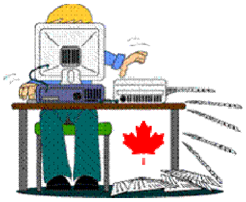
Media Watch… *is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in* ***hospice*** *and* ***palliative care****, and in the quality of* ***end-of-life care*** *in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.*

9 May 2016 Edition | Issue #461



Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to Specialist Publications and 'Coaching family caregivers to become better problem solvers when caring for persons with advanced cancer' (p.13), in *Journal of Social Work in End-of-Life & Palliative Care*.

Canada

Medical assistance in dying

Commons vote on assisted suicide bill suggests final tally will be closer

THE TORONTO STAR | Online – 7 May 2016 – The approval in principle this week of the Liberal assisted death legislation by an overwhelming majority of MPs should not be confused with a show of collective enthusiasm. But by the same token, nor should the 235-75 vote be construed as anything less than a noteworthy government victory. Over and above all else, the will of the House of Commons is – by all appearances – to have a federal law on the books within the next month. The large majority that gave Bill C-14 the nod does include an unspecified number of MPs who will be pushing for the legislation to be amended before it is brought back to the Commons for a final vote. If the government refuses to make changes, some may decline to continue to support the legislation. The definitive vote on Bill C-14 will almost certainly be closer than this week's sounding. But given that the legislation passed second reading by a margin of more than two to one, the Commons dice are loaded in favour of its adoption. https://goo.gl/EAU74v

Transcriptions of parliamentary debate on medical assistance in dying

2 May 2016:
http://goo.gl/jhjTij
3 May 2016:
http://goo.gl/iIk2Zy
4 May 2016:
http://goo.gl/437g1G
5 May 2016:
http://goo.gl/wuH3vw
6 May 2016:
http://goo.gl/MWL4px

N.B. Word search C-14

Related

- *THE GLOBE & MAIL* | – 5 May 2016 – **'Why judges should have the final word in medically assisted suicide.'** Bill C-14 will legalize medically assisted suicide and euthanasia in Canada. How it does that, on what conditions, and in which circumstances matters. Judicial involvement would not only underline the seriousness of the decision, it would also assist in doing the least damage to the foundational value of respect for human life; provide better protection against abuse of medically assisted suicide and of vulnerable people than the proposed legislation does; and help to ensure that it is rarely used and only where all necessary conditions are complied with. This safeguard has a history of judicial recognition and use in the context of medically assisted dying. http://goo.gl/0FXxgW

U.S.A.

Health care denied at 550 hospitals because of Catholic doctrine

FORBES | Online – 7 May 2016 – A disturbing new report ... finds that 1 in 6 hospitals in the U.S. are operated in accordance with Catholic religious rules, known as the Ethical & Religious Directives (ERDs).[1] While perhaps best known for prohibiting abortion, the restrictions go far beyond that, and impact more than reproductive health. Physicians at Catholic hospitals have to agree to abide by the ERDs as a condition of obtaining privileges. Depending in part on the whim of the local Bishop, this could include gag rules prohibiting counseling a patient or referring a patient to a place that would provide necessary services. In Washington state, data shows that 40% of all hospital beds are in a Catholic hospital. There is no other option for care in entire regions. This is especially true in rural regions, and it is frightening when the only access to health care is dictated by someone else's religious doctrine, rather than medical science. http://goo.gl/WLnSmM

Extract from American Civil Liberties Union report

In compliance with federal law, a Catholic health care institution will make available to patients information about their rights, under the laws of their state, to make an advance directive (AD) for their medical treatment. The institution, however, will not honor an AD that is contrary to Catholic teaching.

Specialist Publications

'Medicare and advance planning: The importance of context' (p.10), in *The Hastings Center Report.*

1. 'Health Care Denied,' American Civil Liberties Union, May 2016. https://goo.gl/o0FLMi

Noted in Media Watch, 2 February 2015, #395 (p.5):

- CALIFORNIA | *The Times-Standard* (Eureka) – 24 January 2015 – **'Church dogma a poor fit for some patients' needs.'** There are 56 separate entities that manage the 629 Catholic Hospitals in the U.S. 1 in 6 patients is cared for in a Catholic hospital. The U.S. Conference of Catholic Bishops has steadfastly regulated the delivery of health care throughout this extensive system. http://goo.gl/kYP4pR

Noted in Media Watch, 21 March 2011, #189 (p.9):

- *THE HASTINGS REPORT*, 2011;41(2):28-29. **'Making sense of the Roman Catholic directive to extend life indefinitely.'** In November 2009, the U.S. Conference of Catholic Bishops issued *Ethical & Religious Directives for Catholic Health Care Services*, requiring that all patients be provided with artificial hydration and nutrition if such care could extend life indefinitely. http://goo.gl/kQyNVv

End-of-life care: New threat of under-treatment for pain

MCKNIGHT'S | Online – 4 May 2016 – Amid growing media attention and, active discussions surrounding new recommendations made by the Centers for Disease Control & Prevention,[1] which strongly advise against the use of opioids for the routine management of chronic pain – providers in end-of-life care call for special attention to the exception-to-rule for cancer patients under active treatment, patients receiving palliative care (PC), and those in hospice care. While these policy proposals could help to restrain the sweeping misuse and diversion of opioids, they must be tempered by the need to ensure safe and effective analgesia for those with pain associated with serious medical illness. It can't be emphasized enough that hospice and PC providers are experts in pain management and have been safely prescribing opioids for many years. http://goo.gl/n3b0hd

1. 'CDC Guideline for Prescribing Opioids for Chronic Pain – U.S., 2016,' *Morbidity & Mortality Weekly Report*, 15 March 2016, Centers for Disease Control & Prevention. [Noted in Media Watch, 21 March 2016, #454 (p.3)] http://goo.gl/Ng6PZ5

Despite objections, Ohio Senate passes bill allowing more end-of-life care instruction

OHIO | *The Columbus Dispatch* – 4 May 2016 – Over objections of some abortion opponents, the Senate approved a bill ... that would allow doctors to issue medical orders directing the care a terminally ill patient should receive if death is near. Supporters of Senate Bill 165, including many medical professionals, say the legislation will encourage doctors and their patients to discuss end-of-life care, better clarify their wishes, and ensure they are followed. The legislation, which passed by a vote of 30-3, heads to the House. http://goo.gl/eGCXJi

When a parent directs a child not be resuscitated, what should educators do?

THE CONVERSATION (Boston, Massachusetts) | Online – 2 May 2016 – The impending death of a student is unlike most challenges educators face. There are many dilemmas experienced by educators within schools when they receive a directive from a parent to not resuscitate their child. Parents of other children may not want a child with a DNAR [Do Not Attempt Resuscitation] order in the same class as their child, believing that it could be physically, socially or emotionally harmful to their child. Faculty and staff too could object to being placed in a situation in which they could not act. Schools also need to confront what action to take if a student goes into cardiac arrest, what to do with the students in the vicinity or in classroom and whom to call. Additionally, they are faced with considering questions of whether a student with a DNAR should be kept from participating in off-campus activities such field trips. There has been an increase in the DNARs received by schools. Studies show that DNAR orders in schools increased from 29.7% in 2000 to 46.2% in 2006. This could be partly due to the fact that following the promulgation of laws for children with special needs, not only can children with complex chronic conditions attend school, but their needs must be adequately addressed. http://goo.gl/wDNjvX

N.B. 'The Conversation,' an "independent source of news and views from the academic and research community, delivered direct to the public,' is not to be confused with 'The Conversation Project' *vis-à-vis* end-of-life care. The former was first launched in Australia in March 2011, in the U.K. in May 2013, and in the U.S. in October 2014. ***BRA***

Noted in Media Watch, 25 January 2016, #446 (p.3):

- ALABAMA | *The Decatur Daily* – 21 January 2016 – **'Mother, school district reach agreement on terminally ill student.'** Limestone County Schools has reversed its previous position and reached an agreement with the mother of a terminally ill student that allows the mother and the student's hospice nurse to be on campus with him. The school district has never denied the student, a freshman, access to school, but the district refused to comply with an advanced directive prepared by the family's attorney, which essentially requested he not be provided lifesaving medical care if he had medical problems at school. http://goo.gl/KxOIxd

Noted in Media Watch, 7 July 2014, #365 (p.12):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2014;16(6):355-361. **'Supporting children with life-threatening conditions in the schools.'** Nurses [i.e., survey participants] encountered several types of questions from children with life-threatening conditions, their classmates and families, and school staff. They had questions themselves, in such areas as gaining and disseminating information, promoting understanding of the child's condition and providing support, addressing symptoms in conjunction with school activities and DNR orders in the school setting. http://goo.gl/mB0Zxw

Media Watch: Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.16.

Hospital takes on taboo subject: Mistakes made after patients die

MASSACHUSETTS | Stat News (Boston) – 2 May 2016 – The woman's death, one of almost a thousand every year at a major Boston teaching hospital, was nothing unusual, until her body was shipped to the wrong funeral home. The mix-up delayed the funeral, caused the family distress – and helped prompt Beth Israel Deaconess Medical Center to examine how it handles patients' bodies and supports family members after a death. The issue has received little attention nationally, though the National Center for Health Statistics has found that about one-third of deaths in the U.S. occur in general hospitals. The hospital has created a 20-person working group to focus on the aftermath of a patient's death. It's part of a broader effort to reduce "insults to dignity" – mistakes that cause emotional harm, but haven't traditionally been considered medical errors. https://goo.gl/pzm7a0

Law to honor end-of-life care wishes takes effect in Wyoming

WYOMING | *Wyoming Tribune Eagle* (Cheyenne) – 2 May 2016 – The law seeks to improve care by allowing people to fill out a document that says whether they want advanced life-sustaining treatment. This treatment includes such measures as cardiopulmonary resuscitation, ventilation, and long-term artificial nutrition. When completed and signed by a provider, the document constitutes a medical order which can be transferred to different health-care facilities and providers in Wyoming. The document is for people with irreversible medical conditions who are expected to live less than a year and the frail and elderly. http://goo.gl/X8dEzp

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | *Kaiser Health News* | Online – 5 May 2016 – **'Aid-in-dying: Not so easy.'** Starting 9 June, terminally ill Californians with six months or less to live can request a doctor's prescription for medications intended to end their lives peacefully. If that sounds simple, it won't be. California's End of Life Option Act creates a long list of administrative hurdles that both patients and their doctors must clear. For instance, you must make multiple requests for the drugs, orally and in writing, and provide a written attestation within 48 hours of taking the medication (you must be able to take the drugs yourself, without help, to qualify). Two doctors must confirm your diagnosis, prognosis and ability to make medical decisions, and you must prove you're a California resident. http://goo.gl/ueJaTv

- STATE OF NEW YORK | Reuters – 4 May 2016 – **'New York appeals court says doctors can be prosecuted for aiding terminally ill patients' deaths.'** In a setback for the legalization of assisted suicide in New York, a state appeals court ruled doctors who provide aid-in-dying to terminally ill patients can be prosecuted under state penal law. In a unanimous opinion, the Appellate Division ... upheld a lower court decision dismissing a lawsuit that sought to block physicians from criminal liability if they prescribe lethal medication for patients who want to hasten death. http://goo.gl/PjUIMn

International

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

Too many care providers "flying blind" about end-of-life care workforce

U.K. (England) | Care Appointments – 5 May 2016 – A lack of data about palliative care (PC) staff could lead to staff shortages in the next few years, a new report from the National Council for Palliative Care has said.[1] The report ... found a lack of data about staff working in palliative and end of life care (EOLC), making it hard to know if there will be enough staff to meet the rising need for EOLC. Based on the data it did gather, 44% of senior PC nurses were aged over 50 in 2013, and this percentage has risen in each of the last five surveys. http://goo.gl/jbnzul

1. 'Staff prepared to care? Capacity and competence in the end of life care workforce,' National Council for Palliative Care, May 2016. http://goo.gl/HaJJB0

<u>**Elder care in the U.K.**</u>

Quarter of U.K. care homes "at risk of closure"

U.K. | BBC News – 4 May 2016 – More than a quarter of care homes in the U.K. are in danger of going out of business within three years, figures obtained by BBC Radio Four suggest. About 5,000 homes are at risk of closure because they carry too much debt and do not make enough profit to cover loan repayments. On average, care homes make £17,647 in profit before tax... The Department of Health said it was working to make sure care providers had "strong contingency plans." The research ... found individual care homes were borrowing about 61% of the value of the business on average – a figure that amounted to £4 billion across the industry. There are 20,000 care homes in the U.K., operated by 5,871 individual owners who make, on average, about £60,000 profit as operators. http://goo.gl/rKWV9Y.

Noted in Media Watch, 2 May 2016, #460 (p.3):

- U.K. (England & Wales) | LocalGov.com – 25 April 2016 – **'Care home insolvencies increase as sector pushed to "breaking point."'** New research discovered 47 care home operators in England & Wales became insolvent last year, up from 40 the previous year. It also revealed the number of care home businesses becoming insolvent has risen by 34% over three years. The insolvencies are the result of the decline in council spending on care homes. There will be a £2.9 billion annual funding gap in social care by the end of the decade partly the result of the U.K.'s ageing population, which is predicted to rise by 12% between 2015 and 2020. http://goo.gl/cpuK8v

Hong Kong's ageing population must have a bigger say in their end-of-life care

CHINA (Hong Kong) | *The South China Morning Post* (Hong Kong) – 3 May 2016 – Hong Kong enjoys a very low mortality rate and the highest life expectancy rate in the world: in 2014, life expectancy was 81.2 years for men and 86.9 years for women. The city's evolving demographic and social landscapes continue to have profound effects on how we deliver public health care services with limited resources while managing community expectations. According to the latest projections, Hong Kong's population will increase from 7.2 million in 2014 to a peak of 8.2 million in 2043, after which it will fall to around 7.8 million in 2064. Adding to this challenge is the ageing population trend. The proportion of elderly people aged 65 and above is expected to rise markedly, from 15% in 2014 to 33% in 2064. In 2014, 75% of elderly people were suffering from one or more chronic conditions and this figure is on a rising trend while people are living longer. It is vital for the Hospital Authority to reflect on our progress and experiences over the past 25 years, and to use the knowledge as a springboard for meeting challenges and planning for the future. While we remain consistent in our overarching objectives, how we cope with the challenges must be under continual review to ensure we are pursuing the most effective strategies based on the social environment, our available resources and changes in medical technology and practices. http://goo.gl/nTKmBP

Hong Kong Society of Palliative Medicine
http://goo.gl/jEEWbO

Society for the Promotion of Hospice Care
http://goo.gl/RfuFSL

N.B. Noted in the 15 February 2016 issue of Media Watch, #449 (p.11), are additional articles on end-of-life care in China. The country was ranked 71st of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://goo.gl/nuPWIl

Media Watch: Back Issues

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

DNR policies and practices in England

"Unforgivable" failings in end-of-life care revealed as 40,000 dying patients subject to secret "do not resuscitate" orders every year

U.K. (England) | *The Daily Telegraph* – 2 May 2016 – A national audit of dying patients has highlighted a failure by authorities to tell relatives of plans put in place for their loved ones.[1] It is estimated every year, more than 200,000 patients are issued with do not resuscitate orders, instructing doctors not to attempt cardiopulmonary resuscitation if the patient suffers a cardiac arrest or stops breathing. The official audit of 9,000 dying patients, conducted by the Royal College of Physicians, reveals one-in-five families were not informed that a "do not resuscitate" order had been put in place – equivalent to the families of 40,000 patients. The same study showed that in 16% of cases, there was no record of a conversation with the dying patient, or explanation for the lack of one, for the decision to put in place a do not resuscitate order. The audit is part of attempts to overhaul end-of-life care, with the axing of the discredited Liverpool Care Pathway. The procedure – under which food, fluid and medication was routinely withdrawn from patients thought to be close to death – was abolished in 2014 in response to public concern. http://goo.gl/1xnZA3

Care Quality Commission promise reviews of social care, end-of-life care and Mental Health Act

U.K. (England) | *National Health Executive* – 3 May 2016 – The Care Quality Commission's 2016-2017 business plan ... includes overviews of health and social care, end-of-life care, and the implementation of the Mental Health Act, as well as a commitment to complete its inspections of all hospitals and other services in England. http://goo.gl/qLqNGA

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1. 'End of Life Care Audit – Dying in Hospital National report for England 2016,' Royal College of Physicians, May 2016. https://goo.gl/x2qSih

N.B. To download the report scroll down to 'End of Life Care Audit Report March 2016' (at foot of page). https://goo.gl/bCg4UY The audit is the first to be carried out following the official withdrawal of The Liverpool Care Pathway in 2014. The new audit is a more detailed investigation of the care of dying people against five priorities of care established in 'One Chance to Get it Right: Improving People's Experience of Care in the Last Few Days and Hours of Life,' Leadership Alliance for the Care of Dying People, published in June 2014 and noted in Media Watch, 30 June 2014, #364 (p.7). ***BRA***

Selected articles on DNR policies and practices in England

- U.K. (England) | BBC News – 29 June 2015 – **'Do not attempt to resuscitate orders: East trial could go nationwide.'** Legally, doctors do not need patient consent to issue a Do Not Attempt to Resuscitate Orders, but they must have consulted the patient beforehand. The number of DNAR hospital complaints in the East of England has risen from seven in 2012 to forty-five in 2014. [Noted in Media Watch, 6 July 2015, #417 (p.4)] http://goo.gl/fSnCmR

- *BMJ OPEN* | Online – 13 January 2015 – **'Variation in local trust Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policies: A review of 48 English healthcare trusts.'** There was variation in terminology (85% described documents as policies, 6% procedures, and 8% guidelines). Only one quarter of Trusts used the recommended Resuscitation Council record form (or a modification of the form). There was variation in the terminology used, which included DNAR (Do Not Attempt Resuscitation), DNACPR (Do Not Attempt CPR), CPR, and AND (Allow Natural Death). [Noted in Media Watch, 19 January 2015, #393 (p.9)] http://goo.gl/cxZMNM

- U.K. | British Medical Association, Resuscitation Council and the Royal College of Nursing – Accessed 8 October 2014 – **'Decisions relating to cardiopulmonary resuscitation.'** The three organizations have issued new guidance regarding anticipatory decisions about whether or not to attempt resuscitation in a person when their heart stops or they stop breathing. [Noted in Media Watch, 13 October 2014, #379 (p.11)] https://goo.gl/dBQfcz

Cont.

Related

- U.K. (England & Wales) | *The Daily Telegraph* – 5 May 2016 – **'Patients' life-and-death wishes "overlooked amid surging demand."'** Patients who have made clear they do not want to be given life-saving treatment if their condition deteriorates could be being kept alive against their will because of delays in processing paperwork registering their wishes, lawyers have warned. http://goo.gl/QT7lyL

- U.K. (England) | *The Northamptonshire Telegraph* (Kettering) – 4 May 2016 – **'Emergency ambulances being rushed to "do not resuscitate" patients in Northamptonshire.'** Care homes in Northamptonshire are frequently requesting ambulances under blue lights for pensioners who do not want to be resuscitated. The issue has been raised by East Midlands Ambulance Service medical director Bob Winter, who said such a use of precious medics was inappropriate when Do Not Resuscitate notices were in place. Mr Winter. added that care homes were often the culprits because they were not aware of the proper procedure they should follow. http://goo.gl/tjbRW0

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

Health care ethics committees and palliative care services

AMA JOURNAL OF ETHICS (American Medical Association), 2016;18(5):475-478. In 2000, only 24.5% of hospitals [in the U.S.] with more than 50 beds reported having a palliative care (PC) program; the proportion rose to 72.3% in 2013. Due to their shared clinical, rather than research-oriented, focus, health care ethics committees (HCECs) and PC services have more of a functional overlap than do HCECs and institutional review boards. However, the range of cases handled by PC is much narrower than that of health care ethics consultation. Whereas PC cases almost always involve patients with a limited life expectancy, cases referred for health care ethics consultations involve, in addition to terminal illness, ethical issues pertaining to the entire spectrum of clinical medicine. On the other hand, PC has a clinical focus that is much broader than that of ethics committees because it is concerned with so many aspects of a patient's care, such as pain management. Understanding this difference is helpful for health care practitioners, as it can help them determine which service would be more likely to meet the goals of patients, their loved ones, and members of clinical care teams. http://goo.gl/t5dD5d

Health care ethics consultation in the U.S.

This issue of the *AMA Journal of Ethics* is devoted to the theme of health care ethics consultation in the U.S., whether such consultation is performed individually or as part of the work of an organized committee. Contents page: http://goo.gl/Srn3V3

Noted in Media Watch, 5 October 2016, #430 (p.14):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 September 2015 – **'The growth of palliative care in U.S. hospitals: A status report.'** This study demonstrates continued steady growth in the number of hospital palliative care (PC) programs in the U.S.,[1] with almost universal access to services in large U.S. hospitals and academic medical centers. Nevertheless access to PC remains uneven and depends on accidents of geography and hospital ownership. http://goo.gl/h3RAdY

    1. 'America's Care of Serious Illness: 2015 State-By-State Report Card on Access to Palliative Care in Our Nation's Hospitals,' Center to Advance Palliative Care & National Palliative Care Research Center, September 2015. https://reportcard.capc.org/

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

Family anticipatory grief: An integrative literature review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 5 May 2016 – Despite all the investment in research, uncertainty persists in anticipatory grief (AG) literature, concerning its nuclear characteristics and definition. Twenty-nine articles were selected, the majority with samples composed of caregivers of terminally ill patients with cancer. From systematic comparison of data referring to family end-of-life experience emerged 10 themes, which correspond to AG nuclear characteristics: anticipation of death, emotional distress, intrapsychic and interpersonal protection, exclusive focus on the patient care, hope, ambivalence, personal losses, relational losses, end-of-life relational tasks, and transition. For the majority of family caregivers in occidental society, AG is a highly stressful and ambivalent experience due to anticipation of death and relational losses, while the patient is physically present and needed of care, so family must be functional and inhibit grief expressions. The present study contributes to a deeper conceptualization of this term and to a more sensitive clinical practice. http://goo.gl/70JqZA

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 May 2016 – **'A bereavement common assessment framework in palliative care: Informing practice, transforming care.'** This article describes the development of a bereavement assessment framework for the Western Australia Country Health Service Palliative Care Services bereavement program. The framework is grounded in a clearly articulated evidence base, integrating research from the bereavement field that has informed the development of a standardized assessment framework referred to as the bereavement common assessment framework... http://goo.gl/9wH0YC

Medical record quality assessments of palliative care for intensive care unit patients. Do they hatch the perspectives of nurses and families?

ANNALS OF THE AMERICAN THORACIC SOCIETY, 2016;13(5):690-698. Delivering high quality palliative care in the ICU requires assessing key patient-centered domains. However, assessments from different perspectives do not always agree with technical quality of care as measured through chart-based metrics. The authors found deficits across seven domains of technical quality that were not correlated with either nurse or family ratings. Despite care gaps, families were generally satisfied with the care delivered. They conclude that each measurement perspective provides an independent view that can guide quality improvement and innovation work as well as subsequent research. http://goo.gl/dtm5Np

Related

- *ANNALS OF THE AMERICAN THORACIC SOCIETY*, 2016;13(5):595-597. **'Integrating palliative care in the intensive care unit. Evidence gaps and quality gaps.'** As clinicians, administrators and patients place greater value on care processes to support quality of life, there is a corresponding need to ensure those processes to support quality of life are delivered in expected ways. http://goo.gl/bC2IFs

How can we help family carers manage pain medicines for patients with advanced cancer? A systematic review of intervention studies

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 5 May 2016 – Family carers play a significant role in managing pain and associated medicines for people with advanced cancer. Research indicates that carers often feel inadequately prepared for the tasks involved, which may impact on carers' and patients' emotional state as well as the achievement of optimal pain control. However, little is known about effective methods of supporting family carers with cancer pain medicines. Eight studies were included; all had significant methodological limitations. The majority reported improvements in family carer knowledge and/or self-efficacy for managing pain medicines; no effect on patient pain outcomes; and, no adverse effects. It was not possible to discern any association between particular intervention characteristics and family carer outcomes. http://goo.gl/mzRyQd

Cont.

Noted in Media Watch, 21 March 2016, #454 (p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 14 March 2016 – **'Family caregivers' pain management in end-of-life care: A systematic review.'** Pain management was the most identified burden faced by family caregivers in end-of-life caregiving. This review identified themes similar to previous reviews on family caregivers of patients with cancer or in palliative care: inadequate knowledge and assessment skills in pain management, misunderstanding of pain medications, and poor communication with the care team. http://goo.gl/iE15nG

Noted in Media Watch, 29 September 2014, #377 (p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 25 September 2014 – **'Managing end-of-life medications at home – accounts of bereaved family carers.'** Although some support with medications is provided by GPs and nurses in the community, family carers take primary responsibility for drug administration and storage. They report anxiety about giving correct and timely dosages and concerns about keeping the patient comfortable without overdosing them or risking shortening their lives. http://goo.gl/bHWZCx

Medical end-of-life practices among Canadian physicians: A pilot study

CMAJ OPEN (Canadian Medical Association Journal) | Online – 5 May 2016 – The authors were able to successfully modify existing questionnaires designed to measure the prevalence of medical end-of-life practices and the underlying decision-making processes, and to successfully administer them. Consequently, they were able to determine that it is indeed feasible to study these practices in Canada, even those that are currently illegal. Identification of the response rate will be useful for sample size calculations for larger studies. Additional strategies such as longer intervals between contacts and the use of incentives will be required to enhance the participation rate. Such studies are needed to further understanding of how decisions are made before death, to identify potential areas of improvement and training needs, to study the effect of policy changes on medical end-of-life practices and to monitor their developments over time. http://goo.gl/iu4ewD

"Must do CPR??": Strategies to cope with the new College of Physicians & Surgeons of Ontario policy on end-of-life care

CANADIAN JOURNAL OF ANESTHESIA | Online – 28 April 2016 – The College of Physicians & Surgeons of Ontario recently released a new policy, 'Planning for and Providing Quality End-of-Life Care.'[1] The revised policy is more accurate in its consideration of the legal framework in which physicians practice and more reflective of ethical issues that arise in end-of-life care (EOLC). It also recognizes valid instances for not offering cardiopulmonary resuscitation (CPR). Nevertheless, the policy poses a significant ethical and legal dilemma – i.e., if disputes over EOLC arise, then physicians must provide CPR even when resuscitation would fall outside this medical standard of care. While the policy applies in Ontario, it is likely to influence other physician colleges across Canada as they review their standards of practice. This paper explores the rationale for the mandated CPR, clarifies the policy's impact on the medical standard of care, and discusses strategies to improve EOLC within the policy. These strategies include understanding the help-hurt line, changing the language used when discussing cardiac arrest, clarifying care plans during the perioperative period, engaging the intensive care unit team early in goals-of-care discussions, mentoring hospital staff to improve skills in goals-of-care discussions, avoiding use of the "slow code," and continuing to advocate for quality EOLC and a more responsive legal adjudication process. http://goo.gl/B8AKbl

1. 'Planning for and Providing Quality End-of-Life Care,' College of Physicians & Surgeons of Ontario, September 2015. [Noted in Media Watch, 26 October 2015, #433 (p.9)] http://goo.gl/TuQaUE

Advance care planning: U.S. perspective

Medicare and advance planning: The importance of context

THE HASTINGS CENTER REPORT, 2016;46(3):5-6. In January 2016, a long-delayed Medicare change took effect. The Medicare program will now reimburse doctors for time they spend talking with patients about end-of-life care (EOLC). This is the move that Sarah Palin and other Affordable Care Act critics said would authorize government “death panels” to decide whether older Americans should live or die. Today virtually no one buys into Palin’s death panel rhetoric. But many people do think the Medicare change is a big deal. Representative Earl Blumenauer, a Democrat from Oregon who sponsored the original ACA reimbursement proposal, lauded the Medicare provision as “a turning point in EOLC.” Others are not so sure about that. After all, laws promoting advance care planning (ACP) have existed for decades. The federal Patient Self-Determination Act of 1990 and the many court decisions and state laws supporting ACP have had relatively little impact. Similarly, legal recognition of physician orders for life-sustaining treatment as advance planning instruments have not produced the improvements that were predicted. And from a broad perspective, ACP is a small piece of the puzzle. The effort to improve EOLC must take into account the limitations of advance decision-making, as well as the overriding importance of the general standard of care for terminally ill patients. http://goo.gl/k1eT09

Related

- *CREATIVE NURSING*, 2016;22(2):106-111. **‘Perceptions of advance care planning among Latino adults in the community setting.’** Rates of advance care planning (ACP) among Latinos are as low as 10% compared to an average of 26% among adults living in the U.S. Typical American values of autonomy and self-determination that underlie ACP often conflict with the values of group decision-making, fatalism, and respect for hierarchy that influence decision making in the Latino community. http://goo.gl/ID4OpC

Curative and palliative care: The ethical and economic considerations of a person-centered health care paradigm

CONGRESSIONAL HISPANIC CAUCUS INSTITUTE | Online – Accessed 3 May 2016 – The goal of this paper is to empower individuals to understand that they have options for the most vulnerable time of their lives, and to alleviate some of the stigma attached with planning for a good death experience. https://goo.gl/sUFEPD

Relationship between death anxiety and communication apprehension with the dying

INTERNATIONAL JOURNAL OF BIO-SCIENCE & BIO-TECHNOLOGY, 2016;8(2):373-382. Hospice nurses who provide palliative care (PC) have been reported to be under more work-related stress than nurses working in a general work environment, because the former, besides performing the basic duties of a nurse, take care of patients facing death. Nurses who take care of terminally ill patients experience loss of will and burnout while they watch their patients foreboding death and preparing to be separated from his or her family and society complaining of death anxiety, fear, and severe pain. In previous studies, the higher the death anxiety of a nurse was, the higher his or her terminal care stress was, and the lower the degree of his or her communication with his or her patient and the patient’s family was. Therefore, to lower nurses’ terminal care stress and enhance their communication with their patients and their patients’ families, they must be able to overcome their death anxiety. However, many studies have indicated that nurses have never received professional education on palliative care (PC) and have difficulties in dealing with death. http://goo.gl/l9aazD

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

Regulating and paying for hospice and palliative care: Reflections on the Medicare hospice benefit

JOURNAL OF HEALTH POLITICS, POLICY & LAW | Online – 28 April 2016 – Hospice began as a social movement outside of mainstream medicine with the goal of helping those dying alone in unbearable pain in health care institutions. The National Hospice Study [1980-1983], undertaken to test whether hospice improved dying cancer patients' quality of life while saving Medicare money, found hospice care achieved comparable outcomes to traditional cancer care and was less costly as long as hospice lengths of stay were not too long. In 1982, before study results were final, Congress created a Medicare hospice benefit under a capitated *per diem* payment system restricting further treatment. In 1986 the benefit was extended to beneficiaries living in nursing homes. This change resulted in longer average lengths of stay, explosive growth in the number of hospices, particularly of the for-profit variety, and increases in total Medicare expenditures on hospice care. An increasingly high proportion of beneficiaries receive hospice care. However, over 30% are served fewer than seven days before they die, while very long stays are also increasingly common. These and other factors raise quality concerns about hospice being disconnected from the rest of the health care system. http://goo.gl/OJmC4s

Institute for Clinical & Economic Review

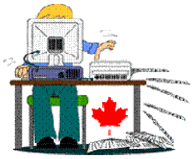
Palliative Care in the Outpatient Setting: A Comparative Effectiveness Report Final Report

This April 2016 review focuses on specific clinical benefits reported in terms of patient quality of life, mood, symptom burden, patient satisfaction, health care resource utilization, psychosocial outcomes, caregiver impact, and survival, as an outcome that might indirectly result from other intervention outcomes. http://goo.gl/qcNC5D

Related

- *JOURNAL OF THE AMERICAN GERIATRICS ASSOCIATION*, 2016;64(4):723-730. **'Impact of hospice use on costs of care for long-stay nursing home decedents.'** In this analysis of costs to Medicare and Medicaid for long-stay nursing home decedents, use of hospice did not increase costs in the last 6 months of life. Evidence supporting cost savings is sensitive to analyses that vary the time period before death. http://goo.gl/Y72D7L

- *POLICY POLITICS NURSING PRACTICE* | Online – 4 May 2016 – **'Social, economic, and political issues affecting end-of-life care.'** Historical perspectives on end-of-life care are presented to enhance understanding of why some clinicians and patients seem to resist change to current practices. End-of-life care issues related to advanced technology utilization, societal expectations of care, clinical practices, financial incentives, palliative care services, and policy reforms are discussed. http://goo.gl/QmND0R



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

Rural district nursing experiences of successful advocacy for person-centered end-of-life choice

JOURNAL OF HOLISTIC NURSING | Online – 5 May 2016 – Choices in care during the end stages of life are limited by the lack of resources and access for rural people. Nursing advocacy based on the holistic understanding of people and their rural communities may increase the opportunity for choice and improve the quality of care for people living and dying at home. In two stages of data collection, rural district nurse informants ... were given the opportunity to reflect on successful advocacy and to write about their experiences before undertaking further in-depth exploration in interviews. They defined successful advocacy as "caring" that empowers people in the "big and small" personal goals important for quality of life. The concepts described that enable successful advocacy were organized into a network with three main themes of "willing" investment in holistic person-centered care, "knowing" people and resources, and feeling "supported." http://goo.gl/cr7QlZ

> **N.B.** Noted in the 18 April 2016 issue of Media Watch, #459 (p.4), are additional articles on end-of-life care in rural communities and remote regions.

Midwifing the end of life: Expanding the scope of modern midwifery practice to reclaim palliative care

JOURNAL OF MIDWIFERY & WOMEN'S HEALTH | Online – 5 May 2016 – There is a current movement across the U.S. to incorporate palliative care (PC) and hospice care into both the home setting and the inpatient setting. Through their education and training, certified nurse-midwives/certified midwives are well equipped to serve as hospice and PC clinicians. Current midwives, skilled in assisting women and families through the transition of pregnancy to motherhood, can use their education and skills to help individuals and their families through the transition from life to death. The similarities between these states of the human experience (pregnancy to birth and terminal illness to death) allow for a fluidity between these experiences from the midwife perspective. The many parallels between these two elements of the human condition include stress, anxiety, and pain. http://goo.gl/DQp1Eq

Noted in Media Watch, 16 November 2015, #436 (p.17):

- *THE PRACTICING MIDWIFE*, 2015;18(10):18-23. **'From pregnancy to palliative care: Advancing professional midwifery practice?'** Historically midwives may have not considered palliative care (PC) as a part of their professional role. Enhanced technologies and antenatal screening have broadened the boundaries of care. However do midwives truly embrace the philosophy of PC into their practice? http://goo.gl/46W3px

Opportunities to maximize value with integrated palliative care

JOURNAL OF MULTIDISCIPLINARY HEALTHCARE | Online – 5 May 2016 – Palliative care (PC) involves aggressively addressing and treating psychosocial, spiritual, religious, and family concerns, as well as considering the overall psychosocial structures supporting a patient. The concept of integrated PC removes the either/or decision a patient needs to make: they need not decide if they want either aggressive chemotherapy from their oncologist or symptom-guided PC, but rather they can be co-managed by several clinicians, including a PC clinician, to maximize the benefit to them. One common misconception about PC, and supportive care in general, is that it amounts to "doing nothing" or "giving up" on aggressive treatments for patients. Rather, PC involves very aggressive care, targeted at patient symptoms, quality-of-life, psychosocial needs, family needs, and others. Integrating PC into the care plan for individuals with advanced diseases does not necessarily imply that a patient must forego other treatment options, including those aimed at a cure, prolonging of life, or palliation. Implementing interventions to understand patient preferences and to ensure those preferences are addressed, including preferences related to palliative and supportive care, is vital in improving the patient-centeredness and value of surgical care. Given our aging population and the disproportionate cost of end-of-life care, this holds great hope in bending the cost curve of health care spending, ensuring patient-centeredness, and improving quality and value of care. https://goo.gl/qO6H9C

Cont.

Related

- *RESEARCH & THEORY FOR NURSING PRACTICE*, 2016;30(2):91-103. **'Unravelling the tensions between chronic disease management and end-of-life planning.'** An increasing appreciation for the burden that chronic conditions represent for people and for societies has triggered an evolving body of popular and professional conceptualizations of the nature of the chronic disease challenge. In this article, the authors trace the trajectory of thinking about chronic illness care, surfacing underlying assumptions and drivers that have shaped current dominant models of service delivery. They note significant gaps in these conceptualizations, especially with respect to the reality that many chronic conditions are life-limiting. http://goo.gl/jykezT

Coaching family caregivers to become better problem solvers when caring for persons with advanced cancer

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE, 2016;12(1-2):63-81. Family caregivers of persons with advanced cancer often take on responsibilities that present daunting and complex problems. Serious problems that go unresolved may be burdensome and result in negative outcomes for caregivers' psychological and physical health and affect the quality of care delivered to the care recipients with cancer, especially at the end of life. Formal problem-solving training approaches have been developed over the past several decades to assist individuals with managing problems faced in daily life. Several of these problem-solving principles and techniques were incorporated into ENABLE (Educate, Nurture, Advise, Before Life End), an "early" palliative care telehealth intervention for individuals diagnosed with advanced cancer and their family caregivers. A hypothetical case resembling the situations of actual caregiver participants in ENABLE that exemplifies the complex problems that caregivers face is presented, followed by presentation of an overview of ENABLE's problem-solving key principles, techniques, and steps in problem-solving support. Though more research is needed to formally test the use of problem-solving support in social work practice, social workers can easily incorporate these techniques into everyday practice. http://goo.gl/aATOcR

Journal of Social Work in End-of-Life & Palliative Care

The focus of the current issue is on family caregiving: Contents page: http://goo.gl/TIDJ8s

Related

- *GERIATRIC NURSING* | Online – 2 May 2016 – **'Supporting home health aides through a client's death: The role of supervisors and co-workers.'** Findings of this study showed that just over one third of home health aides [i.e., study participants] felt they could turn to their supervisors for support and one fifth could turn to their coworkers. Even fewer sought support. Those who did found it to be extremely helpful, in particular when the support came from supervisors. http://goo.gl/kZIxx3

What does "futility" mean? An empirical study of doctors' perceptions

MEDICAL JOURNAL OF AUSTRALIA, 2016;204(8):318. Doctors' conceptions of futility [i.e., study participants] focused on the quality and prospect of patient benefit. Aspects of benefit included physiological effect, weighing benefits and burdens, and quantity and quality of life. Quality and length of life were linked, but many doctors discussed instances in which benefit was determined by quality of life alone. Most described assessing the prospects of achieving patient benefit as a subjective exercise. Despite a broad conceptual consensus about what futility means, doctors noted variability in how the concept was applied in clinical decision making. More than half the doctors also identified treatment that is futile but nevertheless justified, such as short term treatment that supports the family of a dying person. There is an overwhelming preference for a qualitative approach to assessing futility, which inevitably involves variability in clinical decision making. Patient benefit is at the heart of doctors' definitions of futility. Determining patient benefit requires discussing with patients and their families their values and goals as well as the burdens and benefits of further treatment. https://goo.gl/gU7Q0v

Cont.

Related

- *MEDICAL JOURNAL OF AUSTRALIA*, 2016;204(8):289. **'Editorial: Futility and utility.'** Futility is an absolute term; an intervention is either futile or it is not. If it is declared futile, a treatment should be suspended. This finality of the decision that a treatment is futile can disturb both doctor and patient. To the doctor it may bring a sense of failure and disappointment that they have nothing more to offer; the patient may experience despair and abandonment. Both have relied on treatments developed by advanced technologies that held great promise and built high expectations. Neither will wish to fracture a relationship established during the times when therapy achieved effective responses, and this may encourage the doctor to continue a treatment, even one now judged to be futile. https://goo.gl/lwfPFJ

Pediatric palliative care in the U.S.

Staff efficiency trends among pediatric hospices, 2002-2011

NURSING ECONOMICS, 2016;34(2):82-89. This study provides the first examination of staff efficiency trends among pediatric hospices. Although staff efficiency demonstrated large variability from 2002 to 2011, the general trend in efficiency was a 36% decline in efficiency from 2003 to 2010. This means, on average, pediatric hospices had higher operating expenses and used more capacity, but greater amounts of these resources did not translate into greater outputs as measured by visits per patient. The study also highlights the crucial role pediatric hospice nurse managers play in developing effective workforce strategies that allow for responsive changes to workload fluctuations. Due to the associations between efficiency, regulation and growth, nurse leaders' abilities to develop effective strategies are more imperative than ever to ensure quality end-of-life care for children and their families. http://goo.gl/I6ZWbw

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 May 2016 – **'Assessment of the spiritual needs of primary caregivers of children with life-limiting illnesses is valuable yet inconsistently performed in the hospital.'** The majority (16/24) of caregivers [i.e., study participants] desired inquiry about religious and spiritual (R/S) needs by the medical team. Fewer than half (12/25) had these needs assessed. No subjects were uncomfortable with questions regarding R/S needs. Only 35% (8/23) specifically wanted a physician to inquire about R/S needs. Subjects whose R/S needs were assessed perceived higher levels of support from the medical team... http://goo.gl/EsSs4Z

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *MONASH BIOETHICS REVIEW* | Online – 3 May 2016 – **'The right to die: Beyond academia.'** The world's first legal euthanasia death occurred in the Australian City of Darwin on Sunday 22 September 1996 when Bob Dent ended his life under the Northern Territory's short-lived Rights of the Terminally Ill Act 1995. Dent's death intensified argument about euthanasia in Australia, transforming the debate from a textbook discussion in social ethics into a vigorous and divisive social dispute. The day before he ended his life, Dent dictated a letter, written down by his wife. This description of his experience with terminal illness is graphic – the letter, his last effort to bring the plight of those living with terminal illness to public consciousness. In this paper the author outlines issues from the perspective of those, who like Bob Dent, the choice to die with dignity is personal and urgent. Rather than approach the issue purely from the theoretical, academic debate therefore, she presents aspects that are largely unknown unless the experience of life-denying symptoms becomes real. From these aspects, dilemmas and consequences emerge that are not framed through the academic debate and in this way, the author argues for the possibility of a framework that could change the law. http://goo.gl/UwVNGV

Cont.

- *UNIVERSITY OF NEW SOUTH WALES LAW JOURNAL*, 2016;39(1):1-46. **'(Failed) voluntary euthanasia law reform in Australia: Two decades of trends, models and politics.'** In 2013 alone, three Bills seeking to legalise voluntary euthanasia (VE) or physician-assisted suicide (PAS) were introduced into different state parliaments; and two issues and background papers were written to inform those debates. In June 2014, the Australian Greens Senator and now leader of that party ... released an exposure draft of a Bill for consultation which would enable an Australian resident to receive assistance to die. In May 2015, the Victorian Legislative Council directed the Standing Committee on Legal and Social Issues to report on the need for laws to allow citizens to make "end-of-life choices" (a reference that is sufficiently broad to include VE and PAS). Most recently, in December 2015 ... a Bill [was introduced] into the Senate seeking reform in this field. VE and PAS also became a critical policy platform for political parties during the 2013 federal election. Discussion of these issues remains prevalent in the media. https://goo.gl/pgbXdZ

Worth Repeating

The withholding of truth when counselling relatives of the critically ill: A rational defence

CLINICAL ETHICS, 2008;3(1):42-45. In cases of sudden, life-threatening illness where the chance of survival appears negligible to the admitting physician, this opinion is not always revealed during the initial meeting with the patient's relatives. Reasons as to why this withholding of the truth may be acceptable are explored through review of available evidence and personal reflection. Factors identified include: the importance of hope in families' coping mechanisms, and the instinct to preserve it; the fallibility of physicians' perception of poor prognosis in the early phase of illness; the need to avoid large swings in relatives' expectations that occur when patients appear to rally during initial resuscitation; and the adverse effect that an atmosphere of hopelessness can have on the provision of medical care. A strategy for the staged disclosure of information and the confirmation of hopelessness is then described, the aim being to find a compromise between providing a true opinion about a patient's prognosis, and regard for the opposing factors described. http://goo.gl/IFMTB4

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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6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://goo.gl/0Q1Mh4

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/5d1I9K

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

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