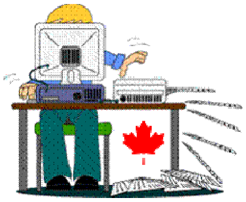
Media Watch...

*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.*

8 February 2016 Edition | Issue #448



Compiled & Annotated by Barry R. Ashpole

A universal challenge: Scroll down to Specialist Publications and 'We must help people to stay out of hospital at the end of life' (p.10), in *European Journal of Palliative Care*.

Canada

Canadian Cancer Society pushes palliative care as Saskatchewan election issue

SASKATCHEWAN | CBC News – 4 February 2016 – Most critically ill Canadians are not receiving adequate end-of-life care, according to a report by the Canadian Cancer Society,[1] and the Saskatchewan chapter of the organization is launching a campaign asking that more be done help people dying of chronic disease. The report says there's a lack of standards, training and funding to properly provide palliative care (PC). The group says not even half of the people who die of chronic illness are able to access treatment, meant to help them die comfortably. In Saskatchewan, there are three full-time PC doctors – two in Saskatoon and one in Regina. The Cancer Society said this leaves family doctors stretched to deliver end-of-life treatment that could ideally be provided by the specialists, and it's calling on the government to change the situation. http://goo.gl/smOkpX

Extract from CBC report

In Saskatchewan, there are three full-time palliative care doctors – two in Saskatoon and one in Regina.

N.B. 15% of the province's population of 1,132,640 is 65 years of age or older.

1. 'Right to Care: Palliative Care for all Canadians,' Canadian Cancer Society, December 2015. [Noted in Media Watch, 18 January 2016, #445 (p.1)] http://goo.gl/f3iFEB

Terminally-ill Canadians wait too long for disability pensions

CTV NEWS | Online – 2 February 2016 – Canadians with terminal illnesses are waiting too long for disability pension benefits from the federal government, and those with grave conditions are being snowed under with paperwork, Canada's auditor general says.[1] In his latest ... assessment of various federal government departments, agencies and programs, Michael Ferguson's most eyebrow-raising findings came from his examination of how Ottawa parcels out Canada Pension Plan disability benefits and deals with disputed denials. While the audit found no documented cases of patients dying while waiting for benefits, it did find that guidelines for decisions weren't always being met. http://goo.gl/sVOR8R

1. 'Report 6 – Canada Pension Plan Disability Program,' Auditor General of Canada. http://goo.gl/zGtcaO

Health care not doing enough to help Canadians who have damaged hearts: Report

THE CANADIAN PRESS | Online – 1 February 2016 – A new report says more needs to be done to help a growing number of Canadians who are living with damaged hearts.[1] About 600,000 people are living with heart failure – an incurable, long-term condition where the heart is not pumping enough blood due to damage from heart attacks and disease, says the Heart & Stroke Foundation study. That growing number is putting a strain on patients, their families, and the economy, says David Sculthorpe, CEO of the foundation. "There is so much we need to do as more Canadians develop this chronic, incurable condition – from earlier diagnosis to better end-of-life care and, ultimately, finding ways to help heal these damaged hearts." Depending on the severity of symptoms, about half of heart failure patients die within five years and most will die within 10 years, the report says. Even with excellent care, heart-failure patients face tough challenges. http://goo.gl/33jzCu

Extract from Heart & Stroke Foundation report

When a chronic illness such as heart failure progresses to a point when medical or surgical treatments don't work, palliative care (PC) ... helps patients achieve the best quality of life until the end. Unfortunately, the unpredictable progression of heart failure – punctuated by deterioration and then improvement – makes it difficult to access PC.

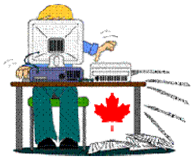
Specialist Publications

'Complex care options for patients with advanced heart failure approaching end of life' (p.10), in *Current Heart Failure Reports*.

1. 'The Burden of Heart Failure,' Heart & Stroke Foundation, January 2016. http://goo.gl/kRh9ZQ

Selected articles on palliative care and heart failure

- *AMERICAN HEART JOURNAL* | Online – 2 July 2015 – **'Unique challenges of hospice for patients with heart failure: A qualitative study of hospice clinicians.'** This study suggests potential opportunities for hospice clinicians, and referring providers who seek to collaborate, to improve care for patients with heart failure during the transition to hospice care. [Noted in Media Watch, 13 July 2015, #418 (p.10)] http://goo.gl/cJPDp0
- *BRITISH JOURNAL OF CARDIAC NURSING* | Online – 3 July 2015 – **'Understanding palliative care needs in heart failure.'** Clinicians [i.e., study participants] often struggled to discuss palliation with heart failure patients owing to the unclear disease trajectory and cardiac-specific barriers to identifying palliation needs. [Noted in Media Watch, 13 July 2015, #418 (p.10)] http://goo.gl/nXUada
- *HEART FAILURE CLINICS*, 2015;11(3):479-498. **'Team-based palliative and end-of-life care for heart failure.'** Clinical practice guidelines endorse the use of palliative care (PC) in patients with symptomatic heart failure. The optimal content and delivery of PC interventions remains unknown and its integration into existing heart failure disease management continues to be a challenge. [Noted in Media Watch, 13 July 2015, #418 (p.10)] http://goo.gl/tiqhnX



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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 6 February 2016 – **'Assisted suicide is here to stay. Now comes the tricky part of figuring out how to make it work.'** Whether Canadians should have the legal right to access assisted suicide is no longer a matter of debate. It remains controversial ... and likely always will. But as a matter of law, it is settled, or near enough. And that gap created by the "near enough" is proving legally tricky. http://goo.gl/9Kf6pT

- ONTARIO | *THE GLOBE & MAIL* – 3 February 2016 – **'Ontario sets protocol for assisted dying ahead of new law.'** Ontario's Superior Court of Justice has issued a list of safeguards for people seeking a doctor's help to end their lives in the months before a new law is in place – asking for both medical and psychiatric assessments, a seven-day notice period and the option of alerting family and others who might be affected. The guidance is included in a practice advisory issued by Ontario Chief Justice Heather Smith. The Ontario court is the first to stipulate the kind of evidence lawyers and their clients will need to make an application – although the guidance is subject to orders by individual judges. Only Quebec has a law in place that sets out a framework for doctor-assisted death. http://goo.gl/FUWRmg

Specialist Publications

'Lawyers face uncharted waters with assisted death applications' (p.18), in *The Lawyers Weekly*.

U.S.A.

A new vision for dreams of the dying

THE NEW YORK TIMES | Online – 2 February 2016 – For thousands of years, the dreams and visions of the dying have captivated cultures, which imbued them with sacred import. Anthropologists, theologians and sociologists have studied these so-called deathbed phenomena. They appear in medieval writings and Renaissance paintings, in Shakespearean works and set pieces from 19th-century American and British novels, particularly by Dickens. One of the most famous moments in film is the mysterious deathbed murmur in [the movie] 'Citizen Kane': "Rosebud!" Even the law reveres a dying person's final words, allowing them to be admitted as evidence in an unusual exception to hearsay rules. In the modern medical world, such experiences have been noted by psychologists, social workers and nurses. But doctors tend to give them a wide berth because "we don't know what the hell they are," said Dr. Timothy E. Quill, an expert on palliative care medicine at the University of Rochester Medical Center. Some researchers have surmised patients and doctors avoid reporting these phenomena for fear of ridicule. http://goo.gl/5uNEnO

Specialist Publications

'Unusual perceptions at the end of life: Limitations to the diagnosis of hallucinations in palliative medicine' (p.8), in *BMJ Supportive & Palliative Care*.

Noted in Media Watch, 26 October 2015, #433 (p.4):

- STATE OF NEW YORK | *The Buffalo News* – 20 October 2015 – **'As people lay dying, vivid dreams or visions bring comfort to nearly all, Buffalo research suggests.'** Dreams and visions are common among the dying, they're so vivid they feel real, and they appear to be part of a process of coming to terms with death. http://goo.gl/vsLiFw

Media Watch: Online

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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- OREGON | Oregon Health Authority – 4 February 2016 – **'Death with Dignity Act Annual Report.'** During 2015, 218 people received prescriptions for lethal medications under the provisions of the Dying With Dignity ACT (DWDA), compared to 155 in 2014. As of 27 January 2016, the Oregon Public Health Division had received reports of 132 people who had died during 2015 from ingesting the medications. Since the law was passed in 1997, a total of 1,545 people have had prescriptions written under the Act, and 991 patients have died from ingesting the medications. From 1998 through 2013, the number of prescriptions written annually increased an average of 12.1%; however, during 2014 and 2015, the number of prescriptions written increased by an average of 24.4%. During 2015, the rate of DWDA deaths was 38.6 per 10,000 deaths. https://goo.gl/GQzA1Q

Specialist Publications

'Major issues developing in bioethics that are certain or likely to have an impact in the year: New end-of-life care options' (p.7), in *Bioethics News Watch 2016.*

'Randomized clinical trials in U.S. hospices: Challenges and the current state of the art' (p.9), in *Clinical Investigation.*

'Toward eliminating hospice enrollment disparities among African Americans: A qualitative study' (p.15), in *Journal of Health Care for the Poor & Underserved.*

'The National LGBT Cancer Action Plan: A White Paper of the 2014 National Summit on Cancer in the LGBT Communities' (p.16), in *LGBT Health.*

International

Morocco: Thousands face needless suffering at end of life

MOROCCO | Human Rights Watch – 4 February 2016 – Tens of thousands of patients with terminal illnesses in Morocco needlessly suffer from debilitating pain and other symptoms, Human Rights Watch said in a report released to coincide with World Cancer Day. The 77-page report[1] ... estimates that each year, more than 62,000 Moroccans need palliative care... While the Moroccan government has taken a number of important steps to improve end-of-life care, Human Rights Watch found only two public hospitals, in Casablanca and Rabat, have specific units that offer this essential health service, and only to cancer patients. Patients suffering severe pain outside of these cities must either undergo difficult travel to these centers or do without effective pain medicine. https://goo.gl/1JRxNm

Specialist Publications

'Advance care planning and place of death in a paediatric palliative care unit in France' (p.11), in *European Journal of Palliative Care.*

'What message do Spanish media convey about palliative care' (p.12), in *European Journal of Palliative Care.*

'Palliative care for people with intellectual disabilities: The European Association for Palliative Care White Paper in a nutshell' (p.13), in *European Journal of Palliative Care.*

'Report of the European Respiratory Society/European Cystic Fibrosis Society task force on the care of adults with cystic fibrosis' (p.13), in *European Respiratory Journal.*

1. 'Pain Tears Me Apart: Challenges and Progress in Ensuring the Right to Palliative Care in Morocco,' Human Rights Watch, February 2016. https://goo.gl/7ifssc

End-of-life care in England

Four in 10 hospitals told to improve care for the dying

U.K. (England) | *The Guardian* – 3 February 2016 – More than 40% of hospitals offer indifferent or poor care for the dying, according to the latest data seen by *The Guardian*, which highlights huge variability between the way National Health Service (NHS) facilities deal with the inevitability of death. Data from the Care Quality Commission ... reveals the differences across England. Eight hospitals have been rated as outstanding for their end-of-life care – three of them are children's hospitals (Alder Hey, Great Ormond Street and Sheffield) – and 94 have been classified as good. But 67 hospitals require improvement and seven are inadequate. Rabbi Julia Neuberger, whose investigation in 2013 upheld shocking stories of the terminally ill people being denied food, water and medicine,[1] said that when it came to care for the dying, there were still plenty of surprises – good and bad – within the NHS. http://goo.gl/F1wxCK

1. 'Review of Liverpool Care Pathway for Dying Patients,' Department of Health, July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] https://goo.gl/ujDKOT

Related

- U.K. (England) | *The Guardian* – 3 February 2016 – **'Meet the death doulas: The women who stay by your side to the end.'** There are at least 100 end-of-life doulas in Britain... They are not medical experts, but often work alongside National Health Service professionals in hospices or in the community to help the dying and their families live their last days as meaningfully and with as much control as possible. http://goo.gl/bAOEo4

N.B. Additional articles on death doulas are noted in Media Watch of 4 May 2015, #408 (p.4).

Compassionate communities: How changing attitudes toward death can effect how we live

U.K. (Northern Ireland) | *The Belfast Times* – 3 February 2016 – A pilot project in Derry is hoping to refocus people's attitudes and responses to dying and life-limiting illnesses and by asking people to undertake small acts of compassion and thus enable all of us to live well within our communities to the very end of our lives. Compassionate Communities is an internationally recognised approach to care for the dying. It evolved from the concept of Compassionate Cities developed by Professor Allan Kellehear, an Australian public health academic. He reminded us that end-of-life care isn't only about hospice and palliative care services, but also a social responsibility. The need for compassionate communities comes from social and medical changes, including people living for longer with long term/chronic conditions including motor neurone disease, Parkinson's and cancer and more people living alone without family nearby. http://goo.gl/Bsh8VZ

Faith at end of life: Public Health Approach Resource for Professionals

U.K. (England) | Public Health England – 29 January 2016 – This resource ... provides information to help ensure that commissioning and delivery of services and practice takes account of spiritual needs of the largest six faith groups in England and remains appropriate to the community setting in which they work. Practice recommendations for health and care professionals include: 1) Identify if the person you care for ascribes to a particular religion, and whether they expect this to have a bearing on their end-of-life care (EOLC); 2) Ask whether they have particular spiritual needs related to the end of life, listen to and record these needs; 3) Determine whether the patient wants visits from a representative of their faith and whether they have a local religious leader they would prefer; 4) Provide care recipients and their families with access to appropriate spiritual support and links to faith leaders; 5) Establish the appropriateness and willingness of care recipients and their families to use the words "death" and "dying"; 6) Identify the role of the family in the decision-making process of the care plan; 7) Ensure information regarding EOLC and support services are provided in the language of choice for the care recipients and their families; and, 8) Seek advice and support in responding to any encounter you are unsure about with other staff, religious leaders or chaplains at the local hospital. https://goo.gl/5KGlYj

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

Internal medicine residents' beliefs, attitudes, and experiences relating to palliative care: A qualitative study

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 2 February 2016 – Internal medicine residents are frequently called upon to provide palliative care (PC) to hospitalized patients, but report feeling unprepared to do so effectively. The authors' findings provide important insights to guide curricular development for internal medicine trainees. The top five learning priorities in PC that residents identified in our study were: 1) Knowing how and when to initiate a palliative approach; 2) Improving communication skills; 3) Improving symptom management skills; 4) Identifying available resources; and, 5) Understanding the importance of PC. http://goo.gl/dixRaq

Decisions in complex clinical situations: Prevalence and factors associated in general public

ARCHIVES OF GERONTOLOGY & GERIATRICS, 2016;64(2):103-110. Analysis of the socio-demographic characteristics and life experiences of the subjects [i.e., study participants] led to the following findings. In situations of very severe prognosis, treatment is mostly rejected. When there is chance of recovery, treatment is mostly accepted, especially in the least aggressive cases and when deciding for another person. A greater propensity to reject treatment was observed among subjects over 55 years, those in poor health, and those who had observed a terminal illness in a family member. Practising Catholics are more likely to accept treatment in all medical situations described. http://goo.gl/kyrXQh

Related

- *AUSTRALIAN FAMILY PHYSICIAN*, 2016;45(1):69-73. **'The role of mediation in advance care planning and end-of-life care.'** This article introduces the key skill set of professional mediators, examines how this approach can be employed in general practice, and presents an "interest mapping tool" to assist the GP in managing advance care planning discussions. http://goo.gl/GsH9Qi

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 3 February 2016 – **'Do patients with lung cancer recall physician-initiated discussions about planning for end-of-life care following disclosure of a terminal prognosis?'** Participants [in this study] had little or no recall of physicians initiating discussions about their concerns or goals of care, and did not perceive that they had been provided with either information about or opportunities to engage in advance care planning. http://goo.gl/qfvBkn

- *INTERNATIONAL JOURNAL OF NURSING PRACTICE* | Online – 28 January 2016 – **'Nurses' knowledge of advance directives and perceived confidence in end-of-life care: A cross-sectional study in five countries.'** This study investigated nurses' knowledge of advance directives and perceived confidence in end-of-life care (EOLC), in Hong Kong, Ireland, Israel, Italy and the U.S. In all countries, older nurses and those who had more professional experience felt more confident managing patients' symptoms at the end-of-life and more comfortable stopping preventive medications at end-of-life. http://goo.gl/k1Beuk

- *JOURNAL OF MEDICAL ETHICS* | Online – 29 January 2016 – **'A new method for making treatment decisions for incapacitated patients: What do patients think about the use of a patient preference predictor?'** Surrogates frequently are unable to predict which treatment their charges would want and also can experience significant distress as a result of making treatment decisions. A new method, the patient preference predictor (PPP), has been proposed as a possible way to supplement the process of shared decision-making to address these two concerns. http://goo.gl/1Qsdwh

- *PALLIATIVE MEDICINE* | Online – 4 February 2016 – **'Advance care planning in motor neuron disease: A qualitative study of caregiver perspectives.'** Four global themes emerged: 1) Readiness for death; 2) Empowerment; 3) Connections; and, 4) Clarifying decisions and choices. Many [participants in this study] felt the letter of future care was or would be beneficial, engendering autonomy and respect for patients, easing difficult decision-making and enhancing communication within families. However, individuals' "readiness" to accept encroaching death would influence uptake. Appropriate timing to commence advance care planning may depend on case-based clinical and personal characteristics. http://goo.gl/pU3pok

End-of-life care: Proactive clinical management of older Australians in the community

AUSTRALIAN FAMILY PHYSICIAN, 2016;45(1):76-78. This article introduces GPs to a framework of care, based on a palliative care approach, which supports proactive management of end-of-life care (EOLC) for older Australians living in the community. Embedding the above framework into routine practice can help GPs deliver care, aligned with patients' preferences, at the right time and in the right place. Experience has shown that implementing proactive management of EOLC can increase satisfaction with GP care and help GPs meet the clinical, legal and ethical challenges associated with caring for older patients with advanced progressive conditions. http://goo.gl/czyFAY

Noted in Media Watch, 23 November 2015, #437 (p.13):

- *MEDICAL JOURNAL OF AUSTRALIA* | Online – 16 November 2015 – **'Routine integration of palliative care: What will it take?'** A whole-of-system approach has been advocated, involving quality-improvement strategies that identify and respond to specific gaps in care, coupled with measures of achievement and accountability. Yet, even in systems without barriers to palliative care, there remain two clinical tasks that appear critical to its successful integration: 1) Recognition of the possibility (and need) for PC; and, 2) Sensitive communication. https://goo.gl/uzZ5Mp

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

Major issues developing in bioethics that are certain or likely to have an impact in the year: New end-of-life care options

BIOETHICS NEWS WATCH 2016 (The Hastings Center) | Online – Accessed 3 February 2016 –Two changes in Medicare that went into effect on 1 January could improve advance care planning (ACP) and end-of-life decision-making and care. Medicare began covering ACP conversations between patients and doctors or other health care providers. In addition, a multi-year pilot program called the Medicare Care Choices Model gives adult patients who are eligible for hospice the option to continue certain curative interventions while also receiving hospice services reimbursed by Medicare. Look for news about the impact of the Medicare ACP reform on end-of-life care in primary and acute care settings, and whether it contributes to other systemic improvements. Also watch for evidence from the Medicare Care Choices Model pilot program concerning the impact on length of stay in hospice, patient and family well-being, and hospice operations. http://goo.gl/7Delrk

Palliative care reimagined: A needed shift

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 31 January 2016 – Palliative care (PC), since its inception over 60 years ago, has set the standard of how to care for people who are dying. Key features among these standards have been the professional development of clinical specialisms such as palliative medicine and palliative nursing; the essential addition of the multidisciplinary team to these two new specialisms that included social, spiritual and allied health workers – an outgrowth of the recognition that routine work with the dying, their carers, and the bereaved required more than solely clinical skills; and, the unique partnership with communities that yielded the volunteer movement within PC. Professional, evidence-based symptom management and the importance of supportive care in its widest possible sense were and remain the cornerstones of the modern PC approach. However, the majority of people with terminal illnesses do not have access to PC teams, whose main focus of care remains patients with cancer. In the context outlined above, this paper poses two key questions: How can we provide an equitable level of care for all people irrespective of diagnosis ...and, how can we increase the range and quality of non-medical/nursing supportive care in a context of diminishing resources? The authors argue that an important opportunity and solution can be found by adopting the principles of a public health approach to end-of-life care. http://goo.gl/XIxCkm

Cont.

Related

- *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. http://goo.gl/6Bz4f9

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

- *PROGRESSING IN PALLIATIVE CARE* | Online – 13 September 2015 – **'Putting the "public" into public health: Innovative partnerships in palliative and end-of-life care: The Kenya experience.'** The Kenya Hospice & Palliative Care Association works together with its stakeholders such as the Ministry of Health, government hospitals, mission hospitals, hospices, and community-based organizations, and training institutions to ensure that there is greater awareness of and access to palliative care across the country. [Noted in Media Watch, 21 September 2015, #428 (p.15)] http://goo.gl/RQt5F5
- *PALLIATIVE MEDICINE* | Online – 12 August 2015 – **'The impact of a new public health approach to end-of-life care: A systematic review.'** Interest is building regarding the application of a public health approach to those facing the end of life, their families and communities. Three themes emerged: 1) Making a practical difference; 2) Individual learning and personal growth; and, 3) Developing community capacity. [Noted in Media Watch, 17 August 2015, #423 (p.17)] http://goo.gl/Yqtvds
- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 22 February 2013 – **'Public health approaches to end-of-life care in the U.K.: An online survey of palliative care services.'** Of those providers [i.e., respondents] 60% indicated that public health approaches to death, dying and loss were a current priority for their organisation. The findings demonstrate the relevance of a public health approach for palliative care services and how they are currently engaging with the communities they serve. [Noted in Media Watch, 4 March 2013, #295 (p.11)] http://goo.gl/x38FN7

Unusual perceptions at the end of life: Limitations to the diagnosis of hallucinations in palliative medicine

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 31 January 2016 – The diagnosis of hallucination for unusual perceptions such as deathbed visions, near-death experiences, or visions of the bereaved, is unhelpful in palliative medicine both academically and clinically. This paper reviews the broad prevalence data about unusual perceptions in the general population as background to identifying the more narrow epidemiological source from which the much smaller focus on hallucinations seem to emerge. Major debates and limitations of current hallucination research are reviewed to show that current academic and clinical certainties are largely confined to unusual perceptions that can be readily linked to psychopathology, quite specific organic disease states and psychoactive drug use. Current state-of-the-art in hallucination studies does not warrant broad or uncritical use of this type of diagnosis in end-of-life care. Conclusions from interdisciplinary (as opposed to single discipline) hallucination studies suggest that the way forward for clinical and research work in palliative medicine may lie in a more biographical and cultural approach to unusual perceptions at the end of life. http://goo.gl/yEerLt

Noted in Media Watch, 27 July 2015, #420 (p.16):

- *PSYCHOLOGY & PSYCHOTHERAPY: THEORY, RESEARCH & PRACTICE* | Online – 16 July 2015 – **'Experiences of continued presence: On the practical consequences of "hallucinations" in bereavement.'** Experiences of continued presence were meaningfully connected to the immediate environments in which they happened, but also to the personal histories of the bereaved. [Noted in Media Watch, 27 July 2015, #420 (p.16)] http://goo.gl/N82VXr

Noted in Media Watch, 6 April 2015, #404 (p.7):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 27 March 2015 – **'Deathbed phenomena reported by patients in palliative care: Clinical opportunities and responses.'** The authors systematically reviewed the literature on deathbed phenomena and provide suggestions for a clinical response to dying patients' recounts of these hard-to-explain phenomena. http://goo.gl/DCYj2p

Randomized clinical trials in U.S. hospices: Challenges and the current state of the art

CLINICAL INVESTIGATION, 2015;5(11):839-846. The authors concur with others who report that there is a dearth of high-quality evidence regarding hospice care and that there are considerable barriers to conducting randomized trials in US hospices. While they did not look for articles written in languages other than English, they did retrieve abstracts of 15 non-U.S. studies that occurred in hospices and did not study hospice admission or a staff intervention. Hence, the relative paucity of randomized trials conducted in hospices is not limited to the U.S. Overcoming the barriers to hospice research is necessary if we are to provide evidence-based, quality care to hospice patients and their families. While uncontrolled pain is frequently cited as a problem for hospice patients, none of the included studies directly addressed pain. The majority of interventions were psychosocial in nature, designed to hopefully improve misconceptions regarding pain management, improve caregiver knowledge, decrease anxiety and depression or improve quality of life for patients and caregivers. These are all important areas for study, but the total body of evidence represented by these trials is small compared with the information need. http://goo.gl/UjFG8B

Stop predatory publishers now: Act collaboratively

ANNALS OF INTERNAL MEDICINE | Online – 2 February 2016 – Researchers trying to publish their work face a duality of tensions. To advance their careers, they must be productive and publish in journals with high impact factors. However, passing the scientific rigor of peer review and editorial approval in these journals makes publishing difficult. Morally corrupt businesses, posing as legitimate publishers, have moved into this space. They offer to publish anything quickly, thus circumventing the very fabric of scientific publishing. This cancer has spread rapidly in part because these publishers have no physical presence – instead, they conduct their ruse through illegitimate online journals. Unless these predatory publishers and journals are stopped immediately, they will permanently undermine the publication record http://goo.gl/mqUKXt

N.B. Selected articles on predatory journals are listed in the issue of Media Watch of 23 November 2015, #437 (p.11)]

Selected articles on evidenced-based end-of-life care

- *THE ASCO POST* (American Society of Clinical Oncology) | Online – 10 December 2015 – **'Evidence-based practice needed in end-of-life care.'** The delivery of equitable, high-quality end-of-life care has suffered from a lack of study-based evidence. [Noted in Media Watch, 14 December 2015, #440 (p.6)] http://goo.gl/eudgG7
- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 October 2015 – **'Toward evidence-based end-of-life care.'** No current policy or practice designed to improve care for millions of dying Americans is backed by a fraction of the evidence that the Food & Drug Administration would require to approve even a relatively innocuous drug. [Noted in Media Watch, 19 October 2015, #432 (p.14)] http://goo.gl/qH3rMQ
- *JOURNAL OF PALLIATIVE CARE*, 2015;31(3):133-140. **'Evidence-based palliative care 13 years on: Has anything changed?'** There is a paucity of data on whether interventions in individual palliative care units are evidence-based. [Noted in Media Watch, 7 September 2015, #426 (p.12)] http://goo.gl/4VJ90P

Palliative care in critical rural settings

CRITICAL CARE NURSE, 2016;36(1):72-78. The U.S. has 1,332 critical access hospitals. These hospitals have fewer than 25 beds each and a mean daily census of 4.2 patients. Critical access hospitals are located in rural areas and provide acute inpatient services, ambulatory care, labor and delivery services, and general surgery. Some, but not all, offer home care services; a few have palliative care (PC) programs. As expert generalists, rural nurses are well positioned to provide care close to home for patients of all ages and the patients' families. http://goo.gl/xWrMCx

Cont.

Noted in Media Watch, 4 January 2016, #443 (p.9):

- *CANCER CONTROL*, 2015;22(4):450-464. **'Systematic review of palliative care in the rural setting.'** Research has informed the development of professional guidelines and integration of the principles of palliation into oncology care, from the time of diagnosis to end of life among patients with curable cancers, high symptom burden, and metastatic disease alike. The rural setting has created a barrier for these advances to reach patients not located near specialty centers. http://goo.gl/wNSuRG

Complex care options for patients with advanced heart failure approaching end of life

CURRENT HEART FAILURE REPORTS | Online – 1 February 2016 – Care for patients with advanced cardiac disease continues to evolve in a complex milieu of therapeutic options, advanced technological interventions, and efforts at improving patient-centered care and shared decision-making. Despite improvements in quality of life and survival with these interventions, optimal supportive care across the advanced illness trajectory remains diverse and heterogeneous. The authors outline challenges in prognostication, communication, and caregiving in advanced heart failure and review the unique needs of patients who experience frequent hospitalizations, require chronic home support, and who have implantable cardioverter-defibrillators and mechanical circulatory support in situ, to name a few. http://goo.gl/PcyMJA

We must help people to stay out of hospital at the end of life

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(1):5. Caring for people in hospital at the end of life is expensive: research by the Nuffield Trust has shown that the largest share of the money spent on end-of-life care (EOLC) goes to hospital care, the bulk of it being for emergency admissions.[1] Yet people who are dying continue to be admitted to hospital when they have no clinical need to be there, and do not want to be there. Recent headlines in mainstream media testify to growing financial problems in the National Health Service (NHS). 'NHS faces worst financial crisis in its history' (*Telegraph*, November 2015); 'NHS pressure worsens as key targets missed' (BBC News, November 2015); 'NHS deficits hit "massive" £930 million' (BBC News, October 2015): however hyperbolic the headlines may be, the reports that they are concerned with indicate growing financial pressure in the NHS. At a time when the NHS is in what has been described as "an unprecedented financial meltdown," it is clear that those who design, plan and deliver care need to think and work differently in order to prevent avoidable admissions. With this in mind, commissioners and service providers should recognise the important role of EOLC in helping to reduce pressure on NHS services. Having people at the end of life in hospital when they do not need and do not want to be there is of no benefit to the NHS – nor to the individuals themselves. And as studies continue to demonstrate, most British citizens would prefer not to be in hospital when they die.

THE JOURNAL OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE
European Journal of
Palliative Care

Access to articles in the current issue of the journal requires a subscription. Contents page: http://goo.gl/qIWex7

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1. 'Exploring the Cost of Care at the End of Life,' The Nuffield Trust, September 2014. [Noted in Media Watch, 26 September 2014, #327 (p.5)] http://goo.gl/ptDxJJ

Related

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(1):19-23. **'When home care falters: Out-of-hours visits to the emergency department.'** A study in Australia looked at why patients cared for at home are advised to attend the emergency department (ED) by a palliative care (PC) out-of-hours telephone support service. The primary reason was that symptoms could not be managed at home. Strategies to decrease out-of-hours admissions to the ED include implementing timely advance care planning, proactively managing common symptoms, educating patients and carers, and providing respite for carers where possible. Journal contents page: http://goo.gl/qIWex7

Cont.

- *CLINICAL MEDICINE*, 2016;16(1):17-11. **'Excellence in cost-effective inpatient specialist palliative care in the National Health Service – a new model.'** There is little in the literature describing hospital specialist palliative care units (PCUs) within the National Health Service (NHS). This paper describes how specialist PCUs can be set up within and be entirely funded by the NHS, and outlines some of the challenges and successes of the units. http://goo.gl/266det

The 2015 Quality of Death Index: Global palliative care ranking

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(1):10-12. Is the ranking of palliative care (PC) across the globe useful? On the day the report was published, most major media outlets in the U.K. – including *The Guardian* and the BBC – carried the story, with headlines stressing the U.K. was in first position, thus unwittingly helping to fulfil one of the recommendations of the report, which is to increase the public's awareness and knowledge of PC. Beyond this immediate media interest, the Lien Foundation's 'Quality of Death Index' clearly shows a correlation between national wealth and PC ranking, but also gives examples of less wealthy countries that have made great strides.[1] Its emphasis on a well-educated workforce is well founded. It highlights many issues, starting with the unacceptable lack of access to opioids in many countries. It also highlights the progress made so far, encapsulated by the 2014 WHA resolution.[2] So yes, all in all, the ranking of PC across the globe is useful as a tool to boost PC development. Journal contents page: http://goo.gl/qIWex7

2015 Quality of Death Index

Omission of paediatric palliative care

The WHO estimates that there are approximately 20 million children with PC needs, the majority of which live in low- and middle-income countries. Children have been omitted in this report, but there is a compelling argument to use, in a future report, a similar framework in order to establish global rankings of the provision of PC for children.

1. '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015, commissioned by the Lien Foundation of Singapore [Noted in Media Watch, 12 October 2015, #431 (p.6)]. http://goo.gl/nuPWll

2. 67th World Health Assembly resolution WHA67.19. 'Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course,' 24 May 2014. [Noted in Media Watch, 30 March 2015, #403 (p.15)] http://goo.gl/m1HJxr

Advance care planning and place of death in a paediatric palliative care unit in France

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(1):16-18. In paediatric palliative care (PC), the difficulties of implementing advance care planning are compounded. On one hand, children are legally too young to make decisions about their care and parents act as their surrogates. On the other hand, the law in France emphasises that parents must take their children's wishes into account, even if these happen to be different from theirs. So neither the parents nor the children are autonomous in the decision-making process. There has to be a discussion between the different family members in order to determine the best solution. Each person's wishes or preferences need to be understood by the others. The decision of one family member affects the others, who have to make sense of it. The autonomy of a relative who makes a decision while allowing other members of the family to make sense of it is referred to in French as konomy (from the Greek *koïne-nomos*). Because grief is always profound after the death of a child, and because bereavement will be more difficult if parents have not been able to make sense of the death, everyone in the family needs to be given a chance to express their fears, concerns and preferences, and be assured that the medical team will act according to their wishes. The authors' experience shows that parents are willing to help medical teams by indicating their preferences for their child's end-of-life care (EOLC). Paediatricians cannot argue, as some of them do, that they do not want to burden the family with too many responsibilities when their child is at the end of life. Journal contents page: http://goo.gl/qIWex7

Cont.

Selected articles on decision making in pediatric palliative care

- *HEALTH PSYCHOLOGY*, 2015;34(4):446-452. **'The parents' ability to attend to the "voice of their child" with incurable cancer during the palliative phase.'** An inability to take into account the child's perspective was largely due [in this study] to the parents' own struggle to cope with loss. Whether or not the voice of children approaching the end-of-life is heard, often depends on their parents' ability to give them a voice. [Noted in Media Watch, 27 April 2015, #407 (p.11)] http://goo.gl/fSgXw5
- *MEDICAL DECISION MAKING* | Online – 21 April 2015 – **'Evolution of pediatric chronic disease treatment decisions: A qualitative, longitudinal view of parents' decision-making process.'** In this study, decision making was an iterative process occurring in three distinct patterns. Understanding these and the varying elements of parents' decision processes is an essential step toward developing interventions that are appropriate to the setting and that capitalize on the skills families may develop as they gain experience with a chronic condition. [Noted in Media Watch, 27 April 2015, #407 (p..11)] http://goo.gl/SWRwE4
- *PEDIATRICS* | Online – 5 January 2015 – **'Talking with parents about end-of-life decisions for their children.'** Overall, 27 physicians participated [in this study], along with 37 parents of 19 children for whom a decision to withhold or withdraw life-sustaining treatment was being considered. All physicians focused primarily on providing medical information, explaining their preferred course of action, and informing parents about the decision being reached by the team. Only in two cases were parents asked to share in the decision-making. [Noted in Media Watch, 12 January 2015, #392 (pp.12-13)] http://goo.gl/WL4uFJ

Related

- *PEDIATRIC BLOOD & CANCER* | Online – 29 January 2016 – **'Communication skills training in pediatric oncology: Moving beyond role modeling.'** Parents, patients, and providers report substantial communication deficits. Poor communication outcomes may stem, in part, from insufficient communication skills training, overreliance on role modeling, and failure to utilize best practices. This review summarizes evidence for existing methods to enhance communication skills and calls for revitalizing communication skills training within pediatric oncology. http://goo.gl/He4wYZ

What message do Spanish media convey about palliative care?

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(1):32-34. The presence of palliative care (PC) in the media does not guarantee the communication of positive messages related to its benefits for patients and families. Ideologically and politically charged messages linked to news stories and social debates can overshadow messages that reflect the reality of care or have an informative purpose. To gain a better understanding of society's perceptions of PC, the messages in the media must be explored in depth, particularly in countries where PC is in its early stages. Additionally, knowing who says what about PC, and how they say it, is very helpful, as it enables us to promote positive messages, giving a picture of PC that is more in line with clinical practice and reflects its contributions to patients, their families, and society as a whole. Journal contents page: http://goo.gl/qIWex7

Communication with the Public, Politicians, and the News Media

Barry R. Ashpole

Section 6.4 (pp.357-359)
5th edition of the *Oxford Textbook of Palliative Medicine*:
http://goo.gl/hn2VJq

Media Watch: Back Issues

Back issues of Media Watch are available on the International Palliative Care Resource Center website at:
http://goo.gl/frPgZ5

Palliative care for people with intellectual disabilities: The European Association for Palliative Care White Paper in a nutshell

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(1):45-47. People with intellectual disabilities often present with unique problems, challenges and disadvantageous circumstances that make meeting their palliative care (PC) needs more difficult. 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] The EAPC White Paper represents a Europe-wide consensus on what should be aimed for in order to achieve good PC for people with intellectual disabilities. 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

Selected articles on end-of-life care for people living with intellectual disabilities

- *JOURNAL OF INTELLECTUAL DISABILITY RESEARCH* | Online – 12 January 2016 – **'Physicians' recognition of death in the foreseeable future in patients with intellectual disabilities.'** More than 20% of physicians [i.e., survey respondents] foresaw death not until the last week of life. In 30% of all patients, they did not discuss the start of the palliative care phase until the last week. [Noted in Media Watch, 18 January 2016, #445 (p.11)] http://goo.gl/yp8GdW

- *RESEARCH IN DEVELOPMENTAL DISABILITIES*, 2016;49-50:47-59. **'Knowing, planning for and fearing death: Do adults with intellectual disability and disability staff differ?'** The authors found that adults with intellectual disabilities had a significantly poorer understanding of the concept of death, knew much less about – and were less self-determined about – end-of-life planning, but reported greater fear-of-death. [Noted in Media Watch, 7 December 2015, #439 (p.13)] http://goo.gl/npKnqs

- *INTELLECTUAL & DEVELOPMENTAL DISABILITIES,* 2015;53(6):394-405. **'A Delphi study on staff bereavement training in the intellectual and developmental disabilities field.'** Results showed that training should help staff identify and support service users experiencing grief. Importantly, staff also needs help in managing their own grief. Organizational policies and resources should be instituted to support the grief processes of both service users and staff. [Noted in Media Watch, 7 December 2015, #439 (p.14)] http://goo.gl/YZx0ar

Report of the European Respiratory Society/European Cystic Fibrosis Society task force on the care of adults with cystic fibrosis

EUROPEAN RESPIRATORY JOURNAL, 2016; 47(2): 420-428. The improved survival in people with cystic fibrosis (CF) has led to an increasing number of patients reaching adulthood. This trend is likely to be maintained over the next decades, suggesting a need to increase the number of centres with expertise in the management of adult patients with CB. These centres should be capable of delivering multidisciplinary care addressing the complexity of the disease, in addition to addressing the psychological burden on patients and their families. Further issues that require attention are organ transplantation and end-of-life management. Lung disease in adults with CF drives most of the clinical care requirements, and major life-threatening complications, such as respiratory infection, respiratory failure, pneumothorax and haemoptysis, and the management of lung transplantation require expertise from trained respiratory physicians. The taskforce therefore strongly recommends that medical leadership in multidisciplinary adult teams should be attributed to a respiratory physician adequately trained in CB management. http://goo.gl/8UDedM

Extract from the task force report

Adult CF centres should ensure they have adequate skills and facilities to deal with palliative care (PC) for people with CF. End-of-life care (EOLC) is ideally delivered in an adult centre where appropriate discussions and arrangements can be facilitated and the autonomy of the individual is respected and protected.

Cont.

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 2 February 2016 – **'Evaluation of pain, dyspnea, and goals of care among adults with cystic fibrosis: A comprehensive palliative care survey.'** Palliative care (PC) is increasingly important in the care of adults with cystic fibrosis (CF). Symptoms such as pain and dyspnea are prevalent, yet severity may be underestimated. Little information is available to describe patient preferences for end-of-life care (EOLC). The objective of this [single-center] study was to describe patient perceptions about pain, dyspnea, and advance care planning. http://goo.gl/KxAIXJ

Noted in Media Watch, 1 February 2016, #447 (p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 26 January 2016 – **'A service evaluation of an integrated model of palliative care of cystic fibrosis.'** The authors introduced an integrated model whereby palliative specialists joined the cystic fibrosis team to provide palliative care in parallel with standard care. http://goo.gl/VCVEoD

Noted in Media Watch, 14 September 2015, #427 (p.10):

- *JOURNAL OF CYSTIC FIBROSIS* | Online – 8 September 2015 – **'Cystic fibrosis healthcare workers feel unprepared in providing suitable end-of-life care and desire more education: Results of a nationwide survey.'** The majority of non-physician cystic fibrosis care providers [i.e., survey respondents] reported that they felt "somewhat" or "very" involved in palliative or end-of-life care in their current role. Yet only 18% reported that they were "fully prepared" and 45% felt that they were only "minimally" or "not" prepared. http://goo.gl/pBBKTc

N.B. Selected articles, reports, etc., on end-of-life care for people living with cystic fibrosis noted in past issues of Media Watch are listed in this issue of the weekly report.

Healing and dying with dignity: Where does India stand?

INDIAN JOURNAL OF MEDICAL ETHICS, 2016;13(1). Palliative care (PC) is a neglected issue in the Indian healthcare system, with few exceptions. The peer community – individuals, patients and their families, medical professionals, and lawyers – is sharply polarised in the discourse on the ethics of assisted dying or euthanasia in the Indian setting. The diversity of socio-cultural contexts, philosophical traditions, and religious and faith systems adds to the complexity of this debate. Individual patients, their families and medical professionals must deal with either poorly equipped public healthcare or exorbitantly priced private healthcare largely driven by profit motives. Both these systems ignore people's PC needs. Patients facing end-of-life situations, as well as their providers, are ensnared in a web of ignorance, apathy and helplessness. Clinicians and institutions in such situations often prevaricate under the pretence that there is inadequate "legal" clarity. This leads to prolongation of futile treatment and hospitalisation with the attendant agony and financial burden, undermining the trust of patients and their families in the medical profession. http://goo.gl/B7U14A

Special issue of *Indian Journal of Medical Ethics*

Te issue includes several articles which offer insights into the complexities of end-of-life care in India from an ethical, legal and medical perspective against the backdrop of the country's healthcare system and the entrenched inequities in access to healthcare. Contents page (scroll down to 'Theme: Healing & Dying with Dignity'): http://goo.gl/O2k0pa

N.B. India was ranked 67th of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015, commissioned by the Lien Foundation of Singapore [Noted in Media Watch, 12 October 2015, #431 (p.6)]. Selected articles on end-of-life care in India are noted in the issues of Media Watch of 18 January 2016, #445 (p.5) and 28 December 2015, #442 (pp.4-5).

Toward eliminating hospice enrollment disparities among African Americans: A qualitative study

JOURNAL OF HEALTH CARE FOR THE POOR & UNDERSERVED, 2016;27(1):219-237. Over the past decade, scholars and practitioners have called for efforts to reduce disparities in the cost and quality of end-of-life care; 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, among them only few who were using hospice care services, 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

Related

- *JOURNAL OF PALLIATIVE MEDICINE*, 2016;19(2):143-148. **'The impact of faith beliefs on perceptions of end-of-life care and decision making among African American church members.'** African Americans underuse palliative care (PC) and hospice services because of a combination of factors including faith beliefs. As the spiritual family for many African Americans, the church presents an opportunity to improve communication about PC and hospice and end-of-life decision making. Participants [who included deacons or deaconesses of two African American churches] perceived that many of their congregants harbor beliefs, perceptions, and feelings about death and dying that were often not communicated to family members or to health providers. Findings support partnerships between hospices and African American churches to provide hospice education to African American communities. http://goo.gl/hO0qUe

JOURNAL OF
Palliative Medicine

The focus of the current issue is on palliative and end-of-life care for African Americans. Contents page: http://goo.gl/6fapNx

Noted in Media Watch, 24 August 2015, #424 (p.17):

- *NARRATIVE INQUIRY IN BIOETHICS*, 2015;5(2):151-165. **'African Americans and hospice care: A narrative analysis.'** Studies suggest terminally ill African Americans' care is generally more expensive and of lower quality than of comparable non-Hispanic, white patients. Scholars argue increasing hospice enrollment among African Americans will help improve end-of-life care for this population... http://goo.gl/AusTj8

Exploring the role that autonomy plays in achieving a good death

JOURNAL OF PARAMEDIC MEDICINE | Online – 11 January 2016 – Currently patients at the end of life, for numerous reasons, often dial 999 when they experience many symptoms that can impact upon their current quality of life, such as pain and breathlessness. These calls regularly elicit a high priority paramedic response, which when taken in context, may be inappropriate, and can often lead to transportation to hospital, which itself can be inappropriate, and or delay in the most appropriate care required. This is worsened somewhat by sporadic or non-existent community palliative care coverage in various areas. The concept of autonomy is key to patient care, but arguably more so at the end of life. This article reviews the available literature and recent evidence in the context of an anonymised case study, to highlight how patient and family autonomy can guide and support the decisions made by paramedics in these cases, and the benefits and challenges this autonomy brings, in the current social context of health care. http://goo.gl/E26qEO

Cont.

Noted in Media Watch, 27 January 2014, #342 (p.11):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2014;20(1):37-44. **'Challenges U.K. paramedics currently face in providing fully effective end-of-life care.'** This article highlights barriers to effective paramedic end-of-life care provision and introduces examples of collaborative work in the U.K. that aim to overcome these. Given the similarities in the international evolution of paramedic education, readers from other countries will be able to relate to these findings. http://goo.gl/3ZkeVM

The National LGBT Cancer Action Plan: A White Paper of the 2014 National Summit on Cancer in the LGBT Communities

LGBT HEALTH, 2016;3(1):19-31. Despite growing social acceptance of lesbians, gay men, bisexuals, and transgender (LGBT) persons and the extension of marriage rights for same-sex couples, LGBT persons experience stigma and discrimination, including within the healthcare system. Each population within the LGBT umbrella term is likely at elevated risk for cancer due to prevalent, significant cancer risk factors, such as tobacco use and human immunodeficiency virus infection; however, cancer incidence and mortality data among LGBT persons are lacking. This absence of data impedes research and policy development, LGBT communities' awareness and activation, and interventions to address cancer disparities. Summit participants were 56 invited persons from the U.S., U.K. and Canada, representatives of diverse identities, experiences, and knowledge about LGBT communities and cancer. This white paper presents background on each of the Summit themes and 16 recommendations. http://goo.gl/nQecRc

Summit recommendation on palliative and end-of-life care

Provision of high-quality healthcare at the end of life is a critically important component of clinical cancer care. LGBT communities have unique needs to be considered and addressed in this phase of care. Many LGBT people want to retain their SOGI [i.e., sexual orientation and comprehensive gender identities] identity and remain "out" at this stage of their life and need care services that will support their full identity without stigma, bias, or discrimination. Advance directives, designated power of attorney for healthcare decision-making, and other legal issues need to be carefully considered. Legal requirements may differ based on the location and jurisdiction where LGBT people live. National access to legal marriage may resolve some of the issues for some same-sex couples and their dependent children. Providers should receive enhanced education about resources addressing LGBT healthcare and other legal needs.

Selected articles on end-of-life care for LGBT communities

- *AUSTRALASIAN JOURNAL ON AGEING*, 2015;34(Suppl):39-43. **'Lesbian, gay, bisexual and transgender people's attitudes to end-of-life decision-making and advance care.'** This study evidenced the relatively low take-up of advance care planning options by LGBT people. With the right promoting – creating conditions for meaningful conversations about about end-of-life care – these barriers may be overcome. [Noted in Media Watch, 9 November 2015, #435 (p.8)] http://goo.gl/0mq1UP

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 26 February 2015 – **'American Geriatrics Society Care of Lesbian, Gay, Bisexual & Transgender Older Adults position statement.'** This position statement addresses the vision of the Society for the care of LGBT older adults and specific steps that can be taken to ensure that they receive the care that they need. [Noted in Media Watch, 2 March 2015, #399 (p.6)] http://goo.gl/bqlLJv

- *ADVOCATE* (U.S.) | Online – 27 December 2013 – **'End-of-life care for an aging LGBT population.'** With the number of self-identified LGBT adults age 65 or older [in the U.S.] expected to double by 2030 – from 1.5 million to 3 million – the time has never been more urgent to discuss this silent challenge: "How do we meet the unique end-of-life care needs for an aging LGBT population?" LGBT seniors are at a greater risk of disability and mental distress than their heterosexual counterparts, and face many barriers to accessing care.[1] [Noted in Media Watch, 30 December 2013, #338 (p.2)] http://goo.gl/gP7t33

    1. 'The Aging and Health Report: Disparities and Resilience Among Lesbian, Gay, Bisexual, and Transgender Older Adults,' National Resource Center on LGBT Aging, New York, NY, November 2011. http://goo.gl/eicjFG

The impact of volunteer befriending services for older people at the end of life: Mechanisms supporting wellbeing

PROGRESS IN PALLIATIVE CARE | Online – 2 February 2016 – Older people at the end of life are particularly vulnerable to social isolation and loneliness, the associated health effects of which are significant. Increasingly, charitable organizations are offering befriending services for people at the end of life. However, there is little research evidence around the mechanisms by which befriending facilitates wellbeing at the end of life. Data indicate that the befriending service had a multi-dimensional impact on a range of outcomes including emotional and psychological wellbeing, and reduced social isolation. Other outcomes included practical support, and family carer support. http://goo.gl/ypswJw

Noted in Media Watch, 1 April 2013, #299 (p.7):

- U.K. | BBC News – 25 March 2013 – **'Social isolation "increases death risk in older people."'** A study of 6,500 U.K. men and women aged over 52 found that being isolated from family and friends was linked with a 26% higher death risk over seven years.[1] http://goo.gl/ZXsgsQ

    1. 'Social isolation, loneliness, and all-cause mortality in older men and women,' Proceedings of the National Academy of Sciences of the United States of America, 25 March 2013. http://goo.gl/Dqmr7E

Noted in Media Watch, 25 June 2012, #259 (p.4):

- U.S. | National Public Radio – 18 June 2012 – **'Loneliness bodes poorly for a healthy old age.'** Loneliness in older people can predict declines in health and an increased risk of death.[1] http://goo.gl/3AoTlo

    1. 'Loneliness in older persons: A predictor of functional decline and death,' *JAMA Internal Medicine*, 2012;172(14):1078-1884. The authors examined the relationship between loneliness, functional decline, and death in adults older than 60 years in the U.S. http://goo.gl/cj2Ufa

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://goo.gl/zIuyY9

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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BIOETHICS NEWS WATCH 2016* (The Hastings Center, Garrison, NY) | Online – Accessed 3 February 2016 – **'Major issues developing in bioethics in the U.S. that are certain or likely to have an impact in the year: Legalization of physician aid in dying (PAD).'** Support for PAD continues to increase. Last year, California became the fifth – and the largest – state to legalize the practice, passing a law that allows physicians to prescribe a lethal dose of medication for terminally ill patients who want to end their lives. California joins Oregon, Washington, and Vermont, which have similar statutes, and Montana, where PAD is legal by case law. In New Mexico, however, a lower court decision permitting the practice was overturned on appeal. Legislation to legalize PAD has been introduced in 22 states. http://goo.gl/7Delrk

- *THE LAWYERS WEEKLY* (Canada) | Online – 5 February 2016 – **'Lawyers face uncharted waters with assisted death applications.'** Lawyers and judges facing people seeking personal constitutional exemptions for physician-assisted death are entering uncharted, and possibly choppy waters, which could include court interventions by family members or interest groups opposed to such a remedy, counsel say. Among the questions for jurists in the trenches dealing with *Carter* applications: when should (or shouldn't) a lawyer take on such a case; is a lawyer bound ethically or otherwise to take on – or refer – such a brief, contrary to his or her conscience; should lawyers seek anonymity for clients and should courts grant anonymity orders; what evidence will be required to support applications for a personal exemption; can family members or interest groups intervene to oppose a *Carter* application; what are the negligence or other pitfalls for lawyers, and how can they avoid them? Also a question mark: what is the role of the attorney general of Canada if named as respondent? http://goo.gl/uT5JUp

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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4. 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.
5. 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.

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