

Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

Culturally competent clinical ethics: Scroll down to [Specialist Publications](#) and 'A family requests that their grandmother, who does not speak English, is not informed of her terminal diagnosis' (p.11), in *Clinical Ethics*.

[Canada](#)

British Columbia group says death midwives' philosophy similar to that of birth midwives

BRITISH COLUMBIA | CTV News (Vancouver) – 13 July 2016 – So-called death midwives provide the dying and their families with a wide range of services similar to birth midwives so the term should not be legally challenged by organizations that govern maternity care, says a spokeswoman for a British Columbia group. “We do not want to be in a battle with the birth midwives,” said Pashta MaryMoon of the Canadian Integrative Network for Death Education & Alternatives. “We have tried so hard to limit the use of the term death midwives whereas other people use the term more loosely.” The College of Midwives of British Columbia has issued a cease and desist letter to the network, saying the word midwife is a protected title for registered members who must meet certain standards in providing maternity care. The Winnipeg-based Canadian Midwifery Regulators Council – a network of provincial and territorial regulatory authorities – also sent a letter to MaryMoon’s group last week asking that it make no further use of the term death midwife. <http://goo.gl/6tX42t>

Selected articles on the use of the term “midwife” in the context of end-of-life care

- *JOURNAL OF MIDWIFERY & WOMEN'S HEALTH* | Online – 5 May 2016 – ‘**Midwifing the end of life: Expanding the scope of modern midwifery practice to reclaim palliative care.**’ Current midwives, skilled in assisting women and families through the transition of pregnancy to motherhood, can use their education and skills to help individuals and their families through the transition from life to death. [Noted in Media Watch, 9 May 2016, #461 (p.12)] <http://goo.gl/DQp1Eq>
- *THE PRACTICING MIDWIFE*, 2015;18(10):18-23. ‘**From pregnancy to palliative care: Advancing professional midwifery practice?**’ Historically midwives may have not considered palliative care (PC) as a part of their professional role. Enhanced technologies and antenatal screening have broadened the boundaries of care. However do midwives truly embrace the philosophy of PC into their practice? [Noted in Media Watch, 16 November 2015, #436 (p.17)] <http://goo.gl/46W3px>
- CBC RADIO | Day 6 (News Magazine) – 26 April 2015 – ‘**Death midwives help families cope with end-of-life care.**’ A death midwife or death doula can help create death plans, provide spiritual care, psychological and social support, and sometimes even physical care. They can also help plan home vigils and home funerals, and offer guidance with respect to what your rights and responsibilities are in caring for someone who’s died. [Noted in Media Watch, 4 May 2015, #408 (p.4)] <http://goo.gl/9KRA73>

Elder care

Here's why the census requires more questions about seniors in long-term care

THE OTTAWA CITIZEN | Online – 10 July 2016 – It has been called the grey wave, a demographic tide that will sweep across this country. However, researchers say Canada is poorly prepared to deal with its ballooning population of senior citizens, in part because of the lack of information we are gathering about changes in the ways they live, and what those changes mean for all of us. Some seniors who live in “collective” dwellings such as retirement homes and nursing homes were incensed last month after they learned Statistics Canada used administrative records to get basic census information about them to “reduce the burden on Canadians.” We need to know more, say researchers.¹ By 2036, almost one in four Canadians will be over age of 65. Consultations for the next census are in 2017. <http://goo.gl/y15yso>

1. ‘Ten questions researchers wish Census Canada would ask seniors in long-term care,’ *The Ottawa Citizen*, 10 July 2016. <http://goo.gl/dQZj3u>

Noted in Media Watch, 4 July 2016, #469 (p.11):

- *CANADIAN JOURNAL ON AGING*, 2016;35(2):175-189. ‘**Staffing in Ontario’s long-term care homes: Differences by profit status and chain ownership.**’ The authors found for-profit long-term care (LTC) homes provided significantly fewer hours of care, after adjusting for variation in the residents’ care needs. Findings from this study offer new information on the impact of organizational structure on staffing levels in Ontario’s LTC homes and have implications for other jurisdictions where a growing presence of private, chain-affiliated operators has been observed. <https://goo.gl/cAg8kr>

N.B. See ‘Integrating Long-Term Care into a Community-Based Continuum: Shifting from “Beds” to “Places,”’ Institute for Research on Public Policy, Montreal, Quebec, February 2016. [Noted in Media Watch, 14 March 2016, #453 (p.2)] <http://goo.gl/ZuMk0s>

Related

- QUEBEC | CTV News (Montreal) – 11 July 2016 – ‘**Quebec increasing spending on home health care.**’ Quebec is giving individual health agencies control over \$51.9 million devoted to people getting medical care at home. Health Minister Gaetan Barrette explained that regional health boards will have autonomy in how they spend the funding, as long as it goes toward helping the elderly and those with chronic health care needs receive home care. <http://goo.gl/uHaP6x>
- *THE NATIONAL POST* | Online – 11 June 2016 – ‘**Canada’s haphazard support for home care is leaving seniors in the cold.**’ Why is our nation lagging behind other Organization of Economic Co-operation & Development countries in home-care spending? And why are we so all over the legislative map, from province to province, in terms of services and support? <http://goo.gl/JReqGm>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MANITOBA | CIBC News (Winnipeg) – 16 July 2016 – ‘**Manitoba has “embarrassingly weak” stance on doctor-assisted death, says ethics professor.**’ Arthur Schafer, founding director of the Centre for Professional & Applied Ethics at the University of Manitoba ... says Manitoba isn’t doing enough to protect the dignity and rights of patients to have access to an assisted death. Recently, the Christian Medical & Dental Association met with Manitoba Health Minister Kelvin Goertzen to discuss conscience protection for doctors opposed to physician-assisted death. In Manitoba, doctors are only required to direct patients to a website that has information about assisted dying. <http://goo.gl/oOd6Dr>

[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.15.

U.S.A.

Cancer patients, doctors often disagree about prognosis

MADISON.COM | Online – 16 July 2016 – Cancer patients and their doctors often hold different opinions about the patient’s chances for survival and how long he or she might live, according to a new study.¹ And, in many cases, patients are unaware there’s any misunderstanding. “First, some patients might know the doctor’s prognosis estimate, but the patient chooses to disagree, often because they believe other sources. And second, some patients think that their doctor agrees with their opinion about prognosis but, in fact, the doctor doesn’t,” said study co-author Dr. Ronald Epstein ... a professor of family medicine, psychiatry and oncology at the University of Rochester Medical Center in New York. For the study, researchers asked 236 patients with advanced cancer about their prognosis. The 38 doctors who treated them independently said they would “not have been surprised” if their patients died within a year. Researchers also asked whether patients knew their opinions about their prognosis differed from those of their doctors and the extent to which life expectancy influenced treatment options. “When people think they’ll live a very long time with cancer despite evidence to the contrary, they may end up taking more aggressive chemotherapy and agreeing to be placed on ventilators or dialysis,

paradoxically reducing their quality of life, keeping them from enjoying time with family and sometimes even shortening their lives,” Epstein said. “So it’s very important for doctors and patients to be on the same page.” The study... found 68% of patients rated their odds for survival differently from their doctors. Almost all patients were more optimistic than their doctor. Of the 68%, only 10% understood their views and their doctor’s differed. <http://goo.gl/wA8QSI>

Specialist Publications

‘Communicating prognostic uncertainty in potential end-of-life contexts: Experiences of family members’ (p.9) in *BMC Palliative Care*.

‘Physician-patient communication: An actionable target for reducing overly aggressive care near the end of life’ (p.10), in *JAMA Oncology*.

‘The current state of palliative care for patients cared for at leading U.S. cancer centers: The 2015 National Comprehensive Cancer Network palliative care survey’ (p.11), in *Journal of the National Comprehensive Cancer Network*.

1. ‘Determinants of patient-oncologist prognostic discordance in advanced cancer,’ *JAMA Oncology*, 14 July 2016. <http://goo.gl/CEvikm>

Younger seniors amass more end-of-life care than oldest Americans, study finds

KAISER HEALTH NEWS | Online – 14 July 2016 – Americans in their 80s and 90s are not the ones amassing the largest medical bills to hold off death, according to a new analysis that challenges a widely held belief about the costs of end-of-life care. Younger seniors – those with potentially longer expectancies – are. Medicare claims data for 2014 for beneficiaries who died the same year shows that average Medicare spending per person peaked at age 73 – at \$43,353. That compared with \$33,381 per person for 85-year-olds and among 90-year-olds, \$27,779 per person. Kaiser researchers said that their findings suggest that providers, patients and their families may favor more costly, lifesaving care for younger seniors, and turn to hospice care when patients are older. <http://goo.gl/YGey8l>

Noted in Media Watch, 20 June 2016, #467 (p.9):

- *HEALTH AFFAIRS* | Online – 15 June 2016 – **‘Identification of four unique spending patterns among older adults in the last year of life challenges standard assumptions.’** The assumption that health care spending skyrockets at the end of life might suggest that policy makers should target the last few months of life to control costs. However, spending patterns leading up to death have not been fully examined. <http://goo.gl/TEZrGr>

Cont.

Related

- *U.S. NEWS & WORLD REPORT* | Online – 14 July 2016 – ‘**10 things seniors should know about hospice.**’ Unfortunately, not everyone who is eligible makes use of hospice. “The truth is half of patients never get hospice at all,” says Joe Rotella, chief medical officer with the American Academy of Hospice & Palliative Medicine. “What we see is patients either avoid hospice or call it very late.” Some people may not use hospice because they are unaware or misunderstand it. Other times, people may not want to go into hospice because it means ending all attempts to cure... <http://goo.gl/CHxgGu>

Palliative care sometimes adds to families’ stress burden, study finds

KAISER HEALTH NEWS | Online – 14 July 2016 – Palliative care (PC) counseling from trained specialists is not routinely needed for all families of patients with chronic critical illnesses and sometimes it might worsen their emotional distress, cautions a recent study.¹ Habitually providing scarce PC services to cases indiscriminately may be ineffective when the meetings are limited to just one or two sessions, reported researchers... Family caregivers were no less depressed or anxious when they received only routine counseling from staff members in intensive care units (ICU), researchers found. With further support and training, ICU teams could deliver primary PC for surrogate decision makers of some patients, they suggested. <http://goo.gl/Tdz4ct>

1. ‘Effect of palliative care-led meetings for families of patients with chronic critical illness: A randomized clinical trial,’ *Journal of the American Medical Association*, 2016;316(1):51-62. [Noted in Media Watch, 11 July 2016, #470 (p.15)] <http://goo.gl/YnECmQ>

More older Americans cared for at home

MICHIGAN | U.S. News & World Report – 12 July 2016 – More older Americans with chronic health problems are opting to live at home, relying on help from family, paid caregivers or friends, a new study finds.¹ In 2012, half of seniors with a disability had some type of home health care, an increase from 42% in 1998, researchers found. If rates from this Michigan study are representative of the nation as a whole, more than 3.1 million more American seniors had home help in 2012 than in 1998... The sharpest increase in home care was observed among seniors with milder disabilities. The researchers also found that paid caregiving accounted for the biggest jump in home health aid, although more seniors also reported relying on spouses and adult children. The percentage using friends for care remained stable. Public policy and the health care system need to pay more attention to caregivers to make sure they’re supported.... This is especially true for unpaid family members and friends... <http://goo.gl/PPshoU>

1. ‘Trends in caregiving assistance for home-dwelling, functionally impaired older adults in the U.S., 1998-2012,’ *Journal of the American Medical Association*, 2016; 316(2):218-220. <http://goo.gl/SLBrE9>

Doctor shortage affecting local hospices

NORTH CAROLINA | Fox 8 News (Lexington) – 12 July 2016 – With a growing population of older Americans, the need for more end-of-life care is growing too. But it’s a field doctors just aren’t going into. “There’s simply not enough physicians that specialize in hospice and palliative medicine,” said Dr. Jennifer Davis, medical director for Hospice of Davidson County. “I do think it’s a calling to do this kind of work; you have to have a lot of compassion, communication skills, and excellent skills to keep [patients] comfortable.” To help fill the gap Dr. Davis has turned to medical residents. According to the American Academy of Hospice & Palliative Medicine ... between 8,000 to 10,000 physicians specialists are needed to meet the demands of hospice nationwide, but only about 4,500 are specializing in the field. By having more residents working here, Dr. Davis hopes it will help more see the joy that comes from helping those at the end of life. A specialty many doctors may have to provide anyway as the aging population grows. <http://goo.gl/Rfbs7u>

Cont.

Selected articles on the palliative care workforce in the U.S.

- *ANNALS OF INTERNAL MEDICINE* | Online – 20 October 2015 – ‘**Evolving the palliative care workforce to provide responsive, serious illness care.**’ The U.S. is currently in the midst of a national crisis in providing accessible and responsive palliative care due to a shortage of professionals trained to provide this care. [Noted in Media Watch, 26 October 2015, #433 (p.8)] <http://goo.gl/6LGk3X>
- *HEALTH LEADERS* | Online – 13 July 2012 – ‘**Palliative care challenged by physician shortage.**’ There is about one cardiologist in the U.S. for every 71 people experiencing a heart attack; one oncologist for every 141 newly diagnosed cancer patients; and, only one palliative care physician for every 1,200 people living with a life-threatening illness. [Noted in Media Watch, 16 July 2012, #262 (p.10)] <http://goo.gl/0IKQHB>

Selected articles on palliative care education in the U.S.

- *JOURNAL OF CANCER EDUCATION* | Online – 9 December 2014 – ‘**Inadequacy of palliative training in the medical school curriculum.**’ The literature expresses concerns about the varied and non-uniform approach to palliative care training across medical schools. The authors recommend the development of more assessment tools in order to aid in the standardization of curriculum involving end-of-life care. [Noted in Media Watch, 15 December 2014, #388 (p.13)] <http://goo.gl/7JLhxb>
- *MEDICAL EDUCATION*, 2014;48(1):59-66. ‘**Palliative care education in U.S. medical schools.**’ A review of U.S. medical school surveys reveals varied and uneven approaches. Palliative care competencies are too complex and universally important to be relegated to a minimum of classroom time, random clinical exposures, and the hidden curriculum. [Noted in Media Watch, 23 December 2013, #337 (p.15)] <http://goo.gl/H7q4tf>

International

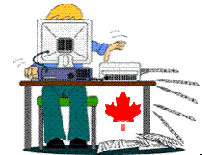
Dying and homeless – where do you go?

Call for funds for a 20-bed refuge in Wollongong Central Business District

AUSTRALIA (New South Wales) | *The Illawarra Mercury* (Wollongong) – 15 July 2016 – A month ago John (not his real name) was given three months – at most – to live. Suffering end stage liver disease due to alcohol abuse and hepatitis C ... the 44-year-old’s life expectancy was “measured in weeks, perhaps two to three months at most.” Yet on Monday, John was discharged from Wollongong Hospital; deemed ineligible for palliative care. He’d heard of the Wollongong Homeless Hub, so walked two kilometres from the hospital to the Kenny Street service. He told workers he was scared he’d have no crisis accommodation after discharge; he was afraid of “dying on the streets.” <http://goo.gl/Lzaa1R>

N.B. Selected articles on end-of-life care for the homeless are noted in Media Watch 14 March 2016, #453 (pp.14-15).

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.¹ 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>

1. Ashpole BR. ‘Communications with the Public, Politicians, and the News Media,’ *Oxford Textbook of Palliative Medicine*, 5th Edition (pp.357-359), Oxford University Press, 2015. <https://goo.gl/Vi07RS>.

Palliative care: The other opioid issue

NATURE | Online – 13 July 2016 – Opioids have been a hot potato since the 1961 United Nations Single Convention on Narcotic Drugs. The U.S.-led war on drugs that followed resulted in widespread reluctance to prescribe and supply opioids for fear patients would become addicted or overdose, or drug cartels would divert opioids to the black market. [Jim] Cleary [oncologist and palliative care specialist at the University of Wisconsin-Madison] says countries such as the U.S. have an “unbalanced” opioid situation, and abuse in these countries has distorted policies elsewhere, restricting legitimate access. More than 5 billion people worldwide cannot get the medical opioids they need. That is a staggering amount of unnecessary agony. Cleary has been working with activists such as [pharmacologist Ravindra] Ghooi and [M.R.] Rajagopal [founder of Pallium India] advocating policies that recognize pain relief as a human right. Such work is slowly reshaping some national drug policies, but changing the status quo entails more than just arguing that patients have a right to opioids – campaigners must also help governments around the world to chart a course to the safe supply of these powerful painkillers. <http://goo.gl/5dqYMr>

N.B. Selected articles on the availability and accessibility of opioids are noted in Media Watch, 23 November 2015, #437 (p.3). See ‘Availability of Opioid Painkillers,’ in ‘2015 Quality of Death Index’ (Figure 5.2, p.42), Economist Intelligence Unit, October 2015. [Noted in Media Watch, 26 October 2015, #433 (p.12)] <http://goo.gl/smDyHy>

End-of-life care in Ireland

Dying at home not open to dementia patients

IRELAND | *The Irish Examiner* (Linn Dubh) – 12 July 2016 – Only one in 20 dementia patients who die each year pass away at home, research by the Irish Hospice Foundation (IHF) shows.¹ Of the 4,200 people with dementia who die in Ireland each year, only 210, about one in 20, die at home while 2,310 die in residential care settings, and a further 1,680 die in acute hospitals. That contrasts with the one in four of the general population who die at home, which in itself is far fewer than the three out of every four who say they would like to die at home. The IHF’s Nurses for Night Care service reaches about half of the dementia patients who die at home each year, but demand for the service is growing. <http://goo.gl/j8mwnz>

1. ‘Supporting people with dementia to die at home, Irish Hospice Foundation Brief Report, July 2016. <http://goo.gl/RwIDVG>

N.B. Additional articles on end-of-life care for people living with dementia are noted in Media Watch, 4 July 2016, #469 (pp.15-16).

Why is Switzerland behind in palliative care?

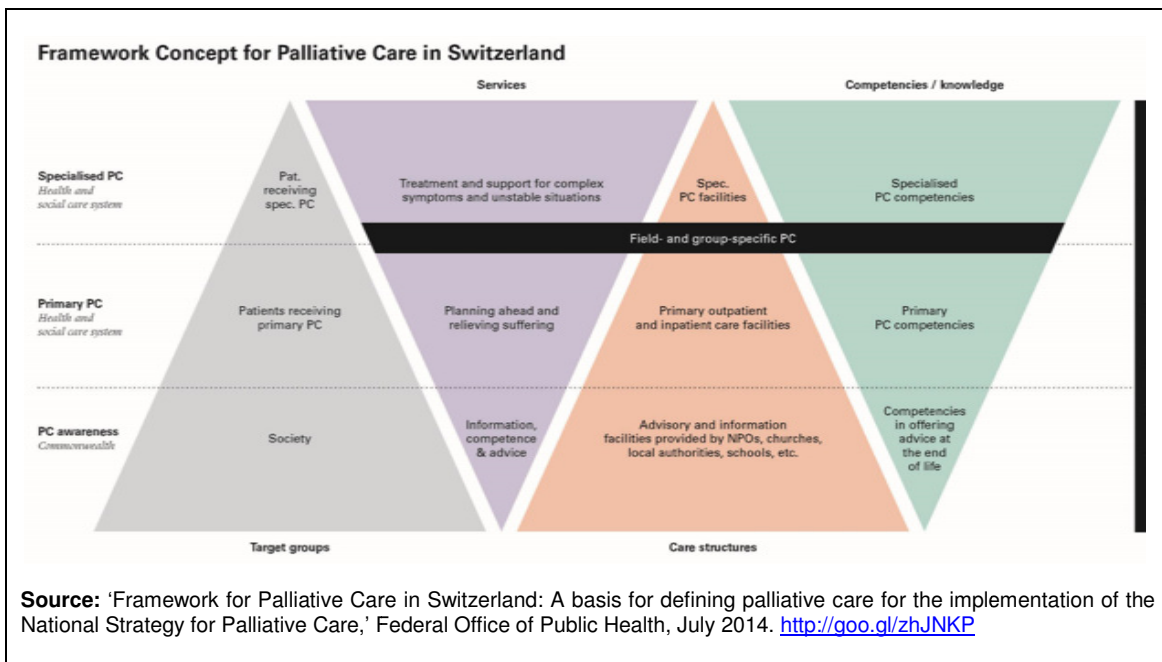
SWITZERLAND | Swissinfo.ch (Bern) – 11 July 2016 – Switzerland has a short history of encouraging palliative care (PC), with more awareness of curative treatment, acute care and assisted suicide as end of life options. Earlier this year, Steffen Eychmüller was appointed Professor of Palliative Care – only the second such position in Switzerland – at the University of Bern. The need for PC – well-planned, multidisciplinary support for terminally ill patients and their families – will increase, given the ageing population. And so will the costs of this care. But these can be lowered if PC is properly planned, as is the case in countries like Australia and the U.K. <http://goo.gl/Szg97H>

Selected articles on end-of-life care in Switzerland

- *JOURNAL OF COMMUNITY & PUBLIC HEALTH NURSING* | Online – 31 May 2016 – ‘**Interprofessional collaboration between family doctors and nurses at the end of life. Challenges of community-based palliative care in Switzerland.**’ This study shows that interprofessional collaboration in community-based palliative care is highly challenging due to many different factors. The authors provide recommendations how to support and instruct collaborative processes between family doctors and nurses in end-of-life care. [Noted in Media Watch, 20 June 2016, #467 (p.11)] <http://goo.gl/kUfEkf>

Cont.

- *BAOJ PALLIATIVE MEDICINE* | Online – 27 August 2015 – ‘**General practice and palliative care: The Swiss approach.**’ This article summarises the current state of end-of-life care (EOLC) and general practice in Switzerland. It focuses on public awareness concerning EOLC, outlines political actions to strengthen EOLC, links general practice and EOLC, shows the situation in undergraduate and post-graduate training, and reimbursement and financing of end-of-life treatments. [Noted in Media Watch, 31 August 2015, #425 (p.11)] <http://goo.gl/SK1W8q>
- *PRIMARY HEALTH CARE*, 2015;5(1):1-5. ‘**Conditions of palliative home care: The case of family physicians in Switzerland.**’ Family physicians (FPs) can be supported in palliative home care by the availability of guidelines and advance directives, community-based palliative care structures, education and training, as well as remuneration of palliative home care services. Availability and use of guidelines as well as advance directives is small in general practice and FPs care and treatment at the end of life only marginally supported by ambulant care structures, especially in rural areas. [Noted in Media Watch, 25 May 2015, #411 (p.14)] <http://goo.gl/uiIzsk>



Related

- *SWITZERLAND* | Swissinfo.ch (Bern) – 11 July 2016 – ‘**Switzerland, leading the way in assisted suicide?**’ Palliative care seeks to give some transparency to the issues of confronting death and the wish to die. It also aims to remove taboos. There is an alternative. Suicide can be a long-term burden for loved ones and end up being an extremely ambivalent act for the patient. Do I want to go or not? It is right that the patient’s wish is of the highest importance. But this wish has to be clear and this is not always the case. This is where palliative support comes in. Experience shows that the desire for suicide not only lessens as the illness progresses, but also lessens with the right information and support. Patients don’t have to make a decision on their own in a moment of weakness. <http://goo.gl/mbnN6S>

N.B. Switzerland was ranked 15th of the 80 countries surveyed in the ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/JsSbW3>

Cont.

Britain's sickest children denied vital care in appalling National Health Service funding betrayal

U.K. (England) | *The Daily Mirror* – 9 July 2016 – Four in five local authorities in England shockingly fail to plan or fund essential care for youngsters with life-threatening conditions, according to new statistics obtained by the *Sunday Mirror*. Families already under pressure caring for seriously ill children are denied out-of-hours community nursing staff, respite care and equipment such as wheelchairs. The worrying revelations, obtained under the Freedom of Information Act, come as yet further cuts to National Health Service (NHS) services are feared in the wake of Brexit. Statistics reveal many families face massive obstacles to get the required care. Children's charity Together For Short Lives received Freedom of Information replies from 144 local authorities and 187 clinical commissioning groups across England after asking what resources were put into palliative care for children.^{1,2} <http://goo.gl/1IU4op>

1. 'Public call to ensure children with short lives aren't short changed,' Together For Short Lives, July 2016. <http://goo.gl/2PNSDs>
2. 'Seriously ill children face a postcode lottery,' Together For Short Lives, July 2016. <http://goo.gl/89mgd9>

Noted in Media Watch, 23 May 2016, #465 (p.8):

- U.K. (England) | *The Northern Echo* (Buckinghamshire) – 19 May 2016 – '**Councils and GP groups "overlooking local end-of-life care needs."**' The charity Hospice UK used the Freedom of Information Act to find out how well councils and National Health Service groups assessed the needs of dying people in their communities. The results showed more than a third (34%) of health and wellbeing boards, which are run by councils, do not consider the needs of dying people in their assessments of local needs. <http://goo.gl/1K8sDk>

Specialist Publications

End-of-life care in Argentina

Opinions of members of the National Civil (Family Proceedings) and Criminal Courts in withholding or withdrawing of life support situations in pediatric

ARCHIVOS ARGENTINOS DE PEDIATRÍA, 2016;114(4):298-304. The possibility of sustaining life functions makes it difficult to distinguish between a dying patient and a patient with chances of survival, raising a dilemma for everyone around them. On the one side, continuing with life support techniques that would only extend an irreversible process and result in physical and psychological damage and harm their dignity. On the other side, withholding or withdrawing life support without an adequate reflection and diagnostic-therapeutic effort which may lead to the death of a potentially recoverable child. In addition, making decisions in this context implies facing barriers that hinder the possibility of pursuing the patient's best interest. Among such barriers, the fear of litigation plays a major role. To what extent is this fear justified? Forty-five percent of survey respondents considered that decisions made involved some form of crime. <http://www.ncbi.nlm.nih.gov/pubmed/27399006>

N.B. For links to the full text of either the Spanish or English language version of this journal article, click on <http://goo.gl/BOq4pb> and scroll down to the article.

Media Watch: Palliative Care Network-e Website

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

Request for organ donation without donor registration: A qualitative study of the perspectives of bereaved relatives

BMC ETHICS | Online – 12 July 2016 – The decision not to consent to donation is attributed to contextual factors bad timing of the request; feeling overwhelmed; insufficient support from other relatives or health care professionals; little knowledge on organ donation (especially on the length of the procedure). These factors are more heavily weighted when the preference of the deceased is unknown. Even when it is informally known that the deceased favoured organ donation, relatives may ignore that wish in the absence of official registration. Healthcare professionals could provide better support for the relatives prior to the donation request, address their informational needs and adapt their message appropriately, especially when relatives are not familiar with talking about death themes. The study findings show that more satisfaction regarding the decision can be expected if relatives experience decoupling, and consecutively more consent when the possibility of donation after circulatory death is offered to those families who otherwise would have refused brain death donation. <http://goo.gl/wKu7U9>

Noted in Media Watch, 9 July 2012, #261 (p.9):

- *END OF LIFE JOURNAL*, 2012;2(2). ‘**The barriers to organ and tissue donation in palliative care.**’ This article explores the involvement of palliative care patients in decisions about donating their tissues, why families may be reluctant to consent to donating organs/tissues of deceased loved ones, and reasons why nurses are wary of discussing the possibility of donation with patients and/or their next of kin. <http://goo.gl/dOua0l>

Communicating prognostic uncertainty in potential end-of-life contexts: Experiences of family members

BMC PALLIATIVE CARE | Online – 12 July 2016 – This study found that nearly half of all family members wanted more information about possible outcomes of care, including knowledge that the patient was “sick enough to die.” Prognostic uncertainty was often poorly communicated, if at all. Inappropriate techniques included information being cloaked in confusing euphemisms, providing unwanted false hope, and incongruence between message and the aggressive level of care being provided. In extreme cases, these techniques left a legacy of uncertainty and suspicion. Family members expressed an awareness of both the challenges and benefits of communicating prognostic uncertainty. Most importantly, respondents who acknowledged that they would have resisted (or did) knowing that the patient was sick enough to die also expressed a retrospective understanding that they would have liked, and benefitted, from

more prognostic information that death was a possible or probable outcome of the patient’s admission. Family members who reported discussion of prognostic uncertainty also reported high levels of effective communication and satisfaction with care. They also reported long-term benefits of knowing the patient was sick enough to die. <http://goo.gl/xfQIHv>

How personal attitudes to death influence end-of-life care

CANCER NURSING PRACTICE | Online – 5 July 2016 – In this American study, researchers conducted semi-structured interviews with clinical oncologists, oncology nurses and physician assistants to better understand how personal and professional perspectives of death affect, and are influenced by, care and communication with the dying. <http://goo.gl/V2h5fv>

Noted in Media Watch, 4 July 2016, #469 (p.3)

- U.S. | *The New York Times* – 1 July 2016 – ‘**What doctors know about how bad it is, and won’t say.**’ Experts have repeatedly urged doctors to talk about the elephants in the room, especially at the end of life. But two recent studies show how achingly slow progress has been.^{1,2} Even terminally ill patients still receive scant information, researchers have found, while family members acting for ICU patients commonly contend with confusion and misinformation. The studies uncover some reasons for the disconnect. Doctors, it seems, shouldn’t get all the blame. <http://goo.gl/sXnslm>

Cont.

1. 'Discussions of life expectancy and changes in illness understanding in patients with advanced cancer,' *Journal of Clinical Oncology*, 23 May 2016. <http://goo.gl/K2szxn> [Noted in Media Watch, 30 May 2016, #464 (p.3)]
2. 'Prevalence of and factors related to discordance about prognosis between physicians and surrogate decision makers of critically ill patients,' *Journal of the American Medical Association*, 2016;315(19): 2086-2094. [Noted in Media Watch, 2016, #463 (p.4)] <http://goo.gl/VG6Xf3>

Related

- *JAMA INTERNAL MEDICINE* | Online – 11 July 2016 – '**Improving communication about serious illness in primary care.**' Literature regarding the role that primary care plays in communication focused primarily on the ambiguity about whether primary care clinicians or specialists are responsible for initiating conversations, the benefits of primary care clinicians and specialists conducting conversations, and the quantity and quality of discussions. Timely and effective communication about serious illness in primary care is hampered by key clinician barriers, which include deficits in knowledge, skills, and attitudes; discomfort with prognostication; and lack of clarity about the appropriate timing and initiation of conversations. System failures in coordination, documentation, feedback, and quality improvement contribute to lack of conversations. <http://goo.gl/sW8R7R>
- *JAMA ONCOLOGY* | Online – 14 July 2016 – '**Physician-patient communication: An actionable target for reducing overly aggressive care near the end of life.**' Despite advances in screening and management, more than half a million Americans will die from cancer this year. Observational studies indicate that many of these patients will receive aggressive treatments near the end of life, raising concerns about deleterious effects on quality of life and costs, along with questions about what factors contribute to this unfortunate pattern. Given that patients' preferences for aggressiveness of care can depend on their understanding of prognosis, a key question is whether physician-patient communication about prognosis is sufficiently robust, given that cancer care near the end of life is a situation that can naturally challenge the capacity of even the most highly skilled clinician. <http://goo.gl/P8USoM>
- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 11 July 2016 – '**Barriers to quality end-of-life care for patients with blood cancers.**' In this large national cohort of hematologic oncologists, standard end-of-life (EOL) quality measures were highly acceptable. The top barrier to quality EOL care reported was unrealistic patient expectations, which may be best addressed with more timely and effective advance care discussions. Other highly-ranked barriers: "clinician concern about taking away hope" (71.3%), and "unrealistic clinician expectations" (59.0%). <http://goo.gl/ZrtxyJ>

The effect of bereavement groups on grief, anxiety, and depression: A controlled, prospective intervention study

BMC PALLIATIVE CARE | Online – 12 July 2016 – Before the bereavement group intervention, most respondents (81 %) reported levels of severe grief. Participants did not fare significantly better than non-participants. Those who did not want to participate reported less grief and anxiety than both participants and non-participants who had wanted to participate. No differences in levels of depression were detected between any groups either before or after the intervention. Open-ended questions revealed anonymous, mostly positive effects of participation in bereavement groups which were not captured by the questionnaires measuring grief, anxiety, and depression. This underlines the need for a qualitative approach to gain better understanding and more in-depth insights of the subjective benefits experienced from participation. <http://goo.gl/s9SQBj>



World hospice &
palliative care day

'Living and dying in pain: It doesn't have to happen'

8 October 2016

<http://goo.gl/iKZH4k>

End-of-life care in hospital is everyone's business

BRITISH MEDICAL JOURNAL | Online – 14 July 2016 – About 500,000 people die each year in England and Wales. Yet the U.K. has only an estimated 519 specialist palliative medicine consultants and fewer than 5,000 crucial specialist palliative care nurses. A national audit of end-of-life care in hospital by the Royal College of Physicians found a median of one palliative medicine consultant and five nurse specialists for every 1,000 adult hospital beds.¹ Some of us will die suddenly. Others may have only weeks to prepare after an unexpected terminal diagnosis, but most will die with or from long term conditions. Multiple contacts with health and care practitioners give us many opportunities to discuss and plan for our deaths. Despite concerted campaigns to improve care in the last year of life and get more people to make advance plans, these opportunities are missed. Only 4% of 9,000 patients in the hospital audit had any form of advance plan made before admission. Nearly half of us die in hospital. We don't have sufficient hospice places, staff, or funding to support everyone to die in other settings. Some people may wish to stay in hospital at the end, and a death in hospital need not be a bad one. <http://goo.gl/cCHhXt>

1. 'National Care of the Dying Audit of Hospitals,' Royal College of Physicians, 14 May 2014. [Noted in Media Watch, 19 May 2014, #358 (p.3)] <http://goo.gl/oOW4Sr>

A family requests that their grandmother, who does not speak English, is not informed of her terminal diagnosis

CLINICAL ETHICS | Online – 10 July 2016 – [This case study] focuses mostly on the issues of autonomy of patient and truth telling, but fails to highlight the most ethically salient feature of the case; the clinician did not talk to the patient. The case study notes that the patient spoke a dialect of Cantonese and felt that translation services might not have been readily available. This is unacceptable practice given the easy availability of professional telephone interpreters. In addition, it rendered the rest of the discussion academic as without a professional interpreter the clinician had no idea exactly what the family member who was interpreting was saying to their grandmother. This is an excellent case to discuss the ethics of the care of culturally and linguistically diverse people and the importance of interpreter use in patients with limited English proficiency. This case is also a good illustration of a limitation of clinical ethics committees. A common norm is that there is no patient involvement in the deliberations of the committee. Without any patient involvement, it is very difficult to understand the patient's position (well illustrated in this case) and impossible to engage in dialogue to find an agreed management plan. <http://goo.gl/4qN8eJ>

Noted in Media Watch, 20 June 2016, #467 (p.15):

- *PSYCHO-ONCOLOGY* | Online – 15 June 2016 – '**Promoting quality care in patients with cancer with limited English proficiency: Perspectives of medical interpreters.**' Language barriers and underuse of medical interpreters have been widely identified as obstacles to equitable and quality care; however, the rate of professional interpreter use remains unknown. Further, no known study has explored patients' reasons for refusing interpreter assistance, rather, existing studies have largely focused on physician and parental barriers. <http://goo.gl/VSe2l8>

N.B. Selected articles on patients with limited English proficiency in the context of end-of-life care are noted in this issue of Media Watch.

The current state of palliative care for patients cared for at leading U.S. cancer centers: The 2015 National Comprehensive Cancer Network palliative care survey

JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK, 2016;14(7):859-866. A total of 22 of 26 institutions responded (85%). All respondents (100%) reported an inpatient palliative care (PC) consult service (staffed by an average of 6.8 full-time equivalents [FTEs], seeing 1,031 consults/year with an average length of stay [LOS] of 10 days). A total of 91% of respondents had clinic-based PC (with an average of 469 consults/year, staffed by an average of 6.8 FTEs, and a 17-day wait time). For clinics, a co-management care delivery model was more common than strict consultation. Home-based PC (23%)

Cont.

and inpatient PC units (32%) were less prevalent. Notably, 80% of institutions reported insufficient PC capacity compared with demand. Across PC settings, referrals for patients with solid tumors were more common than for hematologic malignancies. Automatic or “triggered” referrals were rare. The most common services provided were symptom management (100%) and advance care planning (96%). Most programs were funded through fee-for-service billing and institutional support. Partnerships with accountable care organizations and bundled payment arrangements were infrequent. PC program data collection and institutional funding for PC research were variable across institutions. Despite the prevalence of PC inpatient and clinic services among participating Network member institutions, PC demand still exceeds capacity. Opportunities exist for expansion of home-based PC and inpatient PC units, optimizing referrals, research, and payer collaborations. <http://goo.gl/6Y1x8S>

Related

- *JAMA INTERNAL MEDICINE* | Online – 11 July 2016 – ‘**Trends in cancer-center spending on advertising in the U.S., 2005 to 2014.**’ Between 2005 and 2014, cancer centers in the U.S. substantially increased their advertising spending directed at consumers. For some patients and families, cancer-center advertising may constitute a major source of information, raising concerns in view of evidence that the content of some advertising lacks balance. Spending on advertising is not a measure of quality of care, and physicians and cancer-care organizations should help patients make informed cancer treatment decisions. The effect of cancer-center advertising on the quality and costs of cancer care should be better understood. <http://goo.gl/vnJxA>

Noted in Media Watch, 18 May 2015, #410 (p.6):

- *FORBES* | Online – 11 May 2015 – ‘**What do cancer centers think patients are looking for?**’ Researchers analyzed cancer center advertisement from U.S. consumer magazines and television networks.¹ Advertisements frequently target people’s desire for hope, for miracles, and for a healthcare team that will fight against all odds. Less often, the ads tout quality of life issues and, even more rarely, emphasize the part of medical care which deserves a much larger role in cancer treatment – shared decision-making. Only 2% of cancer center advertisements mention palliative care. <http://goo.gl/6p6v9r>

1. ‘What are cancer centers advertising to the public?: A content analysis of cancer center advertisements,’ *Annals of Internal Medicine*, 2014;160(12):813-820. [Noted in Media Watch, 9 June 2014, #361 (p.13)] <http://goo.gl/IIgsxU>

Resource use and health care costs of chronic obstructive pulmonary disease patients at the end of life: A systematic review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 8 July 2016 – Patients with chronic obstructive pulmonary disease (COPD) in their final months of life potentially place a high burden upon health care systems. Concrete knowledge about resources used and costs incurred by those patients at the end of life is crucial for policymakers. Ten manuscripts fulfilled the [authors’] inclusion criteria. Three, five and two studies described European, North American and Asian health care settings, respectively. All ... were published between 2006 and 2015. The authors’ observed variable resource use, an increased number of hospitalizations, intensive care unit stays, primary care consultations and medication prescriptions, as well as a lack of utilization of formal palliative care services... Specific cost items were not well described. The high use of health care resources in COPD patients in the final months of life suggests a focus on prolonging life and a tendency towards aggressive care. <http://goo.gl/kONp25>

Noted in Media Watch, 15 February 2016, #449 (p.9):

- *BMC PALLIATIVE CARE* | Online – 13 February 2016 – ‘**Towards integration of palliative care in patients with chronic heart failure and COPD: A systematic literature review of European guidelines and pathways.**’ The results of this study illustrate that there is a growing awareness for the importance of palliative care in patients with advanced chronic heart failure and chronic obstructive pulmonary disease. At the same time, however, they signal the need for the development of standardized and conceptually unambiguous strategies so existing barriers are alleviated. <http://goo.gl/YSVbDV>

Cont.

Noted in Media Watch, 25 May 2015, #411 (p.14):

- **AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE** | Online – 17 May 2015 – ‘**Evaluation of the patterns of care provided to patients with COPD compared to patients with lung cancer who died in hospital.**’ The authors compared the end-of-life care provided patients with chronic obstructive pulmonary disease versus patients with lung cancer who died in hospital over a 12-month period... Patients with COPD received less palliative care services and underwent more diagnostic tests and received more life-prolonging measures. <http://goo.gl/YpTdqI>


Bodies and ceremonies: Is the U.K. funeral industry still fit for purpose?

MORTALITY | Online – 5 July 2016 – Funerals may be defined as the ritual or ceremonial disposal of a body; the two essential components are therefore a body and a ceremony/ritual. The U.K. funeral industry’s structure revolves around those who manage the body rather than the ceremony. This structure, in which the client contracts with a funeral director who subcontracts the funeral ceremony to a priest or celebrant, was fit for purpose in the nineteenth century when most of the family’s choices concerned hardware (coffins, carriages, horses, etc.) for the body’s containment and transport. It may no longer be fit, however, in the twenty-first century when, for many families, the major choices concern how to personalise the ceremony. In theory, it might therefore now be more appropriate for at least some families first to contract with a celebrant, who would then subcontract the body’s care, storage and transport, reversing who is contractor and who is subcontractor. In practice, factors on both the demand and supply side keep the industry’s present structure in place. Though the past 25 years have seen much innovation, conservative innovations such as celebrancy and green burial that accept the industry’s existing structure have proved more successful than radical innovations that challenge it. Implications for funeral costs and funeral poverty are discussed. <http://goo.gl/40nQBA>

Measuring the quality of life of people at the end of life: The McGill Quality of Life Questionnaire – Revised

PALLIATIVE MEDICINE | Online – 13 July 2016 – The McGill Quality of Life Questionnaire has been widely used with people with life-threatening illnesses without modification since its publication in 1996. With use, areas for improvement have emerged; therefore, various minor modifications were tested over time. The McGill Quality of Life Questionnaire – Revised consists of 14 items (plus the global quality of life item). A new Physical sub-scale was created combining physical symptoms and physical well-being and a new item on physical functioning. The Existential sub-scale was reduced to four items. The revised Support sub-scale, renamed Social, focuses more on relationships. The Psychological sub-scale remains unchanged. Confirmatory factor analysis results provide support for the measurement structure of the McGill Quality of Life Questionnaire – Revised. <http://goo.gl/bGfXsm>

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MW 487: Compromised autonomy: When families pressure patients to change their wishes

Download the complete issue (PDF 300 KB) [HERE](#)

JOURNAL OF HOSPICE & PALLIATIVE CARE | Online – 17 June 2015 | Living with a life-threatening illness is often deeply challenging. The complex medical and ethical issues that arise surrounding end-of-life decisions often bring difficult medical decisions. When patients are unable to express their wishes to make medical decisions that are not in line with previously held values, beliefs, or perspectives, autonomy is compromised. [Read more...](#)

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Appropriateness and avoidability of terminal hospital admissions: Results of a survey among family physicians

PALLIATIVE MEDICINE | Online – 12 July 2016 – Almost 14% of all terminal hospital admissions were considered to be potentially inappropriate, almost 14% potentially avoidable and 8% both, according to family physicians [i.e., study participants]. The terminal hospital admission was more likely to be considered potentially inappropriate or potentially avoidable for patients who had died of cancer, when the patient's life expectancy at the time of admission was limited, by family physicians who had had palliative care training at basic, postgraduate or post-academic level, and when the admission was initiated by the patient, partner or other family. <http://goo.gl/D6DHCV>

Noted in Media Watch, 18 April 2016, #458 (p.9):

- *HEART* | Online – 11 April 2016 – ‘**Homeward bound, not hospital rebound: How transitional palliative care can reduce readmission.**’ Transitional care programmes have emerged as a potential solution to avert readmissions by monitoring and supporting patients and caregivers for a limited period of time post-discharge. Programmes which incorporate home visits are effective at reducing all-cause readmission and mortality. <http://goo.gl/5ErH1H>

N.B. Selected articles on the avoidability of hospital readmissions in the context of end-of-life care are noted in Media Watch of 14 March 2016, #455 (p.12).

The impact of existential vulnerability for nursing home doctors in end-of-life care: A focus group study

PATIENT EDUCATION & COUNSELING | Online – 12 July 2016 – Nursing home doctors [i.e., study participants] experienced having to balance treatment compromises in order to assist patients' and families' preparation for death, with their sense of professional conduct. This was an arduous process demanding patience and consideration. Existential vulnerability also manifested as powerlessness mastering issues of life and death and families' expectations. Standard phrases could help convey complex messages of uncertainty and graveness. Personal commitment was balanced with protective disengagement on the patient's deathbed, triggering both feelings of wonder and guilt. End-of-life care training for nursing home doctors should include self-reflective practice, in particular addressing treatment compromises and professional conduct in the dialogue with patient and next-of-kin. <http://goo.gl/Zn9Go7>

Noted in Media Watch, 11 July 2016, #470 (p.15):

- *PATIENT EDUCATION & COUNSELING* | Online – 6 July 2016 – ‘**Shared decision-making as an existential journey: Aiming for restored autonomous capacity.**’ The fundamental uncertainty, state of vulnerability, and lack of power of the ill patient, imbue shared decision-making with a deeper existential significance and call for greater attention to the emotional and relational dimensions of care. Hence, the authors propose that the aim of shared decision-making should be restoration of the patient's autonomous capacity. <http://goo.gl/gxQU0c>

End-of-life care in Germany

Generalist palliative care for non-cancer patients: A review article

DER SCHMERZ | Online – 11 July 2016 – Four topics were identified: 1) Specific target groups (e. g., elderly patients, patients with advanced heart failure and pain); 2) Collaboration of general practitioners with other physicians and health professionals; 3) Qualifications in palliative care (PC); and, 4) Provision of primary PC. Most articles reviewed were related to the fourth topic and the sub-topic of barriers and facilitators of PC. Insufficient coordination of the persons involved was a barrier often discussed. Advanced care planning including concrete PC aspects at an early stage can be beneficial for both patients and professionals. <http://goo.gl/lyCaZS>

N.B. German language article.

Law, perception, and cultural cognition near the end of life

WASHBURN LAW JOURNAL (Washburn University, Kansas), 2016;55(3):597-636. It does indeed happen all the time; facts and opinions are all jumbled together. Facts are portrayed as opinions and opinions are portrayed as facts. Some “facts,” it turns out, are opinions, or at least are functions of perspectives and values rather than what a scientist would consider to be “fact.” Facts and opinions are confused a great deal among the general public regarding scientific matters, perhaps because truly understanding science requires a degree of expertise many people do not have. Neuroscience – the science of the brain and the nervous system – is ripe for such confusion: confusion, which can cause great upheaval in medical settings. For example, “the most extraordinary end-of-life case ever” involved a family dispute over what most consider a neuroscientific fact – the diagnosis of a young woman as being in a vegetative state – that erupted into a nationwide spectacle. The case of Theresa Marie Schiavo [1990-2005] prompted twenty-four-hour-a-day news coverage, public protests, state and federal legislative action, and a papal pronouncement. The resulting “culture war” over whether to withdraw her life-sustaining treatment was a vivid reminder of how differently opposing sides of a dispute can view “facts.” <http://goo.gl/75trXQ>

N.B. Click on pdf icon to access full text of the article.

Noted in Media Watch, 13 September 2010, #166 (p.13):

- *JOURNAL OF MEDICAL ETHICS*, 2010;36(9):571-573. ‘**How the public responded to the Schiavo controversy.**’ Opinions expressed in letters to the editor sampled strongly supported the use of living wills and strongly condemned public attention to the case as well as political interventions. Letters tended to be against withdrawal of life support, proxy consent and associated procedures as well as against court decisions and legal procedures. In comparison with reports written by journalists, letters to editors contained fewer controversial claims about Schiavo’s neurological condition and behavioural repertoire, but similar loaded language to describe withdrawal of life support. <http://goo.gl/4qk3zo>

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International

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

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

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

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

Asia

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

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

Canada

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

Europe

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

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

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

Worth Repeating

What evidence is there about the specific environmental needs of older people who are near the end of life and are cared for in hospices or similar institutions?

PALLIATIVE MEDICINE | Online – 19 November 2009 – Relatively little is known about the type of physical environment needed and preferred by patients aged 65 and over, with a prognosis of one year or less, who are receiving care in hospitals, care homes and hospices, and their families and staff. A literature review was conducted to identify and analyse evidence on this issue with twenty-nine papers meeting the inclusion criteria. The patients were found to have a wide range of views on their environment, but there was some variation between the views of patients and those of their families and staff. Four main themes emerged: 1) The physical environment should be “homely”; 2) It should support patients’ need for social interaction and privacy; 3) It should support the caring activities of staff, family members and patients; and, 4) It should allow opportunities for spiritual expression. It is evident the physical environment contributes significantly to the quality of life of older people with a life-limiting illness, and there is a need for more research in this area. Regular assessment of patients’ environmental needs should form part of care planning. [Noted in Media Watch, 23 November 2009, #124 (p.9)] <http://goo.gl/L5dui4>

N.B. Selected articles on the architectural design of hospices and palliative care facilities are noted in Media Watch, 28 July 2014, #368 (p.13).

Media Watch: Editorial Practice

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Something Missed or Overlooked?

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

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