# 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

The correlation between the quality of care and the quality of communication: Scroll down to <a href="Specialist Publications">Specialist Publications</a> and 'Interprofessional communication between oncologic specialists and general practitioners on end-of-life issues needs improvement' (p.10), in *Family Practice*.

### Canada

### Alberta home-care survey validates long-standing concerns with basic needs

ALBERTA | CBC News - 9 September 2016 - A comprehensive survey of seniors who use the home care system in Alberta has found high dissatisfaction in areas key to enabling older people to live in their own homes. Among the lowest-rated responses in the survey conducted by the Health Quality Council of Alberta were tasks of everyday living such as eating, getting dressed and using the bathroom. More than 7,100 home-care clients aged 65 and older responded to the survey, the first of its kind by the Council. It was done in collaboration with Alberta Health Services and Alberta Health. Results in those categories were slightly higher in the rural and less populated areas of Alberta. http://goo.gl/zarzy4

 '2015 Alberta Home Care Client Experience Survey,' Health Quality Council of Alberta, September 2016. http://goo.gl/4HTCL2

**N.B.** The report does not mention palliative or end-of-life care in the home care setting.

### U.S.A.

### What it feels like to die

THE ATLANTIC | Online – 9 September 2016 – James Hallenbeck, a palliative care specialist at Stanford University, often compares dying to black holes. "We can see the effect of black holes, but it is extremely difficult, if not impossible, to look inside them. They exert an increasingly strong gravitational pull the closer one gets to them. As one passes the 'event horizon,' apparently the laws of physics begin to change." What does dying feel like? Despite a growing body of research about death, the actual, physical experience of dying – the last few days or moments – remains shrouded in mystery. Medicine is just beginning to peek beyond the horizon. <a href="http://goo.gl/HB1syJ">http://goo.gl/HB1syJ</a>

### U.S. hospital palliative-care teams suffer staffing gaps

REUTERS HEALTH | Online - 9 September 2016 - Only a quarter of U.S. hospitals had complete, paid palliative care (PC) teams to help seriously ill patients manage pain, address emotional and spiritual needs, and discuss end-of-life wishes, a new study shows. 1 The Joint Commission, the major accreditor of American hospitals, calls on hospitals to deliver PC to Americans suffering from chronic and serious illnesses with paid teams including a doctor, a nurse, a social worker and a chaplain. But according to ... data from 410 hospital programs in 2012 and 2013 showed gaping holes in the service. "A lot of these programs are running on a shoestring," lead author Joanne Spetz said in a telephone interview. Spetz, an economics professor, directs the Health Workforce Research Center at the University of California, San Francisco. She said her study was the first to mine hospital PC staffing data, and she was struck by the fact that about half of the programs failed to pay for a

registered nurse or a social worker. About a third of the programs had no paid medical doctor or osteopath, and nearly two-thirds had no funded chaplain, the study found. <a href="http://goo.gl/bEUikE">http://goo.gl/bEUikE</a>

### **Specialist Publications**

- 'Attitudes of Muslims living in the U.S. toward long-term care decisions and diagnosis disclosure for elderly family members' (p.11), *Journal of the American geriatric Society*.
- 'Effect of a home-based palliative care program on healthcare use and costs' (p.11), in *Journal of the American Geriatric Society*.
- "Mystery shopper" study finds barriers to palliative care at major cancer centers' (p.13), in *MedicalXpress*.
- 'Few hospital palliative care programs meet national staffing recommendations,' Health Affairs, 2016; 35(9):1690-1697. <a href="http://goo.gl/zs3UUr">http://goo.gl/zs3UUr</a>

Noted in Media Watch 16 November 2015, #436 (p.11):

■ JOURNAL OF PALLIATIVE MEDICINE | Online – 10 November 2015 – 'Impact of staffing on access to palliative care in U.S. hospitals.' Hospital-based palliative care (PC) programs [i.e., study participants] reported an average service penetration of 4.4%. Higher staffing levels were associated with higher service penetration; higher service penetration was associated with shorter time to initial PC consultation. http://goo.gl/aoEJfN

### Writing a "last letter" when your healthy

THE NEW YORK TIMES | Online – 7 September 2016 – Over the last 15 years, as a geriatrics and palliative care doctor, I have had candid conversations with countless patients near the end of their lives. The most common emotion they express is regret: regret that they never took the time to mend broken friend-ships and relationships; regret that they never told their friends and family how much they care; regret that they are going to be remembered by their children as hypercritical mothers or exacting, authoritarian fathers. And that's why I came up with a project to encourage people to write a last letter to their loved ones. It can be done when someone is ill, but it's really worth doing when one is still healthy, before it's too late. <a href="http://goo.gl/EyD96X">http://goo.gl/EyD96X</a>

# 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: <a href="http://goo.gl/5CHoAG">http://goo.gl/5CHoAG</a>

### How dementia makes it harder to offer end-of-life comfort

THE WASHINGTON POST | Online – 4 September 2016 – Families often describe a cancer patient's last months as stressful, but meaningful. That isn't the case with dementia patients because the



disease changes the patient's personality and causes behavior issues, according to George Demiris, one of the authors of a recent study and a professor of biobehavioral nursing and health systems at the University of Washington's School of Nursing in Seattle. Caregivers who took part in the study said they worried their loved ones were in pain but were unable to properly express it – and that possibility disturbed them, according to interviews with families taking care of dementia patients in their last stage of life. Multiple participants described feeling frustrated and defeated by patients' cognitive difficulties and changing emotions. Some described the patients as "prisoners" inside their bodies. http://goo.gl/yggfgm

1. 'Pain in hospice patients with dementia: The informal caregiver experience,' *American Journal of Alzheimer's Disease & Other Dementias*, 2016;31(6):524-529. http://goo.gl/mUQh47

#### Related

■ THE NEW YORK TIMES | Online – 2 September 2016 – 'Love and burnout: Caregivers, too, need care.' The health care system is mainly focused on patients; caregivers who are slowly burning out can slip by unnoticed until it is too late. Researchers have found that the human immune system can be weakened by stress and strain for up to three years after caregiving ends. As a result, caregivers can be more prone to having serious illnesses. Yet they rarely complain. http://goo.gl/Vz0D6Y

Noted in Media Watch 7 September 2015, #426 (p.18, under 'Worth Repeating'):

CANADIAN JOURNAL OF PSYCHIATRY, 2004;49(6):359-365. 'Palliative care for families: Remembering the hidden patients.' The illness experience profoundly affects family members' psychological and physical health; recognition of this has coined the term "hidden patients." The authors define the family, emphasizing a systems approach to family care. They describe the impact of the illness on the family in terms of family members' health, family communication issues, psychological issues, needs for information, physical care demands, and family costs of caring. https://goo.gl/UsZ8FL

### Palliative care can help ease symptoms

GEORGIA | *The Augusta Chronicle* – 3 September 2016 – Palliative care (PC) has at times been incorrectly associated with giving up on treatment. Rather, PC teams spend time to understand the patient and advocate for the patient's goals, be that for a surgical pump or transplant, or continuing as best one can with medications at home, or even simply being the voice for the patient's desire to have a better diet. Researchers led by Dr. Deepak Bhatt at Harvard Medical School ... studied approximately 4,500 veterans from across the country with late-stage heart failure. They analyzed trends in the rate of PC in veterans with severe heart failure between 2007 and 2013. Over the seven-year period, they found an increase in the use of PC from 5.5% in 2007 to 10.3% in 2013. However, rates of PC use in heart failure remained lower than PC rates in the patients with cancer. However, there is potential to improve care as rates in heart failure remained lower than rates in cancer. http://goo.gl/CMFHrF

1. 'Trends in palliative care use in veterans with severe heart failure using a large national cohort,' *Journal of the American Medical Association Cardiology*, 2016;1(5):617-619. http://goo.gl/MtqghP



### International

# Thousands of elderly patients in Scotland missing out on palliative care, study from University of Edinburgh and Marie Curie finds

U.K. (Scotland) | *The Herald* (Glasgow) – 8 September 2016 –Thousands of elderly patients in Scotland are missing out on end-of-life care, it has emerged. Concerns have been raised after new research found that those aged 70 and over have more unmet pain and less access to palliative treatment than younger patients: 11,000 of the 40,000 people needing the treatment in Scotland are missing out every year. The study, carried out by the University of Edinburgh and terminal illness charity Marie Curie, examined the end-of-life experiences of 65 patients in Scotland who were diagnosed with brain and bowel cancer, liver failure and frailty. <a href="http://goo.gl/ZkoCzL">http://goo.gl/ZkoCzL</a>

1. 'Why do older people get less palliative care than younger people,' *European Journal of Palliative Care*, 2016;23(3):132-137. [Noted in Media Watch, 6 June 2016, #465 (p.12)]

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

Noted in Media Watch 21 September 2015, #428 (p.6):

- U.K. (Scotland) | The Courier (Dundee) 15 September 2015 'Report says 10,000 people miss out on palliative care before dying.' More than 10,000 Scots who could benefit from palliative care towards the end of their life die without receiving it, a new report has suggested. http://goo.gl/4JWxaz
  - 'International comparisons in palliative care provision: What can the indicators tell us?' Health & Sport Committee, September 2015. <a href="http://goo.gl/KhqtqU">http://goo.gl/KhqtqU</a>

### When parents disagree with doctors on a child's treatment, who should have the final say?

AUSTRALIA (Western Australia) | The Conversation – 7 September 2016 – As the recent case of six-year-old boy Oshin Kiszko highlights, some disagreements between doctors and parents can't be resolved by further information and discussion. Oshin has brain cancer. His doctors believe he should receive treatment aimed at curing his disease, while Oshin's parents believe the potential benefits of treatment don't justify side-effects and other negative outcomes for their son, such as the possibility of long-term health issues. They want Oshin to receive only palliative care to ensure his comfort in the remaining months of his life. In March, Western Australia's Family Court mandated Oshin be given chemotherapy. The most recent judgement, after another two court cases, supports a palliative pathway for Oshin as his chance of a cure has decreased. Oshin's case is unique. Not all disagreements between doctors and parents reach court. Many are resolved in the hospital and many do not involve life-threatening conditions. In our recent research project, we investigated types of conflicts that can arise between doctors and parents in a paediatric hospital and the ethics of these situations. We developed an approach called the "zone of parental discretion" to assist doctors in deciding whether a parental choice should be overridden. This is a tool that holds it is ethical for doctors to accept a treatment option parents want, providing it is good enough, rather than insisting on the best possible treatment. http://goo.gl/DFCHx4

- 1. "This is not about parental rights or doctors...it's about Oshin Kiszko," WA Today (East Perth), 1 September 2016. http://goo.gl/ZliMqP
- 2. 'The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child,' *Clinical Ethics*, 18 December 2015. [Noted in Media Watch 21 December 2015, #441 (p.12)] <a href="http://goo.gl/htkzMf">http://goo.gl/htkzMf</a>

Noted in Media Watch 11 April 2016, #457 (p.5):

AUSTRALIA (Western Australia) | The West Australian (Perth) - 7 April - 2016 - 'Court orders chemo for dying boy, 6, after parents refuse treatment,' A Princess Margaret Hospital doctor took legal action after Angela Kiszko and Adrian Strachan refused chemotherapy and radiotherapy for their son ... who was diagnosed with medulloblastoma in December. The parents argued they could not bear to see their son suffer the side effects of cancer treatment like a "lab rat." https://goo.gl/Q8kAf3

### End-of-life care in New Zealand

### Hospice proposal illustrates failure to plan for palliative care

NEW ZEALAND | The Dominion Post (Wellington) - 7 September 2016 - Mary Potter Hospice's plan for an apartment block in central Newtown graphically illustrates the challenge of looking after New Zealanders at the end of their lives. Residents question the need for a large multi-level building that will change the landscape of their neighbourhood, but it's a response to the changing landscape of palliative care (PC), which is failing in the face of growing demand. Hospices do an incredible job providing care for about 11,500 people each year in their final stage of life. As people live longer, demand for PC is growing - and it's increasingly being provided in other facilities. This year, around 10,500 people will die in an aged care home. A Ministry of Health says that figure is expected to almost double in 20 years, meaning more people will die in aged residential care than hospices, hospitals and private homes combined. Despite this trend, aged care facilities simply aren't set up to provide the sort of wrap-around, intensive care New Zealanders expect at the end of their life - in fact, aged care facilities currently receive no funding specifically for PC at all, despite its resource-intensive nature. The volume of PC that aged care facilities are now required to provide has led to some labelling members of the New Zealand Aged Care Association as "de facto hospices," but without the resourcing or the recognition. This is largely due to policy failing to keep up with the changing nature of aged care. Rest homes aren't seen as providers of PC, but the reality is soon most of us will die in one. http://goo.gl/z6Z65X

### Coping with loss and separation in the workplace

### It is a scandal that parents who lose their children have no legal right to bereavement leave

U.K. | *The Daily Telegraph* – 6 September 2016 – Unbelievably at present, there is no statutory right to take time off on compassionate or bereavement grounds. However, all employees [in the U.K.] have the right to take immediate "time off for dependents" under the Employment Rights Act 1996. In effect, it is a legal right to time off unpaid to deal with family emergencies. Yet there is no set limit of how many days can be taken as leave and a rather vague definition of a "reasonable amount of time." Further there is no statutory right to be paid during this "reasonable amount of time." Most employers are excellent and act with compassion and kindness, offering their bereaved staff the time they need to come to terms with their loss. However, some do not, http://goo.gl/se8NpN

Noted in Media Watch 7 December 2015, #439 (p.6):

• IRELAND | The Irish Times (Dublin) – 4 December 2015 – 'Grieving employees have no legal right to time off for bereavement.' In what it describes as a conservative estimate, the Irish Hospice Foundation says at least one in 10 of the Irish workforce is directly affected by bereavement annually. Yet little legislation or guidance is in place for dealing with grief in the workplace. As a result, someone trying to cope with an unexpected loss may have little or no idea of their rights. <a href="http://goo.gl/ay6xwl">http://goo.gl/ay6xwl</a>

Noted in Media Watch 22 December 2014, #389 (p.16):

- BEREAVEMENT CARE, 2014;33(3):111-112. 'Handling bereavement in the workplace a guide for employers.' The authors discuss the recently published Advisory, Conciliation & Arbitration Service guidance for employers on handling bereavement in the workplace.<sup>1</sup> <a href="http://goo.gl/vpNuEw">http://goo.gl/vpNuEw</a>
  - 'Managing bereavement in the workplace: A good practice guide,' Advisory, Conciliation & Arbitration Service, 2014. [Noted in Media Watch 22 September 2014, #376 (p.15)] <a href="http://goo.gl/HfW62q">http://goo.gl/HfW62q</a>



'Living and dying in pain: It doesn't have to happen' 8 October 2016 http://goo.gl/iKZH4k

### End-of-life care in England, Wales and Northern Ireland

### Minimum Data Set (MDS) for the National Survey of Patient Activity Data for Specialist Palliative Care Services

U.K. | National Council for Palliative Care - 6 September 2016 – The 2014-2015 edition shows trends in palliative and end-of-life care, based on responses from over 800 services across England, Wales and Northern Ireland. The report covers palliative care (PC) services provided by hospice, inpatient, day care, community care, hospital support, outpatient and bereavement support services. Over 1,300 services were asked to provide data. The survey examines details of 126,000 patients cared for in the community, 36,000 patients admitted to palliative or hospice units and 97,000 people seen by hospital teams. The MDS is the only survey of its kind. looking at specialist PC services across England, Wales and Northern Ireland. Findings from this year's survey include: 1) 81% of patients supported by community palliative and hospice teams die out of hospital compared to a national average of 48%. The involvement of a community team more than doubles the chance being able to die at home; 2) The survey indicates that at least a third of those with an expected death are seen by palliative and hospice community teams. Although this is significant, it still demonstrates potential unmet need for many people towards the end of life who could benefit from palliative and hospice care; 3) There has been a steady increase in the proportion of people admitted into specialist PC and hospice beds from

hospital. This is in line with national policy and personal preferences; 4) Access to specialist PC for patients with a non-cancer diagnosis is slowly improving. Over the last 6 years the numbers have doubled from 14% to 29% in hospital and community settings. However all services are still predominantly referred patients with cancer, despite this being the cause of death in only 29% of the population. http://goo.gl/FdllTv







#### Data collection

A total of 1,372 specialist PC services were invited to take part in the most recent Minimum Data Set survey. Specialist PC services are provided both within the National Health Service (NHS) and across a wide range of voluntary sector organisations including hospices, both inpatient and community services. The data collected from hospices and across the NHS is aggregated and includes: the number of people seen by a service; their primary diagnosis, ethnicity and age; length of care/stay; hours of operation; bed availability; location prior to or after care; and, location of death. Currently 70% of the MDS activity reported comes from the hospice sector.

### Number of Irish people aged 85 expected to grow by over 130%

IRELAND | News Talk Radio (Dublin) – 5 September 2016 – Social Justice Ireland say there will be nearly one million people aged 65 and over by 2031 – an increase of 86.4%. Of these, 136,000 will be aged 85 or over – an increase of 132.8%. "This level of population ageing will be associated with higher levels of disability and long-term ill-health and now is the time for planning and investment," says Dr. Seán Healy, director of Social Justice Ireland. "With an ageing population, the acute hospital system will be unable to operate effectively unless there is a greater shift towards primary and community services as a principal means of meeting patient needs," says Michelle Murphy, research and policy analyst for Social Justice Ireland. In its latest National Social Monitor, Social Justice Ireland say there has been a 17% reduction in the number of home help hours delivered since 2008. http://goo.gl/nmOein

1. 'National Social Monitor,' Social Justice Ireland, September 2016. http://goo.gl/QFMBIV

### **Media Watch: Online**

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.17.

### Helping elderly spend last moments at home

JAPAN | *The Japan News* (Tokyo) – 4 September 2016 – With Japan becoming a super-aging society, the current state of the emergency and critical care system has come under constant review. Although the main point is to save lives, there are increasing efforts to help the elderly continue to live in areas they are familiar with until the end of their lives. Under the existing 119 emergency call system, the Tokyo Fire Department dispatches ambulances, but this sometimes results in patients being taken to facilities some distance from their homes, as closer hospitals are unable to accept them. There also have been cases where the patient's wishes regarding life-prolonging treatment were unknown, leaving paramedics with no choice but to take life-saving measures. The new system requires 20 local hospitals to commit to accepting patients beforehand, and each patient is designated a specific hospital. The reason for admitting patients to hospitals in areas where patients live is that it is difficult to have them transferred to their homes or nursing facilities if they are taken to hospitals some distance away and put on such devices as artificial respirators... http://goo.gl/PbmrzL

### When big media goes clueless about big data

### That public health study? No, it didn't say "don't do chemo"

THE REGISTER | Online - 2 September 2016 -"Chemotherapy kills" was bound to pique our interest, especially since in the best traditions of modern research, its source was a badlyreported scientific study. The screaming headlines were just as you'd expect: 'Chemotherapy warning as hundreds die from cancer fighting drugs'2 from Blighty's The Telegraph; almost the same - 'Chemotherapy WARNING: Hundreds die from cancer drug treatment'3 - from The Express: the more measured 'Nineteen National Health Service trusts to review chemotherapy over high death rates'4 from The Daily Mail, and so on. Having a high regard for the boffins that create science, The Register decided to walk through the study with a scientist - Dr. Darren Saunders, cancer researcher at the University of New South Wales. Also, it's a study that can be legitimately put under the heading of "big data" (tens of thousands of records plucked from millions for analysis) - and it's instructive not just about what the data can tell us, but also (and in terms of media reporting), what it can't tell us. http://goo.gl/lbKGFY



AMERICAN MEDICAL WRITERS ASSOCIATION JOURNAL, 1999;14(1);32-42. 'A journalist's guide to writing health stories.' http://goo.gl/vMdolh

# Oxford Textbook of Palliative Medicine

FIFTH EDITION

OXFORD TEXTBOOK OF PALLIATIVE MEDICINE, 'Communications with the Public, Politicians, and the News Media.' <a href="https://goo.gl/Vi07RS">https://goo.gl/Vi07RS</a>.

- 1. '30-day mortality after systemic anticancer treatment for breast and lung cancer in England: A population-based, observational study,' *The Lancet Oncology*, 2016;17(9):1203-1216. <a href="http://goo.gl/xKNnly">http://goo.gl/xKNnly</a>
- 2. 'Chemotherapy warning as hundreds die from cancer fighting drugs,' *The Daily Telegraph*, 30 August 2016. <a href="http://goo.gl/Fw9GBU">http://goo.gl/Fw9GBU</a>
- 3. 'Chemotherapy WARNING: Hundreds die from cancer drug treatment,' *The Sunday Express*, 31 August 2016. <a href="http://goo.gl/6qsaqu">http://goo.gl/6qsaqu</a>
- 4. 'Hundreds of National Health Service cancer patients have been "killed by chemotherapy": 19 hospital trusts with high death rates are told to improve,' *The Daily Mail*, 31 August 2016. <a href="http://goo.gl/mR09pP">http://goo.gl/mR09pP</a>

Noted in Media Watch 2 February 2015, #395 (p.8):

• eCANCER | Online – 29 January 2015 – 'How do medical journalists treat cancer-related issues?' All of the journalists surveyed experienced some difficulties in reporting health issues. Significant concerns included quality of information, social impact, lack of technical knowledge, and difficulty in understanding technical terms. Topic selection was biased, with 35 of 48 journalists having never reported on topics concerning hospices. Physicians were the most trusted source of information about cancer, and journalists attached high importance to interviewing them. As medical knowledge is advancing rapidly, journalists may have increasing difficulty covering cancer-related issues. <a href="http://goo.gl/FH4WUk">http://goo.gl/FH4WUk</a>

Noted In Media Watch 22 December 2014, #389 (p.14):

BRITISH MEDICAL JOURNAL | Online – 10 December 2014 – 'The association between exaggerations in health related science news and academic press releases: Retrospective observational study.' Forty-percent of the press releases [analyzed by the authors] contained exaggerated advice, 33% contained exaggerated causal claims, and 36% contained exaggerated inference to humans from animal research. There was little evidence that exaggeration in press releases increased the uptake of news. Improving the accuracy of academic press releases could represent a key opportunity for reducing misleading health related news. <a href="http://goo.gl/UNYYGy">http://goo.gl/UNYYGy</a>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ UNITED ARAB EMIRATES | *The National* (Abu Dhabi) – 5 September 2016 – 'Law gives United Arab Emirates patients new "right to die." Doctors will no longer be compelled to resuscitate dying patients under sweeping changes to the law governing health care. The new rules permit medical staff to allow natural death to take its course and refrain from performing CPR on dying patients who are suffering from conditions that are probably incurable. If all treatment has failed, or at least three doctors advise against resuscitation, a patient will be allowed to die naturally. Until now, any doctor who fails to resuscitate a patient has been liable to prosecution. The change in the law follows a report in April by a task force set up by the Health Authority Abu Dhabi to examine where improvements could be made in palliative care. <a href="http://goo.gl/htn4LV">http://goo.gl/htn4LV</a>

### **Specialist Publications**

### Fixing the broken image of care homes, could a "care home innovation centre" be the answer?

AGE & AGEING | Online – 8 September 2016 – Even though the majority of care homes receive a rating of "good" from regulators, still significant numbers are identified as requiring "improvement" or are "inadequate." Such findings resonate with the public perceptions of long-term care as a negative choice, to be avoided wherever possible – as well as impacting on the career choices of health and social care students. Projections of current demographics highlight that, within 10 years, the part of our population that will be growing the fastest will be those people older than 80 years old with the suggestion that spending on long-term care provision needs to rise from 0.6% of our Gross Domestic Product in 2002 to 0.96% by 2031. Teaching/research-based care homes have been developed in the U.S., Canada, Norway, The Netherlands and Australia in response to scandals about care, and the shortage of trained geriatric healthcare staff. There is increasing evidence that such facilities help to reduce inappropriate hospital admissions, increase staff competency and bring increased enthusiasm about working in care homes and improve the quality of care. Is this something the U.K. should think of developing? <a href="http://goo.gl/fYaTwf">http://goo.gl/fYaTwf</a>

Cont. next page



Media Watch: Behind the Scenes http://goo.gl/XDjHxz

### Selected articles on end-of-life care in care homes and long term care facilities

- INTERNATIONAL JOURNAL OF OLDER PEOPLE NURSING | Online − 19 July 2016 − 'Dying and death within the culture of long-term care facilities in Canada.' One contextual factor and three beliefs were uncovered [in this study]: 1) The mismatch of care demands in LTC facilities and the resources that are available to meet those demands; 2) The belief that LTC facilities are for living; 3) The belief that no one should die in pain; and, 4) The belief that no one should die alone. The belief that LTC facilities are for living, within a context that separates living and dying, contributed to the delay of a palliative approach to care. [Noted in Media Watch 25 July 2016, #472 (p.8)] http://goo.gl/7hYXQZ
- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online 29 March 2016 'Culturally competent palliative and hospice care training for ethnically diverse staff in long-term care facilities.' Between 2013 and 2030, older adults 65 years and older of racial/ethnic populations in the U.S. is projected to increase by 123% in comparison to the Whites (Non-Hispanics). To meet this demand, training of ethnically diverse health staff in long-term care facilities in palliative and hospice care is imperative. [Noted in Media Watch 4 April 2016, #456 (p.9)] <a href="https://goo.gl/Ef1IV7">https://goo.gl/Ef1IV7</a>
- JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online 24 January 2014 'Attitudes toward death, dying, end-of-life palliative care, and interdisciplinary practice in long term care workers.' Study participants had a relatively positive attitude toward more than one-half of selected aspects of interdisciplinary practice and end-of-life palliative care for long-term residents. Overall, however, there are significant differences between upper-level professionals and managers (registered nurses, physicians, rehabilitation staff, and clinical managers) versus the hands-on caregivers (nursing assistants, patient assistants and volunteers) with regard to some aspects of the care of the dying. [Noted in Media Watch 3 February 2014, #343 (p.9)]http://goo.gl/B5rwp1

### Simultaneous palliative care: From philosophy to practice

EXPERT REVIEW OF QUALITY OF LIFE IN CANCER CARE | Online – 2 September 2016 – Cancer patient can present a set of physical problems, psychosocial and spiritual needs that require additional and specific treatments. The critical factor that presents itself is the planning of an appropriate program of care and treatment defined "Simultaneous Palliative Care." The alleviation of suffering, perceived as a global experience of the whole person, is a central goal of palliative care; interventions that modulate the experiential dimension of suffering can enhance the relief of a cancer patient. A better integration of oncologists and supportive/palliative care specialists could help patients with severe distress to minimize the burden of progressive cancer. Considered in that light, a model of integrated medicine employed in a process of gradual treatment improvement, could represent the beginning of a new medical standard necessary because of the complexity of patients experiencing an advanced cancer. http://goo.gl/47gRwY

### Related

■ ADVANCES IN NURSING SCIENCE | Online - 7 September - 'Death is a social justice issue: Perspectives on equity-informed palliative care.' All too often, palliative care (PC) services are not responsive to the needs of those who are doubly vulnerable, being that they are both in need of PC services and experiencing deficits in the social determinants of health that result in complex, intersecting health and social concerns. In this article, the authors argue for a reorientation of PC to explicitly integrate the premises of health equity. <a href="http://goo.gl/a36zy8">http://goo.gl/a36zy8</a>



### Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials.  $\frac{\text{http://goo.gl/OTpc8I}}{\text{http://goo.gl/OTpc8I}}$ 

# Interprofessional communication between oncologic specialists and general practitioners on end-of-life issues needs improvement

FAMILY PRACTICE | Online – 1 September 2016 – Timely end-of-life (EOL) discussions between patients and physicians are considered essential for high-quality EOL care, but research shows that these discussions frequently do not occur or occur late. In oncology, one barrier for timely EOL discussions is poor collaboration between oncologic specialists and GPs. The authors conducted in-depth interviews with 16 GPs and 14 oncologic specialists. EOL discussions were primarily considered the role of the GP, but oncologists' perceptions of their own roles in discussing EOL issues varied. Interprofessional coordination on who discusses what and when was mostly absent. Interprofessional communication of EOL issues usually proceeded using the patient as intermediary. This functioned well but only if three essential conditions were met: 1) The specialist being realistic to patients about limits of treatment; 2) Informing the GP adequately; and, 3) The GP being proactive in initiating EOL issues in time. <a href="http://goo.gl/huZl6x">http://goo.gl/huZl6x</a>

### Related

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online 6 September 2016 'Advance care planning: Understanding clinical routines and experiences of interprofessional team members in diverse health care settings.' Although interprofessional health care team members consider advance care planning (ACP) a priority and several team members may be involved, clinical settings lack systematic clinical routines to support ACP. Patient educational materials, interprofessional team training, and policies to support ACP clinical workflows that do not rely solely on physicians could improve ACP across diverse clinical settings. http://goo.gl/f6D693
- JAMA ONCOLOGY | Online 9 September 2016 'Effect of a patient-centered communication intervention on oncologist-patient communication, quality of life, and health care utilization in advanced cancer.' Although clinician-patient communication patterns are difficult to change, an intentionally brief communication intervention was effective in improving patient-centered communication in advanced cancer but requires refinement in focus, delivery, support, or timing to promote shared understanding, quality of life, and appropriate use of health care at the end of life. <a href="http://goo.gl/CFrzCc">http://goo.gl/CFrzCc</a>
- JOURNAL OF ONCOLOGY PRACTICE | Online 6 September 2016 'Team leadership and cancer end-of-life decision making.' The challenges demonstrated in this case [study] reflect the importance of the four functions of team leadership: 1) Information search and structuring; 2) Information use in problem solving; 3) Managing personnel resources; and, 4) Managing material resources. Engaging in shared leadership of these four functions can help care providers improve their interactions with patients and families concerning end-of-life care decision making. <a href="http://goo.gl/gP994E">http://goo.gl/gP994E</a>

### Grief and healing in young and middle age: A widower's journey

THE GERONTOLOGIST | Online – 1 September 2016 – The experience of grief is both uniquely personal and universal. Our personality, our relationship with the deceased, the manner in which the deceased died, our life stage, and many other contextual factors matter and impact grief, and yet there are many experiences, phases, stages of grief that are universal. Those who are grieving deeply or who are farther along in their healing are often trying to understand grief and its realities. It has been said that people die but relationships do not. As a widower twice, once at age 25 and then again nearly 30 years later, I agree with that sentiment, and it is the profound relationships with my wives Becky and Susan that propelled me to share my experiences and reflections on grief and healing. As a clinical psychologist and gerontologist I examined the grief and gerontology literature, learning new things that were useful and not as useful. <a href="http://goo.gl/aEJUMf">http://goo.gl/aEJUMf</a>

### Older prisoners' experiences of death, dying and grief behind bars

THE HOWARD JOURNAL OF CRIME & JUSTICE, 2016;55(3):312-327. Prison populations are experiencing rapid increases and many more offenders are dying in prison. This article draws on research that was conducted by the authors in the U.S., and in England and Wales. The study interrogates the meanings older prisoners give to the prospect of dying in prison. The themes identified during data analysis included general thoughts about death and dying, accounts of other prisoners' deaths, availability of end-of-life services, contact with social relations, and wishes to die outside of prison. Current programmes [vis-à-vis end-of-life care] are governed by specific policies and procedures, in-

cluding criteria for admission, special privileges for terminally-ill prisoners, requirements for housing in hospice settings, "do not resuscitate" orders, and the role of prisoner volunteers, among other issues. <a href="http://goo.gl/3dOdUJ">http://goo.gl/3dOdUJ</a>



Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation

of the articles, reports, etc., noted in past issues of the weekly report is available at: http://goo.gl/ZpEJyQ

### Effect of a home-based palliative care program on healthcare use and costs

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 2 September 2016 – Proactive palliative care (PC) provided in the home led to earlier hospice use and greatly reduced the escalation in hospital use and costs commonly seen in the final months of life. The results are similar in magnitude to those demonstrated in previously published controlled studies of community-based PC and home-based primary care and demonstrate a reasonable return on investment for health systems at risk for healthcare costs. Community health systems that cannot afford the resources necessary for prospective, randomized trials can adopt the retrospective, claims-based methods of this study. http://goo.gl/Gj0MLE

### Related

■ PALLIATIVE MEDICINE | Online — 8 September 2016 — 'From neighbour to carer: An exploratory study on the role of non-kin-carers in end-of-life care at home for older people living alone. Towards the end of life, the main challenges [among study participants] emerged around increased physical care needs, issues of decision-making and facing the process of dying. Prior experiences with the latter ... influenced non-kin-carers' steadiness to allow home death and so did reliable formal support, particularly from specialized palliative care teams <a href="http://goo.gl/0bNvNn">http://goo.gl/0bNvNn</a>

# Attitudes of Muslims living in the U.S. toward long-term care decisions and diagnosis disclosure for elderly family members

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 2 September 2016 – Respondents [i.e., telephone interview respondents] were read medical scenarios and asked to indicate their preferences from a list of responses. Scenarios were: 1) If they or a family member were disabled, who would they prefer to care for them; 2) Would they use a Muslim nursing home for themselves or loved one; 3) Who should be informed first if an individual had cancer or would die very soon (the individual or the individual's family); and, 4) Whether these diagnoses should be disclosed to the individual's family without the individual's consent. If disabled, 62% of participants would prefer care at home, and 65.7% would prefer care at home for a disabled loved one. If there were a Muslim nursing home, 78.3% of participants would consider this facility for themselves and 76% would consider it for a loved one. Fifty-six percent of participants believed the individual should be informed first of a cancer diagnosis, and 54.6% believed the individual should be informed first of a cancer diagnosis, and 54.6% believed the individual should be informed first of a cancer diagnosis. Those from Western countries were most likely to believe individuals should be informed first about their cancer diagnosis or imminent death. http://goo.gl/GJF25v

Cont.

### Related

■ MEDICINE, HEALTH CARE & PHILOSOPHY | Online – 9 September 2016 – 'Islamic perspectives on clinical intervention near the end-of-life: We can but must we?' This paper argues that traditional Sunni Islamic ethico-legal views on the obligation to seek medical care and Islamic theological concepts of human dignity (karāmah) and inviolability (ḥurmah) provide the ethical grounds for non-intervention at the end of life and can help calibrate goals of care discussions for Muslim patients. <a href="http://goo.gl/ybZEgi">http://goo.gl/ybZEgi</a>

Noted in Media Watch 1 February 2016, #447 (p.14):

CLINICAL JOURNAL OF ONCOLOGY NURSING, 2016;20(1):11-12. 'Providing culturally appropriate care to American Muslims with cancer.' The population of Muslims in the U.S. is projected to dramatically increase in the next few decades. Understanding the role of Islam for people who believe in and follow Islam will provide nurses with important perspectives that affect health behaviors, cancer screening, treatment decision-making, and end-of-life care. <a href="https://goo.gl/OxOV04">https://goo.gl/OxOV04</a>

N.B. Additional articles on Islam and end-of-life care are noted in Media Watch 1 February 2016, #447 (p.13)

### Why do we find it so hard to discuss spirituality? A qualitative exploration of attitudinal barriers

JOURNAL OF CLINICAL MEDICINE | Online – 1 September 2016 – Despite known health benefits of spiritual care and high patient interest in discussing spirituality with their physicians, the frequency of spiritual discussions in the medical consultation is low. The authors investigated spiritual conversations for doctors caring for patients with advanced cancer; why these conversations so difficult; and, what the underlying challenges are for discussing spirituality with patients. The following themes were identified: 1) Confusing spirituality with religion; 2) Peer pressure; 3) Personal spirituality; 4) Institutional factors; 5) and, 6) Historical factors. http://goo.gl/3Hib6F

Noted in Media Watch 5 September 2016, #478 (p.16):

PALLIATIVE & SUPPORTIVE CARE | Online – 30 August 2016 – 'Spiritual beliefs, practices, and needs at the end of life: Results from a New Zealand national hospice study.' The authors' findings suggest spirituality is broadly understood and considered important for all three of the populations studied. The patient and family populations had high spiritual needs that included a search for meaning, peace of mind and a degree of certainty in an uncertain world. The healthcare professionals in the hospices surveyed seldom explicitly met the needs of patients and families. <a href="http://goo.gl/xGWEv5">http://goo.gl/xGWEv5</a>

**N.B.** Additional articles on spirituality in the context of end-of-life care noted in Media Watch 22 August 2016, #476 (p.8), 27 Jun 2016, #468 (pp.9-10), 4 April 2016, #456 (p.7), and 8 June 2015, #413 (pp.10-11).

# Opportunities and challenges facing the integrated physician workforce of emergency medicine and hospice and palliative medicine

JOURNAL OF EMERGENCY MEDICINE | Online – 6 September 2016 – The American Board of Emergency Medicine joined nine other American board of medical specialties member boards to sponsor the subspecialty of hospice and palliative medicine; the first subspecialty examination was administered in 2008. Since then an increasing number of emergency physicians has sought this certification and entered the workforce. There has been limited discussion regarding the experiences and challenges facing this new workforce. The authors use excerpts from conversations with emergency physicians to highlight the challenges in hospice and palliative medicine training and practice that are commonly being identified by these physicians, at varying phases of their careers. The lessons learned from this initial dual-certified physician cohort in real practice fills a current literature gap. Practical guidance is offered for the increasing number of trainees and mid-career emergency physicians who may have an interest in the subspecialty pathway but are seeking answers to what a future integrated practice will look like in order to make informed career decisions. http://goo.gl/rGzk2l

### Does volunteering experience influence advance care planning in old age?

JOURNAL OF GERONTOLOGICAL SOCIAL WORK | Online – 3 September 2016 – Previous efforts to increase advance care planning (ACP) have mainly focused on information provision in the very late stage of life. This study examines whether a relationship exists between volunteering and ACP, and whether this relationship is associated with social support. Results [of this study] showed that overall ACP and durable power of attorney for health care were both higher for older adults with volunteering experience in the past 10 years than those without such experience. Available social support (relatives and friends living nearby) was not associated with the relationship between volunteering and ACP. Other factors related to ACP included poorer health, death being expected, death due to cancer, older age, and being a racial minority. http://goo.gl/2OosDR

Noted in Media Watch 5 September 2016, #478 (p.12):

■ JOURNAL OF NURSING ADMINISTRATION | Online - 26 August 2016 - 'Honoring patient requests: A volunteer initiative to support the presence of advance directives.' Hospitals seeking to support advance care planning and the execution of advance directives (AD) face challenges in matching patient readiness with the availability of knowledgeable personnel and resources. A volunteer-based AD team represents an innovative approach to providing personalized, timely, and accurate information about advance directives and assisting patients with their completion. <a href="http://goo.gl/ohzq0t">http://goo.gl/ohzq0t</a>

### Related

■ JOURNAL OF GERONTOLOGICAL SOCIAL WORK | Online – 1 September 2016 – 'The influence of socio-demographic and psychosocial factors on advance care planning.' The study found that persons who were older, who were female, who identified themselves as white, and who had higher levels of income and education were more likely to be motivated to complete advance care planning (ACP). Having cancer, suffering from the illnesses for longer periods of time, and having experience of nursing home institutionalization also predicted the completion of ACP. <a href="http://goo.gl/qzjfVt">http://goo.gl/qzjfVt</a>

### Tales: A tool to address death with children

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2016;18(5):429-435. Children are curious about death, but it is also one of their biggest fears and a primary cause of sadness. Several authors argue that tales are an appropriate tool for addressing concepts of death. This article summarizes and evaluates 23 tales dealing with death in terms of their usefulness in helping 3- to 9-year-old children understand and cope with the concept of death. <a href="http://goo.gl/9WyWda">http://goo.gl/9WyWda</a>

### "Mystery shopper" study finds barriers to palliative care at major cancer centers

MEDICALXPRESS | Online - 7 September 2016 - A team of researchers, using a novel approach, found that while many cancer centers offer palliative and supportive care services, patients may face challenges when trying to access them. The study showed that expanding awareness and education to patient-facing cancer center employees about such services could make an important difference. Researchers from Duke University adopted a "mystery shopper" format and placed 160 telephone calls to 40 major cancer centers inquiring about palliative and supportive care needs for a family member. Researchers chose to focus on National Cancer Institute-designated cancer centers because they all provide palliative care (PC) services along with other supportive care services. Results from the qualitative assessment showed that in approximately one-third of calls, researchers had difficulty obtaining information about PC services. In nearly 10% of calls, cancer center staff gave an answer other than "yes" as to the availability of PC services, even though such services were available. Answers varied and included responses such as: PC was for end-of-life patients only; no physicians specialized in symptom management; a medical record review would be needed first; and, 12 staff members said that they were unsure about the availability of PC or were unfamiliar with the term. Overall, only 37% of callers were told all seven supportive care services inquired about were offered. When answering "yes." call recipients were most likely to refer the callers to patient navigation and genetic assessment services. http://goo.gl/SFNryX

# Willingness to use hospice care among caregivers of Latino patients in the U.S.-Mexico border region

PALLIATIVE & SUPPORTIVE CARE | Online – 9 September 2016 – Hospice is an important method of promoting quality end-of-life (EoL) care, yet its utilization is relatively low in underserved populations. The unique characteristics of a border community – such as a lack of healthcare resources and cultural integration – impact end of life (EoL) decision making. The majority (83%) of family caregivers [i.e., study participants] were willing to use hospice services for their loved ones. Caregivers who trusted doctors to make the best decisions for their loved ones and English-speaking caregivers were more willing to utilize hospice services, while caregivers who held a strong belief that hospice care means giving up on life were less likely to consider using hospice care for their loved ones. <a href="http://goo.gl/jmp0SA">http://goo.gl/jmp0SA</a>

# Health care utilisation and transitions between health care settings in the last 6 months of life in Switzerland

PLOS ONE | Online – 6 September 2016 – In Switzerland, palliative care (PC) is not yet available for all patients in need and there are considerable regional variations. Some regions have a broader supply of PC centres, including mobile PC teams (i.e., the Western/French speaking part of Switzerland), whereas other regions (i.e., the Central part of Switzerland) hardly have any offering. According to the National Palliative Care Strategy 2013-2015, as little as four out of 26 cantons have hospices available. Further more, the financing of PC is neither uniformly nor conclusively regulated in Switzerland. And no national regulation exists in terms of hospice funding. Although, the present results of the health care utilisation and the place of death show a need for higher resource allocation. Further research is needed, including patients' preferences, to be able to provide the best possible support for dying patients. Health care utilization was high in the last six months of life and a considerable number of decedents were being transferred at the end of life. Timely discussion about the patients' preferences and advance care planning might prevent patients from numerous and particularly from burdensome transitions at the end of life. http://goo.gl/Jvm5hh

N.B. Switzerland's palliative care strategy. Federal Office of Public Health. http://goo.gl/iBJ3i4

Noted in Media Watch 18 July 2016, #471 (p.6):

■ SWITZERLAND | Swissinfo.ch (Bern) – 11 July 2016 – 'Why is Switzerland behind in palliative care?' 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. 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. <a href="https://goo.gl/Szg97H">https://goo.gl/Szg97H</a>

N.B. Additional articles on end-of-life care in Switzerland are noted in this issue of Media Watch.

# What are the communication skills and needs of doctors when communicating a poor prognosis to patients and their families? A qualitative study from South Africa

SOUTH AFRICAN MEDICAL JOURNAL, 2016;106(9):940-944. Participants [in this study] highlighted that when conveying a poor prognosis, patients and families need practical information that includes addressing uncertainties about the future, available resources, experiencing death, deteriorating health and losing one's dignity. Communication, pain management, loss and grief issues should be part of the curriculum across disciplines and throughout training in medical school. All healthcare professionals should be trained in palliative care (PC) so as to effectively communicate with patients and their families. Support networks are needed for staff conducting this difficult task. Having hospital-based PC teams in all public hospitals will provide support for patients and doctors in handling difficult conversations. Good communication skills are not only important for better patient outcomes, but for improved professional competence and wellbeing. The education and practice needs demonstrated in this study highlight the actions needed to meet the requirements of the World Health Assembly 2014 resolution[6] to integrate PC into the public health sector. http://goo.gl/x6UivT

### End-of-life care in patients with advanced lung cancer

THERAPEUTIC ADVANCES IN RESPIRATORY DISEASE | Online – 1 September 2016 – Four key areas of end-of-life care (EOLC) in advanced lung cancer begin with first recognizing "when a patient is approaching the end of life." The clinician should be able to recognize when the focus of care needs to shift from an aggressive life-sustaining approach to an approach that helps prepare and support a patient and family members through a period of progressive, inevitable decline. Once the needs are recognized, the second key area is appropriate communication, where the clinician should assist patients and family members in understanding where they are in the disease trajectory and what to expect. This involves developing rapport, breaking bad news, managing expectations and navigating care plans. Subsequently, the third key area is symptom management that focuses on the goals to first and foremost provide comfort and dignity. Symptoms that are common towards the end of life in lung cancer include pain, dyspnoea, delirium and respiratory secretions. Such symptoms need to be anticipated and addressed promptly with appropriate medications and explanations to the patient and family. Lastly, in order for physicians to provide quality EOLC, it is necessary to understand the ethical principles applied to end-of-life-care interventions. http://goo.gl/JIVh8U

### Selected articles on end-of-life care for patients with lung cancer

- BMJ SUPPORTIVE & PALLIATIVE CARE | Online 3 February 2016 'Do patients with lung cancer recall physician-initiated discussions about planning for end-of-life care following disclosure of a terminal prognosis?' Participants in this study had little or no recall of physicians initiating discussions about their concerns or goals of care, and did not perceive that they had been provided with either information about or opportunities to engage in advance care planning. [Noted in Media Watch 8 February 2016, #448 (p.6)] <a href="https://goo.gl/qfvBkn">https://goo.gl/qfvBkn</a>
- LUNG CANCER | Online 28 August 2015 'Integrating early palliative care in the management of lung cancer: The role of the thoracic oncologist.' Early introduction of palliative care (PC) in the management of patients with metastatic lung cancer is recommended since it improves quality of life and improves survival rates. How is early PC in this setting implemented in daily oncologic care? In this review the authors want to determine the assignments for the thoracic oncologist in early PC and to give some practical tools how they started early PC in collaboration with the palliative team. [Noted in Media Watch 7 September 2015, #426 (p.15)] <a href="https://goo.gl/FH0XTX">https://goo.gl/FH0XTX</a>
- JAMA INTERNAL MEDICINE | Online 28 January 2013 'Early palliative care in advanced lung cancer: A qualitative study.' The authors conducted a qualitative analysis of data from a randomized controlled trial that demonstrated improved quality of life, mood, and survival in patients with newly diagnosed metastatic non-small cell lung cancer who received early palliative care integrated with standard oncologic care versus standard oncologic care alone. [Noted in Media Watch 4 February 2013, #291 (p.8)] <a href="http://goo.gl/n36Z7t">http://goo.gl/n36Z7t</a>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ MEDICINE, HEALTH CARE & PHILOSOPHY | Online – 31 August 2016 – 'Comments on the Lambert case: The rulings of the French Conseil d'État and the European Court of Human Rights.' This study examines the decisions of the French Conseil d'Etat (Supreme Administrative Court) and the European Court of Human Rights in the Lambert case concerning the withdrawal of life-sustaining treatments. After presenting the facts of this case, the main legal question is analyzed from an ethical and medical standpoint. The decisions of the Conseil d'État and then of the European Court of Human Rights are studied from a comparative legal perspective. This commentary focuses on the autonomous will of an unconscious patient and on the judicial interpretation of the right to life as recognized in article 2 of the European Convention on Human Rights. Furthermore, it medically classifies artificial nutrition and hydration (ANH) as a "treatment" which has ethical and legal implications. While the majority of the bioethical community considers ANH a medical treatment, a minority argues that ANH is basic care. This classification is ambiguous and has conflicting legal interpretations. http://goo.gl/FiP99h

Cont.

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

- FRANCE | Radio France Internationale 16 June 2016 'French doctors asked to decide in right-to-die case.' A French court ordered doctors to decide whether a patient in a vegetative state should be allowed to die after years of legal battles that have torn his family apart. Vincent Lambert, 39, was left severely brain damaged and quadriplegic as a result of a 2008 road accident, but has been kept alive through artificial nutrition and hydration. Lambert has become the centre of a labyrinthine judicial battle that has gone all the way to the European rights court and ignited a heated debate over euthanasia in France. In the latest court ruling, the doctors caring for Lambert were ordered to resume consultations with medical experts and come to a decision over his fate. http://goo.gl/H80IAb
- MEDICINE, HEALTH CARE & PHILOSOPHY | Online 31 August 2016 'Value-impregnated factual claims and slippery-slope arguments.' The heart of slippery-slope reasoning is to claim that a certain course of action should not be adopted or allowed, because once we have taken the first step the trajectory is set, and we are to face very negative consequences. Hence, slippery slope arguments make the estimation that certain undesirable future events are unavoidable, or at least highly likely, once the first unfortunate step on that path is taken. In this paper, the authors have suggested that such factual estimations in slippery-slope arguments may be value-impregnated. That is, the estimations are made because the persons making them have a certain attitude to the action at hand. There is some support that estimations among Swedish physicians regarding the general public's trust in healthcare as a consequence of certain debated reforms, such as legalizing physician assisted suicide, take this form. If we are to take slippery-slope arguments seriously, they must contain reasonable estimations of future events based on carefully conducted empirical investigations, or at least on good theoretical reasons why a certain development is likely to take place. Otherwise, there is a considerable risk that the estimation of the consequences of a certain decision or act is merely a rationalization impregnated by the person's own attitudes or values. <a href="https://goo.gl/14tjHD">https://goo.gl/14tjHD</a>

### **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.

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- **6.** Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### **Something Missed or Overlooked?**

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

## **Worth Repeating**

### Pre-school as palliative care

JOURNAL OF CLINICAL ONCOLOGY, 2008;26(22):3797-3799. One privilege of caring for children with cancer is witnessing the courage with which families face life despite the disease. We don't often think of attending pre-school as either palliative or as an act of courage; in this case, it was both. A courageous mother advocated for her child (Keshaun) to attend school, the care team facilitated school enrolment, and courageous teachers did more than simply accept him into their classroom. Even now several years later, we remain awestruck by the courage of his lower socioeconomic, high school-educated mother. She had the courage to repeatedly challenge the "wisdom" of many health care and school professionals with greater formal education than herself. She is the one who most effectively advocated for her son. We are overwhelmed by the courage of Keshaun's mother, Keshaun, and the teachers who accepted this challenge. If we want to deliver good palliative care to children, we need to follow their lead, even if that takes us to very unfamiliar territory ... even if that takes us to pre-school. [Noted in Media Watch 24 January 2011, #183 (p.11, under Worth Repeating.')] http://goo.gl/9CcdTz

### **Media Watch: Online**

### International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://goo.gl/vjGQws

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: <u>HTTP://GOO.GL/JNHVMB</u>

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

#### Canada

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

### **Europe**

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

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

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

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