

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.

28 November 2016 Edition | Issue #489



Compilation of Media Watch 2008-2016 ©

Compiled & Annotated by Barry R. Ashpole

End-of-life care in Canada: Scroll down to [Specialist Publications](#) and ‘Patient participation in palliative care decisions: An ethnographic discourse analysis’ (p.11), in *International Journal of Qualitative Studies on Health & Wellbeing*.

U.S.A.

Palliative care linked to better, if not longer, life

FOX NEWS | Online – 22 November 2016 – Palliative care (PC) may offer a better quality of life to chronically sick or terminally ill patients even if it doesn’t help them live longer, a research review suggests.¹ Research to date on the impact of PC has produced mixed results. Some studies have shown a survival benefit, but findings have often been muddled by the possibility that there are differences between patients who choose PC and those who opt for other types of treatment. For the current study, researchers examined data from 43 previously published studies with a total of almost 13,000 patients and 2,500 caregivers to see if a pooled analysis could offer a clearer picture. “Our analyses suggest that patients who received PC had better quality of life and less severe symptoms than those patients who hadn’t received PC,” said lead study author Dio Kavalieratos of the University of Pittsburgh. “We also saw that those who received PC were generally more satisfied with their care and so were their caregivers.” <https://goo.gl/pK9Fte>

Specialist Publications

‘Helping patients and families understand the financial impact of end-of-life care’ (p.6), in *American Journal of Nursing*.

‘The role of occupational therapy in end-of-life care’ (p.6), in *American Journal of Occupational Therapy*.

‘The “reckoning point” as a marker for formal palliative and end-of-life care in Mexican American families’ (p.12), in *Journal of Family Nursing*.

‘An ethic of heroism shapes next of kin’s perceptions of veterans’ end-of-life care in Veterans Affairs Medical Centers’ (p.12), in *Military Medicine*.

1. ‘Association between palliative care and patient and caregiver outcomes: A systematic review and meta-analysis,’ *Journal of the American Medical Association*, 2016;316(20):2104-2114. Palliative care may be associated with improved quality of life and symptom burden for patients, but findings for caregiver outcomes were mixed. However, the quality of evidence is limited. <https://goo.gl/cb3x8N>

Cont.

Commentary on University of Pittsburgh study

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2016;316(20):2090-2091. In 1998, only 15% of U.S. hospitals with 50 beds or more had a formal palliative care (PC) program; by 2013, the proportion had increased to 67%. Among larger hospitals (>300 beds), 90% now have PC programs. This expansion coincides with a growing body of high-quality evidence that supports the early involvement of PC specialists, even from the time a serious illness is initially diagnosed. <https://goo.gl/nFO7rY>

No caregiver is an island, though it may seem that way

FORBES | Online – 21 November 2016 – Here is what we know: The population is aging. Older adults typically need caregivers at some point and for some aspects of their lives. Most often, their caregivers are unpaid family members, friends and others they trust. These caregivers need help, too. Here is what we don't know: What does "help" mean? Caregivers don't fit a unique profile. They are young/old, female/male/transgender, highly educated/struggle with literacy, financially secure/living in poverty, urban/rural, living with the person needing care/caring from a distance. If any help is offered a caregiver, too often it is one-size-fits-all. The menu includes what is available, rather than what a particular caregiver wants or needs. A support group? Check. Home-delivered meals? Check. A waiting list for respite services? Check. All good things, but they may not be the specific type of help a caregiver could desperately use. <https://goo.gl/Ov0tPD>

A united family can make all the difference when someone is dying

THE WASHINGTON POST | Online – 20 November 2016 – Participation in the slow decline of an aged parent comes with obligations. There are dues to be paid – for example, showing up regularly for visits, no matter how inconvenient, and taking time to check in with siblings and provide detailed updates. Teamwork, coordination and cooperation help smooth this emotion-wrought journey. When family members do not or cannot work through disagreements, the result can end up punishing the person everyone is trying to comfort and protect. Unfortunately ... an odd sort of competition can crop up in these situations. Some patterns are predictable. The most common is when siblings compete to prove who cares the most. This is frequently seen upon the arrival of an estranged family member at the deathbed, and it has been described in medical journals as "the Daughter from California Syndrome."¹ Classically, the syndrome unfolds as the guilt-ridden newcomer urges overly aggressive treatments. Other patterns are less predictable. In some families, a previously restrained sibling will assert dominance as the designated agent or proxy with power of attorney for health care. That one child has been designated as health-care proxy is not to be envied or taken as a sign he or she is preferred over another. <https://goo.gl/n4Qzmw>

1. 'Decision making in the incompetent elderly: The Daughter from California Syndrome,' *Journal of the American Geriatric Society*, 1991;39(4):396-399. <https://goo.gl/PZuN6L>

[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>

International

End-of-life care in Scotland

Prison healthcare “falling short” under National Health Service, as report warns of plummeting staff morale

U.K. (Scotland) | *The Herald* (Glasgow) – 24 November 2016 – Scotland’s top nurse has warned that there is “little evidence” that health gap between prisoners and the general population has narrowed since the National Health Service (NHS) took over responsibility for inmates five years ago. Theresa Fyffe described the findings of the first major review into the transfer of prisoner care from the Scottish Prison Service to the NHS as “uncomfortable reading,” adding that the ambitions behind the shake-up “have not been achieved.” In a wide-ranging report ... the Royal College of Nursing Scotland highlights “significant concerns” over plummeting morale among prison nurses and failings in mental health and the management of long-term conditions such as dementia and cancer, which are becoming increasingly common with one in 10 prisoners now aged over 50. The number of prisoners aged over-50 have increased 50% in five years due to a trend towards longer sentences, people living longer and convictions for historic sex offences. Nearly half of these inmates have a long-term condition, such as cancer or dementia, but the report found that prison care is “falling short.” Palliative and end-of-life care is also “increasingly a reality” in Scottish prisons. <https://goo.gl/dqolTw>

Extract from Royal College of Nursing Scotland report

There has been progress around the delivery of palliative care in prisons, with joint working by Macmillan, health boards and the Scottish Prison Service. One prison has been working with a Macmillan Nurse Consultant to implement cancer and end-of-life care (EOLC) pathways. There is further work ... around creating a national nursing post to lead on the implementation of Macmillan standards for EOLC in prisons across Scotland.

Specialist Publications

‘The pains of incarceration: Aging, rights, and policy in federal penitentiaries’ (p.9), in *Canadian Journal of Criminology & Criminal Justice*.

‘A consensual qualitative research analysis of the experience of inmate hospice caregivers: Post-traumatic growth while incarcerated’ (p.8), in *Death Studies*.

1. ‘Five Years On: Royal College of Nursing Scotland Review of the Transfer of Prison Health Care from the Scottish Prison Service to National Health Service Scotland,’ Royal College of Nursing Scotland, November 2016. <https://goo.gl/92pQXP>

End-of-life care in England

Public perceptions and experiences of community-based end-of-life care initiatives: A qualitative research report

U.K. (England) | Public Health England – 23 November 2016 – This report is for commissioners of end-of-life care (EOLC) services, to support new ways of commissioning through using public health approaches to build compassionate communities. Research has demonstrated that there are many different levels of needs with regard to EOLC and community initiatives, which vary across conditions, individuals, families, etc. Furthermore, carers and people with conditions are not necessarily aligned – both have different needs, many of which are not fully recognised or acknowledged. The current focus on palliative care as the main element of EOLC is acknowledged by many, with examples of good support accessed. For dementia carers in particular, the research highlights the gulf that can exist in current care provision. For some, there remains a substantial gap between the point of diagnosis and the ongoing support that may be required over the subsequent years until end of life is reached. <https://goo.gl/FGkfEq>

End-of-life care in Ireland

Half of older people died in intensive care units when they would have been better off at home

IRELAND | *The Irish Times* (Dublin) – 22 November 2016 – Admissions to acute hospitals tripled between 1951 and 1964 because of “a growing preference for some years for confinement in hospitals.” People no longer wanted to be treated in their homes by GPs or District Nurses. Fifty years later, the same problems persist because patients’ expectations are not being managed. In fact, a greater proportion of the population is now using acute services than in 1966. Fifty years ago, about 10% of the population were admitted to hospitals each year. According to the Healthy Ireland Survey 2016,¹ 11% of those aged 15 and over were admitted to hospitals in the past 12 months. A further 12% visited an Emergency Department and 14% were admitted as a day patient in the past year. More than a quarter saw a hospital consultant. The planned shift to community and home care

is clearly not working. This is not just an Irish problem. All over the world older people end up in acute hospitals when medicine cannot help. A recent global review carried out by experts in the University of New South Wales, Australia, involving 38 major studies,² found that more than one-third of patients nearing the end of life received non-beneficial treatments in acute hospitals. Non-beneficial tests were performed on almost half of patients with do-not-resuscitate orders. <https://goo.gl/Ew7gWm>

Specialist Publications

‘Building bridges: Palliative care beyond borders’ (p.15), in *Progress in Palliative Care*.

1. ‘Healthy Ireland Survey 2016: Summary Findings,’ Department of Health (Government of Ireland), October 2016. <https://goo.gl/PyJsU0>
2. ‘Non-beneficial treatments in hospital at the end of life: A systematic review on extent of the problem,’ *International Journal for Quality in Healthcare*, 27 June 2016. [Noted in Media Watch 4 July 2016, #469 (p.7)] <http://goo.gl/4mwpLS>

Paediatric palliative care

Children’s hospices struggling with funding crisis, report claims

U.K. (England) | *The Daily Mail* – 22 November 2016 – Children’s hospices are on the brink of a funding crisis owing to cuts and freezes in local authority and National Health Service (NHS) spending, according to a report.¹ The study ... found hospices are struggling due to falling state income as a proportion of their costs, which are rising by about 10% every year. In 2015-2016, 21 children’s palliative charities which provided data received an average of £43,095 in local authority funding. But this was 61% less than they received in 2014-2015, when the average was £110,909 per organisation. The current amount is only 1% of what children’s hospices need to run. The report also found that the NHS England children’s hospice grant has remained static, at £377,106 in 2015-2016 for children’s

hospices compared to £356,166 in 2013-2014. The report said there is a similar picture for adult palliative care, with 65% of hospices for adults having statutory funding frozen or cut in the last financial year. <https://goo.gl/QU3130>

Specialist Publications

‘Contemporary pediatric palliative care: Myths and barriers to integration into clinical care’ (p.14), in *Current Pediatric Reviews*.

‘To research or not to research: An important question in paediatric palliative care’ (p.14), in *Palliative Medicine*.

1. ‘On the Brink: A Crisis in Children’s Palliative Care Funding in England,’ Hospice UK and Together for Short Lives, November 2016. <https://goo.gl/F6yJs0>

Cont.

Related

- IRELAND | *The Irish Times* (Dublin) – 21 November 2016 – ‘**Outreach nurses “significantly enhancing” children’s palliative care.**’ The quality of life for hundreds of children with life-limiting conditions has been significantly improved through improved access to palliative care (PC), an evaluation study has found.¹ The evaluation of the children’s PC programme found initiatives such as the provision of outreach nurses are “significantly enhancing” the quality of PC delivered to children across Ireland. About 350 children die before their 18th birthday every year in Ireland. There are an estimated 3,840 children living with a life-limiting condition. They have an incurable illness that often requires special care and at times they may need PC. The programme was initially 85% funded by the Irish Hospice Foundation at an overall cost of €2.6 million, under an agreement with the Health Service Executive. <https://goo.gl/SPUkAB>

1. ‘Evaluation of the Children’s Palliative Care Programme,’ Irish Hospice Foundation and Department of Health & Health Service Executive (Government of Ireland), September 2016. <https://goo.gl/FRQZ9t>

The policy of non-decision: The case of the dying patient law and the vegetative state patients in Israel

ISRAEL | *Israel Affairs* – 10 November 2016 – Enacted in Israel in 2005, the dying patient law does not apply to vegetative state patients, leaving them with no decision regarding their fate. This article discusses the policy of non-decision using as a case study the treatment and the option of abstaining from treatment of patients who have been classified as “vegetative state” (VS). This analysis was conducted while focusing on the various explanations for adopting a policy of non-decision, and suggests that it is the gap between the national level of policymaking, where a policy of non-decision is adopted, and the local level of policymaking, where concrete decisions are required, that harms those affected both directly and indirectly by the decisions made. With the aim of informing policymakers about their choice, the article explains how a policy of non-decision leads to local medical positions that create a street-level policy, ignoring the shared medical needs of the VS patients as a group. The ramifications of this choice lead to a failure to exhaust all treatment options, or alternately, the impossibility of avoiding treatment of these patients. <https://goo.gl/h56V8s>

Selected articles on end-of-life care in the context of the Jewish faith

- U.S. (California) | *The Jewish Journal* (Los Angeles) – 17 August 2015 – ‘**Tarzana hospital cites living will in attempt to remove Orthodox patient from life support: Children demand life-saving operation.**’ The dispute highlights a conflict at the intersection of modern medical ethics, Jewish medical ethics, civil law as it pertains to the validity of a living will, and the extent to which “quality of life” measures should impact whether a life-saving procedure is appropriate. [Noted in Media Watch 24 August 2015, #424 (p.6)] <https://goo.gl/S84IXL>
- U.S. (State of New York) | *Forward* – 15 October 2014 – ‘**The end-of-life battle over Jewish souls.**’ The philosophy of dying a “good” death is anathema to many Orthodox Jews who believe that life should be sustained at all costs. Many Orthodox Jews believe that as long as the heart beats, the soul is alive. [Noted in Media Watch 20 October 2014, #380 (p.3)] <https://goo.gl/12URC4>
- *JOURNAL OF PALLIATIVE MEDICINE*, 2010;13(10):1267-1271. ‘**Caring for the dying patient from an Orthodox Jewish perspective.**’ These guidelines address profound issues such as the definition of death, organ donation, and caring for the patient at life’s end. The guidelines can be useful for any hospital that serves an Orthodox Jewish population. [Noted in Media Watch 4 October 2010, #169 (p.10)] <https://goo.gl/9mlRYB>



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.18.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA | *The Australian* – 24 November 2016 – ‘**Most doctors would help terminally ill die: Australian Medical Association.**’ A majority of doctors would help terminally ill people die if voluntary euthanasia became law, a landmark survey of GPs and medical specialists by the Association has revealed. The Association unveiled a policy rejecting euthanasia and doctor-assisted suicide, but which acknowledges for the first time that right-to-die laws are “ultimately a matter for society and government.” The position statement ... spells out how doctors can ethically give drugs and treatment to dying patients that hasten death, provided the intent is to relieve suffering. <https://goo.gl/jTtdUZ>

Specialist Publications

The application of palliative care principles in advanced Parkinson’s disease

ADVANCES IN PARKINSON’S DISEASE | Online – 22 November 2016 – Palliative care (PC) has great potential to improve the quality of life of patients with advanced Parkinson’s disease. However, neurologists face multiple barriers in practically applying the concepts of PC including a deficit in education and limitations in time to coordinate this care. In this review, the authors discuss practical ways for neurologists to apply the principles of PC in several domains, including exercising symptom management, managing polypharmacy, managing advanced care planning, supporting patient and families in their psychosocial and spiritual needs, identifying caregiver burden, utilizing multidisciplinary care, and understanding the role of hospice referral. <https://goo.gl/aexj19>

Noted in Media Watch 3 October 2016, #482 (p.10):

- *PALLIATIVE MEDICINE* | Online – 28 September 2016 – ‘**Palliative care for Parkinson’s disease: Patient and carer’s perspectives explored through qualitative interview.**’ People with Parkinson’s disease and their carers [i.e., study participants] were unfamiliar with the term palliative care (PC). When informed of the role of PC, most felt they would benefit from this input. People with Parkinson’s disease and carers experienced a high illness burden and wanted extra support. <https://goo.gl/SMHhHt>

N.B. Additional articles on palliative care for people living with Parkinson’s disease are listed in Media Watch 11 April 2016, #457 (p.12).

Helping patients and families understand the financial impact of end-of-life care

AMERICAN JOURNAL OF NURSING, 2016;116(12):11. It is an unfortunate reality that at the end of life, many patients do not receive the care they need and are unable to attain their goals of care because of financial costs. This is not a problem unique to the U.S. Even in countries such as Canada, which has a single-payer public health care system, there are limits to the services available to patients and caregivers at the end of life. While this article counsels nurses to ensure that patients and families have as much financial information as possible for informed decision making, this is a stopgap measure in a system that too often fails to provide needed care. <https://goo.gl/NF0LMN>

The role of occupational therapy in end-of-life care

AMERICAN JOURNAL OF OCCUPATIONAL THERAPY | Online – Accessed 22 November 2016 – The purpose of this statement is to describe the role of occupational therapy practitioners in providing services to clients who are living with terminal conditions and are at the end of life, as well as providing services and support to caregivers. This statement also serves as a resource for occupational therapy practitioners, hospice and palliative care (PC) programs, policymakers, funding sources, and clients and caregivers who receive hospice and PC services. <https://goo.gl/rjkaYJ>

Cont.

Noted in Media Watch 21 April 2014, #354 (p.7)::

- *AUSTRALIAN OCCUPATIONAL THERAPY JOURNAL*, 2013;60(5):370-373. 'Establishing a role for occupational therapists in end-of-life care in Western Australia,' There are differences between Australia, the U.S. and other countries regarding the role of occupational therapy in end-of-life care. The authors discuss these and recommendations to assist the occupational therapy discipline work towards the "best practice" model discussed by Burkhardt *et al.* <https://goo.gl/yG0SUU>

Perspectives on death and dying: A study of resident comfort with end-of-life care

BMC MEDICAL EDUCATION | Online – 21 November 2016 – Despite the benefits to early palliative care in the treatment of terminal illness, barriers to timely hospice referrals exist. Physicians who are more comfortable having end-of-life (EOL) conversations are more likely to refer to hospice. However, very little is known about what factors influence comfort with EOL care. Most residents [i.e., survey respondents at a single institution] reported little to no classroom training on EOL care during residency. EOL conversations during residency were frequent ... and mostly unsupervised... In contrast, EOL conversations during medical school were infrequent ... and mostly supervised... Most reported little to no classroom training on EOL care during medical school. Physicians that reported receiving education on EOL conversations during residency and those who had frequent EOL conversations during residency had significantly higher comfort levels having EOL conversations... <https://goo.gl/4i0Jnl>

End-of-life care in Bulgaria

Hospice care challenges in small towns

BULGARIAN JOURNAL OF PUBLIC HEALTH, 2016;8(2):31-42. Like most member states of the European Union, Bulgaria is facing a serious challenge posed by an ageing population that increases the need for services for long-term care and, therefore, an increase in public expenditure for these services. Exactly this similar niche "strives to fill a relatively new (not only for Bulgaria) and unexplored sufficiently by the science social phenomenon and institution, such as a hospice." Life needs approve hospice as a necessary part of the social organism, regardless of the reluctance/desire of one or another person, an institution representing the state. <https://goo.gl/lrQ0i1>

N.B. Link is to complete issue of the journal. Scroll down to 'Hospice care challenges in small towns,' beginning p.31. Article published in Bulgarian and English.

The special requirements of old age in terms of dying

BUNDESGESUNDHEITSBLATT GESUNDHEITSFORSCHUNG GESUNDHEITSSCHUTZ | Online – 23 November 2016 – The aim of this study is to report epidemiological data on the causes of death, as well as on the places of death. In addition, the attitudes and behaviour towards death and dying, as well as the different places of death will be discussed. Expecting support in the process of dying, as well as factors that have a more conducive effect on the internal processing of dying, are mentioned. At the same time, the attitudes and behaviours in respect of the accompaniment of dying people, which can be seen in the staff in clinical inpatient facilities, are addressed. Personal intense grappling with dying and death actually has a positive effect on these behaviours and attitudes. Finally, this contribution turns to the question of to what extent the theory of compression of morbidity may be perceived as valid, especially in view of the rising average life expectancy. It is emphasised that chronic diseases, even when no functional loss is present, place not only great demands on the patient, but also on the care system and financial resources. Furthermore, it is demonstrated that frailty can often cause mental disorders. Specific requirements with a view to the care of people with dementia are given. <https://goo.gl/nt7xoj>

N. B. German language article.

Volunteering in end-of-life care: Challenges, problems and perspectives

BUNDESGESUNDHEITSBLATT GESUNDHEITSFORSCHUNG GESUNDHEITSSCHUTZ | Online – 22 November 2016 – Volunteering in the hospice movement has had a profound impact on generating awareness of hospice work and palliative care (PC) in the context of supporting dying persons and their relatives as well as on integrating respective services in the existing health care system. This paper focuses on two specific questions: First, it asks how society is changing with respect to dealing with dying and death, and more precisely with dying persons, which is recognizable by the integration of hospice work and PC in the healthcare system and related to the relevance of volunteering in the sense of a citizens' movement. Second, this paper asks what the specific roles of volunteers are as well as the possibilities and limits of voluntary practice in end-of-life care and accompaniment. To answer these questions, the pivotal objectives of the hospice movement – the transformation of the social awareness regarding dying and death, as well as the reorganization of “institutions of dying” – will first be outlined by reference to the concept of “good dying,” a specific hospice attitude together with hospice culture and palliative competence. In a second step, the relevance of volunteering and the specific role of volunteers in the actual practice of hospice work and PC will be outlined alongside current indicators and recognizable alteration tendencies, before concluding with a discussion of the perspectives of hospices as a citizens' movement. <https://goo.gl/dL45Jc>

N. B. German language article.

Noted in Media Watch 1 August 2016, #473 (p.12):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(7):184-191. ‘**Defining volunteering in hospice and palliative care in Europe.**’ The Taskforce on Volunteering in Hospice & Palliative Care (HPC) presents a White Paper on the definition, typology, role, position, identity and value of HPC volunteering. Consensus was reached on the fact that volunteering in care-focused roles is best understood as a relational activity... The concept of “being there” used by volunteering organisations in several countries seems to offer a good base from which to research the theoretical framework of HPC volunteering, as well as develop training, supervision and self-reflection.

N.B. Access requires a subscription. Contents page for the July/August issue: <http://goo.gl/wo8sxe>

N.B. Additional articles on hospice and palliative care volunteers are noted in Media Watch 25 July 2016, #476 (pp.5-6,11).

A consensual qualitative research analysis of the experience of inmate hospice caregivers: Posttraumatic growth while incarcerated

DEATH STUDIES | Online – 22 November 2016 – A growing number of correctional facilities train inmates to provide end-of-life care for dying inmates. This study explores the phenomenological perspective of inmate-caregivers participating in an inmate-facilitated hospice program (IFHP) with regard to meaning and purpose in life, attitudes on death and dying, and perceived personal impact of participation. Twenty-two inmate-caregivers were interviewed at a maximum-security state correctional facility in the U.S. Findings suggest that participating in an IFHP may facilitate personal growth and trans-

formation that mirrors the tenets of posttraumatic growth. <https://goo.gl/nRcOL4>

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 posted on the Palliative Care Network website at: <http://goo.gl/ZpEjyQ>

Cont.

Related

- *CANADIAN JOURNAL OF CRIMINOLOGY & CRIMINAL JUSTICE* | Online – 22 November 2016 – ‘**The pains of incarceration: Aging, rights, and policy in federal penitentiaries.**’ Correctional Service Canada (CSC) does not acknowledge older prisoners as a vulnerable prison group, and correctional policies thus tend not to include age (and its implications) as a variable worthy of consideration. Data from this study raise some under-explored issues about the matter of aging behind bars that are in need of future research. <https://goo.gl/LKDFQ9>

Technological innovation comes to palliative care: With a shortage of palliative specialists, telemedicine and remote monitoring offer relief

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

Noted in Media Watch 21 November 2016, #488 (p.6):

- *BMC PALLIATIVE CARE* | Online – 17 November 2016 – ‘**Using telehealth to support end-of-life care in the community: A feasibility study.**’ The trial showed that patients and carers [i.e., study participants] could manage the technology and provide data that would otherwise not have been available to the palliative care service. <https://goo.gl/9xHWYg>

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

Understanding the life course through newspaper obituaries

INDIAN JOURNAL OF GERONTOLOGY, 2016;30(4):452-462. Contrary to the commonly held belief that death is hidden from public view, obituary announcements remain the most dominant channels of presentation in the mass media. Obituaries as part of the mourning process truly present life in death. They go beyond a simple announcement of death to include information about the socio-economic status of the deceased and/or his survivors. Obituary announcements represent an alternative data source on a people’s perceptions of life, death and dying, and derive their meanings from the socio-cultural codes of traditions, beliefs, religions and such other practices. Their presentations cover achievements from birth till death, the inevitability of death and the beliefs about the continuity of life after death. However, the practice of not to speak ill of the dead (which is prevalent in many cultures) presents a major limitation to the effective utilization of the data source in cultural analysis. This is evident in this study as no single obituary announcement detailed any wrong doing of the deceased. Nevertheless the authors findings have helped to understand that obituaries can be a useful tool for tracking societal norms and values in the face of rapid societal transformation. <https://goo.gl/iQm5dR>

N.B. Link is to complete issue of the journal. Scroll down to ‘Understanding the life course through newspaper obituaries,’ beginning p.452.



Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials.
<http://goo.gl/OTpc8l>

Palliative care in Pakistan

INDIAN JOURNAL OF MEDICAL ETHICS | Online – 18 November 2016 – Pakistan is a developing country of South East Asia, with all the incumbent difficulties currently being faced by the region. Insufficient public healthcare facilities, poorly regulated private health sector, low budgetary allocation for health, improper priority setting while allocating limited resources, have resulted essentially in an absence of palliative care (PC) from the healthcare scene. Almost 90% of healthcare expenditure is out of the patient's pocket with more than 45% of population living below the poverty line. All these factors have a collective potential to translate into an end-of-life care disaster as a large percentage of population is suffering from chronic debilitating/terminal diseases. So far, such a disaster has not materialised, the reason being a family based culture emphasising the care of the sick and old at home, supported by religious teachings. This culture is not limited to Pakistan, but subsists in the entire sub-continent, where looking after the sick/elderly at home is considered to be the duty of the younger generation. With effects of globalisation, more and more older people are living alone and an increasing need for PC is being realised. However, there does not seem to be any plan on the part of the public or private sectors to initiate PC services. This article seeks to trace the social and cultural perspectives in Pakistan with regards to accessing PC in the context of healthcare facilities available. <https://goo.gl/zsNdWg>



Noted in Media Watch 30 May 2016, #464 (p.13):

- *PALLIATIVE MEDICINE* | Online – 25 May 2016 – ‘**Barriers and perceptions regarding code status discussion with families of critically ill patients in a tertiary care hospital of a developing country: A cross-sectional study.**’ Family-related barriers – a complex background of illiteracy, different familial dynamics, lack of patient autonomy, religious beliefs, and financial constraints – are the most frequent roadblocks in the end-of-life care discussions for physicians in Pakistan. <http://goo.gl/q2m6og>

N.B. Bulgaria was ranked 62nd of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ The Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/nuPWll>

The relevance of palliative care in HIV and aging

INTERDISCIPLINARY TOPICS IN GERONTOLOGY & GERIATRICS, 2017;42:222-233. The connection between palliative care (PC) and HIV infection has deep and wide roots in the U.S. that go back to the time when many gay men in the early 1980s were dying from a disease we knew little about, and there was no way to help but to alleviate symptoms in hospice and end-of-life centers across the U.S. More individuals (adults and children), families, and communities attribute the success of antiretroviral therapies and other therapeutic approaches to advancing quality of life and life itself today. The identity of HIV, like many “life-threatening illness with no cure” has evolved as a “chronic” condition with a longer time period to address physical, social, and emotional experiences that may concern those living with HIV infection. Chronic conditions create an opportunity for healthcare providers from all types of disciplines to rethink and retool their knowledge and skills, to have conversations with those affected by HIV infection as to what they would ideally want in addressing their care needs; care needs that are now complicated by co-morbid conditions of aging and healthcare reimbursement that uniquely intersect with HIV infection. This article addresses the current relevance of PC in HIV history, both nationally and internationally, and offers ideas for health professionals to use a multidisciplinary integration of knowledge to not just cure but align “cure and care” toward healing action while being present to others from their perspective and values. <https://goo.gl/xUHFiQ>

Cont.

Noted in Media Watch 22 February 2016, #450 (p.12):

- *JOURNAL OF THE ASSOCIATION OF NURSES IN AIDS CARE* | Online – 11 February 2016 – ‘**Palliative care, hospice, and advance care planning: Views of people living with HIV and other chronic conditions.** Health policymakers recognize the role of early palliative care (PC) and advance care planning (ACP) in improving health quality for at-risk populations, but misperceptions about PC, hospice, and ACP are common. Overall, [focus group] participants were unfamiliar with the term PC, confused concepts of PC and hospice, and/or associated hospice care with dying. Participants misunderstood ACP, but valued communication about health care preferences. Accepting PC was contingent on distinguishing it from hospice and historical memories of HIV and dying. <http://goo.gl/xBPYfY>

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

Patient participation in palliative care decisions: An ethnographic discourse analysis

INTERNATIONAL JOURNAL OF QUALITATIVE STUDIES ON HEALTH & WELLBEING | Online – 22 November 2016 – There is a scarcity of studies directly observing clinical interactions between palliative patients and their health care providers. The authors aim to understand how patient participation in palliative care (PC) decisions is constructed through discourse in a community hospital-based PC team. Analysis [of consultations with participating PC patients] consisted in looking for the interpretive repertoires (i.e., familiar lines of argument used to justify actions) that were used to justify patient participation in decision-making during clinical interactions, as well as exploring their implications for decision roles and end-of-life care. Patients and their health care providers seldom addressed their decision-making roles explicitly. Rather, they constructed patient participation in PC decisions in a covert manner. Four interpretive repertoires were used to justify patient participation: 1) Exposing uncertainty; 2) Co-constructing patient preferences; 3) Affirming patient autonomy; and, 4) Upholding the authority of health care providers. The results demonstrate how patients and health care providers used these arguments to negotiate their respective roles in decision-making. Patients and health care providers used a variety of interpretive repertoires to covertly negotiate their roles in decision-making, and to legitimize decisions that shaped patients' dying trajectories. Discourse analysis encourages awareness of the role of language in either promoting or hindering patient participation in decision-making. <https://goo.gl/XOn6kx>

Related

- *THE HASTINGS REPORT* | Online – 22 November 2016 – ‘**Competence in plain English.**’ Like many other bioethicists, I often give talks on clinical topics that may touch on the patient's right of autonomy with regard to medical treatment and, from there, may move to questions about whether said patient has the capacity to exercise said right. When I get to that subject, I might ask, “Is this person competent to refuse treatment?” A stunned silence falls over the room, until finally a hand shoots up. “‘Competent’ is a legal term,” I am instructed. “Don't you mean to ask whether he has the capacity to make decisions for himself?” The tone suggests that I'm being helped to make a very important distinction. But it's not a very important distinction; and it's misleading to boot. <https://goo.gl/fAagZZ>

American Geriatric Society Position Statement

Making medical treatment decisions for unbefriended older adults

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 22 November 2016 – The authors define unbefriended older adults (UOA) as patients who: 1) Lack decisional capacity to provide informed consent to the medical treatment at hand; 2) Have not executed an advance directive that addresses the medical treatment at hand and lack capacity to do so; and, 3) Lack family, friends or a legally authorized surrogate to assist in the medical decision-making process. Given the vulnerable nature of this population, clinicians, health care teams, ethics committees and other stakeholders working with UOA must be diligent when formulating treatment decisions on their behalf. The process of arriving at a treatment decision for an UOA should be conducted according to standards of procedural fairness and include capacity

Cont.

assessment, a search for potentially unidentified surrogate decision makers (including non-traditional surrogates), and a team-based effort to ascertain the UOA's preferences by synthesizing all available evidence. A concerted national effort is needed to help reduce the significant state-to-state variability in legal approaches to unbefriended patients. Proactive efforts are also needed to identify older adults, including "adult orphans," at risk for becoming unbefriended and to develop alternative approaches to medical decision making for UOA. <https://goo.gl/68dZQy>

Noted in Media Watch 28 September 2015, #429 (p.5):

- U.S. | *The New York Times* – 25 September 2015 – '**Near the end, it's best to be "befriended."**' The unconscious man in his 90s was brought to emergency. The staff couldn't find any relatives to make medical decisions on his behalf. He had outlived all his family. Nobody could find an advance directive, either. In the end, the hospital's ethics committee had to guide the medical team to decisions about continuing life support. Experts describe patients like this as "unbefriended." <https://goo.gl/qRjkeu>

Noted in Media Watch 30 September 2013, #325 (p.4):

- U.S. | *The New York Times* – 23 September 2013 – '**When there's no family.**' Ten years ago, the American Bar Association's Commission on Law & Aging looked into the problem and cited estimates that approximately 4% of older adults in the U.S. are "unbefriended" elderly.¹ <https://goo.gl/eBFNTt>

1. 'Incapacitated and alone: Healthcare decision making for unbefriended older people,' *Human Rights*, 2004;31(4). Article on Association's Commission on Law & Aging 2003 report. <https://goo.gl/ALdRKK>

The "reckoning point" as a marker for formal palliative and end-of-life care in Mexican American families

JOURNAL OF FAMILY NURSING | Online – 16 November 2016 – Palliative and end-of-life care (PEOLC) in Mexican American caregiving families remains unexplored. Its onset was uncovered in our mixed methods, multisite, interdisciplinary, qualitative descriptive study of 116 caregivers, most of whom had provided long-term informal home care for chronically ill, disabled older family members. This sub-analysis used Life Course Perspective to examine the "point of reckoning" in these families, where an older person is taken in for care, or care escalates until one recognizes oneself as the primary caregiver. Ninety-three of 116 caregivers recognized and spontaneously reported a "reckoning point" that initiated the caregiving trajectory, while eight cited "gradual decline" into caregiving for elders in their homes. This "reckoning point," which marks the assumption of this role, may afford a fertile opportunity for referral to community resources or initiation of formal PEOLC, thereby improving the quality of life for these older individuals and their families. <https://goo.gl/uN0m6s>

An ethic of heroism shapes next of kin's perceptions of veterans' end-of-life care in Veterans Affairs Medical Centers

MILITARY MEDICINE, 2016;181(11):e1575-e1580. Currently 28,000 Veterans die each year within Veterans Affairs Medical Centers [in the U.S.]. As Veterans age, the Department of Veterans Affairs faces a variety of issues, including the need for comprehensive end-of-life care. Appreciation of next of kin's assumptions regarding veterans' care can inform the culture of end-of-life services in Veterans Affairs Medical Centers, contributing to the development of supportive practices aligned with next of kin's perspectives. This study explores next of kin's accounts of Veterans' hospital care during the last days of life to identify salient issues shaping perceptions of Veterans' care. <https://goo.gl/1lRZ5q>

Selected articles on end-of-life care in the U.S. military health system

- *MEDICAL CARE* | Online – 30 August 2016 – '**Race/ethnicity and end-of-life care among veterans.**' Bereaved family members of minority veterans generally rate the quality of end-of-life care (EOLC) less favorably than those of white veterans. Family perceptions are critical to the evaluation of equity and quality of EOLC. [Noted in Media Watch 5 September 2016, #478 (p.11)] <http://goo.gl/lUkl83>

Cont.

- *JAMA INTERNAL MEDICINE* | Online – 26 June 2016 – ‘**Quality of end-of-life care provided to patients with different serious illnesses.**’ In this study, conducted in all 146 inpatient facilities within the Veteran Affairs health system, family-reported quality of end-of-life care was significantly better for patients with cancer and those with dementia than for patients with end-stage renal disease, cardiopulmonary failure, or frailty... [Noted in Media Watch 4 July 2016, #469 (p.5)] <http://goo.gl/lJNYLI>
- *MILITARY MEDICINE*, 2015;180(10):1024-102. ‘**Palliative care in the U.S. military health system.**’ Currently, the military health system (MHS) has only two palliative care (PC) teams across all of its 56 facilities... Although the MHS is a leader in trauma and point of injury care, it is lagging far behind the Veterans Health Administration (VHA) and the civilian sector in providing essential PC services to its patients. [Noted in Media Watch 19 October 2015, #432 (p.13)] <https://goo.gl/mnTOIX>

Chronic illness with complexity: Association with self-perceived burden and advance care planning

OMEGA – JOURNAL OF DEATH & DYING | Online – 22 November 2016 – This study examined how different chronic illnesses and mental illness co-morbidity [chronic illness with complexity (CIC)] associate with components of advance care planning (ACP). The authors also explored the role self-perceived burden plays in the relationship between illness and ACP. Participants with diabetes and those with cardiovascular disease (CVD) were less likely, while participants with CIC were more likely, to plan for the end-of-life. Participants with diabetes were less likely to make formal plans, whereas those with CVD were less likely to hold informal discussions. CIC was associated with increased odds of having an advance directive, but no other form of ACP. Self-perceived burden did not appear to be the gateway by which illness groups differentially engaged in ACP. <https://goo.gl/eJNAVD>

Related

- *NEUROMUSCULAR DISORDERS* | Online – 21 November 2016 – ‘**Advance care discussions with young people affected by life-limiting neuromuscular diseases: A systematic literature review and narrative synthesis.**’ The review found a very limited body of literature regarding end-of-life care (EOLC) conversations between young people affected by neuromuscular diseases and health professionals. The views and preferences of patients themselves have not been investigated. There is a shared reluctance of patients, family carers and healthcare professionals to initiate EOLC discussions. <https://goo.gl/ZNKJ5j>

Voices we forget: Danish students experience of returning to school following parental bereavement

OMEGA – JOURNAL OF DEATH & DYING | Online – 20 November 2016 – Eighteen focus groups with 39 participants, aged 9 to 17, were conducted. All participants had experienced the loss of a primary caregiver [i.e., parent]. Data collection was divided into two phases: in Phase I [of the study] 22 participants from four groups were interviewed four times over the course of a year; and, during Phase II confirmatory focus groups were undertaken with 17 participants. This article explores the findings related to four themes: 1) The initial school response; 2) Long-term support; 3) Challenges within the classroom; and, 4) Academic challenges. The study found that students struggle to reconnect with

classmates following the return to school and often feel alone, schools fail to have guidelines in place for what teachers are allowed to do if students become sad in the classroom; and, schools seem to forget a student’s loss as time passes. <https://goo.gl/kGZx2b>


CANADIAN
Virtual Hospice
CANADIEN EN SOINS
Portail palliatifs

Supporting Grieving or Bereaved Children
<http://goo.gl/ydHfq9>

Rapid response teams and end-of-life care in oncology

ONCOLOGY NURSING NEWS | Online – 25 November 2016 – With the advent of major cancer centers and the trend to provide increasingly aggressive treatments, the dilemma of what constitutes best care for patients with advanced cancer is an important one. Rapid response teams (RRT) are used extensively in many hospitals, including major cancer centers; however, research shows that adverse outcomes are more common for patients who require RRT intervention than among the general hospital population. Furthermore, RRT calls for patients with pre-established do not resuscitate orders occur for a surprising number of patients, with as many as one-third of RRT calls involving patients at the end of life. Equally important are the timing of palliative care consultation, issues related to quality of life, and patient and family satisfaction with end-of-life care. <https://goo.gl/bEm5fS>

To research or not to research: An important question in paediatric palliative care

PALLIATIVE MEDICINE, 2016;30(10):902-903. “Is it ethical to conduct research on children in palliative care (PC) as they are such a vulnerable group and it would be hard to get ethical approval?” This is a question ... often asked and is a concern of many people working in children’s PC. Indeed in the paper by Beecham *et al.*,¹ who identified some of the barriers to undertaking research in children’s PC, the process of getting ethical approval was highlighted as a key barrier. Whilst an important and appropriate question to be thinking of, as any research in children’s PC needs to take into account the vulnerability and well-being of the child and their family, to me, the more important question is “Is it ethical not to conduct research in children’s PC?” In looking through the literature on children’s PC, there is a lack of robust evidence within the field. Much of the children’s PC practice is based on evidence from adult PC, or on clinical/expert practice. Medications are used in ways that they are not licensed for, and the development of services is based on evidence from a limited number of services and countries, with much of the existing evidence coming from the U.K., Europe, North America, Australia and New Zealand. In order to improve the care of children with life-limiting or life-threatening illnesses around the world, it is essential to increase and broaden the evidence base for such care. <https://goo.gl/MNJ3IS>

1. ‘A call for increased paediatric palliative care research: Identifying barriers,’ *Palliative Medicine*, 13 May 2016. [Noted in Media Watch 16 May 2016, #462 (p.15)] <http://goo.gl/EVPHs5>

Related

- *CURRENT PEDIATRIC REVIEWS* | Online – 15 November 2016 – ‘**Contemporary pediatric palliative care: Myths and barriers to integration into clinical care.**’ This article critically reviews eight common assumptions, myths and barriers, which may hinder the implementation of pediatric palliative care (PC) into the care of a child with advanced serious illnesses. Emerging evidence shows that PC involvement results in improved quality of life as well as prolongation of life. <https://goo.gl/VLRxL5>
- *PALLIATIVE MEDICINE* | Online – 23 November 2016 – ‘**“Hope for the best, prepare for the worst”: A qualitative interview study on parents’ needs and fears in pediatric advance care planning.**’ Parents [i.e., study participants] find it difficult to engage in pediatric advance care planning (ACP), but consider it important. They argue for a sensitive, individualized, and gradual approach. Hope and quality of life issues are primary. Parents have many non-medical concerns that they want to discuss. Written advance directives are considered less important, but medical emergency plans are viewed as necessary in particular cases. Continuity of care and information should be improved through regular pediatric ACP meetings with the various care providers. Parents emphasize the importance of a continuous contact person to facilitate pediatric ACP. <https://goo.gl/3tvz8M>

Measuring compassion in healthcare: A comprehensive and critical review

THE PATIENT | Online – 19 November 2016 – Included were studies containing information on the Compassion Competence Scale, a self-report instrument that measures compassion competence among Korean nurses; the Compassion Scale, the Compassionate Care Assessment Tool, and the Schwartz Center Compassionate Care Scale, patient-reported instruments that measure the importance of health-care provider compassion; the Compassion Practices Scale, an instrument that measures organisational support for compassionate care; and, instruments that measure compassion in educational institutions (instructional quality and a Geriatric Attitudes Scale). Each is associated with significant limitations. Most only measure certain aspects of compassion and lack evidence of adaptability to diverse practice settings. The Evaluating Measures of Patient-Reported Outcomes of self-report instruments revealed a lack of psychometric information on measurement reliability, validity, responsiveness and interpretability, respondent, administrative and scoring burden, and use in sub-populations. <https://goo.gl/EC6b3F>

Selected articles on compassion in healthcare

- *BMC PALLIATIVE CARE* | Online – 19 January 2016 – ‘**Compassion: A scoping review of the healthcare literature.**’ This review identifies the limited empirical understanding of compassion in healthcare, highlighting the lack of patient and family voices in research. A deeper understanding of the key behaviors and attitudes that lead to improved patient-reported outcomes through compassionate care is necessary. [Noted in Media Watch 25 January 2016, #446 (p.8)] <http://goo.gl/CoL1EU>
- *JOURNAL OF MEDICAL ETHICS* | Online – 3 November 2015 – ‘**Smiling through clenched teeth: Why compassion cannot be written into the rules.**’ The discourse on the failings of the National Health System often cites lack of compassion as an important factor. This has resulted in proposals to enact rules which aim at enforcing compassion in healthcare workers so as to improve the quality of healthcare... [Noted in Media Watch 9 November 2015, #435 (p.14)] <http://goo.gl/hAb8Fn>
- *INTERNATIONAL JOURNAL OF HEALTH POLICY & MANAGEMENT*, 2015;4(4):199-201. ‘**Why and how is compassion necessary to provide good quality healthcare?**’ In this editorial, the author argues why and how compassion might become a foundation of ethics guiding health professionals and a basis for ethics of care in health service organisations. [Noted in Media Watch 30 March 2015, #403 (p.14)] <http://goo.gl/nvHF60>

Building bridges: Palliative care beyond borders

PROGRESS IN PALLIATIVE CARE | Online – 14 November 2016 – Globalization allows patients, including those with a life-limiting disease, such as cancer, to seek medical advice and second opinions beyond their own countries’ borders, in search for available curative treatments. The increased travel opportunities and a broader access to communication technologies foster patients’ mobility, even in a palliative care (PC) setting. Our patient travelled all the way to Europe from Mongolia to seek a second opinion on available treatments for her relapsing end-stage cervical cancer. Best supportive care as proposed by the Mongolian colleagues was confirmed after a chemotherapeutic trial, leading to the patient’s request for a rapid repatriation. The purpose of this case report is to identify the various factors which may facilitate the care of patients with end-stage disease travelling from foreign countries and to highlight the complexity of a repatriation process for PC recipients. <https://goo.gl/sh61aj>

Selected articles on repatriation to their homeland of patients living with a terminal illness

- U.K. | BBC News – 30 December 2015 – ‘**Why Africans in the U.K. pay so much to send relatives’ bodies home.**’ “My father’s dream was for him to be buried in his birthplace and have the call to prayer resonate over his grave,” says Nadia Elbhiri... Ms. Elbhiri, born and raised in west London, fulfilled her father’s dream when she repatriated his body to Morocco last year, where he was laid to rest in Larache, a small fishing village in the north of the country. The demand is so huge among the British Moroccan community that, according to embassy officials, at least 95% of first generation migrants are buried in Morocco. [Noted in Media Watch 4 January 2016, #443 (p.7)] <https://goo.gl/mNz6W6>

Cont.

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 3 December 2014 – ‘**From Albania to Zambia: Travel back to country of origin as a goal of care for terminally ill patients.**’ Of 336 foreign-born patients, 129 expressed a desire to travel to their country of origin; 60 successfully returned to 24 countries. Although patients with the best functional status were most likely to travel successfully, 16 who wanted to travel despite having the worst functional status also traveled successfully. There were no deaths *en route* or flight diversions due to medical crisis; all trips were made on regularly commercial airline flights. [Noted in Media Watch 8 December 2014, #387 (p.12)] <https://goo.gl/ueUE9k>
- *SUPPORTIVE CARE IN CANCER* | Online – 16 August 2014 – ‘**I want to fly home: A terminal cancer patient’s right to go home.**’ As palliative care physicians, we sometimes find ourselves immersed in the dilemma of a patient with terminal cancer requesting to fly back home, often overseas. This particular situation is filled with an array of complex variables: establishing that the medical condition is stable enough for overseas travel, dealing with a significant cost, securing proper care on the receiving end, symptom management during flight, and dealing with the possibility of in-flight death, among others. [Noted in Media Watch 18 August 2014, #371 (p.11)] <https://goo.gl/WMOtRL>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *DEATH STUDIES* | Online – 22 November 2016 – ‘**Belief in miracles and attitudes towards voluntary euthanasia.**’ Results of logistic regression analysis of data from the [Canadian] General Social Survey finds that those who have a strong belief in miracles are more likely to say that a person with an incurable illness should not be allowed to accept medical treatments that painlessly hasten death than those who have a less strong belief in miracles or do not believe in miracles, net of respondents’ religious affiliations, frequency of religious attendance, views of the Bible, and other socio-demographic controls. Results highlight the need to consider specific religious beliefs when predicting individuals’ attitudes towards voluntary euthanasia. <https://goo.gl/Jnq7So>
- *ETHICS, MEDICINE & PUBLIC HEALTH* | Online – 21 November 2016 – ‘**Personhood, pre-emptive suicide, and legislation.**’ Recent legislation [in Canada] decriminalizing assisted suicide is welcome, but it suffers from a serious flaw. As formulated and presently interpreted, the legislation depersonifies some individuals. It does so by discriminating against them in denying them assistance in suicide while providing it for others. This depersonification occurs when consideration of some persons’ need and request for assistance in suicide is assessed exclusively in terms of the condition of their bodies while their self-assessments, wishes, fears, and decisions are effectively ignored. Furthermore, as the legislation requires, consideration of requests for assistance in suicide focuses on particular terminal illnesses from which appellants suffer, discounting other reasons appellants have for wanting to die. In particular, anticipated and incipient afflictions are not allowed to figure in the assessments. Better formulation of decriminalizing legislation and especially more flexible interpretation of stated conditions is called for. Interpretation of the legislation must recognize the personal complexities and threats of terminal afflictions, both present and developing, as well as the straightforward physical consequences of present ones. <https://goo.gl/Pmbj4w>
- *THE HASTINGS REPORT* | Online – 22 November 2016 – ‘**International perspectives on physician assistance in dying.**’ When the Supreme Court of Canada recognized a constitutional right to “medical assistance in dying” last year – and the nation’s Parliament enacted legislation to implement the right earlier this year – Canadian lawmakers could look to two different models for guidance. The Netherlands and Belgium recognize a broad right to assistance in dying, while Oregon and elsewhere in the U.S. have a narrow right. In some ways, assistance in dying in Canada follows the Dutch-Belgian approach, while, in other ways, it seems more American. Two societal factors seem relevant to the different approaches: the role that religion plays in people’s lives and the trust that people place in their governments and health care systems. As other governments consider legalizing assistance in dying, an important question is whether some restrictions on the right are particularly critical. The experience to date suggests that requiring patients to be terminally ill has provided the best protection against misuse. <https://goo.gl/Rc5298>

Cont.

- *MEDICAL ANTHROPOLOGY* | Online – 15 November 2016 – ‘**Assisted suicide as a remedy for suffering? The end-of-life preferences of British “suicide tourists.”**’ The highly charged debate about the moral status of assisted suicide features regularly in the news media... In the U.K., the debate has been dominated in recent years by a new mode of death: assisted suicide in Switzerland, so-called “suicide tourism.” Drawing on in-depth interviews with people who were actively planning on “going to Switzerland,” alongside participant-observation at a do-it-yourself self-deliverance workshop, the author discusses how participants arrived at their decision to seek professionalized assistance. In doing so, she explores the constituent elements of people’s suffering, examining how participants justified, rationalized or sought authentication from a doctor for their decision to die in light of their own belief system and aesthetic preferences for a good death. <https://goo.gl/zwz4pu>
- *THEOLOGICAL STUDIES* | Online – 22 November 2016 – ‘**May Christians request medically assisted suicide and euthanasia?**’ After a brief discussion of relevant changes in the moral landscape over the last century, two influential, but opposite views on the normative basis for the Christian ethical assessment of medically assisted suicide and voluntary euthanasia are critically discussed. The inadequacy of both the view that the biblical message entails an absolute prohibition against these two practices, and the view that Christians have to decide on them on the basis of their own autonomy, is argued. <https://goo.gl/JHR133>

Worth Repeating

Interpreting educational evidence for practice: Are autopsies a missed educational opportunity to learn core palliative care principles?

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 December 2012 – The educational potential of autopsy attendance during authentic early experience to learn about the social context of death and dying has not been fully explored. The author: 1) Explores how meaning is created from autopsies in authentic early experience; 2) Compares views of students, curriculum designers and pathology supervisors; and, 3) Identifies actual/potential learning about death and dying. The autopsy enabled students to learn about death and dying in a social context. Variance between groups in perceptions of autopsy experiences may reduce educational value. Autopsies were considered by students to be opportunities for “meeting” real people, albeit dead ones, and learning from them. Tensions between lay and medical perspectives influenced learning. Increasing communication and collaboration between medical school curriculum designers and disciplines such as palliative medicine as well as pathology could address concerns regarding student/doctor competencies to deal with death and dying. Further research is needed to evaluate changes in curriculum design and to establish if similar concerns are found in other settings. [Noted in Media Watch 17 December 2012, #284 (p.7)] <https://goo.gl/O5OosK>

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of “current thinking” on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Cont.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/WAbX4S>

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

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

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

Asia

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

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

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <https://goo.gl/IOSNC7>

Europe

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

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

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

Barry R. Ashpole
Guelph, Ontario CANADA

'phone: 519.837.8936
e-mail: barryashpole@bell.net