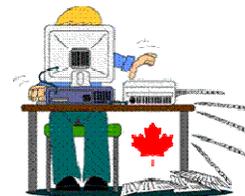


Media Watch...

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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Compilation of Media Watch 2008-2017 ©

Compiled & Annotated by Barry R. Ashpole

Expertise vs. intuition: Scroll down to [Specialist Publications](#) and 'Clinical decision making in the recognition of dying: A qualitative interview study' (p.7) in *BMC Palliative Care*.

Canada

Overhaul of seniors' care needed: Report

BRITISH COLUMBIA | *Tri-City News* (Port Coquitlam) – 25 January 2017 – The provincial government needs to hire more staff and upgrade infrastructure at seniors' homes, a care providers' group says. The BC Care Providers Association released its annual report calling for an immediate and serious investment of \$300 million over the next five years.¹ The group hopes the federal government will chip in the same amount. "Only 29% of British Columbians believe that seniors' care will be there when they need it," CEO Daniel Fontaine told reporters at a news conference in Burnaby. More than 90% are already feeling the crunch, Fontaine added, as part of the "sandwich generation" – people who care for both children and parents. The report said the funding would go toward training, staff time, better infrastructure, and new models of care, and would mean more direct attention for seniors in residential care and double the minimum home care visit to 30 minutes. Currently, 13% of all acute care beds in the province are being used by patients that should be in other levels of care. <https://goo.gl/nA2cUc>

Recommendations in the BC Care Providers Association report include...

"That the BC government support the adoption of new palliative/end-of-life care (EoLC) models and, where necessary, provide new funding to improve the integration between continuing and EoLC."

[Specialist Publications](#)

'Reconciling tensions: Needing formal and family/friend care, but feeling like a burden' (p.8), in *Canadian Journal on Aging*.

'Compassionate communities and their role in end-of-life care' (p.12), in *University of Ottawa Journal of Medicine*.

'Predatory journals: Do not enter' (p.14), in *University of Ottawa Journal of Medicine*.

1. 'Strengthening Seniors Care: A Made-in-BC Roadmap,' BC Care Providers Association, January 2017. <https://goo.gl/z4iTBG>

N.B. Manitoba's Office of the Auditor General recently released its report, 'Future of Home Care Services in Manitoba.' The authors acknowledge that the province's palliative care program remains separate, but "with a close linkage to home care services" (see 'Individuals Receiving Palliative Care,' pp.49-50). <https://goo.gl/3pNgrQ>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | CBC News (Calgary) – 23 January 2017 – **‘Medically assisted deaths could save millions in health care spending: Report.’** New research suggests medically assisted dying could result in substantial savings across Canada’s health-care system.¹ Doctor-assisted death could reduce annual health-care spending across the country by between \$34.7 million and \$136.8 million... The savings outweigh the estimated \$1.5 to \$14.8 million in direct costs associated with implementing medically assisted dying. “The take-away point is that there may be some upfront costs associated with offering medical assisted dying to Canadians, but there may also be a reduction in spending elsewhere in the system and therefore offering medical assistance in dying to Canadians will not cost the health care system anything extra,” said Aaron Trachtenberg, an author of the report and a resident in internal medicine at the University of Calgary. <https://goo.gl/p8mLFm>

1. ‘Cost analysis of medical assistance in dying in Canada,’ *Canadian Medical Association Journal*, 2017;189(3):e101-e105. <https://goo.gl/niDmNY>

U.S.A.

Changes to hospice halted Norwich project

CONNECTICUT | *The Bulletin* (Norwich) – 27 January 2017 – The prospect of unsustainable operating deficits and changes in the hospice care landscape prompted the halt of a project to build a 12-room hospice facility in Norwich, its backers said. The Center for Hospice Care ... said it “reluctantly” canceled its plans to build the \$7.5 million facility, which was announced last May and which, officials said, had close to \$6 million in funding raised. A change in how patients want to receive hospice care was in part the cause of this week’s decision.... A study recently released by the National Hospice & Palliative Care Organization cites a 66% drop in the numbers of general inpatient patients across the nation...¹ Southeast Connecticut has seen a 35% drop in such patients in the last year... <https://goo.gl/G1O0UL>

1. National Hospice & Palliative Care Organization, 2015 Edition. <https://goo.gl/2y7q2N>

Related

- ILLINOIS | *Jacksonville Journal Courier* – 28 January 2017 – **‘Woodhaven Hospice closing its doors.’** Woodhaven Volunteer Hospice & Special Support Services, a not-for-profit organization that has been serving the terminally ill in Morgan and Scott counties since 1989, is closing... “The main reason ... is because we have fewer patients,” Woodhaven board President Terry Maggart said. “We have fewer patients due to the fact that hospitals today receive money back for hospice care. When we were formed, Woodhaven was an all-volunteer hospice.” <https://goo.gl/YD2nLA>

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>

Oncologists could improve prognosis communication: Study

COLORADIO | United Press International – 24 January 2017 – Researchers from the University of Colorado Anschutz Medical Campus found that accurate prognosis of incurable cancer is vital to end-of-life decision making.¹ The study looked at 64 doctor-patient conversations regarding cancer prognosis at four major academic medical centers and found that both patients and doctors tend to avoid end-of-life discussions regarding terminal cancer diagnosis. “It was surprising – at all four of these medical centers, the conversations that oncologists had with their patients tended to follow the same pattern,” Dr. Sarguni Singh, oncology hospitalist at the University of Colorado Cancer Center and author of the study, said in a press release. “They would discuss symptoms, then the oncologist would reveal scan results often followed by an immediate transition to talking about the next steps for treatment. What’s often missing is a discussion of what the scan results mean.” The research was part of a large, multi-site cancer clinical trial and an average of 50% of the conversations regarding a negative diagnosis centered around treatment options. Researchers

found that just 10% of the conversations were about scan results, and there were only four instances where oncologists discussed prognosis with patients. <https://goo.gl/4OaCnv>

Specialist Publications

‘Internet search query analysis can be used to demonstrate the rapidly increasing public awareness of palliative care in the U.S.’ (p.13), in *BMJ Supportive & Palliative Care*.

‘Addressing the palliative setting in advanced lung cancer should not remain a barrier: A multi-centre study’ (p.11), in *Clinical Lung Cancer*.

‘Tailoring palliative care to the changing needs of people facing cancer’ (p.10), in *Journal of Clinical Oncology*.

‘Death of family members as an overlooked source of racial disadvantage in the U.S.’ (p.13), in *Proceedings of the National Academy of Sciences of the United States of America*.

1. ‘Characterizing the nature of scan results discussions: Insights into why patients misunderstand their prognosis,’ *Journal of Oncology Practice*, published online 17 January 2017. <https://goo.gl/dzkC1O>

Noted in Media Watch 11 January 2016, #444 (p.9):

- *CLINICAL ONCOLOGY* | Online – 14 December 2015 – ‘Prognosis, treatment benefit and goals of care: What do oncologists discuss with patients who have incurable cancer?’ Across medical oncology providers [i.e., study participants] there was substantial variation in the frequency of discussing prognosis (range 33-90%), treatment intent (range 55-100%), and goals of care (range 0-17%). In total, 41% (93/222) of patients were seen by palliative care (PC); substantial medical oncology provider variation was observed (range 27-58%). Referral rates to PC did not increase over time (41-44%). In this cohort of ambulatory patients with an estimated life expectancy of 1 year or less, medical oncology documentation of prognosis, treatment benefit and goals of care was poor. <http://goo.gl/W7iooz>

Dying from cancer: Could your location determine your fate?

FOX NEWS | Online – 24 January 2017 – Cancer death rates are steadily rising in certain parts of the U.S. in grim contrast with the declining death rate across the nation as a whole, an exhaustive new analysis has found.¹ In parts of the country that are relatively poor, and have higher rates of obesity and smoking, cancer death rates rose nearly 50%, while wealthier pockets of the country saw death rates fall by nearly half. Stark differences in regional cancer death rates have been found in previous research, but this one stands out for providing detailed estimates for deaths from nearly 30 types of cancer in all 3,100 U.S. counties over 35 years. From 1980 to 2014, the U.S. death rate per 100,000 people for all cancers combined dropped from about 240 to 192 – a 20% decline. More than 19 million Americans died from cancer during that time, the study found. <https://goo.gl/b9f1ot>

1. ‘Trends and patterns of disparities in cancer mortality among U.S. counties, 1980-2014,’ *Journal of the American Medical Association*, 2017;317(4):388-406. <https://goo.gl/k6tDau>

Wyoming Senate approves palliative care bill

WYOMING | KGAB Radio News (Cheyenne) – 24 January 2017 – The Wyoming Senate ... approved a bill creating a palliative care (PC) council for the state. The vote in favor of Senate File 88 was 20-10 on third reading. The bill would create a volunteer council to advise the state on PC issues, including care for those in state institutions who may be suffering from terminal illness. <https://goo.gl/IVhk0z>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **COLORADO | *The Denver Post*** – 26 January 2017 – ‘**About 30 hospitals opting out of Colorado’s medical aid-in-dying law.**’ Up to 30 Colorado hospitals are opting out of the state’s new medical aid-in-dying law, either fully or in part, but whether that means the doctors they employ are banned from writing life-ending prescriptions is a controversy that could wind up in court. At this point, terminally ill Coloradans who want to end their lives under the law will need to find out whether their physicians are allowed to participate. Three major health systems with 30 hospitals among them ... have announced they will not participate in the law. What that means for doctors, though, varies by system. Physicians at HealthOne’s eight hospitals ... are allowed to talk to their patients about aid in dying and can write life-ending prescriptions in a hospital. But hospital pharmacies will not fill those prescriptions and patients are not allowed to take their own lives in the hospital... <https://goo.gl/CcdMXP>
- **KAISER HEALTH NEWS | Online** – 25 January 2017 – ‘**Legalizing aid in dying doesn’t mean patients have access to it.**’ Across California, and in the five other states where medical aid-in-dying is now allowed, access is not guaranteed, advocates say. Hospitals, health systems and individual doctors are not obligated to prescribe or dispense drugs to induce death, and many choose not to. Most of the resistance comes from faith-based systems. The Catholic Church has long opposed aid-in-dying laws as a violation of church directives for ethical care. But some secular hospitals and other providers also have declined. In Colorado, where the nation’s latest aid-in-dying law took effect in December, health systems covering nearly third of hospitals in the state, plus scores of clinics, are refusing to participate, according to a recent STAT report. <https://goo.gl/r5W9GC>
 1. ‘Colorado’s aid-in-dying law in disarray as big Catholic health systems opt out,’ *Stat News* (Boston, Massachusetts), 19 January 2017. [Noted in Media Watch 23 January 2017, #496 (p.4)] <https://goo.gl/MqlgrV>

International

End-of-life care in England

Muslim Women’s Council announces partnership with Forget Me Not Children’s Hospice

U.K. (England) | *Telegraph & Argus* (Bradford) – 26 January 2017 – A women-led mosque being planned for central Bradford looks set to notch up another U.K. first. As well as planning to build Britain’s first mosque governed by women, the Muslim Women’s Council now looks set to be the first to include a children’s hospice service on-site. The group yesterday announced it was partnering with the Forget Me Not Children’s Hospice, which is based in Huddersfield, but also serves Bradford and runs support projects across much of West Yorkshire. <https://goo.gl/weJvoL>



N.B. Muslim Women’s Council: <https://goo.gl/bkVPbR>.

Elder care in Australia

Access to psychologists in aged care is an “urgent priority,” Councils on the Ageing tells minister

AUSTRALIA | *Australian Ageing Agenda* – 24 January 2017 – Seniors are ramping up pressure on the Federal Government over the lack of access to psychological services for older people living in residential aged care, launching a petition calling on the new health minister, Greg Hunt, to reverse the [current] discriminatory policy. “We are calling on him to take it to Cabinet where the government must agree to reverse this historical anomaly so that nursing home residents have the same access to mental health services as everyone else,” said Councils on the Ageing chief Ian Yates. Last week *Australian Ageing Agenda* reported that the government was not committing to remove the restrictions that prevent aged care residents from accessing Medicare-funded psychology sessions, despite a growing chorus of experts calling for a change and mounting media coverage of the issue.¹ Instead the Commonwealth has referred the issue to its ongoing review of the Medicare Benefits Schedule. The Australian Psychological Society, which represents Australia’s psychologists, last week called on the government to allow residents to access the Better Access initiative, which provides 10 subsidised sessions with a psychologist through Medicare.² <https://goo.gl/6X8bjD>

1. ‘Commonwealth not budging on access for seniors in aged care to psychology services,’ *Australian Ageing Agenda*, 18 January 2017. <https://goo.gl/De4OZq>
2. ‘Australian Psychological Society calls for Medicare-funded psychological treatment to be available for older Australians,’ Australian Psychological Society, December 2016. <https://goo.gl/6Jagjm>

Related

- AUSTRALIA | *The Conversation* – 23 January 2017 – ‘**Aussies are getting older, and the health workforce needs training to reflect it.**’ With the demand for the aged care workforce nearly tripling, the need for an appropriately skilled and regulated workforce is needed. We still don’t know how this can be done, or how to make sure workers are properly trained. The baby boomers now needing more care expect a flexible and tailored approach to their needs. At present, the primary, acute and aged care workforce may not be adequately prepared to meet these expectations. <https://goo.gl/CiKBTI>

Home care in England & Wales

13,000 pensioners could be forced into care homes against their will

U.K. (England & Wales) | *The Daily Telegraph* – 23 January 2017 – Thousands of pensioners could be forced into care homes against their will under secret National Health Service cost cutting plans. More than 13,000 elderly people are expected to be effectively evicted as health authorities refuse to fund care in their own homes. Charities expressed alarm, describing the new measures as “outrageous.” At least 37 Clinical Commissioning Groups (CCGs) have drawn up new restrictions governing care for elderly and disabled patients, Freedom of Information disclosures reveal. The responses – from 122 of the country’s 209 CCGs – show that authorities have ruled that they would not pay for help at home if it was cheaper to send pensioners to a care home. <https://goo.gl/r8BhSx>

Related

- U.K. (England) | ITV News – 24 January 2017 – ‘**97% of councils in England tell ITV News council tax hikes will have no impact on social care crisis.**’ Last month the government announced it planned to increase the so-called “social care precept” from 2% to 3%. A survey by the Association of Directors of Adult Social Services ... contacted all 152 councils in England. They were asked whether permission to increase council tax would make a positive impact on social care in their area. Just 112 responded. More than a quarter of directors of adult social services said it would make no difference at all and more than two thirds of them said it would make very little difference. <https://goo.gl/1DCAF3>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BANGLADESH | Agence France-Presse – 24 January 2017 – **‘Bangladeshi father’s plea for sons, grandson sparks debate on euthanasia.’** Bangladesh lacks any kind of free health care and medical treatment is often beyond the reach of the tens of millions of inhabitants who live below the poverty line. An estimated 600,000 Bangladeshis suffer from incurable diseases, yet the country has just one palliative care center and no hospice services. The plight of Tofazzal Hossain has sparked a rarely seen debate about euthanasia in Bangladesh, where even attempted suicide can land one in prison. So-called “mercy killing” is forbidden both under the secular law of the land and by religious code adhered to by the Muslim-majority population. <https://goo.gl/QNq1N>

Specialist Publications

Pulling together and pulling apart

Influences of convergence and divergence on distributed healthcare teams

ADVANCES IN HEALTH SCIENCES EDUCATION | Online – 23 January 2017 – Effective healthcare requires both competent individuals and competent teams. With this recognition, health professions education is grappling with how to factor team competence into training and assessment strategies. These efforts are impeded, however, by the absence of a sophisticated understanding of the the relationship between competent individuals and competent teams. This paper explores the relationship between individual team members’ perceived goals, understandings, values and routines, and the collective competence of the team. Individual interviews with index patients and their healthcare team members formed Team Sampling Units (TSUs). Thirty-seven TSUs consisting of 183 interviews were iteratively analysed for patterns of convergence and divergence (C&D) in an inductive process informed by complex adaptive systems theory. C&D were identifiable on all teams, regularly co-occurred on the same team, and involved recurring themes. C&D had non-linear relationships to the team’s collective functioning. Convergence could foster either shared action or collective paralysis; divergence could foster problematic incoherence or productive disruption. These findings advance our understanding of the complex relationship between the individual and the collective on a healthcare team, and they challenge conventional narratives of healthcare teamwork which derive largely from acute care settings and emphasize the importance of common goals and shared mental models. <https://goo.gl/HRwNca>

End-of-life care in Taiwan

Costs of care at the end of life among elderly patients with chronic kidney disease: Patterns and predictors in a nationwide cohort study

BMC NEPHROLOGY | Online – 26 January 2017 – Despite the urgent need for evidence to guide the end-of-life care (EoLC) for patients with chronic kidney disease (CKD), we have limited knowledge of the costs and intensity of EoLC in this population. The present study examined patterns and predictors for EoLC intensity among elderly patients with CKD. During the last 30 days of life, [in this study] average inpatient costs for elderly CKD patients were approximately US\$10,260, with 40.9% receiving surgical interventions, 40.2% experiencing ICU admission, 45.3% undergoing mechanical ventilation, 14.7% receiving resuscitation, and 42.0% receiving dialysis. Significant variability was observed in the inpatient costs and use of intensive services. Costs were lower among individuals with the following characteristics: 1) Advanced age; 2) High income; 3) High Charlson Comorbidity Index scores; 4) Treatment by older physicians, nephrologists, and family medicine physicians; and, 5) Treatment at local hospitals. Similar findings were obtained for the use of surgical interventions and other intensive services. Overall end-of-life costs and rates of intensive service use among older patients with CKD were high, with significant variability across various patient and provider characteristics. Several opportunities exist for providers and policy makers to reduce costs and enhance the value of EoLC for this population. <https://goo.gl/xppp3y>

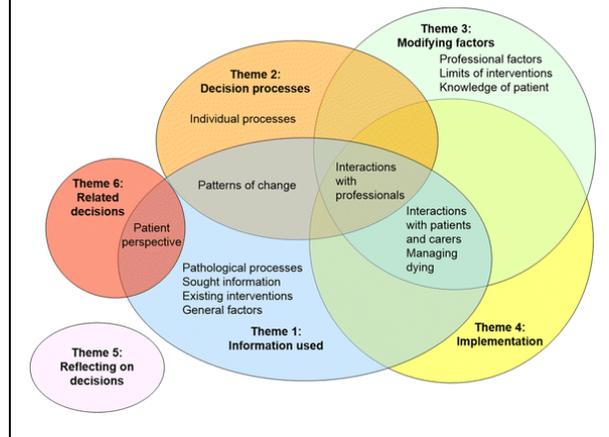
Clinical decision making in the recognition of dying: A qualitative interview study

BMC PALLIATIVE CARE | Online – 25 January 2017 – From a clinical perspective, this study supports the need to acknowledge the strengths and weaknesses of expertise and intuition as part of the decision process, and the importance of placing the recognition of dying in a time-dependent context. Clinicians should also be prepared to accept and convey the uncertainty surrounding these decisions, both in practice and in communication with patients and carers. From a research perspective, this study suggests that detailed exploration of the decision process may be difficult, and that studies seeking to assess the accuracy of professional decision-making (particularly in comparison with mathematical models) should seek to do so realistically, by presenting a decision-maker with time-dependent information, and giving them opportunity to reassess and review decisions. The recognition of dying remains an important skill, highlighted by the multiple initiatives in the U.K. and the Institute of Medicine report in the U.S.^{1,2} Increased research in end-of-life care, with particular reference to the recognition of dying, are common themes. Using decision-making theories as a basis, this study explored the recognition of dying by health care professionals in cardiology and oncology, and high-

lighted important aspects of the decision process, which have an impact on both clinical practice and research. <https://goo.gl/eVvfAY>

Extract from *BMC Palliative Care* article

Overall, six themes representing factors that influence the recognition of dying were generated from the analysis; 1) Information used; 2) Decision processes; 3) Modifying factors; 4) Implementation; 5) Reflecting on decisions; and, 6) Related decisions:



1. 'National Care of the Dying Audit of Hospitals,' Royal College of Physicians in collaboration with the Marie Curie Palliative Care Institute Liverpool, 14 May 2014. [Noted in Media Watch 19 May 2014 #358 (p.3)] <https://goo.gl/2LX7Qe>
2. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine of the National Academy of Sciences, September 2014. [Noted in Media Watch 22 September 2014, #376 (p.4)] <https://goo.gl/W9Dy0Q>

Clinical trials in palliative care: A systematic review of their methodological characteristics and of the quality of their reporting

BMC PALLIATIVE CARE | Online – 25 January 2017 – With palliative care (PC) research becoming increasingly necessary it is not enough to conduct more studies, it is also necessary to improve the quality of evidence. PC research is trying to deal with the large heterogeneity, the ethical and methodological issues resulting from the expansion of its scope of intervention, while at the same time it still seems too tied to the concept of terminal care of oncological patients, with a level of quality of reporting that has not evolved. To the authors' knowledge, this is the most comprehensive attempt to review clinical trials in PC literature. According to their results, it seems that the first step in generating not just valid, but also generalisable knowledge, is to clearly define PC populations, types of intervention and time to referral, establishing a common lexicon for clinicians and researchers. This will allow consensus to be achieved on the best outcomes and clinically meaningful differences, and will facilitate the choice of study design as well as promoting strategies to bypass the major barriers in PC research. The use of tools to help reporting study outcomes, such as CONSORT or SPIRIT, could also be a simple and efficient way of improving the quality of studies. <https://goo.gl/Zo0RWV>

Cont.

Related

- *THE GERONTOLOGIST* | Online – 25 January 2017 – ‘**Practice concepts will become intervention research effective.**’ One of the greatest challenges in improving health care quality is the slow speed with which scientific innovation reaches practice. Only 14% of scientific discoveries reach practice at all, and when a practice is adopted, the process takes an average of 17 years... <https://goo.gl/PiZtK>

Home care in Canada

Reconciling tensions: Needing formal and family/friend care but feeling like a burden

CANADIAN JOURNAL ON AGING | Online – Accessed 24 January 2017 – Within a neoliberal policy context that shifts responsibility for health and well-being from the state to families and individuals, Canadian home care strategies tend to present family members as “partners in care.” This article examines older people’s experiences at the intersections of formal home care and family/friend care arrangements, against the backdrop of policies that emphasize partnerships with family. The core concept derived from the interviews was reconciling tensions between care needs and concerns about burdening others, in the context of available home and community care. Four processes are identified, which illustrate how access to financial and social resources may lead to opportunities and constraints in experiences of care. Findings underscore the emotional and practical challenges that older people may encounter *vis-à-vis* policy discourses that encourage family responsibility for care. Implications for policy and practice are discussed. <https://goo.gl/wt7aWc>

Noted in Media Watch 9 January 2017, #494 (p.6):

- *CANADIAN JOURNAL ON AGING* | Online – 5 January 2017 – ‘**Stakeholder meeting: Integrated knowledge translation approach to address the caregiver support gap.**’ There is a gap between what research evidence shows is beneficial to caregivers and what is actually provided. Three target populations of family caregivers are identified for discussion: 1) Caregivers of seniors with dementia; 2) Caregivers in end-of-life care; and, 3) Caregivers of frail seniors with complex health needs. The findings can and are being used to inform the development of implementation research endeavours and policies targeted at providing evidence-informed caregiver supports. <https://goo.gl/1DJ16g>

Refinement of a conceptual model for adolescent readiness to engage in end-of-life discussions

CANCER NURSING | Online – 20 January 2017 – The purpose of this study was to explore the process of adolescent readiness for end-of-life preparedness discussions, generating a theoretical understanding for guiding clinical conversations when curative options are limited. The authors explored two in-depth cases across time using case-study methodology. An *à priori* conceptual model based on current end-of-life research guided data collection and analysis. Multiple sources including in-depth adolescent interviews generated data collection on model constructs. Analysis followed a logical sequence establishing a chain of evidence linking raw data to study conclusions. Synthesis and data triangulation across cases and time led to theoretical generalizations. Findings led to conceptual model refinement showing readiness is a dynamic internal process that interacts with preparedness. Current awareness context facilitates the type of preparedness discussions (cognitive or emotional). Furthermore, social constraint inhibits discussions. Understanding the dynamic process of readiness for engaging in end-of-life preparedness provides clinician insight for guiding discussions that facilitate shared decision making and promote quality of life for adolescents and their families. <https://goo.gl/mm4k4z>

Cont. next page



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.

Noted in Media Watch 16 January 2017, #495 (p.7):

- *THE HASTINGS REPORT* | Online – 11 January 2017 – ‘**Conflating capacity and authority: Why we’re asking the wrong question in the adolescent decision-making debate.**’ Using data from magnetic resonance imaging and functional MRI studies, authors have argued both that the adolescent brain isn’t sufficiently mature to broadly confer capacity on this population and that the adolescent brain is sufficiently mature to assume adolescent capacity. Scholars then accept these data as sufficient for concluding that adolescents should or should not have decision-making authority. Two critical mistakes are being made here. The first is the expectation that neuroscience or psychology is or will be able to answer all our questions about capacity. The second, and more concerning, mistake is the conflation of decision-making capacity with decision-making authority. <https://goo.gl/ciyAEi>

Noted in Media Watch 24 October 2016, #484 (p.9):

- *JAMA PEDIATRICS* | Online – 17 October 2016 – ‘**Ethics, emotions, and the skills of talking about progressing disease with terminally ill adolescents: A review.**’ The authors reviewed the ethical justifications for and against truth-telling, and considered the published ethical and practice guidance, as well as the perspectives of patients, parents, and clinicians involved in these cases. They also explored particular challenges with respect to the cultural context, timing, and content of conversations at the end of adolescents’ lives. <https://goo.gl/v91oh0>

Making sense of a wish to hasten death

CHISHOLM HEALTH ETHICS BULLETIN, 2016;21(4):7-11. This article draws upon peer-reviewed literature, the practices of palliative care (PC), and the experiences of two PC physicians. The expression of a wish to hasten death does not necessarily imply a genuine desire to hasten death or to be helped to die. To the contrary, almost always this means that the patient has been overwhelmed by one or more serious concerns. While inadequate pain relief may be one such factor, more typically these concerns are social and spiritual, such as loneliness, social isolation, feeling oneself to be a burden on others, hopelessness, and fears about the process of dying. If a patient expresses a wish to hasten death, health professionals should therefore discuss with them the reasons for this request, and then devise and effectively communicate an individualised care plan which begins to address these concerns. <https://goo.gl/YCeivB>

Noted in Media Watch 24 October 2016, #484 (p.13):

- *PALLIATIVE MEDICINE* | Online – 19 October 2016 – ‘**Assessment of the wish to hasten death in patients with advanced disease: A systematic review of measurement instruments.**’ Of the seven instruments identified, the Desire for Death Rating Scale or the Schedule of Attitudes toward Hastened Death feature in 48 of the 50 articles reviewed. The Schedule of Attitudes toward Hastened Death is the most widely used and is the instrument whose psychometric properties have been most often analysed. <https://goo.gl/tgJmM4>

N.B. Additional articles on the desire to hastened death are noted in past issues of Media Watch, e.g., 2 January 2017, #493 (p.10), and 7 March 2016, #452 (pp.8-9).

Palliative care in the elderly injured patient

CURRENT TRAUMA REPORTS | Online – 20 January 2017 – The use and need of palliative care (PC) programs have grown substantially throughout the U.S. in both public and not-for-profit hospitals. The geriatric trauma outcome score has been proposed as a tool to help better explain to patients and their stakeholders the likelihood of mortality in injured geriatric trauma patients. The study of frailty and the differences between patients of similar age has become a focus of many surgical societies. Recent studies also address how to improve end-of-life communication through training programs for health care professionals. PC in trauma and other populations is evolving. Adequately trained staff are needed for facilitating care in this vulnerable patient population, while also providing education on best practices for appropriate discussion of palliation and end-of-life care in the trauma population. <https://goo.gl/qlw5wm>

Cont.

Noted in Media Watch 12 December 2016, #491 (p.10):

- *THE GERONTOLOGIST* | Online – 7 December 2016 – ‘**Trauma-informed hospice and palliative care.**’ This review highlights the need to integrate trauma-informed practices into hospice and palliative care (PC). The pervasiveness of psychological trauma exposure has been established in the general population and among the elderly adults. Moreover, there is emerging evidence for multiple additional opportunities for exposure to psychological trauma at or near the end of life. For example, many people experience intensive medical interventions prior to their admission to hospice and/or PC, and there is increasing recognition that these interventions may be traumatic. <https://goo.gl/CtFIAQ>

Managing ethical dilemmas in end-stage neurodegenerative diseases

GERIATRICS | Online – 20 January 2017 – This article discusses the many ethical and moral dilemmas faced by the clinician and family members as they care for patients with neurodegenerative illnesses approaching the end of life. Topics discussed include steps on how to assess mental capacity and decision-making capability, advance care planning, withholding and/or withdrawing treatment, food refusal, the do-not-resuscitate order, and euthanasia. An approach to ethical decision-making incorporating Jonsen’s 4-topic approach is also be discussed briefly. <https://goo.gl/WBBmeE>

From dispassionate law to compassionate outcomes in healthcare law, or not

INTERNATIONAL JOURNAL OF LAW IN CONTEXT | Online – Accessed 24 January 2017 – Healthcare law presents numerous challenges to the conception of the law as a dispassionate arbiter of disputes or protector of rights. Issues relating to end-of-life care, the assessment of mental capacity, and decision-making for those who lack capacity, amongst others, epitomise the complex nature of healthcare law. They also raise globally applicable questions about discrimination, or equal protection, as well as concerns for relief of suffering, the assessment of best interests, and the exercise of individual autonomy. This paper evaluates the extent to which law’s traditional objectivity (dispassion) is undermined by the introduction of concerns about compassion into judicial and executive decisions. Focusing primarily on the law in England and Wales, but with reference to multi-jurisdictional case law and international instruments, it considers whether the law provides compassionate approaches and outcomes in end-of-life decision-making, and the implications of compassion for legal certainty. <https://goo.gl/OhnQQ2>

Tailoring palliative care to the changing needs of people facing cancer

JOURNAL OF CLINICAL ONCOLOGY | Online – 23 January 2017 – The rapid pace of discoveries in tumor biology and genetics has ushered oncology into a new era of personalized cancer care. In this process, we are learning many lessons about the apt use of these interventions, ranging from patient selection, to dosing and frequency, to management of unique adverse effects. Similarly, in the article that accompanies this editorial, Temel *et al* present data highlighting that a single palliative care (PC) intervention has disparate impacts among different cancer populations.¹ Thus, PC requires a tailored approach to meet the dynamic and specific needs of each unique population of patients with cancer. Here too, one size does not fit all. These findings suggest that if PC is to effectively engage and support patients with cancer and caregivers across the trajectory of cancer care, it must evolve in three key ways: 1) Develop dynamic PC integration models; 2) Clarify the appropriate dose and duration; and, 3) Explore enhanced roles to meet patients’ changing needs. This study adds to the growing body of data supporting early integration of PC in cancer, prompting the most recent update to the American Society of Clinical Oncology Clinical Practice Guidelines.² <https://goo.gl/20VbEc>

1. ‘Effects of early integrated palliative care in patients with lung and gastrointestinal cancer...,’ *Journal of Clinical Oncology*, published online 28 December 2016. <https://goo.gl/Yw4L5k>
2. ‘Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline: Updated,’ *Journal of Clinical Oncology*, published on line 31 October 2016. [Noted in Media Watch 7 November 2016, #486 (p.8)] <https://goo.gl/zaRNuP>

Cont.

Related

- *CANCER* | Online – 24 January 2017 – ‘**Care at the very end-of-life: Dying cancer patients and their chosen family’s needs.**’ This non-systematic review’s aims are to summarise the symptoms most feared by people imminently facing death which is defined as the terminal phase of life, where death is imminent and likely to occur within hours to days or, very occasionally, weeks. Further, this paper explores the incidence and management of problems that may affect the dying person which are most feared by their family. <https://goo.gl/sJ0NfA>
- *CLINICAL LUNG CANCER* | Online – 20 January 2017 – ‘**Addressing the palliative setting in advanced lung cancer should not remain a barrier: A multicentre study.**’ In this ... study, 106 patients with advanced thoracic cancer were issued a questionnaire to survey three dimensions of interest: 1) Illness understanding; 2) Observation of conversation regarding prognosis and end-of-life care (EoLC); and, 3) Information preferences of the patients. Only 45% was aware that the treatment was not curative. When comparing presumed treatment goals between patients who were aware that their treatment could not cure them, and patients likely to think that their treatment could cure them, 39% of the former chose quality of life versus 9% of the latter; whereas 36% of the former chose cure versus 13% of the latter. 75% never had a conversation about EoLC. <https://goo.gl/gUeH8R>
- *SUPPORTIVE CARE IN CANCER* | Online – 24 January 2017 – ‘**Assessment of the integration between oncology and palliative care in advanced stage cancer patients.**’ Chemotherapy is indicated for patients with metastatic malignancy in order to improve quality of life and in some cases to increase survival. However, the greatest difficulty regarding the choice of treatment is to evaluate the clinical benefit and intrinsic toxicity of each procedure. The best strategy is the integration between oncology and palliative care (PC), which is still mostly insufficient. The main objective of this study was to assess time to PC referral for cancer patients with advanced local or metastatic disease and to investigate the impact of covariates on this relationship. <https://goo.gl/NqGzAZ>

What do non-clergy spiritual care providers contribute to end-of life care in Israel? A qualitative study

JOURNAL OF RELIGION & HEALTH | Online – 27 January 2017 – As it emerges in Israel, spiritual care is intentionally built on a non-clerical model. Based on interviews with spiritual care providers in Israel, the authors find that they help patients and families talk about death and say goodbyes. They encourage the wrapping up of unfinished business, offer diverse cultural resources that can provide meaning, and use presence and touch to produce connection. As spiritual care emerges in Israel, providers are working with patients at the end of life in ways they see as quite distinct from rabbis. They offer broad frames of meaning to which patients from a range of religious traditions can connect. <https://goo.gl/N6wZve>

The clinical bioethicist’s role: Should we aim to relieve suffering?

NARRATIVE INQUIRY IN BIOETHICS, 2016;6(3):223-231. Bioethics consultants arrive at their profession from a variety of prior experiences (e.g., as physicians, nurses, or social workers), yet all clarify ethical issues in the care of patients. The integrated bioethicist’s role often extends beyond case consultations. This case presents a young person suffering a prolonged and gruesome end-of-life journey, which raised questions regarding the bioethicist’s role in alleviating suffering as part of the health care team. The case is used to illuminate forms of suffering experienced by patients, families, and health care providers. The question arises as to whether it is in the ethicist’s jurisdiction to alleviate suffering, and if the answer is “yes,” then whose suffering should be addressed? The discussion addresses one approach taken by an integrated bioethicist toward promoting delivery of ethical and compassionate care to the patient. <https://goo.gl/DoF3jJ>



Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials.
<http://goo.gl/OTpc8I>

Same-sex partner bereavement: Non-HIV-related loss and new research directions

OMEGA – JOURNAL OF DEATH & DYING | Online – 25 January 2017 – The experience of same-sex-attracted people who have lost a partner is neglected in the existing literature on bereavement. Previous research on lesbian, gay, bisexual, transgender, intersex, queer and questioning (LGBTIQ) populations tends to focus on the loss of a partner to HIV-related causes, and there is scant research concerning non-HIV-related bereavement. The purpose of this article is to investigate the non-HIV-related bereavement experiences of same-sex partners and to address the potential complications of disenfranchised grief. Coping with the loss of a same-sex partner and the impact of bereavement on subsequent relationships are also discussed. Implications for counseling of bereaved same-sex-attracted individuals are drawn, and recommendations for future psychological research on the experience of bereavement are made. <https://goo.gl/wGWCJZ>

Turning to Waheguru: Religious and cultural coping mechanisms of bereaved Sikhs

OMEGA – JOURNAL OF DEATH & DYING | Online – 22 January 2017 – Grief and loss are universal experiences for all individuals and communities. The experience of a loss due to death and the bereavement process to follow are influenced by an individual's religious values and beliefs. In this article, the authors discuss the Sikh bereavement process in the U.S. They provide brief personal narratives as exemplar case studies, highlight religious and cultural factors, and explain potential challenges of bereavement. Finally, the authors discuss implications for mental health clinicians and other providers of services that surround death and dying. <https://goo.gl/XBHJ5M>

N.B. Waheguru is the name used by Sikhs when referring to God.

Palliative care in humanitarian medicine

PALLIATIVE MEDICINE | Online – 23 January 2017 – Palliative care (PC) interventions have historically been neglected in the practice of humanitarian medicine. This may come as a surprise since it is a sombre reality medical practitioners are frequently witness to death and dying in their response to humanitarian crises. At the World Health Assembly (WHA) in May 2014, the World Health Organization affirmed a commitment to develop and implement policies that integrate PC services across the continuum of care. Three days following the close of the WHA, the Centers for Disease Control & Prevention released cumulative data estimating that 187 people had died from Ebola in Liberia, Sierra Leone, and Guinea. By the end of the summer, this number had increased tenfold. The exceptionally high mortality rates associated with the West African Ebola outbreak have prompted further reflection on the role of PC in humanitarian crises. A similar trend was seen during the height of the HIV/AIDS epidemic in the late 1990s, as health actors were faced with the need to focus on PC in the absence of affordable anti-retroviral treatment (ART). In addition to high mortality situations such as the Ebola and pre-ART HIV epidemics, a substantial proportion of medical humanitarian programmes still focus on the treatment of common diseases in protracted crises in settings with limited health infrastructure. Without the necessary capacity – or the required political commitment – in such circumstances, it is often not possible to deliver clinical care of the same breadth and standard as can be expected in higher resource settings. <https://goo.gl/Yxb8uB>

Related

- *UNIVERSITY OF OTTAWA JOURNAL OF MEDICINE* | Online – Accessed 28 January 2017 – ‘**Compassionate communities and their role in end-of-life care.**’ Death is a universal experience that has often been underrepresented in discussion between loved ones and the healthcare system. Given the need for support throughout all aspects of end-of-life care, an emerging paradigm shift shows Compassionate Communities as a new standard for placing responsibility back in the community and promoting respectful and compassionate care. Development of Compassionate Communities promotes quality end-of-life care designed to meet the individualized needs of the dying as well as their caregivers. <https://goo.gl/rrqQDj>

Death of family members as an overlooked source of racial disadvantage in the U.S.

PROCEEDINGS OF THE NATIONAL ACADEMY OF SCIENCES OF THE UNITED STATES OF AMERICA | Online – 23 January 2017 – Long-standing racial differences in U.S. life expectancy suggest that black Americans would be exposed to significantly more family member deaths than white Americans from childhood through adulthood, which, given the health risks posed by grief and bereavement, would add to the disadvantages that they face. The authors analyze nationally representative U.S. data from the National Longitudinal Study of Youth ... and the Health & Retirement Study ... to estimate racial differences in exposure to the death of family members at different ages, beginning in childhood. Results indicate that blacks are significantly more likely than whites to have experienced the death of a mother, a father, and a sibling from childhood through midlife. From young adulthood through later life, blacks are also more likely than whites to have experienced the death of a child and of a spouse. These results reveal an underappreciated layer of racial inequality in the U.S., one that could contribute to the intergenerational transmission of health disadvantage. By calling attention to this heightened vulnerability of black Americans, findings underscore the need to address the potential impact of more frequent and earlier exposure to family member deaths in the process of cumulative disadvantage. <https://goo.gl/ZBie7H>

Added commentary: Why death haunts black lives

- The authors demonstrate that African Americans are much more likely than whites to experience deaths in their immediate family circle, and that this elevated exposure to death occurs at virtually all stages of the life cycle. Differential exposure to bereavement by race is likely to contribute to long-standing black–white differentials with respect to health and socioeconomic status more generally. As the authors note, human well-being across a range of dimensions is well known to be adversely affected by exposure to the stress of bereavement. <https://goo.gl/2Qlevl>

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

Hospital palliative care teams and post-acute care in nursing facilities: An integrative review

RESEARCH IN GERONTOLOGICAL NURSING, 2017;10(1):25-34. Although palliative care (PC) consultation teams are common in U.S. hospitals, follow up and outcomes of consultations for frail older adults discharged to nursing facilities are unclear. The results of 12 articles reflecting research conducted in five countries are presented in narrative form. Two studies focused on nurse perceptions only, three described patient/family/caregiver experiences and needs, and seven described patient-focused outcomes. Collectively, these articles demonstrate that disruption in PC service on hospital discharge and nursing facility admission may result in high symptom burden, poor communication, and inadequate coordination of care. High mortality was also noted. <https://goo.gl/8Knwqy>

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 27 July 2017 – ‘Internet search query analysis can be used to demonstrate the rapidly increasing public awareness of palliative care in the U.S.’ A lack of public awareness of palliative care (PC) has been identified as one of the main barriers to appropriate PC access. Internet search query analysis is a novel methodology, which has been effectively used in surveillance of infectious diseases, and can be used to monitor public awareness of health-related topics. PC is rapidly growing in the U.S., and the rapidly increasing public awareness of PC as demonstrated in this study, in comparison with the U.K., where PC is relatively well established is encouraging in increasingly ensuring appropriate PC access for all. <https://goo.gl/tBKLqh>



Journal of Palliative Care

The publisher of the *Journal of Palliative Care*, the Centre de recherche, Institut universitaire de gériatrie de Montréal, Canada, recently announced that this highly respected publication has been acquired by SAGE Publishing. This follows the death, in December of 2015, of the journal's founder and editor-in-chief, David Roy. New journal home page: <https://goo.gl/oQP5OB>

Predatory journals: Do not enter

UNIVERSITY OF OTTAWA JOURNAL OF MEDICINE | Online – Accessed 28 January 2017 – Although no standard definition exists for predatory journals, they are best described as journals that recruit authors through high volumes of daily electronic invites, exploit open-access journal formats, and offer to publish submissions quickly, without any peer-review. As such, predatory journals demoralize scholarly publishing, corrupt the exchange of scientific knowledge, and ultimately pollute the evidence needed for improving global health. Due to the current ‘publish or perish’ paradigm, researchers early in their careers may be the most susceptible to invitations from predatory journals and the harms of publishing in them. Because these journals are not indexed in reputable databases, publications in these journals are unlikely to promote effective knowledge translation between colleagues, or influence healthcare practice and/or policy. Therefore, researchers and trainees at all levels are urged to exercise caution, think before they submit, and advise others of the hazardous world of predatory publishers and their journals. Future research aimed at understanding why authors publish in these journals is needed. Such knowledge will help develop programs to prevent submissions to predatory journals. <https://goo.gl/M8dpEf>

Example of an electronic invitation and its features from a potential predatory journal

From: (name of journal)
To: XY@institution.com
Subject: Upcoming Special Issue

Dear Dr/Mr. XY
Greetings from (name of journal)! → **Not easily distinguished from genuine journals/ publishers**

I am writing to introduce (name of journal), which is a newly launched journal by (name of publisher) from (name of country). → **Majority in low/middle income countries, but often claim addresses in US/UK**

We greatly acknowledge your research and contribution to the field of (name of research discipline).
We would like to invite you to submit a research manuscript to our Journal and to give us a chance to associate with an esteemed researcher like you. → **Often include flattering personalized greetings**

→ **Indexed in illegitimate abstracting and indexing services**

The Journal (indexed in *BioXYZ, ABC, Open J-Gate*) is planning to publish a special issue on the topic of (name of topic), and would like to request a contribution from you.

You can submit your manuscript either through email at (email address) or through our online submission system (link). If possible, we would appreciate your submission on or before (date). Kindly let us know your feasibility regarding submission to our Journal.

Kind regards,
XX Editor In Chief. → **No academic information provided about editor/staff/review board members**

N.B. Additional articles on predatory journals are noted in past issues of Media Watch, e.g., 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).

Worth Repeating

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

BMC NURSING | Online – 17 November 2015 – During the 8-month period of observation, 227 encounters within 38 episodes of care were observed among 38 nurses and 47 patients. Within these encounters, 330 psychosocial needs (PNs) were expressed. Nurses were observed immediately responding to expressed PNs in one of four ways: 1) Dealing (44.2 %); 2) Deferring (14.8 %); 3) Diverting (10.3 %); and, 4) Ducking (30.7 %). However, it is rare that one type of PN was clearly expressed on its own: many were expressed at the same time and usually while the patient was interacting with the nurse for another reason, thus making the provision of psychosocial support challenging. The nurses' response patterns varied little according to type of need. This study has allowed an exploration of the actual PNs of patients in a hospice setting, the way in which they were expressed, and how nurses responded to them. The nurses faced the challenge of responding to PNs whilst carrying out the other duties of their shift, and the fact that nurses can provide psychosocial support as an inherent component of practice was verified. [Noted in Media Watch 23 November 2015, #437 (p.9)] <https://goo.gl/7mZ9EU>

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.

Links to Sources

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

<http://goo.gl/XDjHxz>

[Media Watch: Online](#)

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/7jyMed>

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/5d1l9K>

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

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