

## 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

**Loss of intimacy and sexual well-being in the context of terminal illness, grief and bereavement: Scroll down to articles in *The New York Times* (p.4), and in *BMJ Supportive & Palliative Care* and *Omega – Journal of Dying & Death* (p.16).**

## Canada

### Lack of adequate support a barrier for those wishing to die at home

BRITISH COLUMBIA | *The Daily Courier* (Kelowna) – 8 March 2017 – With a growing trend of people choosing to die at home, University of British Columbia (UBC) researchers have determined those caring for palliative loved-ones need more support from healthcare professionals than they are currently getting. Carole Robinson, a nursing professor at UBC's Okanagan campus, says while many people would like to die at home, a sudden decline in health may mean they end up in hospital or a hospice. In previous research,<sup>1</sup> Robinson and her team learned that sheer determination is not enough to make sure that family caregivers (FCGs) are able to achieve a desired home death for their loved ones. This led her team to ask, "what enables FCGs to successfully care for a loved one at home until death?" "The FCGs were willing to do whatever was required to meet the needs of the ill person," says Robinson. "Their determination was based on love, respect, obligation, or giving back to someone who had given them so much — and as a way to honour their ill family member's wishes." However, caring at home was challenging. Her research team interviewed 29 people who cared for someone at home until their death to better understand their experience.

They learned that while caregivers were committed to the task, they faced roadblocks, profound fatigue, and lack of support from health-care professionals. The experience of being on 24/7 was common ... as were symptom-management challenges and crises, and demands associated with multiple co-occurring life events. Regardless of their focused determination, all study participants struggled with lack of co-ordination and continuity of care from health-care providers, Robinson said. Some explained that when support was given, it added other responsibilities such as the need to repeatedly orient new caregivers, and even supervise this outside help. <https://goo.gl/tOfxMD>

### Specialist Publications



**'New evidence on end-of-life hospital utilization for enhanced health policy and services planning'** (p.14), in *Journal of Palliative Medicine*.

**'Mind the gap: Charity and crowdfunding in health care'** (p.15), in *The Lancet Oncology*.

1. 'Caring at home until death: Enabled determination,' *Supportive Care in Cancer*, published online 6 December 2016. [Noted in Media Watch 12 December 2016, #491 (p.15)] <https://goo.gl/9Pkt3Q>

## Palliative care in humanitarian situations – is it achievable?

HUMANITARIAN HEALTH ETHICS RESEARCH NETWORK | Online – Accessed 8 March 2017 – While we have estimates of the need for palliative care (PC) in relatively stable populations, we have no similar assessments in humanitarian situations. We can assume that where populations experiencing humanitarian emergencies remain in their home country, any pre-existing level of need for PC would persist or even increase under the additional strains of the emergency (depending on the humanitarian situation). There is a growing realization that it is precisely in these situations where there is a high level of physical and emotional trauma and death that PC is needed. Whether a humanitarian situation is caused by natural disaster, disease or conflict, those caught up in the disasters may have pre-existing conditions requiring PC such as cancer, HIV, cardiac failure or may develop conditions that would benefit from PC (i.e. Ebola and traumatic disabilities). Babies will continue to be born with congenital anomalies, metabolic conditions and cerebral palsy and others may receive a fresh diagnosis of cancer, heart disease or one of many other serious illnesses. In longer-term situations such as refugee camps people have many different life-limiting and chronic conditions, and they should not be forgotten. With the huge and growing number of refugees and migrants changing the demographics of countries, estimates of the need for PC in those countries receiving refugees and migrants must also be reviewed. <https://goo.gl/MSvXTT>



Noted in Media Watch 30 January 2017, #497 (p.7):

- *PALLIATIVE MEDICINE* | Online – 23 January 2017 – ‘**Palliative care in humanitarian medicine.**’ Palliative care 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. <https://goo.gl/Yxb8uB>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *The Catholic Register* – 10 March 2017 – ‘**Conscience rights to be addressed by Ontario legislators.**’ Now in second reading, Bill 84 is designed to clear up legal ambiguities surrounding doctor-assisted suicide – everything from how coroners are to record assisted suicide deaths to the right of families to collect insurance benefits. However, the legislation currently does not include conscience protection for doctors. Instead, Ontario’s independent regulator for doctors requires all doctors to provide an “effective referral” for procedures, even if the doctor objects on moral, religious or conscience grounds. The College of Physicians and Surgeons of Ontario’s “duty to refer” policy applies to abortions, contraception and doctor-assisted suicide. <https://goo.gl/WYTo0Y>
- BRITISH COLUMBIA | CBC News – 9 March 2017 – ‘**Over 80 Comox Valley doctors want to keep new hospice beds away from St. Joseph’s Hospital.**’ Doctors in the province’s Comox Valley are calling on Vancouver Island Health Authority (VIHA) to keep two newly-funded hospice beds away from the faith-based St. Joseph’s General Hospital, currently the only area hospice, but one where Catholic church doctrine discourages doctor-assisted suicide. Over 80 doctors in the area have penned a letter to VIHA, urging the health authority to develop a new community hospice where patients would be allowed to receive medically-assisted death. <https://goo.gl/27mpsD>

### [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>



## U.S.A.

### Alzheimer's staggering \$259 billion cost could break Medicare

*FORBES* | Online – 7 March 2017 – The annual cost estimate for the deadly disease from the Alzheimer's Association comes as Congress and the White House once again have healthcare reform and funding for entitlement programs like Medicaid for poor Americans and Medicare for the elderly on their agenda.<sup>1</sup> The Alzheimer's Association puts the report out annually in part to remind policymakers that there is no cure for the disease and that research needs to be funded. 5.5 million Americans are living with Alzheimer's dementia and most of them are over the age of 65, the association said. Meanwhile, the disease is taking a financial toll on a U.S. healthcare system that provides more Americans healthcare coverage given the lack of treatments to reduce the prevalence and severity of the disease. Medicare and Medicaid pay for about two-thirds, or \$175 billion, of the "total healthcare and long-term care payments for people with Alzheimer's and other dementias," the association said of data in the report... Medicare, in particular, is hit hard because coverage generally begins for Americans once they reach age 65. Medicare costs for someone with Alz-

heimer's and other dementias is \$23,487, or triple the \$7,223 costs for Medicare beneficiaries without these conditions. <https://goo.gl/EbKfD3>

#### Extract from Alzheimer's Association report

In 2014, 20% of Medicare beneficiaries admitted to hospice had a primary diagnosis of dementia, including Alzheimer's dementia, compared with 17% in 2009. Dementia was the second most common primary diagnosis for Medicare beneficiaries admitted to hospice overall, with cancer being the most common primary diagnosis. For all Medicare beneficiaries admitted to hospice, the average length of stay was 69 days in 2014, with 27% having a stay of seven or fewer days in hospice. While average length of stay for hospice beneficiaries by primary diagnosis was not publicly reported for 2014, the average length of stay was 106 days for hospice beneficiaries with a primary diagnosis of Alzheimer's dementia and 92 days for hospice beneficiaries with non-Alzheimer's dementia in 2009. The average per-person hospice payment for Medicare beneficiaries with Alzheimer's dementia was \$1,966 compared with \$149 for all other Medicare beneficiaries.

1. '2017 Alzheimer's Disease Facts & Figures,' Alzheimer's Association, March 2017. <https://goo.gl/bndLL>

Noted in Media Watch 9 January 2017, #494 (p.8):

- *JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 31 December 2016 – '**Palliative care in dementia 1986-2016: Progress and remaining challenges.**' Palliative or hospice care research and practice for people with advanced dementia have made great strides since in 1986.<sup>1</sup> Research and hospice programs have expanded, and access to palliative care for people with dementia in Western countries has improved. <https://goo.gl/SeH2Jv>

1. 'Hospice approach to the treatment of patients with advanced dementia of the Alzheimer type,' *Journal of the American Medical Association*, 1986;256:2210-2213. <https://goo.gl/sliiEV>

**N.B.** Additional articles on end-of-life care for people living with Alzheimer's and other forms of dementia are noted in this issue of Media Watch.

### Maine lawmakers may OK "do not resuscitate" tattoos

MAINE | *Maine Sun Journal* (Augusta) – 7 March 2017 – A proposal before the legislature would allow Mainers who don't want emergency medical care to get a "do not resuscitate" tattoo on their chests to indicate their wishes. The measure would prohibit "emergency medical treatment providers from starting resuscitation on a person when an order not to resuscitate is presented in the form of an indelible mark on the person's chest." The Maine Medical Association and the Maine chapter of the American College of Emergency Physicians "have substantial concern about this proposal" to revise the protocol for emergency medical services. <https://goo.gl/a9U23A>

Cont.

Noted in Media Watch, 1 October 2012, #273 (p.9):

- *JOURNAL OF GENERAL INTERNAL MEDICINE*, 2012;27(10):1383. **‘DNR tattoos: A cautionary tale.’** By imprinting the letters DNR on their body, a person obtaining a tattoo may wish to increase the certainty that their decision will be respected. Paradoxically, however, such a tattoo may exacerbate the uncertainty of emergency responders at a critical time. <https://goo.gl/VkR6ct>

### When a partner dies, grieving the loss of sex

*THE NEW YORK TIMES* | Online – 6 March 2017 – After Alice Radosh’s husband of 40 years died in 2013, she received, in addition to the usual condolences, countless offers of help with matters like finances, her car and household repairs. But no one, not even close friends or grief counselors, dared to discuss a nagging need that plagues many older women and men who outlive their sexual partners. Dr. Radosh, 75 and a neuropsychologist by training, calls it “sexual bereavement,” which she defines as grief associated with losing sexual intimacy with a long-term partner. The result, she and her co-author Linda Simkin wrote in a recently published report,<sup>1</sup> is “disenfranchised grief, a grief that is not openly acknowledged, socially sanctioned and publicly shared.” Studies have shown

that people are still having and enjoying sex in their 60s, 70s and 80s. They consider their sexual relationship to be an extremely important part of their lives. But when one partner dies, it’s over.” <https://goo.gl/S7TFkf>

#### Specialist Publications

**‘Sexual well-being in cancer and palliative care: An assessment of healthcare professionals’** (p.16), in *BMJ Supportive & Palliative Care*.

**‘A practitioner’s guide to end-of-life intimacy: Suggestions for conceptualization and intervention in palliative care’** (p.16), in *Omega – Journal of Dying & Death*.

1. ‘Acknowledging sexual bereavement: A path out of disenfranchised grief,’ *Reproductive Health Matters*, 2016, Issue #48 (pp.25-33). <https://goo.gl/mgR81t>

**N.B.** Additional articles on sexuality and intimacy in the context of living with a life-limiting or terminal illness are noted in Media Watch 16 May 2016, #462 (p.12).

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALABAMA | *The Montgomery Advertiser* – 8 March 2017 – **‘Senate committee OKs assisted suicide ban, conscience bill.’** The Senate Health Committee ... approved bills outlawing assisted suicide and allowing health care providers to refuse services that violate their consciences. Both bills move to the full Senate. The assisted suicide ban ... would it make it a felony punishable by up to 10 years in prison to assist in a suicide or deliberately prescribe a drug to assist with a suicide. <https://goo.gl/Wyxfn9>
- HAWAII | Hawaii News Now (Honolulu) – 8 March 2017 – **‘Senate approves death with dignity bill after emotional floor debate.’** Hawaii’s controversial death with dignity measure now heads to the state House after an emotional Senate floor debate... If approved, terminally ill, competent adult patients with less than six months to live could receive a lethal dose of medication. They would have to take it themselves and two doctors would be involved in the prescription. <https://goo.gl/VrcmzL>



#### Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials.

<http://goo.gl/OTpc8l>

## International

### Home care in Ireland

#### **Thousands need home care as public to be asked views**

IRELAND | *The Independent* (Dublin) – 11 March 2017 – The first public consultation to gather views on a proposed statutory home care scheme is to be launched in May, it was confirmed yesterday. The consultation, which will allow the public and stakeholders to submit ideas, is the first step on the road to setting up a long-awaited scheme to allow more elderly people and those with a disability to remain in their own homes. <https://goo.gl/6RXoDm>

#### **This Government's cuts to benefits received by bereaved families is not only cruel, it is totally unnecessary**

U.K. (England) | *The Sun* – 10 March 2017 – Among the headlines around Philip Hammond's first Budget, a poorly considered policy coming into force within weeks has gone almost entirely ignored. The cut to bereavement benefit, a payout that supports families when one parent suddenly dies, is both cruel and needless – and goes against Theresa May's stated objective of protecting Britain's soft human underbelly. The new bereavement benefit rules, which take effect from 6 April, significantly reduce the length of time that bereavement support is paid, from until the youngest child is 16 years old to just 18 months after the death of the parent. The Government has also refused to extend entitlement to the benefit to couples who were not married but who had children together, thus missing an opportunity to modernise the benefit and make it fit for today's society. <https://goo.gl/vERC7V>

### End-of-life care in Australia

#### **Palliative care in regional New South Wales at 1960s standards, expert says**

AUSTRALIA (New South Wales) | ABC News (Sydney) – 6 March 2017 – One of Australia's first specialist palliative care (PC) doctors has accused New South Wales health authorities of dropping the ball when it comes to end-of-life care. Yvonne McMaster said regional areas are faring the worst, with standards of care she has not seen since the 1960s. And it is not just small country towns that are struggling to keep up with demand. The New South Wales Cancer Council says the state is short 10 PC doctors and needs another 129 PC nurses just to bring it up to minimum standards. <https://goo.gl/OT82Ry>

Noted in Media Watch 20 February 2017, #500 (p.6):

- AUSTRALIA (New South Wales) | *The Newcastle Herald* – 14 February 2017 – **'24-hour palliative care only available to parts of Lake Macquarie.'** Lake Macquarie residents living south of the Fennell Bay bridge do not receive the same 24-hour palliative care services as their northern neighbours and have to rely on telephone service outside of business hours. <https://goo.gl/mFYz8J>

Noted in Media Watch 2 November 2015, #434 (p.9):

- AUSTRALIA (New South Wales) | ABC News (Sydney) – 22 October 2015 – **'More New South Wales patients spend their final days at home after introduction of care program.'** A program to help terminally ill people die in the familiar surrounds of home is improving the final days of hundreds of patients in New South Wales. <https://goo.gl/IT0Tcu>

## Dying on the streets: The U.K.'s homeless

U.K. | Aljazeera – 6 March 2017 – In one of the world's largest economies, it is usual to see people sleeping on cold, hard beds of concrete. More than 4,000 people slept rough on the streets of England in 2016, according to a recent official snapshot survey – a 16% increase on the year before. It was the sixth successive year of rising numbers since 2010. Many campaigners on the issue of homelessness contend that the government's statistics for people who sleep rough may be an underestimate. The Combined Homelessness & Information Network put the number of individuals seen sleeping rough in London by outreach workers at 8,096 in 2015-2016 – an increase of 7% compared with the previous year. "The number of people sleeping on our streets continues to rise at an appalling rate," says Matt Downie, the head of policy at Crisis, a U.K. homeless charity. "Behind these statistics are thousands of desperate people, sleeping in doorways, bin shelters, stations and parks – anywhere they can find to stay safe and escape the elements. Cuts to housing benefit and a woeful lack of affordable housing are just some of the reasons rough sleeping continues to rise." <https://goo.gl/1NbwwF>

Noted in Media Watch 23 January 2017, #496 (p.7):

- *BULLETIN OF EUROPEAN HEALTH PSYCHOLOGY SOCIETY*, 2016;Suppl. '**Challenges and recommendations in increasing homeless persons' access to palliative care: An international systematic review.**' The U.K. Department of Health strives to provide palliative care at the time of need for everyone, regardless of "wherever the person may be," "irrespective of social economic deprivation." This goal has not been reached for homeless people who face numerous multifaceted challenges, including accessing health care. <https://goo.gl/9ecWXy>

**N.B.** Additional articles on end-of-life care for the homeless are noted in past issues of Media Watch, e.g., 17 December 2017, #495 (p.1); 5 December 2016, #490 (p.6); 8 August 2016, #474 (p.12); and, 14 March 2016, #453 (pp.14-15).

### End-of-life care in England

#### Nurses call for improvement of palliative care for cancer patients

U.K. (England) | United Press International – 6 March 2017 – Researchers from the University of Surrey in England have found palliative and end-of-life care (EoLC) information is a priority for cancer patients. The study surveyed 18 cancer patients and 50 oncology nurses on areas they want to see as part of future research in improving patient care.<sup>1</sup> The cancer patients surveyed identified palliative and EoLC as priorities in oncology care, while oncology nurses prioritized the use of eHealth and technology to manage cancer symptoms at home. Patients also identified cognitive changes from cancer treatment as a priority for future research. The oncology nurses and patients agreed that factors affecting the early presentation of cancer symp-

toms, the availability of psychosocial support services and the management of anxiety following cancer treatment should be key areas of future research. <https://goo.gl/LC6rNE>

#### **Comment by co-author of University of Surrey study**

*Our study demonstrates the importance of seeking the opinions of cancer patients, as what they consider important may not mirror what the profession considers a priority. Too often the voice of cancer patients is unheard, but if services are to improve we should listen to the very people they are affecting. **Professor Emma Ream***

1. 'Establishing priorities for oncology nursing research: Nurse and patient collaboration,' *Oncology Nursing Forum*, 2017;44(2):192-203. <https://goo.gl/NepA6B>



#### 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 beginning p.17.

## Numbers of children with complex needs or life-limiting conditions up by 50% since 2004



U.K. (England) | Council for Disabled Children – Accessed 5 March 2017 – A recent report, 'Understanding the needs of disabled children with complex needs or life-limiting conditions,' identifies clear gaps in current data collection. Data is extremely scarce. The report uses school census data on special educational needs, and also other information sources, in order to shed light on current trends. It finds, for example, that the numbers of children with complex forms of autism have more than doubled since 2004, to 57,615. The swell in numbers may actually be greater, since many children with the most complex needs are educated in the independent special school sector and the Department for Education does not require those schools to return detailed data on these pupils. <https://goo.gl/518daC>

### Extract from Council for Disabled Children report

Evidence and awareness of the rising number of children and young people with life-limiting conditions is somewhat better, but again, not visible in routinely published national data. The Department of Health published a detailed analysis of this cohort in 2007 which estimated that approximately 20,100 children and young people aged 0-19 were likely to require palliative care services annually in England,<sup>1</sup> or 16 in every 10,000 children and young people.

1. 'Palliative care statistics for children and young adults,' Department of Health, 2007. <https://goo.gl/yz5H6s>

**N.B.** To access the Council's report click on  at the organization's website.

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

- *BRITISH MEDICAL JOURNAL* | Online – 8 December 2016 – '**End-of-life care for infants, children and young people with life limiting conditions: Summary of National Institute for Health & Care Excellence guidance.**' The Institute recommends end-of-life care be managed as a long term process that begins at the time of diagnosis of a life-limiting condition and entails planning for the future.<sup>1</sup> It is part of the overall care of the child or young person and runs in parallel with other active treatments for the underlying condition itself. <https://goo.gl/nyUO4n>
  1. 'End-of-life care for infants, children and young people with life-limiting conditions: Planning and management,' National Institute for Health & Care Excellence, December 2016. <https://goo.gl/8GLw37>

Noted in Media Watch 27 January 2014, #342 (p.12):

- *HEALTH & PLACE* | Online – 15 January 2014 – '**Prevalence of life-limiting conditions in children and young people in England: Time trends by area type.**' Recent research determined the prevalence of life-limiting conditions in children in England was double previous estimates. Prevalence is highest for children aged less than one year, but time trends show no increase for the youngest age group but significant increases for older children. Rates are highest in more deprived areas and those typified by multicultural populations. <https://goo.gl/VC0OUX>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GERMANY | Deutsche Welle (Leipzig) – 2 March 2017 – '**German Federal Court rules patients should have access to life-ending drugs.**' The federal administrative court in Leipzig ruled in favor of "the right for a patient who is suffering and incurably ill to decide how and when their life should end" provided the patient "can freely express their will and act accordingly." The purchase of deadly drugs in Germany is forbidden, but the court found the right of self-determination meant there should be exceptions for extreme cases "if, because of their intolerable life situation, they had freely and seriously decided to end their lives" and if there were no palliative-medical alternatives. <https://goo.gl/D43kJL>

## Specialist Publications

### **Primary care physicians' educational needs and learning preferences in end of life care: A focus group study in the U.K.**

*BMC PALLIATIVE CARE* | Online – 9 March 2017 – Primary care physicians (i.e., GPs) play a pivotal role in providing end of life care (EoLC). However, many lack confidence in this area, and the quality of EoLC by GPs can be problematic. This study therefore aimed to explore GPs' EoLC educational needs and preferences for learning and evaluation. Twenty-eight GPs ... participated in five focus groups. Four major themes emerged: 1) Why education is needed; 2) Perceived educational needs; 3) Learning preferences; and, 4) Evaluation preferences. EoLC was perceived as emotionally and clinically challenging. Educational needs included: 1) Identifying patients for palliative care; 2) Responsibilities and teamwork; 3) Out-of-hours care; 4) Having difficult conversations; 5) Symptom management; 6) Non-malignant conditions; and, 7) Paediatric palliative care (PC). Participants preferred learning through experience, working alongside specialist PC staff, and discussion of real cases, to didactic methods and e-learning. 360° appraisals and behavioural assessment using videoing or simulated interactions were considered problematic. Self-assessment questionnaires and patient and family outcome measures were acceptable, if used and interpreted correctly. <https://goo.gl/yNXvBY>

### **Affording opportunities to discuss deterioration in paediatric palliative care consultations: A conversation analytic study**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 7 March 2017 – Discussing the potential deterioration of a child who has a life-limiting condition has recognised benefits for future care, but can be challenging in a clinical context where uncertain illness trajectories are common. Existing research is restricted to indirect forms of evidence such as self-report data from clinicians and families. This study directly explores how discussions about deterioration are managed within actual paediatric palliative care (PC) consultations. Nine consultations were video recorded in an Australian paediatric PC service. Each consultation involved the same paediatric PC specialist. Conversation analysis was used to identify and explore recurrent ways in which discussions about deterioration came to be realised. The study identified two communicative practices used by a paediatric PC specialist that afforded opportunities to discuss deterioration: 1) Soliciting the family's agenda for the consultation; and, 2) Initiating and maintaining topics where discussing deterioration is a relevant possibility. Across these different practices, a common feature was indirect initiation of discussions about deterioration. This approach made such discussions possible, but without mandating or even suggesting that such discussion must occur. <https://goo.gl/tY8cPW>

#### **Related**

- *JAMA ONCOLOGY* | Online – 9 March 2017 – '**Patients' and parents' needs, attitudes, and perceptions about early palliative care integration in pediatric oncology.**' Pediatric oncology patients experience a high degree of symptom-related suffering early in cancer therapy, and very few patients or parents in this study expressed negative attitudes toward early palliative care (PC). The authors' findings suggest that pediatric oncology patients and families might benefit from, and are not a barrier to, early PC integration in oncology. <https://goo.gl/lwQYSJ>
- *OMEGA – JOURNAL OF DYING & DEATH* | Online – 8 March 2017 – '**The long road to farewell: The needs of families with dying children.**' The importance of compassion emerged [in this study] as a salient theme, manifested in myriad ways, and connected to participants' perception of caregiver presence in multiple domains. Families were likewise negatively affected by a wide variety of situations and behaviors that represented individual or institutional abandonment or non-presence, and thus compounded the experience of loss. <https://goo.gl/33Q0YU>

## **Leaky pipeline, gender bias, self-selection or all three? A quantitative analysis of gender balance at an international palliative care research conference**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 7 March 2017 – The “leaky pipeline” in academia is a clearly described phenomenon, but has not been examined in palliative care (PC). The authors analysed the gender balance of speakers at the 9th World Research Congress of the European Association of Palliative Care (EAPC) to test the null hypothesis that there is no difference in the proportion of women and men with senior academic visibility in PC conference programmes. Overall, the majority of speakers at EAPC 2016 (96/130, 73.8%) were women. The proportion of women was highest in the Free Communication sessions (84/107, 78.5%). In the Themed sessions, women made up just over half of speakers (12/22, 54.5%). In 2016, there was 1 invited Plenary speaker, a man. From 2012 to 2016, just 6 of 23 invited Plenary speakers at EAPC conferences have been women (26.1%)... These data reject our null hypothesis and suggest that there is attrition of women along the academic pipeline in PC. Other factors such as self-selection (that women decline invitations to give talks) and unconscious gender bias need further exploration, as well as actions to address the imbalance. <https://goo.gl/MKEIBH>

## **The impact of medical technology on sense of security in the palliative home care setting**

*BRITISH JOURNAL OF COMMUNITY NURSING* | Online – 2 March 2017 – The increase in the use of medical devices in palliative home care requires that patients and next-of-kin feel secure. Therefore, the aim of this study was to describe medical technology’s impact on the sense of security for patients, next-of-kin and district nurses. The use of medical technology was shown to have an impact on the sense of security for all involved. A sense of control was promoted by trust in staff and their competence in managing the technology, which was linked to continuity. Inner peace and being in comfort implied effective symptom relief facilitated by pain pumps and being relieved of responsibility. Health care professionals need to have practical knowledge about medical technology, but at the same time have an awareness of how to create and maintain a sense of security. <https://goo.gl/Y1h4U>

## **Perspectives of older people living in long-term care facilities and of their family members toward advance care planning discussions: A systematic review and thematic synthesis**

*CLINICAL INTERVENTIONS IN AGING* | Online – 3 March 2017 – This review suggests that barriers to advance care planning (ACP) for older people living in long-term care (LTC) facilities are more related to health care professionals’ willingness to initiate ACP conversations than to patients’ and family members’ willingness to be involved in such a process. In fact, the results of this review proposes that residents and their families rely on health care professionals’ expertise and judgment and desire their involvement in end-of-life (EoL) care decision-making. This finding is consistent with previous studies and highlights the urgent need to enhance health care professionals’ knowledge, skills and comfort in ACP conversations. Health care professionals who know an elder well were considered the ideal group of people to initiate ACP, and most elders and their families expected health care providers to initiate and anticipate their needs concerning EoL issues. The findings indicate that elders and their families desired a personalized approach by health care professionals within a relationship based on trust, respect and sensitivity. Regarding the “right time” to perform ACP, further studies are needed in order to develop appropriate guidance on approaching both residents and their family members. This review shows that, at least for the current generation of older people living in LTC settings, planning for non-medical issues is very important, suggesting the need to rethink ACP for this population and also to incorporate non-medical preferences. <https://goo.gl/KBzrgU>

**N.B.** To access full text of article click on

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Cont.

## Related

- *THE GERONTOLOGIST* | Online – 10 March 2017 – “‘**End-of-life care? I’m not going to worry about that yet.**’ **Health literacy gaps and end-of-life planning among elderly dialysis patients.**’ Between 2000 and 2012, the incident dialysis population in the U.S. increased by nearly 60%, most sharply among adults 75 years and older. Despite high mortality risk in this population, only 13% of patients [i.e., study participants] had discussed end-of-life (EoL) preferences with physicians, half had discussed EoL with their social network, and 25% of participants explicitly stated that they had never considered EoL preferences. Less than 30% of participants could correctly define terminology commonly used in EoL conversations. <https://goo.gl/fbLYLc>
- *ILLNESS, CRISIS & LOSS*, 2017;25(2):87-106. ‘**Agency and communion in end-of-life decision-making.**’ The balancing of agency and communion within small communities of support may provide the opportunity to inform end-of-life (EoL) decision-making and acceptance of the dying process. In this sense, the spirit of *communitas* may instill faith that the ending of one’s life journey is both reasonable and meaningful. The role of the small community of support may be akin to that of the guide who assists the aging or dying person through the dialectic of being an autonomous agent and a communicant in the EoL transition. <https://goo.gl/oWKHFW>

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

### **Innovative oncology care models improve end-of-life quality, reduce utilization and spending**

*HEALTH AFFAIRS*, 2017;36(3):433-440. Three models that received Health Care Innovation Awards from the Centers for Medicare & Medicaid Services (CMS) aimed to reduce the cost and use of health care services and improve the quality of care for Medicare beneficiaries with cancer. Each emphasized a different principle: the oncology medical home, patient navigation, or palliative care. Comparing participants in each model who died during the study period to matched comparators, the authors found that the oncology medical home and patient navigation models were associated with decreased costs in the last ninety days of life (\$3,346 and \$5,824 per person, respectively) and fewer hospitalizations in the last thirty days of life (fifty-seven and forty per 1,000 people, respectively). The patient navigation model was also associated with fewer emergency department visits in the last thirty days of life and increased hospice enrollment in the last two weeks of life. These promising results can inform new initiatives for cancer patients, such as the CMS Oncology Care Model. <https://goo.gl/vUkUjU>

## Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 7 March 2017 – ‘**A current guide to processes of care in hospice.**’ Hospice and palliative medicine continues to emerge from being a fringe of the profession to being a core service for the health care industry. We have created standards of care, government regulations have defined core practices and the science of medical knowledge and patient practice has increased. Yet, the art of clinical medicine is still essential given that every patient and family presents with their own individual nuances within their unique spiritual, emotional, biologic, and social make-up. <https://goo.gl/1ALVSy>

### **The Catch-22 of neuro-imaging, disorders of consciousness, and end-of-life decisions**

*JAMA NEUROLOGY* | Online – 6 March 2017 – In 2016, Canada passed legislation to legalize medical assistance in death (MAiD) for patients with severe, irremediable conditions. The passage of this law follows those of Switzerland, Belgium, the Netherlands, Luxembourg, and 5 U.S. states that allow patients to choose to die given specific criteria intended to uphold the principles of beneficence, human rights and dignity, and justice. It signals progress in the arena of end-of-life decision making and opens new discussions about competence and communication where technology, human intervention, or both are needed as intermediaries. The authors consider the case where the legitimacy of technology-assisted, medically assisted dying is tested and, however seemingly far-fetched, is already in the public eye. This specific context pertains to patients with brain injuries in whom functional magnetic resonance imaging that relies on blood oxygen levels in particular brain regions, or electrophysiological measurements from the scalp, have been used to reveal signals that are interpreted as consciousness. <https://goo.gl/IRdrFu>

## The role of a hospital ethics consultation service in decision-making for unrepresented patients

*JOURNAL OF BIOETHICAL INQUIRY* | Online – 6 March 2017 – Despite increased calls for hospital ethics committees to serve as default decision-makers about life-sustaining treatment (LST) for unrepresented patients who lack decision-making capacity or a surrogate decision-maker and whose wishes regarding medical care are not known, little is known about how committees currently function in these cases. This was a retrospective cohort study of all ethics committee consultations involving decision-making about LST for unrepresented patients at a large academic hospital from 2007 to 2013. There were 310 ethics committee consultations, twenty-five (8.1%) of which involved unrepresented patients. In thirteen (52%) cases, the ethics consultants evaluated a possible substitute decision-maker identified by social workers and/or case managers. In the remaining cases, the ethics consultants worked with the medical team to contact previous healthcare professionals to provide substituted judgement, found prior advance care planning documents, or identified the patient's best interest as the decision-making standard. In the majority of cases, the final decision was to limit or withdraw LST (72%) or to change code status to Do Not Resuscitate/Do Not Intubate (12%). Substitute decision-makers who had been evaluated through the ethics consultation process and who made the final decision alone were more likely to continue LST than cases in which physicians made the final decision (50% vs 6.3%). The primary role of ethics consultants in decision-making for unrepresented patients is to identify appropriate decision-making standards. In the absence of other data suggesting that ethics committees, as currently constituted, are ready to serve as substitute decision-makers for unrepresented patients, caution is necessary before designating these committees as default decision-makers. <https://goo.gl/jRHu1y>

Noted in Media Watch 9 May 2016, #461 (p.7):

- *AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS*, 2016;18(5):475-478. 'Health care ethics committees and palliative care services.' Whereas palliative care (PC) cases almost always involve patients with a limited life expectancy, cases referred for health care ethics consultations involve, in addition to terminal illness, ethical issues pertaining to the entire spectrum of clinical medicine. On the other hand, PC has a clinical focus that is much broader than that of ethics committees because it is concerned with so many aspects of a patient's... Understanding this difference is helpful for health care practitioners, as it can help them determine which service would be more likely to meet the goals of patients, their loved ones, and members of clinical care teams. <http://goo.gl/t5dD5d>

**N.B.** This issue of the *AMA Journal of Ethics* is devoted to the theme of health care ethics consultation in the U.S., whether such consultation is performed individually or as part of the work of an organized committee. Contents page: <http://goo.gl/Srn3V3>

## Identifying perceptions of health professionals regarding deathbed visions and spiritual care in end-of-life care: A Delphi consensus study

*JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(2):177-184. Research on end-of-life experiences suggests that deathbed visions are not uncommon, but many doctors and nurses find this a difficult subject to approach. A purposive sample of nurses and doctors was invited from across hospitals and nursing homes to participate in this study. The health professionals' perceptions of the deathbed visions experienced by patients were identified, as well as how these phenomena should be integrated into spiritual care. The research found that healthcare professionals who are experts in end-of-life care (EoLC) tend to remain at the EoLC setting while acknowledging human spirituality as part of a peaceful death. However, they tend to not make conclusions about how death visions should be classified. This study was an attempt to identify a consensus on spiritual care including deathbed visions in EoLC among healthcare professionals. <https://goo.gl/WE1nc3>

Cont.

Noted in Media Watch 15 August 2016, #475 (p.10):

- *NURSING CLINICS OF NORTH AMERICA*, 2016;51(3):489-500. '**Seeing the light end-of-life experiences: Visions, energy surges, and ether death bed phenomena.**' Death bed phenomena are common within the last days and weeks of life and can include visions, dreams, hallucinations, and pre-mortem energy surges. Qualitative studies show that patients and families are often more likely to talk about these experiences to nurses than to other health care providers. Nursing interventions to normalize and validate these phenomena and open channels of communication can impact care during this period and facilitate a more peaceful passing. <http://goo.gl/Z6b3gl>

**N.B.** Additional articles on deathbed phenomena are noted in this issue of Media Watch.

### **Telehealth in palliative care: A systematic review of patient-reported outcomes**

*JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(2):130-139. Multiple databases were searched for articles published between January 2006 and May 2016... Methodological quality was assessed using Cochrane Collaboration's tool for assessing risk of bias for quantitative articles. For studies reporting qualitative outcomes, a checklist was used to evaluate trustworthiness of the methodology. Of the 6 studies reporting quantitative outcomes, 3 studies were rated as having moderate study quality, and 3 studies were rated as having low study quality. Of the 6 studies reporting qualitative outcomes, 3 reported 5 different methods for ensuring trustworthiness, whereas 1 article reported 4 methods, 1 reported 3, and 1 article reported 2 methods. Studies were notably diverse in terms of patient population, technology used, outcomes measures, and methodology. Results across studies were also variable. Methodological factors were major limitations. Recruitment problems, participant attrition, and lack of standardized outcomes measures impacted outcome assessment. Overall, research support for positive patient outcomes in palliative telehealth interventions was weak. However, all studies but one found positive results to support the intervention. <https://goo.gl/esz27H>

Noted in Media Watch 28 November 2016, #489 (p.9):

- *IEEE PULSE* (Engineering in Medicine & Biology Society), 2016;7(6):25-29. '**Technological innovation comes to palliative care: With a shortage of palliative specialists, telemedicine and remote monitoring offer relief.**' At its core, palliative care is a very human side of medicine, relying heavily on talking with and listening to people to understand their experiences and goals. Technology, on the other hand, can often feel impersonal, cold, and one-size-fits-all. Despite this apparent disconnect, researchers and clinicians are finding new ways to harness technology to facilitate communication between patients and caregivers. <https://goo.gl/5D5oQZ>

**N.B.** Additional articles on telehealth in the context of end-of-life care are noted in Media Watch 21 November 2016, #488 (p.6).

### **Hope for a miracle: Treatment requests at the end of life**

*JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(2):115-119. It is not uncommon for patients and caregivers facing medical uncertainties to utilize religious coping as a tool to foster adjustment to changes along an illness trajectory. Religious coping can promote a sense of meaning, emotional well-being, and hope. This article explores requests for aggressive treatment stemming from strongly held religious beliefs and overarching hope for a miracle. A case example highlights the complexities of religious coping, belief in miracles, and requests for life-prolonging treatment at the end of life. The article closes with a discussion of the ethical considerations and strategies for best communicating with and caring for patients who request life-prolonging medical care in advanced illness. <https://goo.gl/JUJiDg>

**N.B.** Additional articles on religious coping in the context of end-of-life care are noted in Media Watch 11 April 2016, #457 (pp.10-11).

## **A review of agents for palliative sedation/continuous deep sedation: Pharmacology and practical applications**

*JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY* | Online – 1 March 2017 – Continuous deep sedation at the end of life (EoL) is a specific form of palliative sedation requiring a care plan that essentially places and maintains the patient in an unresponsive state because their symptoms are refractory to any other interventions. Because this application is uncommon, many providers may lack practical experience in this specialized area and resources they can access are outdated, nonspecific, and/or not comprehensive. The purpose of this review is to provide an evidence- and experience-based reference that specifically addresses those medications and regimens and their practical applications for this very narrow, but vital, aspect of hospice care. Patient goals in a hospital and hospice environments are different, so the manner in which widely used sedatives are dosed and applied can differ greatly as well. Parameters applied in EoL care that are based on experience and a thorough understanding of the pharmacology of those medications will differ from those applied in an intensive care unit or other medical environments. By recognizing these different goals and applying well-founded regimens geared specifically for EoL sedation, we can address our patients' symptoms in a more timely and efficacious manner. <https://goo.gl/ju3ys0>

Noted in Media Watch 11 July 2016, #470 (p.13):

- *CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 1 July 2016 – ‘**A systematic literature review on the ethics of palliative sedation: An update (2016).**’ In a 2010 review of palliative sedation (PS), the following areas were identified as lacking in consensus: 1) Inconsistent terminology; 2) Its use in non-physical suffering; 3) The ongoing experience of distress; and, 4) Concern that the practice of PS may hasten death. This review looks at the literature over the past 6 years and provides an update on these outstanding concerns. <http://goo.gl/qWxPgk>

**N.B.** Additional articles on palliative sedation are noted in this issue of Media Watch.

### **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**

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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.

## End-of-life care in Canada

### **New evidence on end-of-life hospital utilization for enhanced health policy and services planning**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 March 2017 – Long-standing concern exists over hospital use by people near or at the end of life (EoL) related to the appropriateness, quality, and cost of care in hospital. It is widely believed that most people die in hospital after an escalation in hospital use over the last year of life. As most deaths in high-income countries are not sudden or unexpected, opportunities exist for planning compassionate, effective, and evidence-based EoL care. In 2014-2015, 3.5% of hospital episodes ended in death and 43.7% of all deaths in Canada (excluding Quebec) took place in hospital. 95.2% of those dying in hospital were only admitted once or twice during their last 365 days of life. 3.6% of those dying in hospital had been living in the community and receiving publicly funded home care before the hospital admission that ended in death, while 67.0% had been living at home without home care. 79.0% of hospital deaths followed an unplanned admission through the emergency room, with 70.5% arriving by ambulance. The hospital care provided in the last stay was largely non-interventionist. These findings reveal the need for a major re-conceptualization of death, dying, and EoL care to ensure sufficient capacity of palliative home care and other services to support dying people and prevent the health and family caregiver crises that lead to hospital-based EoL care and death. <https://goo.gl/pc0ICf>

### **Barriers to, and opportunities for, palliative care development in the Eastern Mediterranean Region**

*THE LANCET ONCOLOGY*, 2017;18(3):e176-e184. The 22 countries of WHO's Eastern Mediterranean Region (EMR) are experiencing an increase in the burden of non-communicable diseases (NCDs), including cancer. Of the six WHO regions, the EMR is projected to have the greatest increase in cancer incidence in the next 15 years. Furthermore, most cancers are diagnosed at a late stage, resulting in a lower cancer survival rate than in the European Region and the Region of the Americas. With increasing numbers of deaths from cancer, palliative care (PC) should be available to relieve suffering in patients with advanced disease and at the end of life. However, in the EMR, the PC available is variable and inconsistent. Several barriers exist to the development and expansion of PC delivery in this region, including the absence of PC in national policies, little partnership working, insufficient PC education for health-care professionals and volunteers, poor public awareness, and gaps in access to essential pain-relief medicines. In this Review, the authors explore data and evidence from published literature, WHO meeting reports, cancer control mission reports, and the WHO global NCD country capacity survey to identify the status of PC in the EMR, including the challenges and opportunities for development. <https://goo.gl/iL9vYI>



## Mind the gap: Charity and crowdfunding in health care

*THE LANCET ONCOLOGY*, 2017;18(3):269. Gaps in public services have often been filled by charities. In several countries, cancer charities are federally regulated to prevent mismanagement and exploitation of public funds and have a tradition of working with governments to support patient care and research. For example, in Canada, despite the existence of a universal health-care system, cancer charities have propped up cancer care for decades, plugging gaps in home care, travel costs, research funding, and palliative care, as well as helping patients navigate the complexities of the health system itself. Although several provinces do not have a cancer care plan, the Canadian Cancer Society routinely produces one for each province, in addition to working with several government agencies to create a federal strategy. However, ideally charities should provide extra services and assistance in times of crisis, rather than providing basic services integrated into a health-care system. This overreliance on charity in Canada has potentially perilous consequences because of the increasing budgetary strain on charities.

The merger of the Canadian Cancer Society and the Canadian Breast Cancer Foundation was announced at the end of January 2017, to prevent a financial crisis. These two charities together fund more than 10% of all Canadian cancer research, and their combined spending on all services has fallen by CAN\$24 million in the past 4 years. The overburdened health-care system is unlikely to be able to pick up the slack, placing the residual financial responsibility on patients themselves. <https://goo.gl/VUXqie>

### Conflicts of interest for patient-advocacy organizations

*NEW ENGLAND JOURNAL OF MEDICINE*, 2017; 376(9):880-885. In this examination of 104 large patient-advocacy organizations [in the U.S.], 83% receive financial support from drug, device, and biotechnology companies, and industry executives often serve on governing boards. The authors recommend more transparency about industry involvement. <https://goo.gl/enFCw3>

## ***The Golden Room: An innovative choice for end-of-life care*** **(or) Changing the culture to allow for more end of life care option**

*NURSING & PALLIATIVE CARE*, 2017;2(1):1-4. Golden Room care specializes in the last 3-10 days of life as the body is imminently closing down. As such, the care is very sensitive mentally and emotionally to the immediate needs of the dying and their family in, as well as physical comfort care, pain medication and complimentary modalities to relax and release. There are no tests, treatments, or life extending medications that are used in traditional care that suggests recovery. Natural process can occur. Transfers into *Golden Rooms* can occur easily from intensive care settings in acute care hospitals, nursing homes, clinics, and personal homes directly into free standing or inpatient *Golden Room* settings. When one explores the need or desire for yet another care facility, there are a number of facts to consider. One for example, is that approximately 90% of the U.K. population spend some time in hospital in their final year of life, and more than half of the population die in hospital. The statistics are the same in the U.S. A U.K. study explored the experiences of general nurses when providing end-of-life care (EoLC) to patients in the acute hospital setting. Six themes emerged from the literature: 1) Lack of education and knowledge; 2) Lack of time with patients; 3) Barriers arising in the culture of the health-care setting; 4) Communication barriers; 5) Symptom management; and, 6) Nurses' personal issues. The themes cause concern about the quality of EoLC provided in acute care settings. The literature appears to be consistent in the view that terminally ill patients are best cared for in specialized care settings, such as palliative care units and hospices. However, increasing demands on health services will result in greater numbers of dying patients being admitted to the acute hospital settings. The question posed then is, perhaps there is room for more options? <https://goo.gl/nTCZiQ>

## **A practitioner's guide to end-of-life intimacy: Suggestions for conceptualization and intervention in palliative care**

*OMEGA – JOURNAL OF DYING & DEATH* | Online – Accessed 8 March 2017 – Sexuality and intimacy, including contact, tenderness, and love, are important at every life stage. Intimate expression is especially vital at the end of life (EoL), when relationships with loved ones are time limited. Unfortunately, care providers often ignore the potential need for sexual expression, especially at the EoL. The authors consider current research on sexuality and EoL care and situate these two fields in an ecological framework. They explore how EoL sexuality and intimacy can be supported by practitioners in multiple nested contexts and provide suggestions for theoretically-driven interventions. The authors also provide reflexive considerations for practitioners. <https://goo.gl/RIxNy>

### **Related**

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 2 March 2017 – **‘Sexual well-being in cancer and palliative care: An assessment of healthcare professionals’ current practice and training needs.** The majority of healthcare professionals [i.e., study participants] did not routinely assess sexual well-being in cancer and palliative care patients, with only 13.8% of secondary care staff, 7.9% of district nurses and 4% of general practitioners routinely assessing it. The most frequent reason for non-assessment was that it was not the presenting symptom. <https://goo.gl/sGIVON>

**N.B.** Additional articles on sexuality and intimacy in the context of living with a life-limiting or terminal illness are noted in Media Watch 16 May 2016, #462 (p.12).

## **Exploring the contemporary stage and scripts for the enactment of dying roles: A narrative review of the literature**

*OMEGA – JOURNAL OF DYING & DEATH* | Online – 6 March 2017 – This narrative review explores the literature regarding the drama of dying from several academic perspectives. Three key themes were identified including “the impact of blurred boundaries on roles and transitions,” “the orchestration of death and dying through time,” and “contemporary dying and new machinery of control.” This review reveals the manner in which tightly scripted dying roles serve the needs of the living to a greater extent than those of the dying, by ensuring the depiction of both dying and death as phenomena which have been brought under the control of the living, thereby countering death anxiety. An incongruence between the actual experience of dying and contemporary dying scripts is also highlighted. The authors argue that this incongruence is hidden from the broader societal audience through the maintenance of a dying role that demands serenity and acceptance, thus downplaying or even hiding the actual end-of-life experiences of the dying themselves. <https://goo.gl/eaF5AD>

### **“Keep all thee ‘til the end”**

## **Reclaiming the lifeworld for patients in the hospice setting**

*OMEGA – JOURNAL OF DYING & DEATH* | Online – 6 March 2017 – St. Christopher's Hospice, London, was founded to provide specialist care to the incurably ill. The author's studied the dimensions of difference that set St Christopher's Hospice apart from hospital care of the dying, focusing on physical space and social organization. Material from 1953 to 1980 from the Cicely Saunders Archive was analyzed qualitatively. Through thematic analysis, quotes were found and analyzed using open coding. Five themes were developed: 1) Home/homelike; 2) Community; 3) Consideration of others; 4) Link with outside world; and, 5) Privacy. The hospice philosophy functioned as the catalyst for the development of the physical environment of St Christopher's Hospice. Taking [Jürgen] Habermas' concept of lifeworld, it seems that, in contrast to acute care, the need for hospice to formulate their own lifeworld to support and fully engage patients was central. As lifeworlds are culture sensitive, this underlines the need for variation in design and organization of hospices around the world. <https://goo.gl/avLNax>



## Prisoners working with the dying

*PSYCHOLOGY TODAY* | Online – Accessed 8 March 2017 – Angola State Prison in Louisiana is home to approximately 5,000 men. Their crimes range from murder, rape, armed robbery to drug offenses. It is described as the largest and most notorious prison in the country. It has the highest percentage of prisoners in the U.S. serving life sentences and it is estimated that 85% of these prisoners will die there. In the past, dying at the prison meant that you were left alone in a room, without medication, just waiting for death to come. After death, the body was put in a cardboard box for burial. In 1998, Warden Burl Cain changed the face of death in the prison by introducing hospice. The entire death and burial experience was transformed. <https://goo.gl/i3jAHD>

### Related

- *DEATH STUDIES* | Online – 8 March 2017 – ‘**Agency behind bars: Advance care planning with aging and dying offenders.**’ Aging and terminally ill individuals in U.S. prisons are increasing, making critical the need for appropriate end-of-life care and advance care planning. Findings [of this study] included six themes: 1) Decisions in the shadow of the past; 2) What works best for me; 3) Feeling blessed; 4) What is really going on; 5) Can anyone be trusted; and, 6) Turning agency over to someone else. This study provides critical information that will assist professionals who work with dying offenders, as it presents a vivid illustration of their dying process. <https://goo.gl/y7Y2iF>

**N.B.** End-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of the articles, reports, etc., noted in past issues of the weekly report is available at: <http://goo.gl/ZpEjyQ>

## Worth Repeating

### **Knowing loved ones’ end-of-life health care wishes: Attachment security predicts caregivers’ accuracy**

*HEALTH PSYCHOLOGY*, 2011;30(6):814-818. Very little is known about the factors that make caregivers more or less accurate as surrogate decision makers for their loved ones. Previous research suggests that in low stress situations, individuals with high attachment-related anxiety are attentive to their relationship partners’ wishes and concerns, but get overwhelmed by stressful situations. Individuals with high attachment-related avoidance are likely to avoid intimacy and stressful situations altogether. The authors hypothesized that both of these insecure attachment patterns limit surrogates’ ability to process distressing information and should therefore be associated with lower accuracy in the stressful task of predicting their loved ones’ end-of-life (EoL) health care wishes. Surrogates [i.e., the subjects of this study] high on either type of insecure attachment dimension were less accurate in predicting their loved ones’ EoL health care wishes. It is interesting to note that even though surrogates’ attachment-related anxiety was associated with lower accuracy of EoL health care wishes of their loved ones, it was associated with higher accuracy in the non-stressful task of predicting their loved ones’ everyday living conditions. [Noted in Media Watch 12 December 2011, #231 (p.8)] <https://goo.gl/lJw5kA>

### Media Watch: Online

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/o9wzNe>

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

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

Cont.

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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**Barry R. Ashpole**  
**Guelph, Ontario CANADA**

**'phone: 519.837.8936**  
**e-mail: [barryashpole@bell.net](mailto:barryashpole@bell.net)**