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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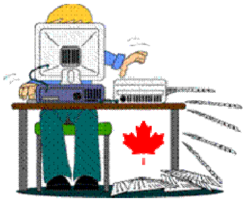

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Compiled & Annotated by Barry R. Ashpole

Respect for patient autonomy: Scroll down to Specialist Publications and ‘Ethically relevant differences in advance directives for psychiatric and end-of-life care’ (p.11), in *Journal of the American Psychiatric Nurses Association*.

Canada

End-of-life care: People slipping through the cracks, says Cancer Society

NEWFOUNDLAND & LABRADOR | CBC News (St. John’s) – 2 March 2016 – 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. Matthew Piercey, chief executive officer with the Canadian Cancer Society in Newfoundland & Labrador, said about nine people are diagnosed in the province every day with cancer – a troubling figure for the society, given that the province’s population is only about 528,000. ”Whether we know it or not, we’re in a crisis mode right now in health care within our province because of the number of cases, just with cancer, but then you have all the other illnesses,” said Piercey. ”In the next 15, 20 years, that’s going to go up 40%. [That] is what we’re predicting, so there’s a strain on our health care.” http://goo.gl/9x7Ckg

Noted in Media Watch, 29 February 2016, #451 (p.2):

- NEWFOUNDLAND & LABRADOR | CBC News (St. John’s) – 21 February 2016 – **‘Palliative care in Newfoundland headed in right direction, says director.’** The Newfoundland & Labrador Medical Association says the provincial government should use its fiscal crisis to design a leaner and stronger public health system including improved palliative care (PC) for an ageing population. In 2009, a report slammed the (PC) system that was in place, calling it completely inadequate.[1] http://goo.gl/lOYe6W

[1] ‘Thousands “suffer hideously,” palliative care report finds,’ CBC News, 2 June 2009. [Noted in Media Watch, 8 June 2009, #100 (p.1). CBC News obtained a copy of the report, which was not publicly released. http://goo.gl/QP8xCv

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.14.

Multi-centre study

Palliative care at home reduces overall costs in last month of patient's life: Study

iPOLITICS | Online – 29 February 2016 – A new Canadian study suggests that boosting palliative home-based care services in the last month of a patient's life reduces healthcare costs overall by keeping patients out of hospitals.[1] The research suggests that savings come from more attention to patients from palliative care nurses, which leads to avoiding or shortening hospitalizations. The study ... was done by researchers in Ontario, Nova Scotia and British Columbia (BC), and looked at the patterns in health care use over the last six months of life of almost 60,000 people who were dying from cancer. The study examined patients in those three provinces over five years. Roughly 10% of provincial health care budgets are spent on patients in their last year of life, and most of those costs come from hospital care. "The results indicate that investing more financial resources into palliative home-care nursing services could potentially lead to cost savings from either shorter or avoided hospitalizations, even when accounting for the additional costs of increased nursing," the study concludes. The findings were consistent across all three provinces, researchers wrote, and took into account differences in organization of provincial home-care systems. Total savings for each patient receiving home-based care in the final month of life ranged from several hundred dollars to just over a thousand dollars per patient. The savings varied by province and by how much nursing care patients would receive, but an analysis showed a "statistically significant decrease in average relative hospital costs as nursing costs increased." The researchers, from Ontario's Institute for Clinical Evaluative Sciences, the Centre for Health Services & Policy Research in BC, and Dalhousie University in Nova Scotia, said this is the largest study they know of internationally that looks at these costs across multiple jurisdictions. http://goo.gl/JNL8JI

Specialist Publications

'The wish to die among palliative home care clients in Ontario, Canada: A cross-sectional study' (p.8), in *BMC Palliative Care*.

'Unpacking the impact of older adults' home death on family caregivers' experiences of home' (p.10), in *Health & Place*.

1. 'Temporal association between home nursing and hospital costs at end of life in three provinces,' *Current Oncology*, 2016;23:S42-S51: http://goo.gl/MuBD9M (The focus of this issue of Current Oncology is "original cancer costing research using Canadian data.' Contents page: http://goo.gl/54DDbQ)

Related

- *YORK UNIVERSITY NEWS* | Online – 29 February 2016 – **'Lesbian, gay, bisexual, transgender and queer people often invisible in home care, research project reveals.'** "The lesbian, gay, bisexual, transgender and queer (LGBTQ) community faces discrimination in health care services and barriers in finding responsive and relevant care," says Judith MacDonnell in the York University School of Nursing. "While this has been well documented in hospital and other clinical settings, this study shows similar findings, highlighting the unique concerns that affect home care access for LGBTQ people across Ontario. http://goo.gl/9ssXPy

Assisted (or facilitated) death

Representative sample of recent news media coverage regarding the pending recommendations of the Federal government:

- NOVA SCOTIA | CBC News – 4 March 2016 – **'Nova Scotia Supreme Court issues draft guidelines on doctor-assisted death.'** The Supreme Court of Nova Scotia has drawn up rules for dealing with the issue of physician-assisted death for those who don't want to wait until the federal government comes up with legislation later this year. The court released a draft memorandum[1] ... in response to the so-called Carter decision last year by the Supreme Court of Canada, which declared sections of the Criminal Code dealing with this issue to be unconstitutional. http://goo.gl/Vhsgvm

Cont.

1. 'Draft Temporary Practice Memorandum on Physician Assisted Death,' Supreme Court of Nova Scotia, 1 March 2016. http://goo.gl/sDfA45

- CBC NEWS | Online – 2 March 2016 – **'When it comes to physician-assisted death, could religious hospitals ethically refuse?'** Decades after Ottawa legalized abortion, few hospitals with historic Catholic ties perform them – raising the question of whether the courts will force publicly funded health institutions to offer physician-assisted suicide when it becomes legal in Canada. A Providence Health Care memo circulating last week revealed the network of hospitals in Vancouver would not permit physician-assisted death, citing conformity with the ethical guidelines of the Catholic Health Alliance of Canada. Those same guidelines also forbid abortion, except in cases where it's performed to save the life of the mother. http://goo.gl/LinFhv

- *THE GLOBE & MAIL* | Online – 1 March 2016 – **'Should right-to-die law apply to mentally ill people?'** Most Canadians know that the right to die will soon be the law of the land. Most Canadians enthusiastically approve. But how many know that right may well extend to the mentally ill – people whose sufferings are psychological? The answer is, very few. Almost no one seems to be aware that we are rushing headlong into a moral quagmire, with profound questions that have not been debated in Parliament and have largely been ignored in the news media. http://goo.gl/sFsmWI

- *THE GLOBE & MAIL* | Online – 29 February 2016 – **'Doctors urge Ottawa to provide more clarity on assisted dying law.'** Canada's doctors are pleading with the federal government to put specific guidelines in its medically assisted dying law regarding patients who want to end their lives because of psychological suffering. Jeff Blackmer, vice-president of medical ethics at the Canadian Medical Association, said doctors recognize that psychological suffering can be as painful as physical suffering. But he said he hopes the law will not leave the definition of it "open to interpretation," and will require the patients to see a psychiatrist or mental-health team throughout the process. They also want detailed regulations for the provinces. http://goo.gl/7dhhqr

- *THE NATIONAL POST* | Online – 29 February 2016 – **'Canada is making suicide a public service. Have we lost our way as a society?'** Once you have normalized suicide, from a tragedy we should seek to prevent to a release from suffering we should seek to assist, it is logically incoherent – indeed, it is morally intolerable – to restrict its benefits to some, while condemning others to suffer interminably, merely on the grounds that they are incapable of giving consent. So it is that assisted suicide has gone, in the space of a year, from a crime, to something to be tolerated in exceptional circumstances, to a public service. http://goo.gl/2llf1D

U.S.A.

What makes a hospice nurse?

THE EXAMINER | Online – 4 March 2016 – The essence of nursing is caring and this is especially true of hospice nurses. A nurse in a facility is present to help patients and their families in a time of sickness, where as, hospice nurses are present to help patients and families steer the end-of-life travel. Hospice Nurses deal with terminally ill patients and not all patients are at the end of life. One of the largest parts of being a hospice nurse involves helping patients, and their families, feel more comfortable about death and providing them with the emotional support they need. Many use patient center care which is providing care that is respectful and responsive to the individual patient's preferences, needs, and values, and ensuring that patient values and wishes guide all care decisions. Hospice nurses provide care at a time when patients have stopped life-prolonging medical treatments and have begun pain management and other comfort measures for the remainder of their life. It a special type of person with the right personality and temperament who can adjust to the powerful emotions that come with grief and loss. Being a hospice nurse is an important job that has a meaningful impact on individuals. http://goo.gl/hZEGDY

Doctors issued a do-not-resuscitate for a newborn without telling his parents. A Missouri Bill now bears his name

MISSOURI | Lake Expo (Laurie) – 2 March 2016 – Simon Crosier lived for 88.5 days. He was born with a birth defect ... that ultimately proves fatal for those who carry it, but some children can live for a year or more with it, and Simon's parents say his doctors never gave him the chance. He was adored by his family, but he died. Now his mother Sheryl Crosier travels the country advocating to protect families from physicians who might issue a do not resuscitate order for a child, without ever telling the parents. 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

Reforming our end-of-life healthcare system

WASHINGTON DC | *The Hill* – 2 March 2016 – Our society is in the midst of a profound shift in attitudes toward end-of-life healthcare. We are increasingly aware that too many suffer needlessly in their dying. Too many endure tests and treatments that increase suffering but do nothing to extend life. Too many carry memories of the pain, confusion and agony of a dying loved one. Every day, 10,000 people turn 65. The proportion of the population reaching age 85 is 48 times larger than a century ago. Increased life expectancy brings challenges of advanced illnesses among the aged. Our medical system focuses almost exclusively on extending life at any cost, often at the expense of its quality. The Centers for Medicare & Medicaid Services reinforces this focus by reimbursing doctors generously for complicated tests, ICU stays and medical device implantations, but not for conversations and comfort care. People who do not communicate their values and priorities as illnesses advance often pay dearly for this failure. Lacking clear guidance on how an individual weighs the quality of life against its absolute duration, physicians often assume the latter, so they propose agonizing tests and treatments that steal life's joys as they prolong the dying process. http://goo.gl/CvJZwz

Related

- *MEDICAL DAILY* | Online – 2 March 2016 – **'Legal definition of "death" may not be enough to pinpoint when we medically kick the bucket.'** Death, in theory, should be clear cut, but its technical and medical definition is anything but. How can the body still function without the brain? And how can we call someone dead if there's any chance we could resuscitate them later? The 21st century has crushed the idea of death as we always knew it. Thanks to advancements in medicine and technology, we've grown uncertain about what death really is – and this uncertainty goes beyond the medical world. http://goo.gl/jxcJGx

Dying better, even if it means sooner

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. And while some studies have argued for cost savings associated with hospice care,[1] others show cost neutral effects of engaging hospice in the last months of life,[2] depending on how cost is measured and over what period of life. Meanwhile, a number of states are passing aid-in-dying laws, which will have moral, social and economic impacts, but the bills are simply directed at ending suffering; the changes in dying made possible by such laws (notably in Oregon) have not been the subject of economic analysis to date. In short, driving down end-of-life costs will be slow because these costs are sustained by medical practice and patient choice, both social and behavioral practices subject to slow change. While this level of spending is unsustainable, there are greater costs – constantly fighting against death's inevitability is also deeply unsatisfying. http://goo.gl/U5ekov

1. 'Association between the Medicare Hospice Benefit and health care utilization and costs for patients with poor-prognosis cancer,' *Journal of the American Medical Association*, 2014;312(18):1888-1996. [Noted in Media Watch, 17 November 2014, #384 (p.4)] http://goo.gl/C7bM1C

Cont.

2. ‘Changes in Medicare costs with the growth of hospice care in nursing homes,’ *The New England Journal of Medicine*, 2015;372(19):1823-1831.[Noted in Media Watch, 11 May 2015, #409 (p.12)] http://goo.gl/hZswf1

Related

- INDIANA | *The News-Sentinel* (Fort Wayne) – 29 February 2016 – **‘Lack of knowledge about palliative care limiting its benefits to patients, hospitals.’** Despite the evidence for positive outcomes, referrals for palliative care (PC) services still come too late or, in many cases, not at all, said Dr. Andrew Esch, a PC specialist and faculty member of the Center to Advance Palliative Care (CAPC). “Providers associate PC with hospice, and that’s one reason referrals come late,” Esch said. Esch cites two other key reasons for failure or delays in PC referrals: lack of access because of too few specialty-trained PC physicians; and physicians, in general, inadequately trained and skilled to discuss end-of-life issues. http://goo.gl/O8UEul

International

End-of-life care in New Zealand

Extra funding wanted to help Kiwis in care die in comfort

NEW ZEALAND | TVNZ News (Auckland) – 3 March 2016 – Around 10,000 Kiwis die each year in residential care, more than in hospitals, and some say they are struggling without ring-fenced funding for end-of-life care. Most are paid around $180 a night for palliative patients, the same for rest home hospital patients, but they say that doesn’t cover the complex needs of those dying or those of their families. Rest homes are Government-funded for four types of patients – rest home, hospital, dementia and psycho-geriatric – but not specifically palliative. The Health Ministry says it is reviewing nationwide palliative care services, and will be making recommendations by the end of year. It says last year’s budget allocated an extra $76 million to support the terminally ill. https://goo.gl/EEpeQg

Specialist Publications

‘Māori and cancer care in Aotearoa/New Zealand – responses to disparities’ (p.10), in *European Journal of Cancer Care*.

The end-of-life care in India

“Every government hospital should have a palliative care unit”

INDIA (Tamil Nadu) | *The Hindu* (Chennai) – 29 February 2016 – Palliative care (PC) units should be opened in every government hospital, said Revwathy Kailairajan, Dean, Karur Medical College Hospital, while inaugurating Nethravathi Pain, Palliative Care & Rehabilitation Centre... Citing the example of Kanyakumari Government Medical College Hospital, where an old building had been modified as a PC unit, Dr. Revwathy said that the same should be replicated in all hospitals. “The government is considering proposals in this regard,” she said. Pointing out that PC remained a neglected field owing to which a large number of the terminally-ill, particularly cancer patients, with none to care [for them] were left to suffer, Dr. Revwathy appreciated a group of doctors who had come together to start the centre. http://goo.gl/A9c161

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

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

Cancer patients are suffering "undignified deaths" because doctors aren't comfortable discussing end-of-life treatments with them

U.K. (England, Northern Ireland, Scotland & Wales) | *The Daily Mail* – 27 February 2016 Marie Curie ... revealed shocking figures that suggest up to one in four terminal cancer patients is being denied access to palliative care. A report by the charity found people with terminal blood and brain cancer are most likely to not have their needs met.[1] Policy adviser Scott Sinclair said end-of-life care was being discussed too late by some doctors. "They may feel they don't want to take hope away from their patients by discussing death too early, but this can backfire. Not having a frank conversation can lead to rushed decisions at the end of life." Lack of planning can lead to "avoidable" hospital admissions close to death, which mean people may not get to fulfil their final wishes. The report revealed that sufferers of leukaemia and lymphoma ... are twice as likely to die in hospital compared to those with more common types of cancer, often because their final admission is an unplanned emergency. http://goo.gl/0yGrBl

Palliative and end-of-life care in Scotland: The rationale for a public health approach

U.K. (Scotland) | Scottish Public Health Network – Accessed 3 March 2016 – 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 5 briefing papers and includes 17 recommendations. http://goo.gl/FeVDfk

Specialist Publications

'To what degree is palliative care integrated in guidelines and pathways for adult cancer patients in Europe: A systematic literature review' (p.8), in *BMC Palliative Care.*

1. 'The Hidden Challenges of Palliative Cancer Care,' Marie Curie, February 2016. http://goo.gl/8woB9c

Related

- U.K. (Scotland) | *The Courier* (Dundee) – Online – 3 March 2016 – **'Hospice At Home service for terminally ill patients to be axed in Fife.'** A £1 million pilot project that gives people with terminal illnesses the chance to die at home is to be axed at the end of the month. Nurses fear the loss of Fife's Hospice At Home service will have a huge impact on the dying and could worsen the region's already challenging bed-blocking figures. http://goo.gl/wLpbtu

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SWITZERLAND | Swiss Broadcasting Corporation (Bern) – 2 March 2016 – **'EXIT reports jump in assisted suicide numbers.'** Swiss assisted suicide organisation EXIT helped 782 people end their lives in 2015 – 199 more than the previous year. Of the deceased, 55% were women and 45% men... Among them, the most common reason for wanting to die was terminal cancer, followed by age-related health problems and chronic pain disorders. The average age of each person at the time of death was 77.4. In 2015, EXIT received some 3,500 requests for euthanasia, and looked into 1,100 of those cases in detail – bringing the number of opened cases up by 20%. EXIT, active in German-speaking Switzerland and in Ticino [an Italian-speaking region in southern Switzerland], attributes the rise to the steady increase in membership and the significant ageing of society. http://goo.gl/7PxNAf

Specialist Publications

'Medical end-of-life practices in Switzerland: A comparison of 2001 and 2013' (p..14), in *JAMA Internal Medicine.*

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

Improving medical graduates' training in palliative care: Advancing education and practice

ADVANCES IN MEDICAL EDUCATION, 2016;7:99-113. The needs of an aging population and advancements in the treatment of both chronic and life-threatening diseases have resulted in increased demand for quality palliative care (PC). The doctors of the future will need to be well prepared to provide expert symptom management and address the holistic needs (physical, psychosocial, and spiritual) of patients dealing with serious illness and the end of life. Such preparation begins with general medical education. It has been recommended that teaching and clinical experiences in PC be integrated throughout the medical school curriculum, yet such education has not become the norm in medical schools across the world. This article explores the current status of undergraduate medical education in PC as published in the English literature and makes recommendations for educational improvements which will prepare doctors to address the needs of seriously ill and dying patients. https://goo.gl/DQg2Of

Selected articles giving a U.S. perspective on training in palliative care

- *ANNALS OF INTERNAL MEDICINE* | Online – 20 October 2015 – **'Evolving the palliative care workforce to provide responsive, serious illness.'** The U.S. is currently in the midst of a national crisis in providing accessible and responsive palliative care due to a shortage of professionals trained to provide this care. [Noted in Media Watch, 26 October 2015, #433 (p.8)] http://goo.gl/6LGk3X
- *JOURNAL OF CANCER EDUCATION* | Online – 9 December 2014 – **'Inadequacy of palliative training in the medical school curriculum.'** The literature expresses concerns about the varied and non-uniform approach to palliative care training across medical schools. [Noted in Media Watch, 15 December 2014, #388 (p.13)] http://goo.gl/7JLhxb
- *MEDICAL EDUCATION*, 2014;48(1):59-66. **'Palliative care education in U.S. medical schools.'** A review of U.S. medical school surveys reveals varied and uneven approaches. Palliative care competencies are too complex and universally important to be relegated to a minimum of classroom time, random clinical exposures, and the hidden curriculum. [Noted in Media Watch, 23 December 2013, #337 (p.15)] http://goo.gl/H7q4tf

Near-death and other transpersonal experiences occurring during catastrophic events

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 2 March 2016 – The purpose of this article is to describe examples of near-death and other transpersonal experiences occurring during catastrophic events like floods, wars, bombings, and death camps. To date, researchers have limited their investigations of these transpersonal events to those occurring to seriously ill patients in hospitals, those dying from terminal illnesses, or to individuals experiencing a period of grief after the death of a loved one. Missing is awareness by first responders and emergency healthcare professionals about these transpersonal experiences and what to say to the individuals who have them. Some responders experience not only deaths of the victims they assist, but also deaths of their colleagues. Information about these transpersonal experiences can also be of comfort to them. It is hoped the information will provide knowledge of these experiences to those who care for those near death, or dying, or grieving because of catastrophic events, and encourage researchers to further investigate these experiences during disasters. http://goo.gl/fONh7S

Media Watch: Back Issues

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

To what degree is palliative care integrated in guidelines and pathways for adult cancer patients in Europe: A systematic literature review

BMC PALLIATIVE CARE | Online – 3 March 2016 – Five studies were found to fulfil at least 10/11 of the criteria for completeness on integrated palliative care (IPC). These guidelines/pathways proposed very similar strategies for the realization of these criteria and were based on high levels of evidence. Consequently, they could serve as benchmarks of how palliative care (PC) can be integrated in cancer guidelines. As such, they also can provide a base to further investigate what constitutes integrated PC in cancer. The review has revealed the importance of a holistic approach and interventions aimed at reducing suffering by deploying an integrated palliative care approach. Additionally, the results illustrate that there is disagreement on the appropriate referral criteria for IPC, which remains a contentious and challenging topic in terms of the integration of PC in cancer care. The included guidelines/pathways do not embody aspects of implementation. Therefore, even though the theoretical framework of these guidelines / pathways conforms reasonably well to the state of the art in IPC, their applicability in practice needs to be further investigated. http://goo.gl/6XGcZ0

Noted in Media Watch, 15 February 2016, #449 (p.9):

- *COCHRANE DATABASE OF SYSTEMATIC REVIEWS* | Online – 12 February 2016 – **'End-of-life care pathways for the dying.'** This is an updated version of a Cochrane review published in 2013 in the Cochrane Library.[1] In many clinical areas, integrated care pathways are utilised as structured multidisciplinary care plans that detail essential steps in caring for patients with specific clinical problems. Since the last update, there have been sustained concerns about the safety of implementing end-of-life care pathways, particularly in the U.K. http://goo.gl/OY9j86

    1. 'End-of-life care pathways for improving outcomes in caring for the dying,' *Cochrane Database of Systematic Reviews*, 18 November 2013. [Noted in Media Watch, 25 November 2013, #333 (p.15)] http://goo.gl/ImbPlO

Related

- *BMC PALLIATIVE CARE* | Online – 5 March 2016 – **'Implementing the care programme for the last days of life in an acute geriatric hospital ward.'** Implementing the Care Programme for the Last Days of Life in the geriatric ward was successful; a steering group was formed consisting of two facilitators, health care staff of the geriatric ward were trained in using the Care Guide for the Last Days of Life which was subsequently introduced onto the ward and approximately 57 % of all dying patients were cared for according to the Care Guide for the Last Days of Life. http://goo.gl/Fsq8oZ

- *PALLIATIVE MEDICINE* | Online – 2 March 2016 – **'Measuring healthcare integration: Operationalization of a framework for a systems evaluation of palliative care structures, processes, and outcomes.'** The examination of community-based palliative care (PC) networks provides an ideal opportunity for the advancement of integration measures, in consideration of how fundamental provider cohesion is to effective care at end of life. http://goo.gl/7ITIlh

The wish to die among palliative home care clients in Ontario, Canada: A cross-sectional study

BMC PALLIATIVE CARE | Online – 29 February 2016 – Findings suggest there are multiple factors associated with person's expressions of a wish to die (WTD). If clinicians see a pattern where clients are widowed, have a shorter estimated prognosis, at moderate to high risk of depression, exhibiting severe functional impairment, experiencing too much sleep, have a sense of financial completion, and who are struggling with the meaning of life then they should use their best judgment and consider initiating a conversation about the person's wishes as they near the end of life. If a client exhibits moderate to severe risk of depression or are sleeping too much then the clinician may also probe into the clients psychosocial characteristics and consider whether treating depression symptoms may affect or change the client's preference to WTD. Increased media attention addressing supporting person-centered preferences at the end of life and more specifically, reports discussing right to die, assisted suicide, and euthanasia, further complicate the navigation of this topic. http://goo.gl/QyHRwz

Cont.

Selected articles on the desire to hastened death

- *PSYCHO-ONCOLOGY* | Online – 16 September 2015 – **'Desire for hastened death: How do professionals in specialized palliative care react?'** Health professionals (HP) are often underprepared when presented with desires for hastened death. Interviews were conducted with specialized palliative care HP at four German University Hospitals. Twelve response categories and six corresponding functions were identified. [Noted in Media Watch, 21 September 2015, #428 (p.15)] http://goo.gl/gU8vw3

- *PALLIATIVE MEDICINE* | Online – 23 March 2015 – **'The desire to hasten death: Using grounded theory for a better understanding – "When perception of time tends to be a slippery slope."'** Emerging hypotheses: a) Patients try to balance life time and anticipated agony, and the perception of time is distressing in this balancing act; b) Anticipated images of agony and suffering in the dying process occur frequently and are experienced by patients as intrusive; c) Patients expressing a desire to hasten death are in need of more information about the dying process; and, d) Patients wanted their caregivers to listen to and respect their wish to hasten death, and they did not expect the caregivers to understand this as an order to actually hasten their death. [Noted in Media Watch, 30 March 2015, #403 (p.19)] http://goo.gl/Ni8cLp

- *PALLIATIVE MEDICINE*, 2006;20(7):703-710. **'Responding to desire to die statements from patients with advanced disease: Recommendations for health professionals.'** Given the lack of guidelines to assist health professionals with this issue, the authors prepared multidisciplinary recommendations for responding to a desire to die statement, underpinned by key principles of therapeutic communication and a systematic review of empirical literature. [Noted in Media Watch, 17 March 2014, #349 (p.16, under 'Worth Repeating')] http://goo.gl/SwYhiG

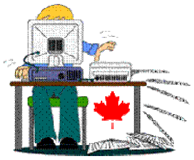
End-of-life care in Ireland

Experiences of palliative care nurses in the utilisation of palliative sedation in a hospice setting

END OF LIFE JOURNAL | Online – 3 March 2016 – Nurses are centrally involved in the utilisation of palliative sedation in end-of-life care; however, there is minimal research available in relation to their experiences in this regard. Data analysis led to the identification of four core themes: 1) Information sharing; 2) Timing of palliative sedation; 3) Level of sedation; and, 4) Palliative sedation as a last resort. The results indicate that the participants were generally satisfied with the processes that underpinned decisions to introduce palliative sedation. They saw it as a highly complex intervention, in part because it involved individuals with very complex conditions and symptoms. Palliative care patients, families and the general public in Ireland need to have greater understanding of the role of palliative sedation in the treatment of refractory symptoms at the end of life. http://goo.gl/YZBmfk

Noted in Media Watch, 10 November 2014, #383 (p.12):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2014;20(10):474-481. **'Sedation at the end of life: A hospice's decision-making practices in the U.K.'** This article details the evolution of sedation decision-making practices at a 14-bedded U.K. hospice over the course of 5 years. Key areas, such as documented consideration of hydration status and discussion with family members have been improved following the implementation of a checklist of decision-making prompts, demonstrating how practice can be improved and sustained over time. http://goo.gl/v4v0ON



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

Māori and cancer care in Aotearoa/New Zealand – responses to disparities

EUROPEAN JOURNAL OF CANCER CARE, 2016;25(2):214-218. Cancer inequalities between indigenous and non-indigenous peoples are part of the spectrum of social, economic and political disparities experienced by indigenous peoples in high- and low-income countries across the globe (United Nations 2009). The World Health Organisation (2015) is committed to reducing inequalities by supporting member States to protect, respect and fulfil the right of Indigenous Peoples to the highest attainable standard of health, by addressing the social determinants of health and increasing access to high-quality health care. In Aotearoa/New Zealand (NZ), the Treaty of Waitangi, signed in 1840 between Māori leaders and the British Crown, affirms the right to collective self-determination, recognised in contemporary Māori health policy as including the right to provide health care (Ministry of Health 2014), and the right to equitable health outcomes (Robson & Harris 2007). Cancer is the leading major cause of death among Māori women and the second leading cause after circulatory system disease for Māori men (Ministry of Health 2015a). Cancer incidence was 25% higher for Māori than for non-Māori during 2010–2012 while cancer mortality was 79% higher (Ministry of Health 2015b). Although the Māori population is relatively youthful with a median age of 23.9 years, the number of Māori aged 45 years and over (the age group in which at least 85% of Māori cancer registrations occur) is projected to increase by nearly a third between 2013 and 2020 (Statistics New Zealand 2014). http://goo.gl/tSy3LI

N.B. Aotearoa is the Māori name for New Zealand.

Extract from *European Journal of Cancer Care* article

The public health system does not currently provide a support service for patients although there are now a number of small cancer specific support groups throughout Aotearoa. It is also timely to look more closely at the role of specific cancer services not previously well utilised by Māori, such as palliative care and psychosocial support services.

N.B. Selected articles on Māori beliefs and practices in the context of end-of-life care are noted in issues of Media Watch dated 15 June 2015, #414 (p.5), 16 June 2014, #362 (p.8), and 17 March 2014, #349 (p.9).

The futility in cardiology

GIORNALE ITALIANO DI CARDIOLOGIA, 2016;17(1):6-10. This paper examines some considerations and applications of the concept of medical futility, particularly about the various definitions of futility, the complexities of management when care is considered futile, and the ethical and clinical criteria to withdrawing or withholding aggressive treatments. Patient-centered care, based on physician-patient communication, seems to be the best approach to this problem, even with a patient with advanced heart disease. The increasing power of technology and its relationship with the current cultural values of the developed societies are outlined, particularly when end-of-life decisions are addressed. http://goo.gl/tGVaOM

N.B. Italian Language article. Journal contents page: https://goo.gl/vk5IrC

End-of-life care in England

Unpacking the impact of older adults' home death on family caregivers' experiences of home

HEALTH & PLACE, 2016;38(103-111. Public Health England (2013) survey data indicates that while the place of death is geographically uneven across England, given a choice, many older people nearing end of life would prefer to die at home.[1] There is, however, a growing critique that policies designed to support home death fail to understand the needs and preferences of older people and the impact on family carers. Such policies also make assumption about within whose home the home death takes place. Hence, there are major gaps in our understanding of, firstly, where and how care work undertaken by family members within domestic settings takes place; and, secondly, how it can create tensions between home and care

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that fundamentally disrupt the physical and socio-emotional meaning of home for family carers, impacting on their sense of home post-death. This can have consequences for their own well-being. The authors draw on interview data from their 'Unpacking the Home' study to elicit an in-depth understanding of how facilitating a home death can create an ambiguity of place for family carers, where the issues faced by them in caring for a dying older person at home, and the home death itself, can fundamentally reshape the meaning and sense of home. http://goo.gl/Qe0on7

1. 'Health Survey for England – 2013' (Chapter 4: End-of-Life Care), Health & Social Care Information Centre, December 2014. http://goo.gl/qTzz5U

Evaluating a pilot paediatric hospice-at-home service: A literature review

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING | Online – 29 February 2016 – This literature review aims to offer practitioners an overview of the key components involved in designing the evaluation of a paediatric hospice-at-home pilot that will assess the effectiveness, efficiency and sustainability of the programme. The literature was reviewed in two stages: the first examined existing literature in the area of paediatric palliative care (PC). The second looked at the wider field of adult PC to gain further insights into evaluation tool design. The findings are presented as a conceptual model to highlight each component of the pilot development stage as identified for evaluation purposes, emphasising their role and impact on the resultant delivery of integrated care. The clarity and transparency of this model offers a comprehensive overview of the evaluation process to all involved in the pilot. http://goo.gl/5oJYKv

Noted in Media Watch, 5 October 2015, #430 (pp.11-12):

- *EUROPEAN JOURNAL OF PEDIATRICS* | Online – 28 September 2015 – **'Experiences in palliative home care of infants with life-limiting conditions.'** Data on home-based palliative care of all neonates and infants, who were being taken care of by our paediatric palliative care team between 2007 and 2014, was analysed. A total of 31 patients (pts) were analysed. The majority were diagnosed with congenital malformations or chromosomal abnormalities. Twenty died, five of them in hospital. http://goo.gl/ndHwEu

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 29 September 2015 – **'Community palliative care nurses' challenges and coping strategies on delivering home-based pediatric palliative care: A qualitative study.'** The results of this study reinforces the need for integration of pediatric palliative care teaching and communication skills training into all undergraduate health care programs. http://goo.gl/v44oB9

Ethically relevant differences in advance directives for psychiatric and end-of-life care

JOURNAL OF THE AMERICAN PSYCHIATRIC NURSES ASSOCIATION, 2016;22(1):52-59. Psychiatric advance directives (PADs) represent a shift from more coercive to more recovery-oriented care and hold the promise of empowering patients while helping fill the gap in treatment of non-dangerous patients lacking decision-making capacity. Advance directives for end-of-life and psychiatric care share an underlying rationale of extending respect for patient autonomy and preventing the harm of unwanted treatment for patients lacking the decision-making capacity to participate meaningfully in planning their care. Ethically relevant differences in applying advance directives to end-of-life and psychiatric care are discussed. These differences fall into three categories: 1) Patient factors, including decision-making capacity, ability to communicate, and prior experience; 2) Decisional factors, including expected outcome and the nature of the decisions; and, 3) Historical-legal precedent. Specific recommendations are offered. Clinicians need to appreciate the ethical implications of these differences to effectively invoke PADs or assist patients in creating PADs. http://goo.gl/kTw7r2

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Related

- *JOURNAL OF THE AMERICAN PSYCHIATRIC NURSES ASSOCIATION*, 2016;22(1):31-42. **'No right place to die.'** – Nursing attitudes and needs in caring for people with serious mental illness at end-of-life.' Approximately 6% of the U.S. population suffer from a serious mental illness (SMI). People with SMI reportedly die 20 to 25 years earlier than the general population. Six themes were identified [among participating hospice/palliative care nurses and psychiatric/mental health nurses): 1) Stigma of mental illness; 2) Effect of SMI symptoms on communication and trust; 3) Chaotic family systems; 4) Advocacy issues around pain and comfort; 5) Need for formal support; and, 6) No right place to die. Participants discussed the need for better education and collaboration between psychiatric and palliative. http://goo.gl/pEys9I

Missing data in randomised controlled trials evaluating palliative interventions: A systematic review and meta-analysis

THE LANCET, 2016;387(S53). This review of international randomised controlled trials testing a range of palliative interventions found that the overall weighted proportion of missing data is at a level that poses a substantial risk to the validity of trial results. Trial burden and duration need consideration when adjusting sample-size calculations for missing data. Differential reasons and rates of missing data at trial-level also present a risk of bias. http://goo.gl/khgWMR

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 28 February 2016 – **'Using routine data to improve palliative and end-of-life care.'** This article ... describes the benefits of routine data research and identifies major challenges for the future use of routine data, including: access to data, improving data linkage, and the need for more palliative and end of life care specific data. http://goo.gl/TSivOb

Place of death in rural palliative care: A systematic review

PALLIATIVE MEDICINE | Online – 4 March 2016 – There have been many studies on the actual and preferred place of care and death of palliative patients; however, most have been whole population surveys and/or urban focused. Data and preferences for terminally ill rural patients and their unofficial carers have not been systematically described. A total of 25 studies described actual place of death; 12 preferred place of care or death (2 studies reported both); most deaths occurred in hospital with home as the preferred place of care deaths; however, qualitative studies suggest that preferences are not absolute; factors associated with place are not adequately described as rurality was an independent variable; significant heterogeneity (rural setting and participants), however, many areas had a greater chance of home death than in cities; rural data are embedded in population reports rather than from specific rural studies. Home is the preferred place of rural death; however, more work is needed to explore influencing factors, absolute importance of preferences and experience of providing and receiving palliative care in rural hospitals which often function as substitute hospice. http://goo.gl/PYW3KX

Improving the wellbeing of staff who work in palliative care settings: A systematic review of psychosocial interventions

PALLIATIVE MEDICINE | Online – 4 March 2016 – There is an urgent need to address the lack of intervention development work and high-quality research in this area. A total of 1,786 potentially eligible articles were identified – nine remained following screening and quality assessment. Study types included two randomised controlled trials, two non-randomised controlled trial designs, four one-group pre–post evaluations and one process evaluation. Studies took place in the U.S. and Canada (5), Europe (3), and Hong Kong (1). Interventions comprised a mixture of relaxation, education, support and cognitive training and targeted stress, fatigue, burnout, depression and satisfaction. The randomised controlled trial evaluations did not improve psychological wellbeing of palliative care staff. Only two of the quasi-experimental studies appeared to show improved staff wellbeing although these studies were methodologically weak. http://goo.gl/f1y1FK

The bereavement experiences of lesbian, gay, bisexual and/or trans* people who have lost a partner: A systematic review, thematic synthesis and modelling of the literature

PALLIATIVE MEDICINE | Online – 4 March 2016 – Lesbian, gay, bisexual and/or trans* people are at increased risk of certain life-limiting illnesses and may not receive the care and support they need at the end of life and into bereavement. A total of 23 articles reporting on 13 studies were identified. Studies described universal experiences of the pain of losing a partner; however, additional barriers and stressors were reported ... including homophobia, failure to acknowledge the relationship, additional legal and financial issues and the "shadow" of HIV or AIDS. A novel model was developed to explain how the experience for lesbian, gay, bisexual and/or trans* people is shaped by whether the relationship was disclosed and acknowledged in life and into bereavement and how this impacts upon needs and access to care. http://goo.gl/vIxM4r

Culture and spirituality: Essential components of palliative care

POSTGRADUATE MEDICAL JOURNAL | Online – 1 March 2016 – Cultural background can shape how patients respond to life-threatening illness, as can the beliefs held by the patients, whether religious or more broadly spiritual. Research evidence shows the importance of identifying and addressing cultural and spiritual aspects of care held by patients, families and staff. These are often neglected in clinical practice due to the focus on biomedical concerns and staff discomfort in engaging with beliefs and culture. Recent studies have highlighted gaps in the research, and some methodological difficulties and indicate many patients welcome healthcare staff enquiring about the importance of their beliefs and culture. Identifying research priorities is necessary to guide future research and strengthen the evidence base. http://goo.gl/9rCTUe

N.B. Selected articles on spirituality in the context of end-of-life care are noted in Media Watch of 8 June 2015, #413 (pp.10-11).

Improving palliative care for prisoners: The 'Both sides of the fence' study

PRISON SERVICE JOURNAL, 2016;224:42-47. The study began in June 2013 and will be completed by the end of May 2016. It is taking place in Her Majesty's Prison Wymott, a Category C prison with a high number of older prisoners, and is funded by the charity Marie Curie. The overall aim is to develop a model of palliative and end-of-life care for prisoners that can be shared with other prisons to improve practice. The study uses action research methodology, in which the research participants (in this case, prison staff and prisoners) and the research team work together to make changes to practice. The research is designed in two main phases, with a short third phase for consolidating the findings and sharing them with other prisons. Analysis of data is ongoing and the final results will be published at the end of the study. However, it is already clear that the number of prisoners requiring palliative and end-of-life care is likely to continue to increase in the foreseeable future. This is in part because the prison population, like the wider population, is ageing, and with increasing age comes increasing ill health and frailty. This change in the prison population presents significant practical, ethical and emotional challenges for prison staff and prisoners, but the prison service needs to respond to these challenges in order to ensure high quality palliative care for the growing numbers of prisoners who need it. http://goo.gl/Inu6xa

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

N.B. Click on 'PSJ 224 March 2016.pdf' to download complete issue of the journal; scroll down to p.42.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *JAMA INTERNAL MEDICINE* | Online – 29 February 2016 – **'The challenge of new legislation on physician-assisted death.'** This Viewpoint discusses the need for international cooperation in deciding how professional societies, academic medical centers, medical groups, and health care systems can best integrate physician-assisted death into their practices. By the end of 2016, more than 80 million people in the U.S. and Canada will live in a jurisdiction allowing physician-assisted death (PAD). As such, this practice can no longer be considered a quirky experiment in a few states. The North American experience with PAD began in 1994, when voters in Oregon approved a ballot measure, the Death With Dignity Act, allowing a physician to prescribe a lethal dose of a medication that a patient voluntarily self-administers. Oregon stood alone for 14 years until Washington (2008), Vermont (2013), and now California (2015) approved similar laws. As of January 2016, the effective date of the California law, known as the End of Life Option Act, is uncertain. These laws are in general very similar, with safeguards that include requirements for a waiting period and that eligible patients be mentally competent, not mentally ill, and have a life expectancy of less than 6 months. In 2009, the Montana Supreme Court removed prohibitions against (PAD) for competent patients. There are no reporting requirements in Montana, so little is known about the actual practice of PAD in that state. In 2015, the Canadian Supreme Court unanimously reversed a federal law that prohibited PAD and gave the government until June 2016 to establish mechanisms for access to such assistance. http://goo.gl/R76ynx

- *JAMA INTERNAL MEDICINE* | Online – 29 February 2016 – **'Medical end-of-life practices in Switzerland: A comparison of 2001 and 2013.'** Physician-assisted suicide, but not euthanasia, is legal in Switzerland. The Netherlands and Belgium, where euthanasia is legal, regularly monitor the incidence of medical end-of-life practices. As part of a study in six European countries, reliable data on medical end-of-life practices were collected in the German-speaking part of Switzerland in 2001. To assess trends in physician-assisted suicide and other medical end-of-life practices, we conducted an identical study in Switzerland in 2013. http://goo.gl/YRBNgq

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

Media Watch: Editorial Practice

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

Distribution

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

Links to Sources

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

Something Missed or Overlooked?

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

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