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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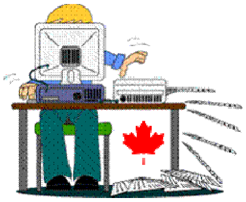

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Compiled & Annotated by Barry R. Ashpole

Palliative care integration in community settings: Scroll down to Specialist Publications and 'Opportunities for palliative care in public health' (p.7), in *Annual Review of Public Health*.

Canada

Newfoundland & Labrador doctors recommend changes to avoid harmful health care cuts

NEWFOUNDLAND & LABRADOR | CBC News (St. John's) – 24 March 2016 – While Newfoundland & Labrador doctors say reducing departmental spending would dramatically harm the quality of health care services in the province, the [provincial] physicians' association has recommendations on how to save millions and improve patient care. Those recommendations include greater centralization of services in fewer facilities, reducing unnecessary medical testing, and expanding the use of technology like telemedicine to give patients access to specialists without travel. The provincial government is facing a $2.4 billion deficit. It has asked all departments, including Health & Community Services, to identify ways to reduce spending by 30%. http://goo.gl/M00V8r

Specialist Publications

'Family caregivers' social representations of death in a palliative care context' (p.12), in *Sage Open.*

Extract from CBC report

Among the association's recommendations is a call to improve "end-of-life care." Doctors are recommending a "strategy for improved palliative care and care of the frail elderly that avoids expensive hospital costs and unnecessary treatments," and also "adopts greater use of advanced health care directives."

Noted In Media Watch, 7 March 2016, #452 (p.1):

- NEWFOUNDLAND & LABRADOR | CBC News (St. John's) – 2 March 2016 – **'End-of-life care: People slipping through the cracks, says Cancer Society.'** Supports for patients and families dealing with end-of-life situations are not adequate in Newfoundland & Labrador, says a top official with the Canadian Cancer Society. http://goo.gl/9x7Ckg

N.B. In 2009 an unpublished report criticised palliative care in the province. See Media Watch, 8 June 2009, #100 (p.1). http://goo.gl/QP8xCv

Palliative care in Northeastern Ontario a patchwork of service levels

ONTARIO | *The Timmins Daily Press* – 20 March 2016 – While there are a number of qualified health-care providers in the area who specialize in palliative care (PC) treatments, there are limited outlets for patients to access these services. Currently, PC is provided to patients in their homes through the North East Community Care Access Centre, palliative nurse practitioners, primary health care clinicians and teams, community support services and pain and symptom management consultants. There are cancer centre outpatient clinics and long-term care homes providing the service as well as the outpatient services provided by the Horizon-Timmins Palliative Care facility. The providers at the facility currently work on a volunteer basis. There are no specifically designated PC beds at the Timmins & District Hospital and patients requiring PC are cared for within the existing beds of the hospital's Integrated Medical Program, two of which were renovated to be more comfortable and private for those in the end stages of life. There is, however, no designated hospice facility in the city. http://goo.gl/VeUKZQ

Numerous gaps in Ontario's system for palliative care, report finds

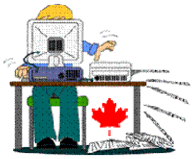
ONTARIO | *The Ottawa Citizen* – 11 March 2016 – The way Ontario's health system cares for the dying is full of holes that need patching, Ottawa South Member of the Provincial Parliament John Fraser says in an official report the provincial government is to use as a guide to those fixes.[1] [Noted in Media Watch, 14 March 2016, #453 (p.2)] http://goo.gl/GEFYP1

1. 'Palliative & End-Of-Life Care Provincial Roundtable Report,' Ontario Minister of Health & Long-Term Care, March 2016. http://goo.gl/eRyw8K

Selected reports on end-of-life care in Northeastern Ontario

- ONTARIO | CBC News – 14 December 2015 – **'Hospice care for dying kids slowly starting to increase in Northeastern Ontario.'** A hospice in Sudbury has launched a pilot project to provide end-of-life care for teens – and eventually small children – in an effort to help families in the northeast trying to cope with dying children. [Noted in Media Watch, 21 December 2015, #441 (p.2)] http://goo.gl/OPMrPK
- ONTARIO | CBC News – 26 June 2015 – **'Growing seniors population taxes homecare services in Northeastern Ontario.'** The Northeast Community Care Access Centre says it's feeling the demand of seniors needing more complex home care. The agency serves 16,000 patients in the region, and more than half of them are elderly. [Noted in Media Watch, 29 June 2015, #416 (p.1)] http://goo.gl/qoqvtR
- ONTARIO | CBC News – 12 May 2015 – **'Study finds 18% of Northeastern Ontario cancer patients die before seeing specialist.'** A new study reveals some cancer patients die in Northeastern Ontario without ever meeting with a medical specialist.[1] Researchers examined 6,500 cancer patients in the Sudbury-Manitoulin area over five years. They found just over 18% never met with an oncologist or got palliative care. http://goo.gl/Px2c9K

1. 'Access to oncology consultation in a cancer cohort in Northeastern Ontario,' *Current Oncology*, 2015;22(2):e69-375. http://goo.gl/poC13X



Barry R. Ashpole

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

U.S.A.

Senate advances bill on child "do not resuscitate" orders

KANSAS | *The Capital-Journal* (Topeka) – 21 March 2016 – Health care professionals would be barred from filing "do not resuscitate" orders on patients under 18 years old without parent permission under legislation endorsed by the Kansas Senate. The bill, known as "Simon's Law," would prohibit health care professionals from withholding life-sustaining care from patients under 18 without a parent's consent. The legislation forces health care providers to provide patients with end-of-life policies. It requires written parent permission for a DNR for a minor and also would require health care facilities to give patient information on end-of-life care. http://goo.gl/CYl80b

Specialist Publications

'African Americans and hospice care: A culture-centered exploration of enrollment disparities' (p.10), in *Health Communication.*

'Common components of efficacious in-home end-of-life care programs: A review of systematic reviews' (p.11), in *Journal of the American Geriatrics Society*

Noted in Media Watch, 7 March 2016, #452 (p.3):

- MISSOURI | *Lake Expo* (Laurie) – 2 March 2016 – **'Doctors issued a do-not-resuscitate for a newborn without telling his parents. A Missouri Bill now bears his name.'** Missouri HB 1915, "Simon's Law," is a bill that would protect the rights of parents concerning any surviving medical choices for their minor children. http://goo.gl/qmQik1

Old law puts adult children on hook for parent's nursing home care

PENNSYLVANIA | *The Pittsburgh Tribune* – 19 March 2016 – A law dating back to 16th-century English Poor Laws is being used increasingly in Pennsylvania to force adult children to pay for their parents' nursing home care regardless of their personal relationship. Many states have repealed what is known as the filial (family) support law, which generally holds that a spouse, child or parent of an impoverished person has a responsibility to care for or financially assist them. It remains on the books in 29 states, but most don't enforce it. Among the exceptions is Pennsylvania. Although not widely used, court rulings on the law have set precedent for nursing homes and/or patients' family members to sue other relatives for payment. http://goo.gl/HjSJwU

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | KQED News (San Francisco) – 22 March 2016 – **'Pharmaceutical companies hiked price on aid in dying drug.'** When California's aid-in-dying law takes effect this June, terminally ill patients who decide to end their lives could be faced with a hefty bill for the lethal medication. It retails for more than $3,000. Valeant Pharmaceuticals, the company that makes the drug most commonly used in physician-assisted suicide, doubled the drug's price last year, one month after California lawmakers proposed legalizing the practice. http://goo.gl/qpdI7y

- CALIFORNIA | *U.S. News & World Report* – 21 March 2016 – **'Californians can choose to die – with the help of taxpayers.'** California's aid-in-dying law contains a provision allowing doctors and hospitals to opt out of helping terminally ill patients access medications that would help them hasten their deaths, but that same exemption will not be carved out for state taxpayers... The state government plans to assist in the cost of providing life-ending medications and doctor visits… Of five states that offer aid-in-dying options, California will be the second, after Oregon, that covers the prescriptions using public funds. The program covers a third of California residents, and state officials haven't yet announced whether private health care plans will also be obligated to participate. http://goo.gl/UV7b4J

International

End-of-life care in Scotland

Children's Hospice Association Scotland launches its first election manifesto

U.K. (Scotland) | *The Brechin Advertiser* – 23 March 2016 – Children's Hospice Association Scotland (CHAS) has launched its first ever Scottish Parliament election manifesto for improving holistic palliative care for babies, children and young people aged 0-25 years in Scotland.[1] The document offers a blueprint for politicians to put hospice services for babies, children and young people with life-shortening conditions at the heart of Scotland's healthcare debate in this year's Scottish Parliament election. The charity is calling for the new intake of Members of the Scottish Parliament to work together to ensure that every child who needs CHAS services has the opportunity; that families have the widest range of support that meets their individual needs; and, to support the principle that statutory funding for CHAS must be brought in line with the 50% of agreed costs rightly provided to adult hospice services. Research in 2015 has shown a far higher number of babies, children and young people in Scotland aged 0-25 years have life-shortening conditions than previously estimated.[2] The number is more than 15,000 and includes those with oncology and neurology diagnoses, as well as with congenital abnormalities. http://goo.gl/vUq94v

1. 'Better Care for Children with Shorter Lives,' Children's Hospice Association Scotland, March 2016. http://goo.gl/ev9OzB

2. 'Children in Scotland Requiring Palliative Care,' Managed Service Network for Children & Young People with Cancer and Children's Hospice Association Scotland, October 2015. [Noted in Media Watch, 9 November 2015, #435 (p.6)] http://goo.gl/K5wC16

Scots expert says doctors must learn to "diagnose death"

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 21 March 2016 – Doctors need to be trained in the art of "diagnosing death" to prevent unnecessary distress at the end of life, a top academic has warned.[1] Dr. Erna Haraldsdottir ... has called for a more holistic approach to treating older people after watching her elderly father-in-law die in hospital. The 84-year-old had been diagnosed with dementia five years previously and his family watched his gradual decline until he was admitted to hospital. Although he was elderly and very frail, doctors attempted to discharge him at one point and tried to resuscitate him as a do not resuscitate note had not been arranged. Doctors were also reluctant to issue a death certificate as they were unsure of his cause of death… http://goo.gl/Mmk3ES

1. 'Diagnosing dying: Listen to the family's perception,' *European Journal of Palliative Care*, 2016;23(1):24-25. Access requires a subscription: http://goo.gl/WKvCC4

Specialist Publications

'The role of psychology in pediatric palliative care' (p.12), in *Journal of Palliative Medicine*.

Media Watch: Back Issues – http://goo.gl/frPgZ5

GLOBAL PALLIATIVE CARE NEWS ARCHIVE

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Please feel free to share this weekly report with your colleagues.
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MW 452: Dying better, even if it means sooner

Download the complete issue (PDF 275 KB)

U.S. REPORT & WORLDS NEWS | *Online – 29 February 2016* | Defying and delaying death often remains the focus of many care providers even when patients reach their 80s, 90s and 100s. These individual decisions add up to the single greatest expenditure in the national health system: care in the last 12 months of life accounts for over 25% of total expenditures for both Medicare and Medicaid. **read more...**

Media Watch Archives

- 2014, July - December
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- 2012, July - December
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Terminal illness "should be a protected characteristic"

U.K. | Chartered Institute of Personnel & Development – 21 March 2016 – Politicians and unions are backing a campaign to make terminal illness a protected characteristic in the workplace, which is being led by an employee with breast cancer who claims she was "intimidated" and "bullied" by her employer following her diagnosis. Jacci Woodcock, a 58-year-old regional sales manager from Derbyshire, was given a year to live. She was dismissed from her role following a "capability assessment," and, although she reached a settlement with her employer, was surprised that she was not afforded the same rights as those with protected characteristics such as pregnancy. She is now the face of the 'Dying to Work' campaign, which is being backed by the Trade Union Congress and a cross-party group of MPs, and aims to change both the European Union equal treatment directives and, in turn, U.K. equality legislation. Terminal illness, it argues, is degenerative, which means reasonable adjustments for employees should be both made and regularly reviewed. http://goo.gl/oIDwyY

Specialist Publications

'Factors associated with variation in hospital use at the end of life in England' (p.6), in *BMJ Supportive & Palliative Care.*

'The right to palliative care: A "mirage" in the jurisprudence of the European Court of Human Rights and Inter-American Court of Human Rights' (p.9), in *Cuadernos de Derecho Transnacional.*

N.B. 'Dying at Work' website: http://goo.gl/rSO6kF

Noted in Media Watch, 13 July 2015, #418 (p.7):

- U.K. | *The Leicester Mercury* – 6 July 2015 – **'GP call to protect jobs for terminally ill patients.'** A Leicestershire GP is backing a national campaign to secure more rights for workers with terminal illness. Dr. Terri Eynon fears some patients are facing discrimination from employers and sometimes end up being sacked from their job. She wants to see legal protection, similar to that of maternity leave, to cover workers. http://goo.gl/ohDB4z

Noted in Media Watch, 16 August 2010, #162 (p.3):

- U.K. | *Personnel Today* – 10 August 2010 – **'Terminally ill employees: HR's role and responsibilities.'** The author investigates the growing trend of people working with a terminal illness and looks at the role of Human Resources. According to cancer charity MacMillan, more people than ever are working through terminal illnesses, often to within days of their death. http://goo.gl/5UCugO

With an ageing population is healthcare sustainable?

AUSTRALIA | *The Age* – 20 March 2016 – We hear it all the time: the population is ageing. For the health system, the numbers are frightening. Since 1960 the world's population has grown from 3 billion to 7.2 billion. By 2025 it will have passed 8 billion. And the billions are getting older. In developed countries the over-60s now make up more than 20% of the population. By the 2030s they will make up 30% – in Japan and Switzerland, 40%. As this bulging cohort of oldies approaches, medical treatments are stretched. Hospital stays have become shorter over the last 30 years. Treat quicker and discharge fast is increasingly the strategy. Where will the patients go? As the years roll on, more and more homes in our suburbs and residential aged care facilities will house old people who are being cared for – or are caring for themselves – supported by travelling medical and geriatric services. This means new ways of doing things: interconnected health services delivered outside hospitals, visiting clinicians caring for people in community settings, and systems to transfer patients flexibly in and out of primary, home or aged care, or rehabilitation when need-ed. http://goo.gl/ExhO6S

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.16.

Specialist Publications (e.g., in-print and online journal articles, reports, etc.)

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

A good death for the oldest old

AGE & AGING | Online – Accessed 24 March 2016 – People aged over 85 are the fastest growing segment of the population, both in the U.K. and across all high-income countries. This is also the group of people who are most likely to die. So it is pertinent to consider how we can ensure that for the oldest old, their deaths, as well as their lives, are as good as we can help them to be. Pocock and colleagues give a valuable snapshot of where deaths occur in the U.K. for the oldest old.[1] The results, based on a large, representative sample of U.K. deaths in those aged 85 and over, show that the majority of the oldest old die in hospital. Frail older people who had been resident in care homes, those with dementia or cancer and those aged over 95 were less likely to die in hospital; however, those from deprived postcodes, those with more severe co-morbidities and those with multiple hospitalisations in the previous year were more likely to die in hospital. Due to the large-scale nature of the data sources used, some key variables could not be incorporated in the analyses – in particular, we do not know the preferred place of death for individuals or what type of hospital death occurred. Also, we are unable to ascertain what their symptom burden or care needs were at the end of life, and the data are dependent on the quality of coding from death certificates... http://goo.gl/jmj0yG

University of Bristol study: Findings

Researchers found 62% of older people still die in hospital, although this proportion decreases with increasing age. The data also showed older people who live in deprived areas are more likely to die in hospital, and that older people who die of non-malignant disease are more likely to die in hospital than those who die of cancer.

1. 'Factors associated with hospital deaths in the oldest old: A cross-sectional study,' *Age & Aging*, 5 March 2016. http://goo.gl/Y6VtsV

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 24 March 2016 – **'Factors associated with variation in hospital use at the end of life in England.'** Difference in hospital use was associated with a range of patient descriptors (age, gender and ethnicity). The variables with the greatest "explanatory power" were those that described the diagnoses and causes of death. So, for example, 65% of the variability in the model of hospital admissions was explained by diagnoses. Only moderate levels of variation were explained by the hospital provider variables for admissions and deaths in hospital, though the impacts on total bed days was large. http://goo.gl/xdzPPZ

Too ill to will? Deathbed wills: Assessing testamentary capacity near the end of life

AGE & AGING | Online – 23 March 2016 – Assessing testamentary capacity in the terminal phase of an illness or at a person's deathbed is fraught with challenges for both doctors and lawyers. Numerous issues need to be considered when assessing capacity for a will. These issues are exacerbated when such an assessment needs to be undertaken at the bedside of a dying patient. The nature and severity of the illness, effects on cognition of the terminal illness, effects of medication, urgency, psychological and emotional factors, interactions with carers, family and lawyers, and a range of other issues confound and complicate the assessment of capacity. What is the doctor's role in properly assessing capacity in this context and how does this role intersect with the legal issues? Doctors will play an increasing role in assessing testamentary capacity in this setting. The ageing of society, more effective treatment of acute illness and, often, the prolongation of dying are only some of the factors leading to this increasing need. However, despite its importance and increasing prevalence, the literature addressing this challenging practical area is scarce and offers limited guidance. This paper examines these challenges and discusses some practical approaches. http://goo.gl/KXoMJW

Choosing words wisely in communication with heart failure patients and families

AMERICAN JOURNAL OF CARDIOLOGY | Online – 17 March 2016 – The complex and often unpredictable course of heart failure provides many opportunities for communication between clinicians and patients about important subjects as advance care planning, disease-state education, therapeutic options and limitations, and end-of-life care (EOLC). Studies of heart failure patients demonstrate that, when engaging in such complex communication, specific language matters in patient experience and in shared decision-making with providers. To date, clinical literature has outlined useful frameworks for communication with heart failure patients, but has not yet broached specific language crucial to furthering whole-person care, particularly in the complex and emotional realm of advancing disease and transitions to EOLC. In this work, the authors unpack language commonly employed in advanced heart failure care and provide explicit suggestions to better provide such pivotal communication. In conclusion, specific phrasing may significantly impact patient experiences and outcomes. Communication that focuses on the disease itself and the therapy or intervention in question may help remove the patient from potential negative emotions, thus facilitating more objective shared decision-making with the clinician. http://goo.gl/BFrgnA

Noted in Media Watch, 23 February 2015, #398 (p.10):

- *JOURNAL OF CLINICAL OUTCOMES MANAGEMENT*, 2015;22(2):73-82. **'Advance care planning among patients with heart failure: A review of challenges and approaches to better communication.'** Although most patients with heart failure (HF) prefer to receive thorough and honest information about their health condition and prognosis, the unpredictability of the HF trajectory coupled with physician barriers including discomfort with emotionally-laden topics and difficulty identifying the "right" time to engage in advance care planning (ACP), and systems barriers such as inadequate clinic time and limited reimbursement, impede timely engagement in advance ACP discussions. http://goo.gl/2UeN30

Related

- *AGE & AGING* | Online – 24 March 2016 – **'Discussing end-of-life issues in nursing homes: A nationwide study in France.'** In this post-mortem cohort study in a nationwide, representative sample of 78 nursing home facilities in France end-of-life issues were discussed with at most 21.7% of the residents who died during the study period. In one-third of the situations, no discussion about end-of-life-related topics ever occurred, either with the resident or with the relatives. http://goo.gl/IP8DWX

- *DEUTSCHE MEDIZINISCHE WOCHENSCHRIFT*, 2016;141(6):399-402. **'Advance care planning and decisions to limit treatment at the end of life – the view from medical ethics and psycho-oncology.'** Decisions to limit treatment are important in order to avoid overtreatment at the end of life. They proceed more than half of expected deaths in Europe and the US, but are not always communicated with the patient in advance. One reason for non-involvement is that conversations that prepare patients for end-of-life decisions and work out their preferences do not take place on a regular basis. https://goo.gl/tHKoiq

  N.B. German language article.

Opportunities for palliative care in public health

ANNUAL REVIEW OF PUBLIC HEALTH, 2016;37:357-374. In May 2014, the World Health Assembly, of the World Health Organization (WHO), unanimously adopted a palliative care (PC) resolution, which outlines clear recommendations to the United Nations member states, such as including PC in national health policies and in the undergraduate curricula for health care professionals, and highlights the critical need for countries to ensure that there is an adequate supply of essential PC medicines, especially those needed to alleviate pain. This resolution also carries great challenges: Every year over 20 million patients (of which 6% are children) need PC at the end of life (EOL). However, in 2011, approximately three million patients received PC, and only one in ten people in need is currently receiving it. The authors describe this public health situation and systems failure, the history and evolution of PC, and the components of the WHO public health model. They propose a role for public health for PC integration in community settings to advance PC and relieve suffering in the world. http://goo.gl/0cwich

Cont.

Selected articles on a public health approach to end-of-life care

- U.K. (Scotland) | Scottish Public Health Network – Accessed 3 March 2016 – **'Palliative and end-of-life care in Scotland: The rationale for a public health approach.'** The report aims to examine the rationale for applying a public health approach to palliative and end-of-life care, and to explore where and how public health approaches could be applied to support local service planning and delivery. The report is accompanied by five briefing papers and includes 17 recommendations. [Noted in Media Watch, 7 March 2016, #452 (p.6)] http://goo.gl/FeVDfk
- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 17 February 2016 – **'The forgotten people in British public health: A national neglect of the dying, bereaved and caregivers.'** This paper reports a content analysis of 7 key British public health journals, 14 major public health textbooks and 3 public health websites to assess the size and quality of interest in populations related to ageing, dying, caregiving, and grief and bereavement. Compared with other public health issues, such as obesity and tobacco use, for examples, interest in the social experience and epidemiology of end-of-life experiences is extremely low. [Noted in Media Watch, 22 February 2016, #450 (p.10)] http://goo.gl/sv0i6p
- *PROGRESS IN PALLIATIVE CARE* | Online – 8 January 2016 – **'Research in public health and end-of-life care: Building on the past and developing the new.'** This paper considers the research challenges related to examining new public health approaches to end-of-life care and how learning from more traditional or classic public health research can influence a future research agenda. [Noted in Media Watch, 8 February 2016, #448 (p.7)] http://goo.gl/6Bz4f9

N.B. Additional articles on a public health approach to end-of-life care are listed in this issue of Media Watch (p.8)]

Health status of prisoners in Canada: Narrative review

CANADIAN FAMILY PHYSICIAN, 2016;62(3): 215-222. Canadians in correctional facilities have poor health across a range of health status indicators, a finding that is consistent with international data on persons who experience imprisonment. This information is relevant to physicians who assess and treat persons while in custody or after release, as it might inform history taking, counseling regarding pre-test probability, investigations, and management strategies. Information on health status is also important for defining areas of focus for improving health and health care. Health care in correctional facilities is largely delivered by government authorities in Canada, which makes the lack of data on some key indicators of health striking, including on mortality after release, chronic diseases, injury, and health care access and quality. Among other measures, the implementation of electronic medical records, which are still not available in correctional facilities in many jurisdictions, could facilitate the collection and management of data on many health status indicators. http://goo.gl/VgRXFf

Prison Hospice Backgrounder

End-of-life care – or the lack of – in the prison system has been highlighted on a regular basis in Media Watch. An updated compilation of the articles, reports, etc., noted in past issues of the weekly report is available on the Palliative Care Community Network website at: http://goo.gl/qgd4hp

Media Watch: Palliative Care Network-e Website

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

The right to palliative care: A "mirage" in the jurisprudence of the European Court of Human Rights and Inter-American Court of Human Rights

CUADERNOS DE DERECHO TRANSNACIONAL, 2016;8(1):5-16. Little attention has been paid so far to the right to palliative care (PC) from an international legal viewpoint. This is despite the fact that the European Court of Human Rights (ECtHR) and the Inter-American Court of Human Rights (IACtHR) have been confronted with issues related to PC on some occasions. The purpose of this paper is to fill this gap and to assess and subsequently compare and contrast the respective approaches of the ECtHR and of the IACtHR to PC. The paper addresses, through some relevant examples, the enduring resistance by these two human rights courts to the affirmation of a human right to PC. It also formulates some proposals for overcoming these difficulties, including among others: 1) An interpretation of the right to life under Article 2 of the ECHR aimed at distinguishing euthanasia from PC; 2) a care-oriented interpretation of the prohibition of inhuman and degrading treatments under Article 3 ECHR by the ECtHR; 3) a constant use of the notion of the "vida digna" ["dignified life"] under Article 4 of the ACHR in the medical jurisprudence of the IACtHR; 4) a use of the Inter-American Convention on the Rights of Older Persons of 2014 that explicitly recognizes a right to PC in the ACtHR's case-law; and, 5) a use of the WHO recommendations related to PC in the medical case-law of the ECtHR and the ACtHR. http://goo.gl/o1YyA3

N.B. English language article.

Selected articles on palliative care as a human right

- *CANCER CONTROL* | Online – Accessed 30 June 2014 – **'Palliative care as a human right.'** This article explains how human rights relate to palliative care (PC) and where to find the relevant information, as well as the need to remove barriers and integrate PC into health care. [Noted in Media Watch, 7 July 2014, #365 (p.6)] http://goo.gl/Hc91Ua

- *PALLIATIVE MEDICINE*, 2013;27(2):101-102. **'The Prague Charter: Urging governments to relieve suffering and ensure the right to palliative care.'** The European Association for Palliative Care, the International Association for Hospice & Palliative Care, the World Palliative Care Alliance, and Human Rights Watch have formulated 'The Prague Charter for Palliative Care as a Human Right.' [Noted in Media Watch, 11 February 2013, #292 (pp.10-11)] http://goo.gl/kiGxK5

  N.B. The Prague Charter: http://goo.gl/kiLmT2

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 January 2013 – **'The Lisbon Challenge: Acknowledging palliative care as a human right.'** Access to palliative care has been advocated as a human right by international associations, based on the right to the highest attainable standard of physical and mental health. [Noted in Media Watch, 4 February 2013, #291 (p.7)] http://goo.gl/a8EASG

  N.B. The Lisbon Challenge: http://goo.gl/W7KbBk

Developing a research strategy in a hospice in England

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(2):70-73 There are many reasons why hospices should be active in palliative care research, one of them being the need for them to show that they are providing evidence-based treatment and care. In 2013, Princess Alice Hospice in England developed a research strategy and has now started generating its own research projects. A strategic approach to conducting research in hospices involves identifying priority areas, setting up project steering groups, engaging staff and service users, creating a research governance infrastructure and establishing external partnerships. Hospices who want to become research-active will face challenges such as patient vulnerability, attrition, staff training, gatekeeping and lack of attractiveness to academics and grant providers.

European Journal of Palliative Care

Access requires a subscription:
Home page: http://goo.gl/WKvCC4

Cont.

Related

- *BMC PALLIATIVE CARE* | Online – 24 March 2016 – **'Developing research priorities for palliative care of people with intellectual disabilities in Europe: A consultation process using nominal group technique.'** The proposal of four major priority areas and a range of minor themes for future research in intellectual disability, death, dying and palliative care will help researchers to focus limited resources and research expertise on areas where it is most needed and support the building of collaborations. http://goo.gl/fNxm6x

Palliative care for cirrhosis: A U.K. survey of health professionals' perceptions, current practice and future needs

FRONTLINE GASTROENTEROLOGY, 2016;7(1):4-9. All respondents acknowledged the role of specialist palliative care (SPC) in caring for those dying with cirrhosis and need for further training to improve confidence and enable joint working between SPC, general practice and liver teams. Low response rates, however, make it difficult to generalise these findings, which require further validation. While there are plans to address the high mortality from liver disease, these initiatives will be slow to demonstrate any impact on mortality figures and many will continue to die with high symptom burden and little care planning at the end of life. The financial challenges faced by the National Health Service (NHS) over the next years as outlined by the NHS England Chief Executive confirm that we cannot expect significant financial support to address the problem. http://goo.gl/I1m9PW

African Americans and hospice care: A culture-centered exploration of enrollment disparities

HEALTH COMMUNICATION | Online – 23 March 2016 – Over the past decade, scholars and practitioners have called for efforts to reduce disparities in the cost and quality of end-of-life care (EOLC); a key contributor to these disparities is the underuse of hospice care by African American patients. While previous studies have often relied on interviewing minority individuals who may or may not have been terminally ill and of whom few were using hospice care services, this essay draws upon the culture-centered approach to report the findings of a grounded theory analysis of 39 interviews with 26 African American hospice patients and lay caregivers. Participants identified several barriers to hospice enrollment and reported how they were able to overcome these barriers by reframing/prioritizing cultural values and practices, creating alternative goals for hospice care, and relying on information obtained outside the formal health system. These findings have implications for understanding hospice experiences, promoting hospice access, and improving EOLC. http://goo.gl/hAJPYw

JOURNAL OF
Palliative
Medicine

The focus of the February 2016 issue is on palliative and end-of-life care for African Americans. [Noted in Media Watch, 8 February 2016, #448 (p.15).] Contents page: http://goo.gl/6fapNx

Noted in Media Watch, 8 February 2016, #448 (p.14):

- *JOURNAL OF HEALTH CARE FOR THE POOR & UNDERSERVED*, 2016;27(1):219-237. **'Toward eliminating hospice enrollment disparities among African Americans: A qualitative study.'** This essay reports the findings of a grounded theory analysis of interviews with 26 African American hospice patients and lay caregivers. Participants identified several barriers to hospice enrollment and reported how they were able to overcome these barriers by reframing/prioritizing cultural values and practices, creating alternative goals for hospice care, and relying on information obtained outside the formal health system. Finally, participants offered suggestions for eliminating barriers and providing salient information about hospice care to other African Americans. http://goo.gl/Q6XS8f

Perceived needs for support among care home staff providing end of life care for people with dementia: A qualitative study

INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY | Online – 14 March 2016 – This study revealed rich and complex understandings of the practice dimensions of caring for people with dementia at the end of life and the impact these have on staff. There is a need to develop effective psychosocial interventions that focus on emotional support for care home staff. There will be challenges in providing this in employment settings that are generally low paid, low status, have high turnover and are reliant on temporary or migrant staff, where training is not rewarded, mandatory or culturally valued. Care home staff found the external demands on them and difficulties associated with interacting with people with dementia sometimes challenging, stressful and anxiety-provoking, particularly as residents approached end of life. Emotional aspects of caring for dying residents were sometimes heightened by close attachments with residents and their families. Staff were able to recognise these unmet needs and identified a need for further training and emotional support to manage these stressors. http://goo.gl/ti4aHU

Related

- *REVISTA MÉDICA DE CHILE*, 2016;144(1):95-101. **'Palliative care of patients with severe dementia.'** The aim of this article is to consider the issues that arise from the use of commonly administered therapies in patients with severe dementia. Scenarios where excessive or futile therapeutic interventions might occur are discussed. The authors concludes that it is advisable to analyze the clinical criteria and ethical considerations related to the administration of those treatments in order to develop and disseminate better practice guidelines for health professionals. http://goo.gl/wqygpX

  N.B. Spanish language article.

Noted in Media Watch, 9 November 2015, #435 (p.9):

- *BMC PALLIATIVE CARE* | Online – 4 November 2015 – **'Identification of the palliative phase in people with dementia: A variety of opinions between healthcare professionals.'** Three different time points in the disease trajectory when people with dementia were considered to be eligible for palliative care (PC): 1) Early in the disease trajectory; 2) When signs and symptoms of advanced dementia are present; and, 3) From the time point that curative treatment of co-morbidities is futile. Yet, none of these time points was uniformly considered by the professional teams across Europe. In some cases, professionals working in the same nursing home didn't even reach consensus when considering persons with dementia eligible for PC. http://goo.gl/uj825G

  N.B. See Media Watch of 15 June 2015, #414 (pp.13-14), for selected articles on end-of-life care for people living with dementia.

Common components of efficacious in-home end-of-life care programs: A review of systematic reviews

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY, 2016;64(3):632-639. Multiple randomized controlled trials on in-home end-of-life (EOL) programs, often with multifaceted and varying components, have shown benefits and reduced costs. The objective of this review was to determine which components of these programs are most commonly associated with better outcomes than usual care. Original quantitative studies were included from these reviews, and the details of every program that had a significant positive effect on any outcome measured were extracted. Nineteen reviews met the inclusion criteria, from which 40 relevant studies were identified. Thirty unique components emerged from the content analysis of the program descriptions. On average, each program contained 11 components; the six most common were linkage with acute care, multidisciplinary nature, EOL expertise and training, holistic care, pain and symptom management, and professional psychosocial support. Linkage, around-the-clock availability, and customized care planning were most common to the nine interventions for which a significant cost reduction was reported. http://goo.gl/TPAkl0

Cont.

Related

- *SAGE OPEN* | Online – 23 May 2016 – **'Family caregivers' social representations of death in a palliative care context.'** The finding [of this study] showed that family caregivers (FCGs) had different images that specifically represented death: 1) Losses as different kinds of "deaths"; 2) PC as a place to negotiate with death; and, 3) Last times as confirmation of the end. These images highlight the meaning attributed to the body and the position of the dying person in our Western society. Representations of PC reveal a kind of paradox, a place of respect and of "gentle death," and a place where death is almost too omnipresent. http://goo.gl/C3Vm7B

Immigrants accessing end-of-life care in Italy: The Tuscany Tumor Association experience

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 23 March 2016 – In a recent publication[1] ... the authors drew the attention of the scientific community to the problem of end-of-life care access for undocumented Hispanic immigrants in the U.S. They state that the lack of residency permission in a country and the subsequent fear of deportation, as well as limited economic resources and cultural, social and linguistic barriers, all contribute to make the implementation of an appropriate and efficient palliative care service for foreign patients impossible. http://goo.gl/bRcn03

1. 'End-of-life care for undocumented immigrants with advanced cancer: Documenting the undocumented,' *Journal of Pain & Symptom Management*, 8 December 2015. http://goo.gl/9cyL2e

Noted in Media Watch, 18 August 2014, #371 (p.13):

- *NARRATIVE INQUIRY IN BIOETHICS*, 2014;4(2)83-85. **'Undocumented and at the end of life.'** Three of the most contentious issues in contemporary American society – allocation of medical resources, end-of-life care, and immigration – converge when undocumented immigrant patients are facing the terminal phase of chronic illness. The lack of consistent, pragmatic policy in each of these spheres leaves us with little guidance for how to advocate for undocumented patients at the end of life. http://goo.gl/LBmczm

Noted in Media Watch, 4 June 2012, #256 (p.12):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 31 May 2012 – **'Palliation for dying undocumented immigrants.'** At first glance, sending dying patients home at their request may appear to be an approach that would please advocates on both sides of the debate over illegal immigration. http://goo.gl/8OWSm6

The role of psychology in pediatric palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 23 March 2016 – Pediatric medicine increasingly has recognized the value of integrating behavioral health in medical care, but this trend has not yet extended to pediatric palliative care (PC). Results from a recent survey of pediatric PC programs across the U.S. indicate that team composition almost never included a psychologist. This article presents a model of collaborative care to optimize the integration of psychosocial and medical aspects of treatment in pediatric PC, delineating how a psychologist adds to this model. This article argues that psychology brings specialized skills in assessment, intervention, and research that fit with the premise of PC as a holistic approach that relieves symptoms. http://goo.gl/IGqMEm

Noted in Media Watch, 4 May 2015, #408 (p.15):

- *PALLIATIVE MEDICINE* | Online – 28 April 2015 – **'Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review.'** Despite standardization in disease assessments and curative interventions for childhood cancer, palliative assessments and psychosocial interventions remain diverse and disparate. http://goo.gl/l0VgL1

Perspectives of people with mild intellectual disabilities on care relationships at the end of life: A group interview study

PALLIATIVE MEDICINE | Online – 24 March 2016 – Two dimensions of care relationships were found: 1) "Ascertain, record and honour wishes' of the ill person. Adequately dealing with care wishes, 'last wishes' and funeral wishes was of central importance: "it's about their life." The authors found an emphasis on control that seemed to reflect the participants' experience that respecting autonomy does not always happen; and, 2) "Being there": ill people need people who are there for him or her, practically, as well as emotionally, socially and spiritually. Participants placed specific emphasis on providing positive experiences. The views of people with mild intellectual disabilities (ID) highlight the high demands which end-of-life care imposes on relational qualities of caregivers. This study shows the added value and potential of involving people with ID in studies on end-of-life care. http://goo.gl/eUEHmE

Noted in Media Watch, 8 February 2016, #448 (p.13):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(1):45-47. **'Palliative care for people with intellectual disabilities: The European Association for Palliative Care White Paper in a nutshell.'** The Taskforce on Palliative Care for People with Intellectual Disabilities of the European Association for Palliative Care (EAPC) recently published a White Paper containing 13 norms and related statements, real-life examples, and available resources.[1] Journal contents page: http://goo.gl/qIWex7

    1. 'Defining Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe, Using Delphi Methods: A White Paper from the European Association of Palliative Care,' Palliative Medicine, 11 August 2015. [Noted in Media Watch, 17 August 2015, #423 (p.19)] http://goo.gl/FQUsti

N.B. This issue of Media Watch lists selected articles on end-of-life care for people living with intellectual disabilities

The physician as patient in palliative care: A retrospective case-note audit

PALLIATIVE MEDICINE | Online – 24 March 2016 – Dying physicians may present unique challenges to palliative care (PC) teams. Studies of dying physicians are scarce, but those that exist suggest a potential absence of a coordinating clinician, prolongation of curative treatments, resistance to PC input and barriers to discussing psychosocial needs. There was evidence [in this study] of medically qualified friends or family members initiating referrals and directing treatment decisions. There was some evidence of increased consultant-led decision-making and bypassing of usual referral pathways and systems for providing after-hours advice and calling consultants directly. There also appeared to be some reluctance by junior doctors to make decisions, because of the patient's desire for consultant-level advice only. This study adds to the growing body of literature that identifies the potential difficulties associated with caring for medical practitioners. By understanding some of the complexity of this particular doctor–patient relationship, clinicians can approach the management of physician-patients facing the end of their lives with a more sound understanding of their particular care needs. http://goo.gl/JXSmK8

Noted in Media Watch, 25 January 2016, #446 (p.4):

- U.S. | ABC News – 19 January 2016 – **'Many doctors choose end-of-life care differently than the general population, two studies show.'** The way many doctors face end-of-life care differs from the approach of the general public, according to two new studies...[1,2] http://goo.gl/Bn4ZkB

    1. 'End-of-life care intensity for physicians, lawyers, and the general population,' *Journal of the American Medical Association*, 2016;315(3):303-305. http://goo.gl/TdqUx8

    2. 'Association of occupation as a physician with likelihood of dying in a hospital,' *Journal of the American Medical Association*, 2016; 315(3):301-303. http://goo.gl/nCrpJ8

Cont.

Noted in Media Watch, 17 August 2015, #423 (pp.5-6):

- U.S. | CNN News – 11 August 2015 – **'How doctors want to die is different than most people.'** A Stanford University study shows almost 90% of doctors would forgo resuscitation and aggressive treatment if facing a terminal illness.[1] http://goo.gl/QN6YzZ

    1. "Do unto others": Doctors' personal end-of-life resuscitation preferences and their attitudes toward advance directives,' *PLoS One*, 28 May 2014. [Noted in Media Watch, 2 June 2014, #360 (p.11)] http://goo.gl/TBNL8w

N.B. This issue of Media Watch lists selected articles on doctors' preferences in terms of their own end-of-life care.

Patient perspectives of dignity, autonomy and control at the end of life: Systematic review and meta-ethnography

PLOS ONE | Online – 24 March 2014 – Research in the end-of-life context has explored the sense of dignity experienced by patients with advanced disease, examining the factors associated with it. Whereas certain perspectives regard dignity as an intrinsic quality, independent of external factors, in the clinical setting it is generally equated with the person's sense of autonomy and control, and it appears to be related to patients' quality of life. Twenty-one studies recording the experiences of 400 participants were identified. Three themes emerged: 1) Dignity mediated by the loss of functionality, linked to the loss of control; 2) Dignity as identity; and, 3) Autonomy as a determining factor of perceived dignity, understood as the desire for control over the dying process and the desire for self-determination. The authors propose an explanatory model which highlights that those patients with an intrinsic sense of dignity maintained a positive view of themselves in the face of their illness. http://goo.gl/V9VUBf

Noted in Media Watch, 4 January 2016, #443 (p.7):

- *BMC RESEARCH NOTES* | Online – 28 December 2015 – **'What facilitates the delivery of dignified care to older people? A survey of health care professionals.'** Facilitators and barriers to delivering dignified care were categorised into three domains: "organisational level"; "ward level," and "individual level." http://goo.gl/nH93id

N.B. This issue of Media Watch lists selected articles on dying with dignity.

Phenomenological and contemplative approaches to vigiling with persons who are nearing death

SPIRITUALITY IN CLINICAL PRACTICE, 2016;3(1):69-72. Although medical staff do all they can to make the person comfortable, there is no way to know how much the person may be suffering, what their emotional state is, how he or she is experiencing the dying process, nor are there opportunities for them to heal, ask and receive forgiveness, express thanks or love and say goodbye. This article aims to introduce the potential for being and communicating with another who is nearing death through the phenomenological and contemplative mediums of silence, image, empathy and the lived body. http://goo.gl/2OU5PF

Related

- *DEUTSCHE MEDIZINISCHE WOCHENSCHRIFT*, 2016;141(6):399-402. **'Personal and dignified death. The role of pastoral care in palliative medicine.'** Palliative pastoral care is not about adding days to life, but about adding life to days. It does not matter whether the dying process is short or long. What matters is to ensure the best possible quality of life until the very end through mindful companionship. https://goo.gl/ly3Ul5

    N.B. German language article.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE HASTINGS REPORT* | Online – 21 March 2016 – **'Why bioethics needs a disability moral psychology.'** The deeply entrenched, sometimes heated conflict between the disability movement and the profession of bioethics is well known and well documented. Critiques of prenatal diagnosis and selective abortion are probably the most salient and most sophisticated of disability studies scholars' engagements with bioethics, but there are many other topics over which disability activists and scholars have encountered the field of bioethics in an adversarial way, including health care rationing, growth-attenuation interventions, assisted reproduction technology, and physician-assisted suicide. The tension between the analyses of the disabilities studies scholars and mainstream bioethics is not merely a conflict between two insular political groups, however; it is, rather, also an encounter between those who have experienced disability and those who have not. This paper explores that idea. http://goo.gl/ak0Ra3

- *JOURNAL OF MEDICAL ETHICS* | Online – 23 March 2016 – **'Canada on course to introduce permissive assisted dying regime.'** Canada's Supreme Court decided in February 2015 that the criminalisation of assisted dying in the country violates the country's citizens and residents constitutional rights. This paper reviews policy recommendations produced by a special expert advisory panel appointed by Canada's provinces and territories, where the responsibility for the provision of health care lies. It also reviews a similar document produced by a special federal parliamentary committee. Based on the review of these two milestone documents it is argued that a Canadian consensus seems to emerge that foreshadows a permissive regulatory regime in that country. http://goo.gl/iQNPAq

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Media Watch: Editorial Practice

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

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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.

- *THE MEDICAL POST* (Canada) | Online – 15 March 2016 – **'It's time to welcome death into our practices.'** The issue of physician-assisted dying is getting a lot of airplay these days. It's a huge issue fraught with many justifiable fears and concerns. But the element that is often lost in the "slippery-slope-until-you're-knocking-off-grandma-for-the-inheritance" argument against PAD is the common desire to live a life with meaning and to have control over our bodies. Physicians are in the crosshairs of the debate about PAD, as we are about to become, if we aren't already, the gatekeepers to this service. Yet it makes sense that some doctors are fearful of involvement with PAD—we may want to help some people achieve their version of a "good death," but this is an area where none of us has received any substantial training. One prevalent concern is that the massive responsibility of PAD decisions will be placed on two already busy specialities: family medicine and psychiatry. It's not hard to see why.

  N.B. Access requires a subscription: Publication home page: http://goo.gl/SyDmD4

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://goo.gl/zJ7jOo

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

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

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

Asia

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

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

Canada

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

Europe

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

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

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

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