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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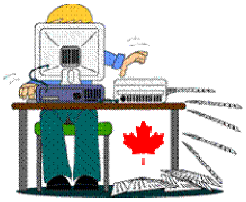

Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to Specialist Publications and 'A qualitative analysis of a healthcare professional's understanding and approach to management of spiritual distress in an acute care setting' (p.12), in *Journal of Palliative Medicine.*

Canada

Take care of caregivers: Doctors of BC report

BRITISH COLUMBIA | *The Vancouver Sun* – 18 October 2016 – A report by the Doctors of BC[1] ... calls on the provincial ministry of health to recognize the unpaid efforts of family, particularly in seniors' care. The policy paper ... notes that about eight million Canadians – one million in this province – provide in-home support to a loved one that keeps them out of hospitals or long-term care. Yet surveys have found one-third of them are distressed by those demands. Vancouver palliative care specialist Dr. Romayne Gallagher says the trend toward much shorter hospital stays for a variety of conditions means many patients can't keep up without extra help. "As technology has advanced and we've tried to reduce the number of hospital days for people, we've downloaded a lot of the work to family caregivers. You used to go into hospital the night before surgery, you used to stay in hospital longer. Now stays are shorter, more care goes on at home and we haven't really acknowledged that," says Gallagher. https://goo.gl/1q41xk

1. 'Circle of Care: Supporting Family Caregivers in B.C.,' A Policy Paper, Doctors of BC, October 2016. https://goo.gl/mv9dz1

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 21 October 2016 – **'Why some doctors may seem to know very little about assisted death.'** Although it is hard to get a clear picture of what is happening across Canada, anecdotal reports suggest that access to medical assistance in dying (MAID) has been inconsistent since the federal government passed the law in June that established the criteria for its use. Many hospitals have developed procedures to handle the requests that come from patients under their care, including putting together internal lists of physicians willing to take part in MAID, says Sally Bean, a policy adviser and ethicist at the Sunnybrook Health Sciences Centre. However, Catholic hospitals and health-care institutions have essentially opted out of MAID, citing their objection to assisted death on religious grounds. https://goo.gl/Xs93DU

Cont.

- QUEBEC | *The Montreal Gazette* – 21 October 2016 – **'Dying with dignity: Quebec paves way, but critics point to problems.'** [Marie-Paule] Laliberté was among at least 166 Quebecers who, since 10 December 2015, have resorted to what the provincial government calls "end-of-life care" and what Ottawa refers to as voluntary euthanasia. The common term for such deaths is physician-assisted suicide, but that's a misnomer. Technically, that term defines a patient who is prescribed lethal doses of medication by a doctor and who then self-administers the drugs. The Quebec law does not permit doctor-assisted suicide, only what is known in French as "aide médicale à mourir" – meaning it's the physician who injects the fatal cocktail of medications, not the patient, and only under strict conditions. https://goo.gl/NqWYvl

- BRITISH COLUMBIA | *The Globe & Mail* – 18 October 2016 – **'B.C. doctor takes stand against Catholic hospital's assisted dying policy.'** A Vancouver Island doctor is resigning from the ethics committee at a local Catholic hospital because it refuses to offer assisted dying on site, a stand that he says is unnecessarily causing critically ill patients more suffering as they are transferred to facilities dozens of kilometres away. Jonathan Reggler, a general physician who makes daily patient visits to St. Joseph's Hospital in Comox, said he knew the facility, like other faith-based hospitals across the country, had developed a "strict" policy of transferring patients asking for assisted deaths. But it wasn't until recently, he says, that such patients began streaming into St. Joseph's – and transferring out – after a federal law came into force 17 June that legalized medically assisted dying for patients whose suffering is intolerable and whose deaths are reasonably foreseeable. https://goo.gl/GgN9Ll

- MANITOBA | CBC News (Winnipeg) – 18 October 2016 – **'Manitoba to change laws to prepare for doctor-assisted dying.'** The Progressive Conservatives introduced amendments to two pieces of legislation ... that would change current rules to clarify that doctor-assisted dying is not homicide or suicide. Current rules are not in compliance with the Supreme Court ruling from earlier this year that allowed for medical assistance in dying, said Justice Minister Heather Stefanson... The amendments also include a component to allow for regulatory changes on collecting and sharing assisted dying records in anticipation of federal legislation to come. If passed, the legislation will change Manitoba's Fatalities Inquiries Act so doctor-assisted death isn't deemed a suicide or homicide. In turn, that change will remove the current need for the Chief Medical Examiner to lead an inquest into the death, which is legally required for all suicides and homicides. https://goo.gl/YMahOV

U.S.A.

The VSED exit: A way to speed up dying, without asking permission

THE NEW YORK TIMES | Online – 21 October 2016 – In end-of-life circles, this option is called VSED (usually pronounced VEEsed), for voluntarily stopping eating and drinking. It causes death by dehydration, usually within seven to 14 days. To people with serious illnesses who want to hasten their deaths, a small but determined group, VSED can sound like a reasonable exit strategy. Unlike aid with dying, now legal in five states, it doesn't require governmental action or physicians' authorization. Patients don't need a terminal diagnosis, and they don't have to prove mental capacity. They do need resolve. "It's for strong-willed, independent people with very supportive families," said Dr. Timothy Quill, a veteran palliative care physician at the University of Rochester Medical Center. He was speaking at a conference on VSED, billed as the nation's first, at Seattle University School of Law this month. What the gathering made clear was that much about VSED remains unclear. Is it legal? For a mentally competent patient, able to grasp and communicate decisions, probably so, said Thaddeus Pope, director of the Health Law Institute at Mitchell Hamline School of Law in St. Paul, Minnesota. His research has found no laws expressly prohibiting competent people from VSED, and the right to refuse medical and health care intervention is well established. https://goo.gl/EF7H8b

Specialist Publications

'Assessment of the wish to hasten death in patients with advanced disease: A systematic review of measurement instruments' (p.13), in *Palliative Medicine*.

Cont.

Noted in Media Watch 17 October 2016, #483 (p.14):

- *NARRATIVE INQUIRY IN BIOETHICS*, 2016;6(2):109-113. **'Voluntary stopping eating and drinking: Death with dignity or without?'** Twelve compelling narratives [in this issue of Narrative Inquiry in Bioethics] represent a dramatic groundswell of attention to the practice of VSED.[1] In a review of these narratives, numerous statements of significance emerged along with common ethical themes which bring to light matters that might otherwise remain idle. As such, integrity and autonomy become paramount while, unfortunately, logical fallacies like that of the slippery slope argument are asserted. https://goo.gl/sTN2h9

    1. Journal contents page: https://goo.gl/4JWuve

Doctors' guidance on how to talk to terminally ill teens

CBS NEWS | Online – 17 October 2016 – Speaking to terminally ill patients about their disease is always difficult, but the conversation becomes even more delicate when a child or teen is involved. To shield their children from a devastating diagnosis, some parents may go so far as to keep their child in the dark about the severity of their illness. "Out of fierce love, they wish to protect their child from the immeasurable amount of pain they, the parents, are experiencing from the knowledge of their child's pending death," Dr. Lisa Humphrey, medical director of Palliative Care at Nationwide Children's Hospital, told CBS News. But a [recent] paper [see sidebar] … argues that while that strategy may be less painful initially, when it comes to adolescents or teens with a life-threatening illness, telling the truth is the best option. https://goo.gl/OSyKXs

Specialist Publications

'Ethics, emotions, and the skills of talking about progressing disease with terminally ill adolescents: A review' (p.9), in *JAMA Pediatrics.*

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW JERSEY | Associated Press – 21 October 2016 – **'Assisted suicide bill passes New Jersey Assembly.'** Terminally ill residents with prognoses of less than six months to live would be permitted to obtain prescriptions for drugs to end their lives under a bill just approved by the New Jersey Assembly. Its future in the Senate remains uncertain. https://goo.gl/dT06wl

International

End-of-life care in Australia

Fresh call for improved palliative care in residential aged care

AUSTRALIA | *Australian Ageing Agenda* – 21 October 2016 – Advocates say that latest official figures show not all aged care residents who need palliative care (PC) are receiving it. New data ... released this week showed that of the 231,500 residents with completed Aged Care Funding Instrument (ACFI) appraisals in 2014-2015, one in 25, or 9,144 residents, had an appraisal indicating the need for PC. These figures highlighted the "extremely concerning" gap between the need among residential aged care residents for palliative care and the levels of recognition and response to this need, said Odette Waanders, CEO of Palliative Care Victoria. She pointed to a 2011 government review in the U.K. which found "a minimal estimate of 37% of deaths" required PC, which if applied to the Australian figures would suggest that "at a minimum you would expect the number of permanent residents with a completed ACFI appraisal would be at least double what it was in 2014-2015." https://goo.gl/hFcV6C

1. 'Palliative care in residential aged care,' Australian Institute of Health & Welfare, Australian Government, October 2016. https://goo.gl/ahxu44

Cont.

Noted in Media Watch 30 May 2016, #464 (p.6):

- AUSTRALIA | ABC News – 24 May 2016 – **'Ageing population blamed for 80% increase in palliative care spending.'** In 2013-2014, $5.3 million in palliative care (PC) medicine services was paid from the Medicare Benefits Schedule, up from $3 million five years prior, according to a new report by the Australian Institute of Health and Welfare (AIHW).[1] Spending remained relatively steady in 2014-2015, at just over $5.3 million. The report also revealed a nation-wide increase in the number of people admitted to both private and public hospitals to receive PC. But in all states and territories public hospitals were responsible for the majority of palliative care patients. http://goo.gl/odQDIK

  1. 'Palliative Care Services in Australia 2016,' Australian Institute of Health & Welfare, May 2016. http://goo.gl/aA60BK

End-of-life care in Japan

Ministry considers program to share end-of-life wishes of elderly with ER doctors, paramedics

JAPAN | *The Japan Times* (Tokyo) – 17 October 2016 – Aging Japan has increasing numbers of elderly terminally ill patients, and doctors have no choice but to try to revive them following collapse when they aren't sure whether the patients would want to be resuscitated. The current system does, however, respect the requests of close relatives, such as the spouse of an incapacitated patient, to end life support. The Health, Labor & Welfare Ministry recognizes that some people may not want to be put on life support. It will back a system … that allows nurses, paramedics and doctors who provide home care for elderly patients to share information about their patients and, crucially, makes a record of their end-of-life wishes. The Japanese Society for Emergency Medicine is considering drafting guidelines that would allow paramedics not to attempt resuscitation if requested by the patient or their doctor. https://goo.gl/XuEG7u

Noted in Media Watch 26 October 2015, #433 (p.10):

- *GAN TO KAGAKU RYOHO* (Japanese Journal of Cancer & Chemotherapy), 2015;42(9):1087-1089. **'Availability of palliative care units and outpatient services in Japan: A nation-wide survey.'** Eighteen percent of survey respondents reported patients undergoing anti-cancer treatment are not able to apply for admission... Only 10% reported that all patients who expressed a desire for admission were actually able to be admitted. https://goo.gl/zWnidl

Standard for terminally ill patients devised, scope of hospice services likely to expand

대한의학회
Korean Academy of Medical Sciences

SOUTH KOREA | Korean Broadcasting System World Radio (Seoul) – 17 October 2016 – The Academy ... unveiled standards determining patients at the terminal and agonal stages. It marks the first time for the medical sector to present, in detail, a criterion for terminally ill patients who are suffering from maladies other than cancer. Patients suffering from acute or chronic diseases will be categorized as being in the agonal stage if their conditions worsen and death is expected. Patients with chronic critical illnesses will be regarded being in the agonal stage if discussions begin on whether or not to suspend life-sustaining treatment. Based on the standards, the scope of hospice care, which is currently only provided to terminal cancer patients, will be expanded to include patients with illnesses such as cirrhosis, COPD and AIDS in the end stage starting from next August. The Academy also presented related standards for five diseases, including chronic heart disease, cerebrovascular disease and late stage dementia, claiming that the illnesses should be included among those eligible to receive hospice care. https://goo.gl/fmM4wo

Noted in Media Watch 20 June 2016, #467 (p.13):

- *KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE*, 2016;19(2):99-108. **'Hospice palliative care in South Korea: Past, present, and future.'** Hospice palliative care in Korea has developed steadily since its introduction in 1965. Currently, it is targeted only towards terminal cancer patients and their families, and the national health insurance scheme covers only inpatient hospice care for said patients. http://goo.gl/Aa6FL3

Home care in England

Home care services should give people more responsibility to manage their medicines, says National Institute for Health & Care Excellence

U.K. (England) | National Institute for Health & Care Excellence (NICE) – 17 October 2016 – In a new draft guideline being published for public consultation NICE has set out how staff can help adults who are receiving social care support at home to manage their medicines safely and correctly. The latest report from the Care Quality Commission into the state of the care system in England said home care services that were rated as outstanding achieved this mainly because staff took enough time to have meaningful discussions with people. NICE says staff should discuss with each individual their needs and preferences and record decisions about what support they need in their personal home care plan. If a home care worker needs to offer support, the draft guideline outlines how to approach this. It covers areas such as ordering prescriptions, administering medicines and what records to take. https://goo.gl/sLzAyK

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

End-of-life care in Australia

Elderly dying with dignity: Sydney doctors trial plan to help patients decide

AUSTRALIA (New South Wales) | *The Daily Telegraph* (Sydney) – 15 October 2016 – Elderly patients suffering chronic illnesses will be told when they can expect to die so they can avoid pointless treatments and long hospital stays. Many older people spend their final days undergoing procedures such as chemotherapy, X-rays and blood tests that do little more than make this time painful and lonely. Professor of Intensive Care at the University of New South Wales, Ken Hillman, a leading authority on intensive care, has developed a way to estimate whether a patient is at high, moderate or low risk of dying in the months after diagnosis, based on medical history. The intervention model, which will be introduced at Liverpool Hospital next year subject to funding and ethics approval, will give doctors the confidence to be honest about death and provide patients the information they need to make choices about end-of-life care. A diagnostic checklist includes 29 criteria – such as frailty, advanced chronic illness and frequent hospital admissions – although only five or more need to be present for doctors to consider an intervention. It is based on a review of decades of data on the lifespans of elderly people who presented to hospital with age-related issues. https://goo.gl/zCp7Ut

N.B. Additional articles on the accuracy of prognosis in the context of end-of-life care noted in Media Watch 17 October 2016, #483 (p.7) and 29 August 2016, #477 (p.10).

Specialist Publications

An analysis of common ethical justifications for compassionate use programs for experimental drugs

BMC MEDICAL ETHICS | Online – 18 October 2016 – In this paper the arguments given in favour of compassionate use or expanded access programs have been put into three broad categories. Compassionate use programs could be justified by claiming that they allow for a fair distribution of experimental drugs to patients with no other means to access the drug. Such compassionate use programs could also be justified by appealing to the ethical principle of beneficence. Terminally ill patients, one could argue, stand to benefit greatly and risk relatively little (as they are already facing inevitable death). In this case even a small benefit (e.g., a small chance of recovery or extended life-expectancy) outweighs the (small or non-existent) risks. Last, for the justification of compassionate use or expanded access programs appeals could be made to autonomy. Terminally ill patients are autonomous and are able to give free and informed consent. If terminally ill patients, the argument goes, freely take on the risks of an experimental drug for the chance of great benefit, who are we to refuse them. The author argues that – currently – appeals to justice and beneficence are highly problematic. https://goo.gl/jHLAey

> **N.B.** Additional articles on the "right-to-try" unapproved drugs noted in Media Watch 17 October 2017, #483 (pp.3-4).

"Massive potential" or "safety risk"? Health worker views on telehealth in the care of older people and implications for successful normalization

BMC MEDICAL INFORMATICS & DECISION MAKING | Online – 13 October 2016 – In this study, rural health clinicians and residential aged care staff were enthusiastic about the potential of telehealth to enhance healthcare access for their clients. Experience and exposure to telehealth technology appeared to aid normalization, particularly among health workers providing services in less-rationed urban areas. However, changes in the way new interventions are conceptualised and perceived in relation to existing, conventional services may be more critical to attitudinal change and the normalization process. It will be important to show that telehealth is a feasible alternative to more traditional service delivery if we are to achieve widespread coherence and cognitive participation among staff expected to facilitate implementation and embedding of new telehealth services. The attention paid to necessary changes to organizational, systemic and technological infrastructure, as well as training and skill recalibration are also highlighted in this study as important factors to successful normalization of telehealth services in rehabilitation, aged and palliative care. https://goo.gl/YSYVx3

Related

- *RURAL AND REMOTE HEALTH* | Online – 17 October 2016 – '**Telehealth services in rural and remote Australia: a systematic review of models of care and factors influencing success and sustainability.**' This review collates information regarding the telehealth services in Australia and describes models of care and characteristics of successful and sustainable services. We identified a wide variety of telehealth services being provided in rural and remote areas of Australia. There is great potential to increase this number by scaling up and replicating successful services. This review provides information for policy makers, governments and public and private health services that wish to integrate telehealth into routine practice and for telehealth providers to enhance the sustainability of their service. https://goo.gl/Gw4XST

Noted in Media Watch 21 September 2015, #428 (p.17):

- *TELEMEDICINE & E-HEALTH* | Online – 11 September 2015 – '**A systematic review of telehealth in palliative care: Caregiver outcomes.**' All the studies measuring caregiver quality of life showed no significant difference after telehealth interventions. The caregiver anxiety score decreased after the intervention in two studies, and one reported significantly reduced caregiver burden. Although feasibility of caregiver satisfaction with the telehealth intervention was not the focus of this review, most studies reported such findings. https://goo.gl/MOxlKc

Reasons for transferral to emergency departments of terminally ill patient: A French descriptive and retrospective study

BMC PALLIATIVE CARE | Online – 21 October 2016 – The authors observed the most frequent reasons/diagnosis for presentations were generalized weakness and social isolation. These are not medical illnesses, but rather descriptions of health or social states. Another French study [in 2002] reached the same conclusion about end of life in emergency departments. This study is a retrospective one, so the authors could not evaluate the impact of families' exhaustion or fear of death at home, which can play an important role in the decision to transfer patients to an emergency department. Other authors point out the difficulty in evaluating extra medical background. The results show that the most frequent reasons are not acute medical events, but mostly degradation of chronic complex situations, for which home care is too difficult. Social isolation is not an acute or unpredictable event, the real problem being the degradation of a chronic situation that was initially manageable at home. https://goo.gl/RCrfH2

Using linked administrative and disease-specific databases to study end-of-life care on a population level

BMC PALLIATIVE CARE | Online – 18 October 2016 – Linking and accessing various routinely collected population-level databases involves challenges, but offers substantial opportunities to study patterns in the use, quality and costs of end-of-life care both in the full population and for specific diagnostic groups. This study has identified that it is possible to combine data from different databases in order to obtain a rich database for such analysis, including information about all reimbursed care and medication as well as disease, demographic, socio-economic and environmental information. While some aspects may be specific to the Belgian context, this study has a much broader application as most developed countries collect similar population-level databases. The process described can be a helpful aid for researchers in these countries to compile similar data and eventually develop an international comparative end-of-life care research agenda using administrative health care data. https://goo.gl/gna7nU

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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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.

"What makes it worth the investment to say it?" – Care experiences of lesbian, gay, bisexual and/or trans people facing life-limiting illness: A qualitative interview study

BMJ SUPPORTIVE & SUPPORTIVE CARE, 2016;6(3):388. People who identify as lesbian, gay, bisexual and/or trans (LGBT) have increased risk of certain life-limiting illnesses. Evidence suggests they may not receive the care and support they need towards the end of life and into bereavement. Forty LGBT people were interviewed: 20 patients, 6 informal carers, 14 bereaved informal carers; 21 described cancer experiences, 16 non-cancer, 3 co-morbid cancer/non-cancer; and mean age was 60 (range 27–94). Five main themes emerged: 1) Palliative care needs that may require additional or different consideration for LGBT people; 2) Communicative or service level barriers and stressors, including heteronormative assumptions, and homophobic/transphobic behaviours; 3) Internalised or invisible barriers and stressors, including fears, or experiences, of discrimination; 4) Which shape individuals' preferences for disclosure and exploration of identity; and, 5) Communicative or service level facilitators to accessing care and support. Despite recent legislative change for LGBT people, experiences of discrimination and exclusion in advanced disease and palliative care are still evident. A resource, co-designed with the LGBT community, is being piloted, and learning events being delivered nationally. https://goo.gl/OELgVf

COMPASSION IN DYING.
SUPPORTING YOUR CHOICES

Your treatment and care:
Planning ahead for the LGBT community

OPENING DOORS LONDON

Produced in the U.K. by Compassion in Dying in collaboration with Opening Doors London, this new publication is designed specifically for the LGBT community. https://goo.gl/Yp9pVR

N.B. Additional articles on end-of-life care for LGBT communities noted in Media Watch 23 May 2016, #463 (p.3) and 8 February 2016, #448 (p.16).

A systems approach to improving care for all bereaved families

DIMENSIONS OF CRITICAL CARE NURSING, 2016;35(6):315-322. Bereavement services for families are an established part of hospice and palliative care (PC). However, patients also die in the acute care and long-term care environments. Often, hospice is not involved, creating a potential gap in care. This article recounts a journey to improve care for all families of deceased patients, despite the presence or absence of hospice. A PC clinical nurse specialist led a quality improvement team, which used a systems thinking approach to develop and implement a downloadable bereavement booklet for families. Expected and unexpected outcomes are discussed for this replicable project. https://goo.gl/uNs4Pd

Noted in Media Watch 27 June 2016, #468 (p.9):

- *AMERICAN JOURNAL OF CRITICAL CARE*, 2016;25(2):110-117. **'Bereavement services offered in adult intensive care units in the U.S.'** Most [survey] respondents reported that their ICUs did not offer bereavement follow-up services, and many barriers were noted. When bereavement follow-up care was offered, it was mainly informal (e.g., condolence cards, brochures). ICUs in hospitals with palliative care (PC) were almost eight times more likely to provide bereavement support than were ICUs in hospitals without PC. http://goo.gl/48KIL7

Cont.

Noted in Media Watch 11 July 2016, #470 (p.12):

- *JOURNAL OF ADVANCED NURSING* | Online – Accessed 9 July 2016 – **'Grief and loss in older people residing in nursing homes: (Un)detected by nurses and care assistants?'** A common denominator was the necessity to further develop a supportive and multidisciplinary grief care policy ingrained in the existing care culture. Suggested components: 1) Centring attention on non-death-related loss and the cumulative nature of loss in residents; 2) Building capacity by means of reflective practices; and, 3) The importance of self-care strategies for nursing staff. http://goo.gl/GR7zRR

A staggered edge: End-of-life care in patients with severe mental illness

GENERAL HOSPITAL PSYCHIATRY | Online – 20 October 2016 – Approximately 6% of the [U.S.] population suffers from severe persistent mental illness (SPMI) ... that is chronic or recurrent, requires ongoing intensive psychiatric treatment, and significantly impairs functioning. SPMI is associated with premature mortality across all age groups. Despite common misassumptions that most individuals with SPMI die prematurely from violence and suicide, the majority of excess mortality is due to chronic diseases such as cancer, heart disease, chronic obstructive pulmonary disease, and dementia. https://goo.gl/5vzDG1

Noted in Media Watch 1 August 2016, #473 (p.11):

- *BMC PSYCHIATRY* | Online – 22 July 2016 – **'Palliative psychiatry for severe persistent mental illness as a new approach to psychiatry? Definition, scope, benefits, and risks.'** Despite psychiatrists' efforts to prevent mental illness and to promote recovery, some patients will develop "severe persistent mental illness" (SPMI). These represent a particularly vulnerable population, at risk of either therapeutic neglect or overly aggressive care. As proposed, a new variation on an old approach – the explicit application of palliative care principles to psychiatric illnesses – has the potential to improve quality of care, person-centredness, and autonomy for these patients. http://goo.gl/M1GRkY

Ethics, emotions, and the skills of talking about progressing disease with terminally ill adolescents: A review

JAMA PEDIATRICS | Online – 17 October 2016 – The authors reviewed the ethical justifications for and against truth-telling, and considered the published ethical and practice guidance, as well as the perspectives of patients, parents, and clinicians involved in these cases. They also explored particular challenges with respect to the cultural context, timing, and content of conversations at the end of adolescents' lives. In most cases, clinicians should gently, but persistently engage adolescents directly in conversations about their disease prognosis and corresponding hopes, worries, and goals. These conversations need to occur multiple times, allowing significant time in each discussion for exploration of patient and family values. While truth-telling does not cause the types of harm that parents and clinicians may fear, discussing this kind of difficult news is almost always emotionally distressing. The authors suggest some "phrases that help" when clinicians strive to deepen understanding and facilitate difficult conversations with adolescents, parents, and other family members. https://goo.gl/v91oh0

Palliative medicines for children –
a new frontier in paediatric research

JOURNAL OF PHARMACY & PHARMACOLOGY | Online – 13 October 2016 – Most medicines used in children receiving palliative care are old and off-patent drugs, developed for and tested in an adult population. Many are not available in suit-able formulations for administration to children,. There are often no age-related profiles of adverse drug reactions or for safe dosing. https://goo.gl/LCJHLD

Cont. next page

Related

- *JOURNAL OF PAEDIATRICS & CHILD HEALTH* | Online – 13 October 2016 – **'Hope and despair.'** Physicians caring for dying children who are no longer curable face difficult problems regarding counselling the family about prognosis and management. They may be uncertain of how soon the child will die, what will be the quality of the child's life, with or without medications, and how much to involve older children in treatment decisions. Physicians are often reluctant to tell parents their child is dying, and if asked why they say because they are afraid to take away hope. They fear that where there is no hope there is only despair. https://goo.gl/C7pxuK

- *SUPPORTIVE CARE IN CANCER* | Online – 17 October 2016 – **'Communication preferences of pediatric cancer patients: Talking about prognosis and their future life.'** The American Academy of Pediatrics recommends healthcare providers communicate information to patients in a truthful and developmentally appropriate manner. However, there is limited guidance about how to translate these recommendations into clinical practice. Overall, participants [i.e., study participants] wanted medical information to be provided to them by their healthcare providers and wanted to be direct participants in medical con-versations. However, many participants displayed some ambivalence or conveyed conflicting wishes for prognostic information. https://goo.gl/0EYbNK

Noted in Media Watch 8 February 2016, #448 (p.12):

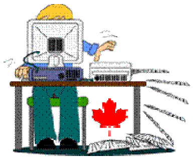
- *PEDIATRIC BLOOD & CANCER* | Online – 29 January 2016 – **'Communication skills training in pediatric oncology: Moving beyond role modeling.'** Parents, patients, and providers report substantial communication deficits. Poor communication outcomes may stem, in part, from insufficient communication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

Rationing conscience

JOURNAL OF MEDICAL ETHICS | Online – 12 October 2016 – Decisions about allocation of limited healthcare resources are frequently controversial. These decisions are usually based on careful analysis of medical, scientific and health economic evidence. Yet, decisions are also necessarily based on value judgements. There may be differing views among health professionals about how to allocate resources or how to evaluate existing evidence. In specific cases, professionals may have strong personal views (contrary to professional or societal norms) that treatment should or should not be provided. Could these disagreements rise to the level of a conscientious objection? If so, should conscientious objections to existing allocation decisions be accommodated? https://goo.gl/npU73M

Noted in Media Watch 20 April 2015, #406 (p.10):

- *THE HASTINGS REPORT*, 2015;45(2):15-19. **'Why it's not time for health care rationing.'** Discussion of health care rationing, which was hotly debated in the nineties, has become much more muted. Is health care rationing *passé*? The author contends that debates about health care rationing have waned not because the need to ration has dwindled nor because ethical debates about how or whether to ration have been resolved. https://goo.gl/tv3OQ2



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

Estimating the global need for palliative care for children: A cross-sectional analysis

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 17 October 2016 – This work builds on previously published methods developed by the International Children's Palliative Care Network, UNICEF, and WHO and tested in three African countries. The findings show estimated need for children's palliative care (PC) ranged from almost 120 per 10,000 children in Zimbabwe to slightly more than 20 per 10,000 in the U.K. Overall, among the over 21 million with conditions that will benefit annually from a PC approach, more than 8 million need specialized children's PC worldwide. The estimation of the need for children's PC is a critical step in meeting the needs of children with life-threatening conditions and provides a sound platform to advocate for closure of the unacceptably wide gaps in coverage. https://goo.gl/d1zpN9

World Health Organization

Setting up a palliative care service for children

The recently published 'World Health Organization's Planning & Implementing Palliative Care Services: A Guide for Programme Managers' includes a section (beginning on p.29) on setting up a palliative care service for children. Included is a case example of a partnership in South Africa between St. Nicholas Children's Hospice, Bloemfontein, and the country's formal health services. https://goo.gl/aXVTsC

Selected articles with a global perspective on pediatric palliative care

- *ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 14 September 2015 – **'Children's palliative care in low- and middle-income countries.'** This paper reviews the status of children's palliative care (PC) services in low- and middle-income countries highlighting examples of best practice among service models in Malawi, Indonesia and Belarus. [Noted in Media Watch 21 September 2015, #428 (p.8)] http://goo.gl/gy6DpL
- *BMC PALLIATIVE CARE* | Online – 4 August 2015 – **'Priorities for global research into children's palliative care: Results of an International Delphi Study.'** Research priorities identified included: 1) Children's understanding of death and dying; 2) Managing pain in children where there is no morphine; 3) Funding; 4) Training; and, 5) Assessment of the WHO two-step analgesic ladder for pain management in children. [Noted in Media Watch 10 August 2015, #422 (p.13)] https://goo.gl/Xu8Voq
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 September 2014 – **'Reported availability and gaps of pediatric palliative care in low- and middle-income countries: A systematic review of published data.'** Most pervasive gaps were in national health system support (unavailable in 7 of 17 countries), specialized education (unavailable in 7 of 19 countries), and comprehensive opioid access (unavailable in 14 of 21 countries). [Noted in Media Watch 22 September 2014, #376 (p.12)] https://goo.gl/A0sGf7

N.B. See also: 'Children's Palliative Care,' 2015 Quality of Death Index: Ranking Palliative Care across the World' (p.44), Economist Intelligence Unit, October 2015. [Noted in Media Watch 2 November 2015, #434 (p.15)] https://goo.gl/hH57ek

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.

Continuous deep sedation: A proposal for performing more rigorous empirical research

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 13 October 2016 – This paper proposes a provisional definition of two types of continuous deep sedation (CDS). As there are two types of CDS proposed in world-wide literature, the authors recommend to prepare two types of intervention protocol for CDS: "continuous deep sedation as a result of proportional sedation" (gradual CDS), and "continuous deep sedation to rapidly induce unconsciousness" (rapid CDS). In addition, they recommend researchers characterize study patients' general condition using a validated prognostic tool, Prognosis in Palliative Care Study predictor model-A. Using this conceptual framework, we can compare the outcomes following the same exposures among homogenous patients throughout the world. https://goo.gl/M2vLVy

Noted in Media Watch 11 July 2016, #470 (p.13):

- *CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 1 July 2016 – '**A systematic literature review on the ethics of palliative sedation: An update (2016).'** In a 2010 review of palliative sedation, the following areas were identified as lacking in consensus: 1) Inconsistent terminology; 2) Its use in non-physical suffering; 3) The ongoing experience of distress; and, 4) Concern that the practice of palliative sedation may hasten death. This review looks at the literature over the past 6 years and provides an update on these outstanding concerns. http://goo.gl/qWxPgk

Noted in Media Watch 12 May 2014, #357 (p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 May 2014 – **'Palliative sedation: Analysis of international guidelines and position statements.'** Guidelines, etc., have been published by the American College of Physicians-American Society of Internal Medicine (2000), Hospice & Palliative Nurses Association (2003), American Academy of Hospice & Palliative Medicine (2006), American Medical Association (2008), Royal Dutch Medical Association (2009), European Association for Palliative Care (2009), National Hospice & Palliative Care Organization (2010), and National Comprehensive Cancer Network (2012). http://goo.gl/lUy00q

A qualitative analysis of a healthcare professional's understanding and approach to management of spiritual distress in an acute care setting

JOURNAL OF PALLIATIVE MEDICINE | Online – 18 October 2016 – Essentially all participants spoke of the high importance of spirituality and spiritual care, particularly for those facing end of life. However, the majority of healthcare professionals (HCPs) had difficulty in formulating definitions/descriptions of spiritual care and spiritual distress, in marked contradistinction to the importance they ascribed to this aspect of holistic care. Almost universally provision of spiritual care was seen as critical, yet in the domain of chaplaincy/dedicated spiritual care providers. Reasons frequently cited for HCP's reluctance to provide such care themselves included time available, lack of training and expertise, and the sense that others could do a better job. Despite spirituality being highlighted as important to care, few HCPs felt able to provide this, raising questions around how such care can be encouraged and developed in busy acute care settings. https://goo.gl/pr1hPT

Nurses' experiences of spiritual communication with seriously ill children

JOURNAL OF PALLIATIVE MEDICINE | Online – 18 October 2016 – Nurses' spiritual conversations with children revealed that children question God and the reason for their illness, have a desire to talk about the afterlife as a way of understanding their limited lifespan, and to share descriptions of an afterlife, in these cases described as heaven. Nurses conveyed the importance of being present and engaging in spiritual communication with children. Communication training is needed and should prepare providers to respond to a child's spiritual questioning, assist parents when the child initiates discussion about the afterlife, and help parent and child understand the spiritual meaning of their illness. https://goo.gl/oOJnhx

Cont.

Noted in Media Watch 17 October 2016, #483 (p.13):

- *OPEN JOURNAL OF NURSING* | Online – Accessed 13 October 2016 – **'The hole in holistic patient care.'** Contributing factors to the "hole in holistic patient care" include: 1) Blurring of boundaries in the language and definitions of "spirituality" and "religion"; 2) Insufficient attention to definitions of spirituality and spiritual distress; 3) Confusion and role conflict with professional identity among disciplines related to responsibility for spiritual care; and, 4) Insufficient education and skill development for nurses and other healthcare professionals in the assessment, intervention and appropriate referral of patients experiencing spiritual distress. https://goo.gl/yjqgcO

N.B. Additional articles on "spiritual care" in the context of end-of-life care noted in Media Watch 12 September 2016, #479 (p.12).

Do doctors gain more confidence from a longer palliative medicine posting?

JOURNAL OF PALLIATIVE MEDICINE | Online – 17 October 2016 – Doctors report inadequate training and lack confidence in providing palliative care (PC). Although PC training improves self-assessed competence, it is not known whether the duration of a palliative medicine (PM) posting affects the extent of improvement in confidence. A one-month posting may suffice in training a doctor in basic end-of-life (EOL) medical issues, but a longer posting duration results in a greater improvement in the doctors' confidence across different domains of PC, particularly in EOL communication. Trainee doctors in specialties that frequently deal with terminally ill patients should undertake a longer posting in PM to be further equipped with greater confidence to better care for these patients. https://goo.gl/VasGZj

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 18 October 2016 – **'Palliative care bedside teaching: A qualitative analysis of medical students' reflective writings after clinical practices.'** A short bedside clinical experience in palliative care (PC), encouraging student reflection, provides a deeper understanding of PC and even of core medicine values. The data the authors gathered cannot explain only new skill acquisition, but seems to suggest a life-changing personal experience for the student. https://goo.gl/sYD5Zl

Assessment of the wish to hasten death in patients with advanced disease: A systematic review of measurement instruments

PALLIATIVE MEDICINE | Online – 19 October 2016 – A total of 50 articles involving assessment of the wish to hasten death were included. Eight concerned instrument validation and were evaluated using COnsensus-based Standards for the selection of health Measurement INstruments criteria. They reported data for between two and seven measurement properties, with ratings between fair and excellent. Of the seven instruments identified, the Desire for Death Rating Scale or the Schedule of Attitudes toward Hastened Death feature in 48 of the 50 articles. The Schedule of Attitudes toward Hastened Death is the most widely used and is the instrument whose psychometric properties have been most often analysed. Versions of the Schedule of Attitudes toward Hastened Death are available in five languages other than the original English. https://goo.gl/tgJmM4

Worth Repeating

'Responding to desire to die statements from patients with advanced disease: Recommendations for health professionals' in *PALLIATIVE MEDICINE*, 2006;20(7):703-710. [Noted in Media Watch 17 March 2014, #349 (p.16, under 'Worth Repeating')] http://goo.gl/SwYhiG

N.B. Additional articles on the desire to hastened death noted in Media Watch 7 March 2016, #452 (pp.8-9)

Home-based end-of-life care in Sweden

Patients' experiences of care and support at home after a family member's participation in an intervention during palliative care

PALLIATIVE & SUPPORTIVE CARE | Online – 17 October 2016 – Increasing numbers of interventions aimed at supporting family members in palliative care (PC) have been described and evaluated. It is not known whether and how these interventions actually affect the care or support provided to a patient, even though it has been suggested that family members would be likely to provide better care and support and thus allow for positive experiences for patients. However, this has not been studied from the perspective of the patients themselves. [In this study) patients' experiences were represented by three themes: "safe at home," "facilitated and more honest communication," and "feeling like a unit of care." Patients felt that their needs were better met and that family members became more confident at home without risking their own health. https://goo.gl/OJFS5i

Noted in Media Watch 25 July 2016, #472 (p.10):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 22 July 2016 – **'Experiences of security and continuity of care: Patients' and families' narratives about the work of specialized palliative home care teams.'** Experiences of security are fostered through the 24/7 availability of the team, sensitivity and flexibility in meeting patients' and families' needs, and practical adjustments to enable care at home. Experiences of continuity of care are fostered through the team's collective approach, where the individual team member knows the patients and family members, including their whole situation, and cares about the little things in life as well as caring for the family unit. http://goo.gl/UwaBrh

Noted in Media Watch 21 December 2015, #441 (p.17):

- *SCANDINAVIAN JOURNAL OF PRIMARY HEALTH CARE* | Online – 10 December 2015 – **'"It is not the fading candle that one expects": General practitioners' perspectives on life-preserving versus "letting go" decision-making in end-of-life home care.'** Many GPs are willing to provide end-of-life home care for their patients. Disruptive medical events, however, threaten the prospect of a peaceful end-phase and death at home and force the GP either to maintain the patient's quality of life for the time being or recognize the event as a step to life closure... https://goo.gl/d9JApZ

Oncologists' communication about end of life: The relationship among secondary traumatic stress, compassion satisfaction, and approach and avoidance communication

PSYCHO-ONCOLOGY | Online – 17 October 2016 – Despite the importance of communicating on this topic, many oncologists avoid these conversations. Oncologists [i.e., survey respondents] reported high levels of secondary traumatic stress and high compassion satisfaction. Scores on the approach and avoidant communication scales were in the mid-range of the scale. Lower reports of secondary traumatic stress and higher compassion satisfaction were associated with higher approach communication strategies: however, only higher secondary traumatic stress was associated with higher avoidant communication strategies. The authors' findings indicate that there is an association between emotional factors and approach communication ... [and] ... clinical implications in designing effective communication skills training. https://goo.gl/LZ63tB

Noted in Media Watch 12 September 2016, #479 (p.10):

- *FAMILY PRACTICE* | Online – 1 September 2016 – **'Interprofessional communication between oncologic specialists and general practitioners on end-of-life issues needs improvement.'** [Among study participants] interprofessional communication of end-of-life (EOL) issues usually proceeded using the patient as intermediary. This functioned well, but only if three essential conditions were met: 1) The specialist being realistic to patients about limits of treatment; 2) Informing the GP adequately; and, 3) The GP being proactive in initiating EOL issues in time. http://goo.gl/huZl6x

Chemotherapy

The role of palliative care in the last month of life in elderly cancer patients

SUPPORTIVE CARE IN CANCER | Online – 13 October 2016 – The purpose of our study is to evaluate the administration of chemotherapy in the last month of life (CLML) and to evaluate the impact of the palliative care consult (PCC) in the elderly patients. This study enrolled 231 patients that fulfilled the eligibility criteria. CLML was administered in 91 patients (39.4%) among which 43 patients (47.3 %) had their treatment within the last 2 weeks of life. Seventy-seven patients (33.3%) had a PCC with a median duration of follow up of 13 days (range 2-56 days). Overall, PCC failed to decrease CLML administration, the duration of hospitalization, and ICU admissions. However, CLML administration decreased by 69% among patients that had their PCC before receiving treatment... PCC also led to a change in the pattern of treatment administered in the last month of life with less cytotoxic therapy ... and higher rates of oral agents being prescribed... https://goo.gl/nDDJON

Related

- *INTERNAL MEDICINE JOURNAL* | Online – 17 October 2016 – **'Use of palliative chemotherapy in patients aged 80 years and over with incurable cancer: experience at 3 Sydney cancer centres.'** One quarter of patients 80 years and older received first-line palliative chemotherapy. Despite most receiving a modified dose, one third were hospitalised during treatment. These findings highlight the need for careful clinical assessment and selection of older cancer patients for chemotherapy. https://goo.gl/OaEuXA

Selected articles on chemotherapy at the end of life

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 16 February 2016 – **'Chemotherapy use in the months before death and estimated costs of care in the last week of life.'** Half of the patients [studied] were receiving chemotherapy four months before death. Given evidence of limited benefit and potential harm of chemotherapy for end-stage cancer patients, the cost-effectiveness of such care is questioned... [Noted in Media Watch 22 February 2016, #450 (p.13)] http://goo.gl/RG3aqX

- *JAMA ONCOLOGY* | Online – 23 July 2015 – **'Chemotherapy use, performance status, and quality of life at the end of life.'** Although palliative chemotherapy is used to improve quality of life for patients with end-stage cancer, its use did not improve quality of life near death (QOD) for patients [i.e., study participants] with moderate or poor performance status and worsened QOD for patients with good performance status. [Noted in Media Watch 27 July 2015, #420 (p.4)] http://goo.gl/Z1Cgijj

- *CANCER* | Online – 11 February 2015 – **'Patient beliefs that chemotherapy may be curative and care received at the end of life among patients with metastatic lung and colorectal cancer.'** A third of the patients [i.e., study participants] recognized chemotherapy was "not at all" likely to cure their cancer. Such patients were no less likely than other patients to receive end-of-life chemotherapy... [Noted in Media Watch 23 February 2015, #398 (p.10)] http://goo.gl/5Vhp4y

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *ACTA PAEDIATRICA* | Online – 11 October 2016 - **'Physician-assisted dying for children is conceivable for most Dutch paediatricians, irrespective of the patient's age or competence to decide.'** Most paediatricians [i.e., survey respondents] said performing physician assisted dying (PAD) on request was conceivable (81%), independent of the patient's age and whether the patient or parent(s) requested it. The paediatricians interviewed felt a duty to relieve suffering, irrespective of the patient's age or competency to decide. When this was not possible through palliative care, PAD was seen as an option for all patients who were suffering unbearably, although some paediatricians saw parental agreement and reduced life expectancy as prerequisites. https://goo.gl/8Wn7TY

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/aNcShR

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

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

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

Asia

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

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

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): 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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Barry R. Ashpole
Guelph, Ontario CANADA

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