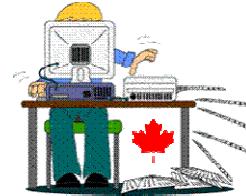


Media Watch...

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 illness experience: Scroll down to [Specialist Publications](#) and
'Now and at the hour of death' (p.10), in *Journal of Patient Experience*.

Canada

Advancing Collective Priorities: A Canadian Carer Strategy

CANADIAN CANCER ACTION NETWORK, CANADIAN HOME CARE ASSOCIATION & CARERS CANADA | Online – 26 July 2017 – Over 8 million carers (i.e., family caregivers) impact the lives of Canadians every day. They provide care and support to loved ones, family members and friends; and contribute over \$25 billion in unpaid care every year. 'Advancing Collective Priorities: A Canadian Carer Strategy' ... showcases the policies and practices that are in place to recognize and support these important individuals. As our population ages and the number of individuals diagnosed with cancer and other chronic conditions increases,^{1,2} nearly every Canadian will take on a caring role for someone they love.

<https://goo.gl/6vb9vn>

1. 'Canadian Cancer Statistics, 2017,' Canadian Cancer Society, June 2017. [Noted In Media Watch 26 June 2017, #518 (p.1)] <https://goo.gl/mKxtp5>
2. 'Nearly 1 in 2 Canadians expected to get cancer: Report,' Canadian Cancer Society, June 2017. [Noted In Media Watch 26 June 2017, #518 (p.1)] <https://goo.gl/jKPNfv>

N.B. A number of hospice and palliative care programs, etc., are listed in the carer strategy under national and provincial "supports" (beginning on p.4); however, there is no discussion or acknowledgement of the specific needs of family caregivers caring for a family member or loved one living with a terminal or life-limiting illness. Selected articles on family caregivers in the context of elder care in Canada are noted in the 15 May 2017 issue of Media Watch (#521, p.2). **BRA**

Specialist Publications

'Broadening end-of-life comfort to improve palliative care practices in long term care' (p.8) in *Canadian Journal on Aging*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MANITOBA | *The Reminder* (Flin Flon) – 24 July 2017 – ‘**Medically assisted suicide figures for North remain confidential.**’ The Northern Health Region (NHR) is not at liberty to say whether it has received requests for medically assisted suicides in the year-plus since the practice became the right of Canadians. Since 17 June 2016, federal law has entitled eligible Canadians to medical help in ending their own lives. The practice is known as medical assistance in dying (MAiD). “Due to confidentiality, we will not provide sites or dates of any MAID requests the NHR may have received,” Twyla Storey, communications coordinator for the NHR, told *The Reminder*. <https://goo.gl/Vl6ac>

Specialist Publications

‘**MAiD is legal in Canada: I was not trained to do this!**’ (p.16), in *Health Ethics Today*.

U.S.A.

I saved an old man’s life. He didn’t want it.

THE WASHINGTON POST | Online – 29 July 2017 – When doctors disagree with patients and families, it is usually the family choosing aggressive care in the face of overwhelming illness even though the benefits of life support are negligible or nonexistent. It gives a reprieve of sorts, allowing for further discussion. But what if it’s the reverse? What if the patient’s decision for no intervention leads to a potentially premature or unnecessary death from a treatable illness? What if a patient’s limits were stated without ever considering the current context? And what if this is your own family member writhing in pain, struggling to breathe? We often talk about decisions of life and death, of aggressive care or comfort, of full “code” – do everything possible – versus do not resuscitate/do not insert a breathing tube. One or the other. Binary options. But in real life, applying these decisions can get messy. There is nuance and context and uncertainty. <https://goo.gl/N76YCS>

Taking too long to die: Some “terminal” patients can lose hospice benefits

FLORIDA | *The News-Press* (Fort Myers) – 28 July 2017 – John Tagtmeir, 67, has end-stage chronic obstructive pulmonary disease and only a 10th of his lung capacity. For him, hospice care has meant weekly visits from a nurse, equipment to aid his breathing and allow him to move around, and powerful painkillers to help ease his eventual passing. That may now be going away, something the Tagtmeirs didn’t even think was possible. Their situation exposes some uncomfortable, and largely unknown, truths about the limits of Medicare coverage, the veracity of terminal diagnoses, and the reliability of hospice care for people in their final stages of life. The issue is of particular importance for Florida, which has the nation’s second largest population of hospice patients, behind California. <https://goo.gl/e3jYU6>

Specialist Publications

‘**Physician preferences for aggressive treatment at the end of life and area-level health care spending: The Johns Hopkins Precursors Study**’ (p.9), in *Gerontology & Geriatric Medicine*.

‘**Charting the Future of Cancer Health Disparities Research: A position statement from the American Association for Cancer Research, the American Cancer Society, the American Society of Clinical Oncology, and the National Cancer Institute**’ (p.10), in *Journal of Clinical Oncology*.

‘**End-of-life services among patients with cancer: Evidence from cancer registry records linked with commercial health insurance claims**’ (p.10), in *Journal of Oncology Practice*.

‘**Culturally relevant palliative and end-of-life care for U.S. indigenous populations: An integrative review**’ (p.11), in *Journal of Transcultural Nursing*.

‘**Resisting the hospice narrative in pursuit of quality of life**’ (p.15), in *Qualitative Research in Medicine & Healthcare*.

How to get long-term care at home without busting the bank

KAISER HEALTH NEWS | Online – 27 July 2017 – The vast majority of older adults receive long-term care (LTC) at home, not in nursing homes. But few people plan for this expense. Nor do they see LTC insurance as a viable option – because it's expensive and is often seen as protection against the cost of nursing home care. That should change, some experts contend. If the LTC insurance industry focused more on helping people cover home-based services, they argue, policies would be more affordable, and potentially appealing. Currently, more than 6 million older Americans are thought to have a "high need" for LTC...¹ About 52% of adults reaching age 65 today will need these services – 26% for two years or less; 12% for two to four years; and, 14% for more than five years... Yet fewer than 10% of older adults have purchased LTC insurance, which has declined in popularity as premiums skyrocketed and insurers exited the market over the past decade. <https://goo.gl/iFbjJ7>

1. 'Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief,' U.S. Department of Health & Human Services, July 2015. <https://goo.gl/DovSeb>

Noted in Media Watch 17 July 2017, #521 (p.4):

- *FORBES* | Online – 12 July 2017 – **'How to keep long-term care from bankrupting us.'** When policymakers, health care analysts and financial journalists talk about the staggering costs of long-term care (LTC), it's often wonky, devoid of humanity. We throw around statistics like this one from the U.S. Department of Health & Human Services: 52% of individuals turning 65 will require LTC supports and services at some point in their lives. <https://goo.gl/dWmTmY>

For kids with cancer, focusing on quality of life

THE NEW YORK TIMES | Online – 27 July 2017 – Many people associate palliative care (PC) with hospice care, but medical professionals are offering it to children and adolescents living with cancer as well as to those dying from it. In the process, they are redefining both PC and cancer care, focusing on helping each patient achieve the best quality of life possible. About 15,780 American babies, children and adolescents receive a cancer diagnosis each year; approximately 1,960 die. Each one raises shocking questions about the suffering of the innocent. Children with cancer pose the problem of consciousness and agency. Can toddlers understand why they are receiving medicines that deplete them? Will teenagers discover the means to get through the tough challenges of postoperative recovery? Physicians now agree that whether or not these children are explicitly informed of their condition, they discern it – even if they want to protect themselves or their caregivers by not disclosing their understanding. They are therefore as vulnerable as adults to the fears that cancer spawns. And like adults, they must deal with invasive testing, surgery, radiation and chemotherapy as well as their miserable side effects. But they may lack the resources that some adults have to find restorative activities to lessen the psychological stress and physiological distress of standard care. <https://goo.gl/cykTXS>

Texas Senate gives early O.K. to bill regulating do-not-resuscitate orders

TEXAS | *The Texas Tribune* (Austin) – 26 July 2017 – The Senate ... gave early approval to a bill that would force physicians to take certain steps before issuing do-not-resuscitate orders (DNRs) to patients. Senate Bill 11 ... regulates the issuance of DNRs, directives that instruct medical professionals not to perform certain life-sustaining actions if a patient goes into cardiac or respiratory arrest. The bill seeks to ensure that a patient or the patient's legal guardian gives consent before a doctor issues a DNR. At a committee hearing for the bill earlier in the session, opponents – including the Texas Hospital Association – criticized the legislation as too vague, arguing that it would needlessly complicate the DNR process. The bill ... will now head to the House. <https://goo.gl/vWtKXd>

Why it's so hard to die in peace

THE WASHINGTON POST | Online – 26 July 2017 – For those of us who had hoped that American attitudes toward death were shifting in ways that would promote a wider reconstruction of the health-care system, there's discouraging news from *Health Affairs*, the preeminent journal of health policy. It devotes its latest issue to "end-of-life" care and finds that – at least so far – the power to make health care more compassionate and cost-effective is limited. That was the vision. Americans would become more realistic about death. Through "living wills," they'd reject heroic – often futile – treatment to keep them alive. Health spending would be lower (by one estimate, a quarter of Medicare spending occurs in the last year of life). People would die with dignity. They'd be spared needless suffering. Superficially, the vision seems to be triumphing, according to the 17 studies in *Health Affairs*. By one study, a third of American adults – and nearly half those 65 and older – have some sort of living will. From 1999 to 2015, the share of Americans who died in hospitals dropped from more than half to 37%. Over the same period, the number dying at home or in a hospice rose from less than a quarter to 38%. Moreover, at 8.5% of health costs, spending in the last year of life is lower in the U.S. than in some other countries. <https://goo.gl/sccPjC>

Noted in Media Watch 10 July 2017, #520 (p.10):

- *HEALTH AFFAIRS*, 2017;36(7):1167. '**Advanced illness and end-of-life care.**' Few areas of health care are as personal, or as fraught, as care for people with serious illnesses who are approaching death. At a point in their lives when their needs are often as much social and spiritual as they are medical, people are confronted with a fragmented, rescue-driven health care system that produces miraculous results, but also disastrous failures. <https://goo.gl/HtHKxf>

N.B. Journal contents page: <https://goo.gl/jebK3j>

Related

- *KAISER HEALTH NEWS* | Online – 25 July 2017 – '**Jump-starting hard conversations as the end nears.**' Most Americans avoid end-of-life (EoL) decisions, although some people may be more likely to make them if a doctor or social worker starts the discussion. In California, the state's attorney general's office offers an EoL planning checklist on its website. In the past few years, other websites have encouraged those conversations, with their own suggestions on how to get started. <https://goo.gl/jcmepf>

When can the government override a parent's medical decision in the U.S.?

CALIFORNIA | ABC10 News (Sacramento) – 25 July 2017 – In the U.S., patients have the right to informed consent before receiving medical treatment or procedures. California also has a set of laws protecting a minor's right to consent and confidentiality under specific circumstances such as pregnancy and abortion. However, when a child is not competent enough to decide what's in their best interest, like an infant or toddler, the parent or legal guardian steps in. U.S. parents are given medical authority over their children for several reasons... For one, parents are usually better situated to understand what their child needs and what the best option is to provide the most beneficial care for their child. There can be clashes between family members on what a child's best interests are but the American government generally believes parental decisions overrule that of others in the family. Parents are also allowed to raise their kids according to their own values and standards, and the government doesn't intrude on the family unit unless a child is in danger. However, there are situations where doctors can disagree with a parent's decision if a child is in a severe medical dilemma. The *parens patriae doctrine* gives the state the right to intervene with a parent's decision when it's believed they are not acting in the best interest for the child's well-being.¹ <https://goo.gl/XA8iSR>

1. The power of the state to act as guardian for those who are unable to care for themselves, such as children or disabled individuals. Under this doctrine a judge may change custody, child support, or other rulings affecting a child's well-being, regardless of what the parents may have agreed to.

Cont.

Noted in Media Watch 16 January 2017, #495 (p.9):

- MEDICAL LAW REVIEW | Online – 11 January 2017 – ‘**Protecting patients from their bad decisions: Rebalancing rights, relationships, and risk.**’ Patients have a right to autonomy that encompasses making medical decisions that others consider “bad.” The ambitions of this right in law and clinical practice are explored in this article, which describes an expansion of welfare protections across different aspects of medical law and explores their justifications and implications. <https://goo.gl/y4t9OH>

Noted in Media Watch 21 December 2016, #441 (p.12):

- CLINICAL ETHICS | Online – 18 December 2015 – ‘**The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child.**’ Dealing with situations where parents’ views about treatment for their child are strongly opposed to doctors’ views is one major area of ethical challenge in paediatric health care. The traditional approach focuses on the child’s best interests, but this is problematic for a number of reasons. <https://goo.gl/8ik8vm>

International

Charlie Gard dies: Baby's life-support withdrawn in hospice as parents “denied final wish”

U.K. (England) | *The Daily Telegraph* (London) – 28 July 2017 – Charlie Gard has died after his life-support was withdrawn soon after he was moved to a hospice, denying his parents their “final wish” for him to spend his final hours at home. Chris Gard and Connie Yates had asked for more time with their son after he was transferred from Great Ormond Street Hospital, but High Court judge Mr Justice Francis said doctors could stop providing treatment shortly after 11-month-old arrived at the hospice. An order issued by court officials ... and drawn up by the judge set out arrangements for Charlie’s final hours, which would “inevitably result in Charlie’s death within a short period thereafter.” Mr. Justice Francis has drawn five months of litigation to a close by making the order, which saw Charlie leave the London hospital where he has been cared for since late 2016 and moved to a hospice. Doctors at Great Ormond Street and Charlie’s parents had initially disagreed over whether Charlie, who suffers from a rare genetic condition, should be allowed to travel to the United States for a therapy trial. Mr. Justice Francis in April ruled in favour of the hospital which said the therapy was experimental and would not help Charlie. He said Charlie should be allowed to die with dignity. <https://goo.gl/Zkys99>

N.B. Selected articles/reports on the Charlie Gard case are noted in the 3 July 2017 issue of Media Watch (#519, p.5).



Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://goo.gl/5CHoAG>

Specialist Publications

‘Development of palliative care in China: A tale of three cities’ (p.13), in *The Oncologist*.

‘Implementation of palliative care in Palestine: Cultural and religious perspectives’ (p.14), in *Palliative Medicine & Hospice Care*.

Care homes with bars

U.K. (England & Wales) | *Inside Time* – 28 July 2017 – The Prisons & Probation Ombudsman has just published a thematic review ... about older prisoners.¹ As the number of older people in our prisons increases, both proportionately and in absolute terms, the number of deaths we see in prisons will inevitably follow suit. In the last decade, the number of naturally-caused deaths of prisoners over 50 has more than doubled. The substantial increase of older people dying in prison has meant that the Prison Service increasingly has to grapple with risks and procedures they were not previously forced to consider, when prisons in England and Wales were more likely to hold fit young men. The Care Act clarified that Local Authorities are responsible for assessing the care needs of older prisoners and providing support. This legislation, along with the national and international expectations that require prisoners to be able to access a level of care equal to that in the community, are significant and positive developments for health and social care in prisons. However, faced with an increase in the population of older prisoners and without a properly resourced and coordinated strategy for this group, prisons still face a number of challenges associated with ageing populations. <https://goo.gl/nHTpfq>

1. ‘Learning from Prisons & Probation Ombudsman Investigations,’ Prisons & Probation Ombudsman, June 2017. <https://goo.gl/Cfusiq>

Noted in Media Watch 24 July 2017, #522 (p.3):

- U.K. (England & Wales) | *The Daily Telegraph* – 18 July 2017 – “**Old people’s homes with walls required for elderly prisoners, says watchdog.**” The Government should build “care homes with walls” to house a growing number of elderly prisoners, the chief prisons inspector has said. Speaking at the launch of his annual report...¹ The number of over-70s in prison is predicted to increase from 1,400 in June of last year to 1,900 over the next three years. <https://goo.gl/hTRqai>
 1. ‘HM Chief Inspector of Prisons,’ Annual Report for 2016-17,’ July 2017. <https://goo.gl/BgarSA>

End-of-life care in England

National Health Service plan to sell-off £535 million of end-of-life care SCRAPPED (but only after spending £840,000)

U.K. (England) | *The Sentinel* (Stoke on Trent) – 27 July 2017 – Four clinical commissioning groups in Staffordshire have been working on the Transforming Cancer & End-of-life Care programme – described by critics as the largest ever National Health Service (NHS) privatisation – since 2013. But the CCGs have now decided to not proceed with awarding the 10-year contract for end-of-life care to either of the remaining bidders – the Together Consortium and Virgin Care Limited. This comes months after the clinical commissioning groups (CCGs) opted against awarding a contract covering £687 million of cancer ser-

Extract from Prisons & Probation Ombudsman report

We also offer lessons about palliative and end-of-life (EoL) care – something prisons increasingly have to deal with. Here, we acknowledge it is not only prisoners who are ageing – often our facilities are older and not designed to adequately accommodate disability or palliative care needs. We recommend that prisons try to ensure the terminally ill are treated in a suitable environment. We also identify a lesson to improve healthcare coordination at the EoL, by ensuring that care plans are initiated at an appropriate, and ideally early, stage for those who are diagnosed with a terminal illness.

N.B. See ‘Palliative and end of life care’ (p.19-20).

Palliative Care Network Community

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 can be downloaded/viewed at:

<http://goo.gl/ZpEJyQ>

Cont.

vices to the sole remaining bidder. The four-year procurement process has cost the CCGs around £840,000. But the CCGs say the NHS “landscape” has “changed significantly” since 2013 with the introduction of the sustainability and transformation partnerships. The transformation programme would have introduced “prime providers” to better co-ordinate the fragmented cancer and end-of-life services. But, more than 70,000 people signed a petition against the plans, which they condemned as NHS privatisation – an allegation the CCGs denied. Critics also questioned the logic of inserting an additional layer of management in order to rationalise the services. <https://goo.gl/HHpBG9>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Victoria) | *The Australian* – 26 July 2017 – ‘**Palliative care system being starved of oxygen.**’ In an ageing community, we potentially have millions who are vulnerable, who are fearful of becoming a burden, whose suffering is not just physical pain but also isolation or depression. Surely, as a community, we should ask how we can alleviate that suffering, how we can address our society’s widespread anxiety about death and dying, how to make quality palliative care truly accessible to all, before reaching for the convenient alternative of an assisted exit. The former takes time and effort. The latter may take only 10 days if the Victorian legislation passes. What does that say about our priorities? The expert panel says there are 68 safeguards for Victoria’s assisted suicide model. That’s 68 potential areas where things can go wrong – a scary proposition. <https://goo.gl/yFveoE>

Specialist Publications

Severely affected by Parkinson disease: The patient’s view and implications for palliative care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 26 July 2017 – People severely affected by Parkinson disease (PD)/atypical parkinsonism (AP) comprise a heterogeneous group with distinct needs, which so far remain largely unexamined. Eight hundred fourteen questionnaires were analyzed. Most common reasons for feeling severely affected were mobility impairment (34.9%), coordination problems (17.0%), speech problems (12.2%), and limited day-to-day activities (7.8%). Most often expressed unmet needs were support in everyday life (28.1%), medical treatment (15.2%), help with financial services (11.6%), and social integration (9.9%). To meet the complex needs, an integrated multidisciplinary and multi-professional approach is indicated befitting palliative care principles. Home-based services seem of special importance for patients in advanced disease stages. <https://goo.gl/LBKK6X>

Noted in Media Watch 24 July 2017, #522 (p.15):

- *THE PHARMACEUTICAL JOURNAL* | Online – 19 JUL 2017 – ‘**New guidelines on Parkinson’s disease released by National Institute for Health & Care Excellence.**’ England’s health technology assessment body, has released new clinical guidelines on the diagnosis and management of Parkinson’s disease in adults aged 18 years and over.¹ <https://goo.gl/FqGSuH>
 1. ‘Parkinson’s disease in adults,’ National Institute for Health & Care Excellence, July 2017. (Scroll down to ‘1.9 Palliative care.’) <https://goo.gl/CgY1QZ>

Noted in Media Watch 22 May 2017, #513 (p.16):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 18 May 2017 – ‘**Palliative care and Parkinson’s disease: Caregiver perspectives.**’ Study participants discussed the immediate impact of motor and non-motor symptoms as well as concerns about the future, including: finances, living situation, and caretaking challenges in advanced disease. <https://goo.gl/lxw9bl>

N.B. Additional articles on palliative care for people living with Parkinson’s disease are noted in the 27 March 2017 (#505, p.12) issue of Media Watch.

“Futile care” – an emergency medicine approach: Ethical and legal considerations

ANNALS OF EMERGENCY MEDICINE | Online – 26 July 2017 – Although there is substantial literature describing the meaning and use of futility, little of it is specific to emergency medicine. Furthermore, the literature does not provide a widely accepted definition of futility, and thus is difficult if not impossible to apply. Some argue that even a clear concept of futility would be inappropriate to use. This article reviews the origins of and meanings suggested for futility, specific challenges such cases create in the emergency department (ED), and the relevant legal background. The authors propose an approach to cases of perceived futility that is applicable in the ED and does not rely on unilateral decisions to withhold treatment, but rather on avoiding and resolving the conflicts that lead to physicians’ believing that patients are asking them to provide “futile” care. <https://goo.gl/iiJUuG>

Behind the smile: Qualitative study of caregivers’ anguish and management responses while caring for someone living with heart failure

BMJ OPEN | Online – 20 July 2017 – Caregivers support self-management in heart failure, but often experience stress, anxiety and ill health as a result of providing care. The authors found that caregivers [i.e., study participants] often hide the extent of their emotional stress or anguish. They identified four main themes with explanatory sub-themes – 1) Emotional impact (fear for the future and sense of hopelessness); 2) Role definition (changing sense of who I am, reduced resilience, learning care skills, role conflict and changing role); 3) Exclusion (exclusion by the cared-for person and by health professionals and feeling alone); and, 4) Ignoring one’s own health – that were associated with anguish. From these findings, the authors produced a caregiver needs assessment model in the context of caring for a person with heart failure. The model may be used by health and social care professionals to identify needs and to provide caregivers with targeted practical and emotional support; and, for researchers developing interventions to enhance self-management in heart failure. <https://goo.gl/7RF6NH>

Broadening end-of-life comfort to improve palliative care practices in long term care

CANADIAN JOURNAL ON AGING | Online – 27 July 2017 – This study aimed to explore how palliative care (PC) in long-term care (LTC) addresses the tensions associated with caring for the living and dying within one care community, and to inform how PC practices may be improved to better address the needs of all residents living and dying in LTC as well as those of the families and support staff. This article reports findings from 19 focus groups and 117 participants. Study findings reveal that LTC home staff, resident, and family perspectives of end-of-life (EoL) comfort applied to those who were actively dying and to their families. Findings further suggest that eliciting residents’ perceptions of EoL comfort, sharing information about a fellow resident’s death more personally, and ensuring that residents, families, and staff can constructively participate in providing comfort care to dying residents could extend the purview of EoL comfort and support expanded integration of palliative principles within LTC. <https://goo.gl/ZhGxvo>

Noted in Media Watch 12 June 2017, #516 (p.9):

- *JOURNAL OF CANADIAN STUDIES*, 2017;50(2):396-421. ‘**Intensifying relational care: The challenge of dying in long-term residential care.**’ Although the culture change movement has sought to transform residential care facilities from *warehouses of death* into homes for living, there is growing recognition of the need to address dying within these settings. Drawing on data from an international and interdisciplinary study, this paper explores the state of end-of-life care (EoLC) in residential care facilities, identifying barriers to the provision of compassionate care for the dying, as well as promising practices and areas for future inquiry. <https://goo.gl/f37VGM>

N.B. Additional articles on palliative and end-of-life care in care homes and nursing homes are noted in this issue of Media Watch.

Palliative care physicians' experiences of end-of-life communication: A focus group study

EUROPEAN JOURNAL OF CANCER CARE | Online – 22 July 2017 – The results show that the participants saw themselves as being responsible for accomplishing breakpoint communication (BPC), and they were convinced that it should be regarded as a process of communication initiated at an early stage, i.e., proactively. However, BPC was often conducted as a reaction to the patient's sudden deterioration or sometimes not at all. The barriers to achieving proactive BPC included physicians' uncertainty regarding the timing of BPC, primarily due to difficulties in prognostication in terms of time of death, and uncertainty as to what BPC should include and how it should best be approached. Furthermore, there was insufficient documentation regarding previous BPC, which impeded proactive BPC. Although this study shows that physicians are ambitious when it comes to the communication of information to patients and families, there is a need for further training in how to conduct BPC and when to initiate the BPC process. Furthermore, there should be documentation that different professionals can access as this would appear to facilitate a proactive BPC process. <https://goo.gl/iSP1WD>

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

Physician preferences for aggressive treatment at the end of life and area-level health care spending: The Johns Hopkins Precursors Study

GERONTOLOGY & GERIATRIC MEDICINE | Online – 24 July 2017 – This is one of the few studies that have used direct measures of physician preferences to examine the influence on health care spending. Physician preferences may be an important determinant of health care use, and these preferences may be important to address in measures intended to alleviate geographic variations in cost. Strategies intended to better align health care spending with patient values will need to consider individual physician preferences and practice style as well. Choosing Wisely is an effort of the American Board of Internal Medicine Foundation with over 70 professional organizations as partners to encourage conversations between providers and patients to carefully consider the value of tests and procedures that may be of limited benefit to the patient. However, it remains to be seen whether such efforts are sufficient to change physician and patient behaviors and reduce health care spending. <https://goo.gl/87jdvz>

N.B. Additional articles on the Choosing Wisely campaign are noted in the 22 May 2017 issue of Media Watch (#513, pp. 9-10).

Expanding the horizon of our obligations in the clinician-patient relationship

THE HASTINGS CENTER REPORT, 2017;47(4):40-41. Johan Brännmark's article ... identifies some important problems with the way we in clinical practice conceive of our obligations to our patients.¹ As a solution, he helpfully suggests augmenting our focus on autonomy and informed consent with a broader menu of considerations drawn from the literature on human rights. Respect for autonomy is, of course, one of the hallowed principles of bioethics. In our traditional understanding, our patients deserve our respect because they are capable of autonomous choice, and the way we demonstrate our respect is by seeking their informed consent for our care. This model is so deeply ingrained that many of us have difficulty imagining that there could be any other way of thinking about it. But this model has two very serious drawbacks, problems that speak to much of what is wrong with health care today. <https://goo.gl/cBZ429>

1. 'Patients as rights holders,' *The Hastings Center Report*, 2017;47(4):32-39. <https://goo.gl/AEnGRf>



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.

Cancer care in the U.S.

Charting the Future of Cancer Health Disparities Research: A position statement from the American Association for Cancer Research, the American Cancer Society, the American Society of Clinical Oncology, and the National Cancer Institute

JOURNAL OF CLINICAL ONCOLOGY | Online – 24 July 2017 – The field of cancer health disparities has evolved into a complex science and an established multidisciplinary field of cancer research. Unfortunately, the rigor required to conduct this research has not been uniformly applied, and the infrastructure needed to take it to the next level, where lasting solutions can be found, is limited. The purpose of this article, which has been jointly written by experts from these four esteemed organizations, is to guide the development of advances in this area. The hope is that this statement will be used by both public and private organizations to inform specific investments made to improve cancer health disparities research, thereby ultimately eliminating identified disparities in cancer incidence, quality of care, and outcomes. Several recommendations for action items emerged. <https://goo.gl/mgbHF9>

N.B. There is no mention in the position statement of hospice or palliative care. **BRA**

Related

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 19 July 2017 – ‘**End-of-life services among patients with cancer: Evidence from cancer registry records linked with commercial health insurance claims.**’ Hospitalization and high-cost imaging scans are burdensome to patients and caregivers at the end of life (EoL). The authors’ findings suggest that policies that facilitate appropriate imaging, opioid, and hospice use and that encourage supportive care may improve EoL care and quality of life. <https://goo.gl/hYNvrX>

One size does not fit all: Disease profiles of serious illness patients receiving specialty palliative care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 24 July 2017 – This study is one of the first to describe symptom burden and functional scores by diagnostic categories and care settings across a community-based interdisciplinary specialty palliative care program. Results demonstrate statistically significant and clinically relevant differences among settings of care, functional status, and symptom profiles between patients with various serious illnesses. The authors evaluated the first visit consultation records of 1,615 patients. Most prevalent diagnosis was neurologic (564; 35%), followed by cardiovascular (266; 16%), pulmonary (229; 14%), and cancer (208; 13%). Patients in the study with the highest symptom burden were those diagnosed with cancer or pulmonary disease, with 45% and 37% of cancer and pulmonary patients, respectively, having two or more moderate to severe symptoms. 26% of cardiovascular disease patients reported two or more moderate to severe symptoms while 11% reported three or more. Patients with a neurologic or infectious diagnosis had less symptom burden, but a large percentage of neurologic patients were unable to respond. <https://goo.gl/PZKNSq>

Now and at the hour of death

JOURNAL OF PATIENT EXPERIENCE | Online – 17 July 2017 – With Alzheimer disease, the challenge of death can be unique to each who experience it: the caretaker, the family, the health-care professional, and the victim himself. Death of personality, of memory, and of physical skills wears away the fabric of relationships, leaving little hope of any return to normalcy. To some, this reflection exhibits how faith sustains hope and comforts those afflicted, despite the odds of inevitable loss. To others it reflects upon the poignant complexities associated with palliative care and the demand for individualized attention to the beliefs, norms, and values of each situation, no matter the culture, religion, age, or race. No two cases are ever the same in the face of death, yet for those who experience it, all must appreciate how difficult, unique, personal, and memorable such moments can be. <https://goo.gl/G7bzw4>

Communicating prognosis with parents of critically ill infants: Direct observation of clinician behaviors

JOURNAL OF PERINATOLOGY | Online – 27 July 2017 – The authors analyzed 19 family conferences. Most prognostic discussion targeted predicted infant functional needs, for example, medications or feeding. Clinician approach to prognostic disclosure ... tended to be broad and optimistic, without detail regarding implications of infant health for infant/family quality of life. Families and clinicians left these conversations with little consensus about infant prognosis. <https://goo.gl/7fSpkc>

Stepwise psychosocial palliative care: A new approach to the treatment of Posttraumatic Stress Disorder at the end of life

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 28 July 2017 – Although evidence-based therapies for Posttraumatic Stress Disorder (PTSD) exist for physically healthy populations, these often do not adequately address PTSD in dying patients. These interventions require 8-16 weekly sessions, and the median stay in U.S. hospices is 17.5 days... There is a potentially serious timing mismatch. Moreover, these treatments may temporarily increase trauma symptoms..., resulting in some patients dying in greater distress than had they not received care. <https://goo.gl/4BKBwc>

Culturally relevant palliative and end-of-life care for U.S. indigenous populations: An integrative review

JOURNAL OF TRANSCULTURAL NURSING | Online – 22 July 2017 – American Indians/Alaska Natives (AIs/ANs) have higher rates of chronic illness and lack access to palliative/end-of-life (EoL) care. Twenty-nine articles were identified, 17 remained that described culturally specific palliative/EoL care for AIs/ANs. Synthesis revealed four themes: 1) Communication; 2) Cultural Awareness/Sensitivity; 3) Community Guidance for Palliative/EoL Care Programs; 4) Barriers ...and ,two subthemes: 1) Trust/Respect, and 2 Mistrust. Limitations are lack of research funding, geographic isolation, and stringent government requirements. Palliative/EoL care must draw on a different set of skills that honor care beyond cure provided in a culturally sensitive manner. <https://goo.gl/yegFi2>

Selected articles on palliative and end-of-life care for U.S. indigenous populations

- *THE GERONTOLOGIST* | Online – 7 December 2016 – “**Just let me go”: End-of-life planning among Ojibwe elders.**’ Despite seeing little need for advance care planning, the elders were generally open to discussing the care they would want at end of life (EoL). Many were readily able to describe their wishes for a peaceful death and had already developed funeral and burial or cremation plans. Although establishing one’s individual legacy was not a salient EoL concern for the elders, several found meaning in describing their contributions to preserving their families, the community, and their cultural lifeways. [Noted in Media Watch 12 December 2016, #491 (p.11)] <https://goo.gl/abISCD>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 November 2016 – ‘**Palliative care for American Indians and Alaska Natives: A review of the literature.**’ Little is known about optimal palliative and end-of-life care for American Indians and Alaska Natives (AIs/ANs). Common themes included the importance of culturally appropriate communication, multiple barriers to treatment, and less frequent use of advance directives than other populations. Heterogeneity of study types, population, and small sample sizes makes it hard to draw broad conclusions regarding the best way to care for AIs/ANs. [Noted in Media Watch 14 November 2016, #487 (p.8)] <https://goo.gl/a6MQS4>
- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2014;16(7):404-413. ‘**American Indians’ experiences of life-threatening illness and end of life.**’ The study focus was identification of tribal values, contributing factors, and decision making regarding end of life (EoL). Participants’ EoL experiences focused on the concept of struggle, coping by seeking knowledge, and applying connectedness to family, community, spirituality, and health care providers. Their culturally ideal EoL was identified as being a proud Indian and living the Indian way of life to the end. [Noted in Media Watch 15 September 2014, #375 (p.13)] <https://goo.gl/W0VORL>

Approaching the third decade of paediatric palliative oncology investigation: Historical progress and future directions

THE LANCET CHILD & ADOLESCENT HEALTH | Online – 24 July 2017 – In the past two decades since WHO defined paediatric palliative care (PPC) and called for its inclusion in paediatric oncology care, rigorous investigation has provided important insights. For example, the first decade of research focused on end-of-life experiences of the child and the family, underscoring the high prevalence of symptom burden, the barriers to parent-provider concordance with regards to prognosis, as well as the need for bereavement supports. The second decade expanded PPC oncology investigation to include the entire cancer continuum and the voices of patients. Other studies identified the need for support of parents, siblings, and racial and ethnic minority groups. Promising interventions designed to improve outcomes were tested in randomised clinical trials. Future research will build on these findings and pose novel questions about how to continue to reduce the burdens of paediatric cancer. <https://goo.gl/WtyRsa>

N.B. Log on for free access to the full text.

The particularity of dignity: Relational engagement in care at the end of life

MEDICINE, HEALTH CARE & PHILOSOPHY | Online – 27 July 2017 – This paper articulates dignity as relational engagement in concrete care situations. Dignity is often understood as an abstract principle that represents inherent worth of all human beings. In actual care practices, this principle has to be substantiated in order to gain meaning and inform care activities. The authors describe three exemplary substantiations of the principle of dignity in care: 1) As a state or characteristic of a situation; 2) As a way to differentiate between socio-cultural positions; or, 3) As personal meaning. They continue their analysis by presenting cases on dignity in care related to them in focus groups with medical professionals. The authors' empirical ethical lens in this paper is to analyse, not the meaning of dignity, but the way in which it emerges in practices where it is pursued, within relationships between people, technologies, places, regulations, and the values cherished by or embedded in them. They show that professional caregivers recognize in the dignity of the person they care for their own dignity; giving up on the one implies no less than giving up on the other. <https://goo.gl/rMBfwe>

Home care in the U.S.

Community nurses with poor work environments “more likely to miss care”

NURSING TIMES | Online – 25 July 2017 – Better working environments, including time to care and access to training, are linked with better patient and workforce outcomes in community nursing, according to the first study of its kind.¹ U.S. nurse researchers examined the factors influencing the likelihood of missed nursing care in home care settings. They said their findings indicated that home care nurses with poor working environments were more likely to miss required care, in a similar way to previous evidence for acute settings. Among other questions, nurses were asked whether they had omitted any required or necessary care activities due to a lack of time. As has been found in hospitals, nurses working in agencies with poor work environments were more likely to report not having enough time to complete necessary patient teaching, counselling, and care co-ordination. Categorising agencies into poor, mixed, and better work environments, the researchers found those in better environments were less than half as likely to report missing necessary care co-ordination, counselling, or education of patients and their carers, compared to those in poor settings. They also identified an impact on nursing staff as well. Specifically, nurses in the best work environments were less than one-third as likely to experience burnout, job dissatisfaction, or intend to leave their jobs, compared with nurses working in the worst work environments. <https://goo.gl/UXWjuV>

1. ‘Pathway to better patient care and nurse workforce outcomes in home care,’ *Nursing Outlook*, published online 2 June 2017. <https://goo.gl/hnHHcN>

Cont.

Related

- **HEALTH & SOCIAL CARE IN THE COMMUNITY** | Online – 20 July 2017 – ‘**Attractiveness of working in home care: An online focus group study among nurses.**’ The findings [of this study] showed that home-care nurses find it attractive that they are a “linchpin,” in the sense of being the leading professional and with the patient as the centre of care. Home-care nurses also find having autonomy attractive: autonomy over decision-making about care, freedom in work scheduling and working in a self-directed team. Variety in patient situations and activities also makes their work attractive. <https://goo.gl/s6o7Jk>

Development of palliative care in China: A tale of three cities

THE ONCOLOGIST | Online – 24 July 2017 – With a population of 1.3 billion, China is the most populous country in the world and cancer is the leading cause of death. However, only 0.7% of hospitals offer palliative care (PC) services. The authors describe the program development and infrastructure of the PC programs at three Chinese institutions, using these as examples to discuss strategies to accelerate PC access for cancer patients in China. The three examples of PC delivery in China ranged from a comprehensive program that includes all major branches of PC in Chengdu, a program that is predominantly in-patient-based in Kunming, and a smaller program at an earlier stage of development in Beijing. Despite the numerous challenges related to the limited training opportunities, stigma on death and dying, and lack of resources and policies to support clinical practice, these programs were able to overcome many barriers to offer PC services to patients with advanced diseases and to advance this discipline in China through visionary leadership, collaboration with other countries to acquire PC expertise, committed staff members, and persistence. <https://goo.gl/ZwBaob>

N.B. To access full text click on pdf icon.

Noted in Media Watch 27 February 2017, #501 (p.6):

- **EUROPEAN JOURNAL OF PALLIATIVE CARE**, 2017;24(1):12-17. ‘**Exploring the challenges of implementing palliative care in China.**’ Uneven allocation of health resources, medical and cultural attitudes, and social and political factors make the speedier development of palliative care (PC) services in China highly challenging. PC in China is still in its infancy, which provides opportunities for developing innovative models of PC, obtaining policy and financial support, deepening global collaborations and promoting PC as an independent discipline.

N.B. Access to the journal requires a subscription. Contents page for the January/February 2017 issue:
<https://goo.gl/lzN0zd>

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

- **CHINA** | Sixth Tone (Shanghai) – 16 February 2017 – ‘**China issues first end-of-life care standards.**’ Thirty years after China’s first hospice center opened its doors in Beijing, the country’s top health authority has finally released a set of standards for palliative care. China’s end-of-life health care is desperately under resourced. In a country where 7 million people die each year, there are just 2,103 hospices and 289 nursing homes for dedicated palliative services. <https://goo.gl/iGyO7m>

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

Implementation of palliative care in Palestine: Cultural and religious perspectives

PALLIATIVE MEDICINE & HOSPICE CARE | Online – Accessed 28 July 2017 – The Palestinians living in the West Bank and Gaza suffer from the same barriers reported by the neighboring Arab countries including the lack of support by health policies and education, little or no knowledge of the principles and practices of palliative care (PC) among healthcare providers and patients and their families. In addition to the weak healthcare system and the scarcity of resources and unavailability of medications especially opioids, the Palestinians have additional barriers due to the peculiar political situation since the West Bank and Gaza governed by the Palestinian authority are still under Israeli occupation.

Introducing and implementing PC for Palestinians in the West Bank and Gaza require integrated local and international efforts and support. At the local level, Palestinian ministries and stakeholders should place PC on their priority list. Additional budget should be allocated to the Ministry of Health to capacity build the human resources and the premises of the Palestinian healthcare system. The extra budget should be invested in improving cancer screening, early and proper diagnosis, and follow-up, which consequently will decrease the number of terminally ill patients who are in need of PC. Moreover, professional and well-structured training programs should be conducted especially in hospitals with oncology and geriatric departments to improve the qualifications of the healthcare providers and to train them to adopt the skills and the attitudes that are part of PC. The international community such as WHO, Middle East Cancer Consortium and other cancer-related organizations could significantly contribute to this training. Furthermore, a national policy and legislation regarding PC provided at hospitals and homes should be implemented and integrated with the healthcare system and the health insurance to warrant the availability and access to opioids. <https://goo.gl/Asxyff>



End-of-life care in Japan

End-of-life experiences of family caregivers of deceased patients with cancer: A nation-wide survey

PSYCHO-ONCOLOGY | Online – 20 July 2017 – Family caregivers' experiences were divided into three domains: 1) Protect children from the patient's imminent death; 2) Little regard for the children; and, 3) Worry and concern about the children's emotional reaction. Family caregivers' common experiences were as follows: "I wanted to know how the children felt," "I wanted to avoid making the children confused," and "I did not have much time to talk with and/or play with the children." About 30% of family caregivers reported that they "did not talk" about death and dying of patients to minor children. Spouses of patients and family caregivers who did not talk about death tended to experience distress and worry. Most family caregivers experienced worry and fear regarding minor children's emotional reaction, therefore, clinicians need to explain children's emotional and psychological reaction to family caregivers when a patient is at the end-of-life. <https://goo.gl/9FaYr5>

Related

- PSYCHO-ONCOLOGY | Online – 25 July 2017 – **'Prevalence and predictors of conflict in the families of patients with advanced cancer: A nationwide survey of bereaved family members.'** Many families of patients with advanced cancer experienced conflict during end-of-life care. Greater family conflict was significantly associated with younger family age, with family members asserting control over decision-making for patient care and with communication constraints among family members, although absent family members "coming out of the woodwork" reduced conflict. <https://goo.gl/8fSn7k>

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

Resisting the hospice narrative in pursuit of quality of life

QUALITATIVE RESEARCH IN MEDICINE & HEALTHCARE, 2017;1(2):63-72. The overall hospice philosophy is to provide care that enhances a dying person's quality of life (QoL). Most individual's QoL is improved when they embrace hospice eligibility and reimbursement requirements, such as stopping burdensome and ineffective curative treatment, addressing pain and other symptoms, and seeking avenues for closure. However, this institutionalized prescription for enhancing QoL at the end of life (EoL) does not work for all patients. This article considers what happens when patients' personal definitions of QoL at the EoL resist the prevailing narrative of appropriate hospice care. Using a series of examples from more than 600 hours of participant observation, the authors' findings reveal narratives of resistance that fall into three themes: 1) Patients and/or family members who deny the imminence of death despite an admission to hospice; 2) Patients who request treatments usually defined as curative; and, 3) Patients who resist the organizational constraints imposed by the institutionalization of the hospice model of care. Analysis of these themes illustrates the subjective nature of QoL at the EoL and the pressures of standardization that may accompany the growth and maturity of the hospice industry in the U.S. <https://goo.gl/1St5vr>

N.B. To access full text click on pdf icon.

Related

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 19 July 2017 – ‘**End-of-life services among patients with cancer: Evidence from cancer registry records linked with commercial health insurance claims.**’ In the last month of life, among 6,568 commercially insured patients, 56.3% were hospitalized and 48.6% underwent at least one imaging scan. Among patients younger than 65 years of age, 31.4% were enrolled in hospice; of those younger than 65 years of age who were not enrolled in hospice, 40.5% had received an opioid prescription. Over time, opioid use in the last 30 days of life among young adults not enrolled in hospice dropped from 44.7% in the period 2007 to 2009 to 42.5% in the period 2010 to 2012 and to 36.7% in the period 2013 to 2015. <https://goo.gl/yhVJ29>

Elder care in Brazil

The frail elderly and integral health management centered on the individual and the family

REVISTA BRASILEIRA DE GERIATRIA E GERONTOLOGIA, 2017;20(3). The rapid aging of the Brazilian population, combined with an increase in longevity, has had serious consequences for the structure of health care networks, with an increased burden of chronic diseases and especially of functional disabilities. Unfortunately, the care offered to frail elderly people with multiple chronic health conditions, poly-disabilities or complex needs is fragmented, inefficient, ineffective and discontinuous, which can further harm their health. The hospital-based health system of the 19th and 20th centuries that is designed to deal with acute and especially infectious diseases is inadequate for meeting the needs of chronic patients for long-term, continuous treatment. The response of the health system to the new demands means the use of a set of management technologies that are capable of ensuring optimal standards of health care in a resolute, efficient, scientifically structured manner, which is safe for patients and health professionals, timely, equitable, humanized and sustainable, is essential. <https://goo.gl/QxtvPa>

N.B. Article available in both English or Portuguese.

Noted in Media Watch 5 September 2016, #478 (p.7):

- *AGE & AGEING* | Online – 1 September 2016 – ‘**Developing a model of short-term integrated palliative and supportive care for frail older people in community settings: Perspectives of older people, carers and other key stakeholders.**’ Stakeholders agreed a model of short-term integrated palliative and supportive care services for frail older people with non-malignant conditions has potential benefits within community settings, but differed in opinion on the optimal timing and indications for this service. <http://goo.gl/Sv2oQz>

Cont.

Noted in Media Watch 8 August 2016, #474 (p.7):

- *BRITISH JOURNAL OF COMMUNITY NURSING*, 2016;21(8):385-389. ‘**Frailty: A term with many meanings and a growing priority for community nurses.**’ This article discusses what frailty is, what it may mean for patients, and attempts to expand on why the construct of frailty is a prevalent issue for community nurses. The link between frailty and mortality is discussed and how targeted appropriate advanced care planning may be used to address this demographic challenge. <http://goo.gl/aP7nS9>

N. B. Additional articles on end-of-life care for frail older people are noted in this issue of Media Watch.

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *HEALTH ETHICS TODAY*, 2017;25(1):6-13. ‘**MAiD is legal in Canada: I was not trained to do this!**’ It is clear that our current practice of compassionately withdrawing or withholding life-sustaining treatment in specific clinical situations has become a standard approach to end-of-life care, one that is accepted within our values as physicians, and one for which I was trained. Fortunately, very few patients actually request medical assistance in dying (MAiD), but the numbers are growing while palliative care investments and availability are not. Medical societies still affirm that MAiD is not part of the “medical ethos,” so conscientious objection should be validated. Institutions need to adapt and respect such choice. Finally, “...we must say to the broader community that if it insists on tolerating or legalizing active euthanasia, it will have to find non-physicians to do its killing” (Gaylin, Kass, Pellegrino, & Siegler, 1988).
- See also “Protecting the rule of law and the vulnerable”: Examining the Canadian legal landscape surrounding assisted dying’ (p.3); ‘Mental health professionals, medical assistance in dying and mental illness: Challenges and possible alternative (p.13); and, “Conscientious objection” and medical assistance in dying (MAiD): What does it mean? (p.16). Newsletter: <https://goo.gl/3AgLqC>
- *THE HASTINGS REPORT*, 2017;47(4):5-6. ‘**On legalizing physician-assisted death for dementia.**’ Soon after Colorado became the latest state to authorize physician-assisted suicide (PAS, National Public Radio’s The Diane Rehm Show devoted a segment to legalization of “physician assistance in dying,”¹ a label that refers to both physician-assisted suicide and voluntary active euthanasia. Although the segment initially focused on PAD in the context of terminal illness in general, it wasn’t long before PAD’s potential application to dementia patients came up. A caller said that her mother had Alzheimer’s disease and was being cared for at great expense. Suspecting that she will suffer the same fate, the caller reported that she had included in her will “my specific request that if I should be diagnosed, and it is legal to do so, I would like to opt out of a life and many years of suffering.” A few countries, such as The Netherlands and Belgium, already allow PAD for dementia in certain circumstances. It wouldn’t be surprising to see a U.S. legalization effort in the coming years. <https://goo.gl/8mCLgX>

1. ‘The debate across the nation over “death with dignity” laws,’ November 2016. <https://goo.gl/bNv13z>

Worth Repeating

Benefits of health and social care integration

BMJ SUPPORTIVE & PALLIATIVE CARE, 2014;4(18). Scotland’s health boards and local authorities are moving towards integrated funding and service provision. Effective integration will depend on health, social care and third/independent sector partners pooling resources and planning care together, led by clinicians and other professionals. Over seventy-seven patients [i.e., study participants] would have required hospital admission without the integrated service [i.e., Integrated Health & Personal Care Community Support]. Eight-three percent of respondents thought the service had enabled more input into decision making about their care; and, 66% were able to spend more time with their loved ones and have reported an improved quality of life. The voluntary sector is a key partner in supporting the integration agenda with specific expert knowledge. <https://goo.gl/RiCj6X>

Cont.

Noted in Media Watch 13 May 2013, #305 (p.13):

- **HEALTH SERVICE JOURNAL** | Online – 8 May 2013 – ‘**Redesigning end-of-life care in the community.**’ The challenges for the health and social care system in our rapidly ageing society and the pressure associated with ongoing public spending constraints are clear for all to see. Faced with these twin challenges, we can either stand by and oversee a gradual decline in the quality of care provided or we can seize the opportunity to fundamentally change the way we do things. <https://goo.gl/t9vjJx>

Media Watch: Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/nZMuK7>

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 'Media Watch by Barry Ashpole']

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/lXO4mD>

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

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLgxy2>

[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>

[Scroll down to 'Additional Resources']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <https://goo.gl/lOSNC7>

ONTARIO | Mississauga Halton Palliative Care Network: <https://goo.gl/ds5wYC>

[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W>

[Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Magyar Hospice Alapítvány: <http://goo.gl/5d1l9K>

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



14 October 2017

Universal health coverage and palliative care – Don't leave those suffering behind

<https://goo.gl/diYn7i>

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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