agreement to quietly increment pain relief to life-shortening doses. *The Economist* and Ipsos MORI have recently confirmed this attitude across Western Europe and the US. State legislations have proposed bills, some of which introduce a default presumption in patients lacking capacity in the absence of unambiguous evidence stating otherwise. <https://goo.gl/Flds9T>

Cont.

- *JOURNAL OF MEDICAL ETHICS* | Online – 21 March 2017 – ‘**Aid-in-dying laws and the physician’s duty to inform.**’ On 19 July 2016, three medical organisations filed a federal lawsuit against representatives from several Vermont agencies over the Patient Choice & Control at End of Life Act. The law is similar to aid-in-dying (AID) laws in four other U.S. states, but the lawsuit hinges on a distinctive aspect of Vermont’s law pertaining to patients’ rights to information. The lawsuit raises questions about whether, and under what circumstances, there is an ethical obligation to inform terminally ill patients about AID as an end-of-life option. Much of the literature on clinical communication about AID addresses how physicians should respond to patient requests for assisted dying, but neglects the question of how physicians should approach patients who may not know enough about AID to request it. The author examines the possibility of an affirmative duty to inform terminally ill patients about AID in light of ethical concerns about professional responsibilities to patients and the maintenance of the patient–provider relationship. <https://goo.gl/izhiaU>

- *NEUROLOGY* | Online – 17 March 2017 – ‘**Physician-assisted death in chronic neurologic diseases.**’ In the U.S., a growing number of states have legalized physician-assisted death (PAD) since Oregon’s pioneering law 20 years ago. PAD is also and more accurately called physician-assisted suicide. Currently, nearly 20% of U.S. citizens live in jurisdictions in which PAD is lawful (Oregon, Washington, Montana, Vermont, California, Colorado, and the District of Columbia). In Canada in 2016, federal legislation permitted PAD for patients with a “serious and incurable illness, disease, or disability” that causes intolerable suffering and as a result of which death was “reasonably foreseeable.” <https://goo.gl/5gNkq5>

[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.

Worth Repeating

The parallels with human end-of-life care

Veterinary hospice and palliative care: A comprehensive review of the literature

VETERINARY RECORD, 2016;178(15):369-374. The death of a pet is a universal experience for those who share their lives with animals. In parallel with a rising interest in palliative medicine, hospice care and advance care planning within human medicine, increasing attention is currently being given to serious illness and death within veterinary medicine. Our ability to prolong life has created the need for thoughtful end of life discourse. Interest in hospice and palliative care (PC) for companion animals is on the rise, yet there has been limited scholarly research in these areas to date. This review concludes that veterinary hospice and PC is currently hindered by an inadequate amount of scholarly research to guide clinicians. Given a lack of prospective studies in veterinary hospice and PC to date, a significant opportunity exists for veterinary teaching institutions to contribute to the literature in an important and growing field. [Noted in Media Watch 11 April 2016, #457 (p.14)] <https://goo.gl/CxowcL>

Media Watch: Online

International

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

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

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

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

Asia

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

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

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <https://goo.gl/IOSNC7>

Europe

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

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

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

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