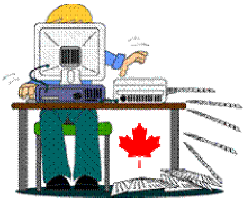
Media Watch...

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.*

27 May 2019 Edition | Issue #615



Compiled & Annotated by Barry R. Ashpole

> ***The term "informal" suggests "casual, unstructured, unofficial care – pleasant but not essential"; today's caregivers would tell you they find this term invalidating and that there is absolutely nothing "informal" or unessential about the care they provide.***
>
> **'Words matter: The language of family caregiving' (p.12), in *Journal of the American Geriatric Society*.**

Canada

Does geography matter in mortality? An analysis of potentially avoidable mortality by remoteness index in Canada

STATISTICS CANADA | Online – 15 May 2019 – The avoidable mortality rate is a key indicator of overall health and health care utilization. However, the avoidable mortality rate may differ by the relative remoteness of a community. Avoidable mortality rates specific to remote areas cannot be investigated unless there is a clear geographic classification of remoteness. This research uses a newly developed remoteness index to explore the geographic variability of avoidable mortality in Canada. Despite the tremendous amount of ongoing research, the mechanism of urban-rural health disparities is not fully understood in Canada. Although rural and remote location in itself may not necessarily lead to poor health, it may influence other socioeconomic, environmental and occupational health determinants. There is noticeable heterogeneity within and between rural communities in Canada in terms of socioeconomic and geographic characteristics. However, in general, people who live in rural communities have limited access to health care services and have worse health outcomes than their urban counterparts. This may lead to disproportionate mortality rates between urban and rural communities. **Download/view at:** http://bit.ly/2LTK9nS

Noted in Media Watch 15 April 2019 (#610, p.7):

- *JOURNAL OF HEALTH SERVICES RESEARCH & POLICY* | Online – 10 April 2019 – '**Awareness as a dimension of healthcare access: Exploring the case of rural palliative care provision in Canada.**' This analysis identifies awareness-associated barriers to delivering rural palliative care (PC) services, along with suggestions for improving service delivery from the perspective of local healthcare providers. Identified barriers to awareness and suggestions on how to enhance this awareness, and ultimately PC delivery, corresponded with three key themes: 1) Limited PC knowledge/education; 2) Communication; and, 3) Coordination. A thorough understanding of these as well as the connections between them, may help enhance how rural PC is delivered in the future. **Abstract:** http://bit.ly/2Z7ubcj

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N.B. Additional articles on PC in rural and remote regions of Canada noted in 25 February 2019 issue of Media Watch, #603, p.7.

Noted in Media Watch 18 February 2019 (#602, p.7):

- *BMC PALLIATIVE CARE* | Online – 14 February 2019 – **'Cultural safety strategies for rural Indigenous palliative care: A scoping review.'** The review of peer-reviewed and grey literature about Indigenous palliative care (PC) in rural and small-town settings in Canada, the U.S., New Zealand, and Australia revealed various strategies to improve the relevance and cultural appropriateness of PC for Indigenous clients. Two types of recommendations emerged, those aligned with a culturally competent framework, and those that were more oriented towards cultural safety. Although search was focused on rural Indigenous populations, because of the lack of specificity to rural contexts of recommended activities these initiatives are likely applicable to other contexts. **Full text:** http://bit.ly/2EcF6ZO

N.B. Additional articles on PC for the Indigenous peoples of Canada noted in 4 June 2018 issue of Media Watch, #566, p.9.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | *The Montreal Gazette* – 23 May 2019 – **'Some Quebec doctors still resisting assisted dying, commission chair says.'** One out of two doctors who have turned down requests for medical assistance in dying by terminally-ill patients have probably done so without justification under the Quebec law, says the head of the province's commission on end-of-life care. "It's 50-50," Dr. Michel Bureau told *The Montreal Gazette* in an interview. "Are there some doctors who are too strict in the application of the criteria? We have observed this (attitude) in several cases." Despite the progress made in implementing the so-called dying with dignity law, some physicians continue to resist carrying out assisted dying, although in fewer numbers than when the legislation came into effect on 10 December, 2015, Bureau added. The latest report by the commission does not specifically address the problem of physicians who are flouting the law. Instead, the report includes statistics on the "non-administration" of assisted dying. For the first 28 months of the provincial law, 2,462 Quebecers made requests for physician-assisted dying. Of that number, doctors conducted the procedure on 1,632 individuals, delivering lethal intravenous infusions to patients who met specific criteria. http://bit.ly/2YMy6KS

U.S.A.

Trends in cancer and heart disease death rates

CENTERS FOR DISEASE CONTROL & PREVENTION | National Vital Statistics Reports – 22 May 2019 – Cancer death rates for middle-aged adults aged 45-64 declined by 19% from 1999 to 2017, whereas heart disease death rates declined by 22% from 1999 to 2011 and then increased 4% from 2011 to 2017. The cancer death rate was always higher than the heart disease death rate from 1999 to 2017, and was 37% higher in 2017. For non-Hispanic white and non-Hispanic black men and women, cancer death rates declined over the 1999-2017 period, whereas heart disease death rates declined and then increased since 2009 for non-Hispanic white men and women, and since 2011 for non-Hispanic black men and women. Hispanic men and women experienced different trends than their non-Hispanic white and black counterparts – both cancer and heart disease death rates for this group had periods of decline and stability. **Download/view at:** http://bit.ly/2JzQinb

Specialist Publications

'Improving advanced care planning through Physician Orders for Life-Sustaining Treatment (POLST) expansion across the U.S.: Lessons learned from state-based developments' (p.7), in *American Journal of Hospice & Palliative Medicine*.

'Improving critical care for Americans with terminal illness' (p.14), in *The Lancet Respiratory Medicine*.

Inclusive care at the end of life: The LGBTQ+ experience

KAISER HEALTH NEWS | Online – 21 May 2019 – For a generation of lesbian, gay, bisexual, transgender and queer (LGBTQ+) people who lived through unprecedented social change, getting older poses new challenges. When it comes to seeking elder care, concerns about lack of services, discrimination, neglect and even abuse threaten to reverse recent progress. What are the hurdles to quality care that face growing numbers of aging LGBTQ+ people? By 2030, an estimated 7 million LGBTQ+ people in the U.S. will be older than 50, and as many as 4.7 million will be seeking care and services. This panel discussion is aimed at people who may be part of the LGBTQ+ community – as well as their loved ones and their caregivers. Panelists talked about what quality care for elder LGBTQ+ individuals looks like, what types of overt and covert discrimination they may face and the documented concerns of the community revealed in recent research. also heard how two longtime hospice experts are facing end-of-life issues in a personal way. http://bit.ly/2HLann7

N.B. Additional articles on end-of-life care for LGBTQ+ people noted in 10 December 2018 issue of Media Watch, #593, p.4 & p.14.

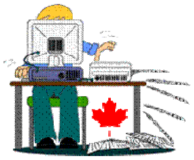
The good that can come when we stop seeing cancer as a battle to win or lose

CALIFORNIA | *The Los Angeles Times* – 19 May 2019 – When Alex Trebek, the longtime 'Jeopardy' host, revealed to the world that he'd been diagnosed with Stage 4 pancreatic cancer this spring, his statement echoed the words of many patients I've treated. "I'm going to fight this," Trebek promised. "I plan to beat the low survival statistics for this disease." Though I mourned his diagnosis, I also winced at his use of the familiar language of "fighting" and "beating" cancer. As a palliative care physician, I know patients can find it empowering to describe their approach to illness as a battle. But others have shown me that the language of "fighting" a disease or "giving up" is a toxic binary. It divides the sick into winners and losers – those who beat cancer and those whom cancer beats. This militaristic approach to sickness is perhaps rooted in the notion that our personal outlook on disease can change our biological outcomes. But in my experience, these words just as often stand in the way of honest, vulnerable conversations about fear and anxiety, and the peace and dignity most people want as an illness worsens. For some, fighting words are armor that doubles as a veil. https://lat.ms/2JsJjwf

Noted in Media Watch 4 March 2019 (#604, p.4):

- IRELAND | *The Irish Times* (Dublin) – 25 February 2019 – **'Let's stop the war talk when it comes to cancer.'** The modern use of military terminology in medicine received a boost when, in 1971, the then U.S. president Richard Nixon publicly declared "war" on cancer and referred to it as a "relentless and insidious enemy." It has evolved pretty much unchecked since then. We speak to patients about "killer cells" and "magic bullets" We refer to "beating illness" and remind people to "keep up the good fight." Whatever else, don't give in. It's a blunt message: cancer will "beat you" because you lack courage. This is absolutely unfair to most patients. http://bit.ly/2Vjw17i

N.B. Additional articles on the use of metaphors in relation to "combating" life-limiting or life-threatening illness, notably in cancer, noted in 4 February 2019 issue of Media Watch, #600, p.5.



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://bit.ly/2RPJy9b

International

European Association for Palliative Care Atlas of Palliative Care in Europe 2019

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Online – Accessed 24 May 2019 – Responses were received from 321 experts from 94% (51/54) of European countries. The survey identified 6,388 specialised services for adults … and a variety of programmes specific to palliative care (PC) for children in 38 countries: home care teams, hospital programmes and hospices. Most countries have established legal frameworks for the provision of PC, with specific laws reported in eight countries and other laws or decree-laws present in 63% of the countries. Twenty-nine nations have a process of specialisation in palliative medicine for physicians and PC has been included in the undergraduate curricula of medical and nursing schools in 43% of the countries with variations in the number of teaching hours and clinical practice. Full professors have been reported in medical schools in 14 countries and in nursing schools in five. The integration of PC into different fields is noticeable. Although only 12/34 countries have systems to identify patients in need of PC at the primary level, the majority of countries provide PC in the last month of life. PC is being integrated into oncology and clinical trials on early integration of PC in the course of the oncological disease registered in 10 countries. Eight reference cardiology centres providing PC were also identified and the presence of PC trained staff in long-term care facilities is increasingly common (14/19 countries). Volunteers are active throughout Europe and eight countries report over 1,000 registered PC volunteers while others even report the existence of volunteer-led hospices. The professional vitality of the discipline is demonstrated by the rise of national PC associations in 41/51 countries. **Download/view at:** http://bit.ly/2whaYrF

Specialist Publications

'Advance directives in European long-term care facilities: A cross-sectional survey' (p.9), in *BMJ Supportive & Palliative Care*.

'How to talk with dying patients and their families after disasters and humanitarian crises: A review of available tools and guides for disaster responders' (p.10), in *International Journal of Humanitarian Action*.

Things I wish I knew about dying to support my dad

AUSTRALIA | Australian Broadcasting Corporation (Adelaide) – 22 May 2019 – He'd had cancer for a long time but I still wasn't ready for this. On his second day in palliative care he started to lose his grip on this reality. Normally sharp, witty and alert, he went into a dream-like state speaking of the past. His face went grey and gaunt. I really felt like he was dying. I panicked and asked for a doctor to do something to help him. After some tests they finally gave him a saline drip which brought back his kidney function and he became instantly more coherent, wondering where he was and how he had arrived there. I didn't know this at the time, but the drip would give him another two months of life during which he was transferred to a hospice and suffered a slow process of deterioration in a place he never wished to die. It was only recently when I was speaking with a death doula (also known as an end-of-life consultant) that the distressing and confusing time began to make more sense. Had any of us been more informed about the dying process, perhaps we could have more readily accepted that my dad was dying. Perhaps we could have decided not to intervene, instead leaving him to go quickly, just days before his 70th, when we were all there to see him off. These are the things I wish I had known when my dad was dying. And some of them are things I intend to do now to prepare for my own death. https://ab.co/2Qliw5N

Alms race: The search for housing fit for the end of life

U.K. | *The New Statesman* – 22 May 2019 – Balancing the differing care needs of the elderly, the infirm and those approaching the end of life, has become an ethical and financial minefield. The borders between the care of the elderly and "end of life" care remain strictly demarcated – attracting differential status and funding – even though both are part of the same "continuum of need," to use a phrase from the late philosopher Mary Warnock. This makes no sense at all given that, as American physician and writer Atul Gawande suggests … "most of us will spend significant periods of our lives too reduced and debilitated to live independently." Two trends are clear. There is growing disillusionment with institutionalised care homes ("God's waiting rooms"), and this is now producing a political movement towards "ageing in place" programmes, where people are cared for at home as long as possible; both trends can be seen across Europe… The rationale for home-based care is as much financial as ethical, given the cost to the public purse of residential care. In the U.K. local authorities pay on average £600 per week for a care home place, £800 per week for a nursing home place, and the cost to the National Health Service for an elderly patient to occupy a bed in a general hospital (where many old people spend their last months) is in the region of £2,000 per week. http://bit.ly/2X1sLif

Your hospice is fighting a financial black hole

U.K. (Scotland) | *The Daily Record* (Ayr) – 22 May 2019 – The Ayrshire Hospice is in a cash crisis, battling a financial black hole of more than half a million pounds. Staff are being asked to take voluntary redundancy or reduce hours in a bid to thwart compulsory job cuts. The dire finance issue has been caused because the Board agreed a cost of living pay rise, including allowing the charity to become a Scottish Living wage employer. Staff will be paid 2.8% more this year and 2.95% next year. The hospice has a staff of 189, backed by a massive group of 525 loyal volunteers. The latest financial accounts show it turned over £7.8 million, a fraction up . Wages and pensions cost £5.7 million – three staff are paid over £100,000 a year. Hospices across the U.K. are under financial pressure. http://bit.ly/2WUo6yt

Never return home: Rise in palliative care patients dying in hospital

AUSTRALIA (New South Wales) | *The Sydney Morning Herald* – 21 May 2019 – Rising numbers of palliative care (PC) patients are dying in hospitals despite the majority wanting to spend their final days at home, national data shows.[1] The rate of patients admitted to hospital for PC is rising faster than any other type of hospital admission, according to the latest Australian Institute of Health & Welfare (AIHW) report. PC-related hospitalisations rose by over 25.6%, from just under 62,000 to 77,369 between 2012-2013 and 2016-2017, the report found. Over the same period, hospitalisations overall rose by 17.6%. Dying is increasingly becoming institutionalised, with more than half of PC hospitalisations ending with the patient's death in 2017-2018 (51.6%) - up from 42.1% in 2012-2013. Yet surveys have consistently shown the majority of Australians want to die at home.[2] The data prompted the AIHW to urge the population to plan their end-of-life care and discuss their wishes with their loved ones and health professionals. Up to 70% said they wanted to die at home, yet 15% do so, Australian Bureau of Statistics and AIHW data shows. http://bit.ly/2waftEl

Australian Government
Australian Institute of Health and Welfare

1. 'Palliative care services in Australia,' Australian Institute of Health & Welfare, May 2019. **Download/view at**: http://bit.ly/2QekeFX

2. 'Non-beneficial treatments in hospital at the end of life: A systematic review on extent of the problem,' *International Journal for Quality in Healthcare*, published online 27 June 2016, noted in 4 July 2016 issue of Media Watch, #469, p.7. **Full text:** http://bit.ly/2JV6NJY

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Related

- AUSTRALIA | Palliative Care Australia – 20 May 2019 – **'Survey shows Australians not planning for one of life's certainties.'** A survey of 1,000 Australian adults found that 79% think it is important to think and talk about their preferences for care at the end of life, but only 25% had talked to their family, and only 6% had talked to a doctor. These results show a large disconnect between what people think is important, and their actions. **Download/view survey at:** http://bit.ly/2YEPeSE

French court orders life support to resume for man in vegetative state

FRANCE | *The Guardian* (London, England) – 20 May 2019 – A Paris appeals court has ordered the resumption of life support for a Frenchman from whom doctors had only hours earlier begun withdrawing treatment, in a wrenching case that has divided his family and country. The court ordered authorities "to take all measures" to keep alive Vincent Lambert, a 42-year-old quadriplegic with severe brain damage who has been in a vegetative state for a decade, pending a review by the United Nations committee on the rights of persons with disabilities. Doctors in France had earlier halted the nutrition and hydration Lambert receives, in line with the wishes of his wife and other relatives. Other courts had backed their assessment that nothing more could be done for Lambert, who has been kept alive ever since a car accident in 2008. The case has reignited a contentious debate over France's right-to-die laws, which allow so-called "passive" euthanasia for severely ill or injured patients with no chance of recovery. Lambert's parents, devout Catholics, have repeatedly launched court action to keep him alive, putting them at odds with his wife and six siblings who believe the most humane course is to let him die. http://bit.ly/2WcHutz

N.B. Selected articles on patient rights and the doctor obligations under France's Claeys-Leonetti Law noted in 14 January 2019 issue of Media Watch, #597, pp.6-7.

Nurses say too many patients are being subjected to "do not resuscitate" orders without families being told

U.K. | *The Daily Telegraph* (London) – 20 May 2019 – Nurses have warned that too many hospital patients are being subjected to "do not resuscitate orders" without relatives being told... The Royal College of Nursing heard repeated warnings that "failures to communicate" meant families were left shocked to discover such decisions had been taken about their loved ones. The National Health Service England constitution says patients and their families have the right to be involved in discussions about whether such orders should be made. Speaking at the Royal College of Nursing Congress in Liverpool, nurses said they had repeatedly encountered cases where families were shocked to find out such decisions had been taken. http://bit.ly/2JTjAg4

Thousands missing out on palliative care in Greece

GREECE | *Kathimerini* (Athens) – 19 May 2019 – Up to 135,000 people in Greece require relief from the pain of terminal illnesses yet only around 10% of them receive the appropriate treatment as there is no institutional framework for the dispensing of palliative care (PC). According to a report carried out by a Health Ministry committee in cooperation with the executive director of the Worldwide Hospice Palliative Care Alliance, Stephen Connor … Greece lags behind its European Union counterparts in terms of offering PC, together with Bulgaria, Estonia and Latvia.[1] In Greece, the relief is chiefly offered by nongovernment organizations via three programs while the 57 "pain clinics" in Greek hospitals mostly operate on a voluntary basis. http://bit.ly/2Ej7WYj

1. 'Presentation of Study Findings on Palliative Care in Greece,' Stavros Niarchos Foundation, May 2019. **Download/view Greek language report at:** http://bit.ly/2WSMssv

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Sunday Times* (London) – 12 May 2019 – **'Royal College of Physicians questioned over policy change on assisted dying.'** One of Britain's most prestigious medical bodies could face an official reprimand after the Charity Commission expressed "concerns" about how it dropped its opposition to assisted dying. The Royal College of Physicians is to be questioned by the regulator after senior figures, including former trustees, complained that the decision was taken through a "sham poll," producing a policy not supported by most members. In March the College, a registered charity, adopted a position of neutrality on assisted dying, despite the option coming last in a ballot of members. In a letter dated 23 April, a Charity Commission official said it was "unclear how the decision to change the [RCP's] position to neutral was determined… http://bit.ly/30ymBYO

Specialist Publications

Improving advanced care planning through Physician Orders for Life-Sustaining Treatment (POLST) expansion across the U.S.: Lessons learned from state-based developments

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 23 May 2019 – In the U.S., POLST program development occurs at the state-level. Substantial differences between states has left POLST implementation largely unstandardized. No peer-reviewed studies to date have evaluated state-based POLST program development over time. All POLST coalition representatives reported continuous POLST expansion with improved outreach and community partnerships. Significant barriers to expansion included difficulty in securing funding for training and infrastructure, lack of statewide metric systems to adequately assess expansion, lack of provider support, and legislative concerns. Medical barriers … were rated higher than legislative... Based on the experiences of developing coalitions, the authors were able to identify strategies to expand POLST programs and overcome barriers. Ultimately the "lessons learned" in this study can serve as a guide to improve the reach of POLST or similar programs. **Abstract:** http://bit.ly/2wib16A

Much ado about fried chicken: Abetting aspiration or respecting autonomy?

AMERICAN JOURNAL OF SPEECH-LANGUAGE PATHOLOGY | Online – 21 May 2019 – A common challenge in managing patients near their end of life is the complexity of navigating clinical decisions and finding achievable and realistic goals-of-care that are in line with the values and wishes of patients. This often results in differing opinions and conflicts within the multidisciplinary team. This article describes a tool derived from the biopsychosocial model and the 4-quadrant ethical model. The authors describe the use of this tool in managing a patient who wishes to have fried chicken despite aspiration risk and how this tool was used to encourage discussions and reduce conflict and distress within the multidisciplinary team. **Abstract:** http://bit.ly/2VSl6pQ

Noted in Media Watch 7 May 2018 (#562, p.13):

- *JOURNAL OF FAMILY PRACTICE*, 2018;67(4):249-251. **'How well do Physicians' Orders for Life-Sustaining Treatments (POLST) forms assure that patients get the end-of-life care they requested?'** Quite well, for cardiopulmonary resuscitation (CPR). Most patients (91%-100%) who select "do not resuscitate" on their POLST forms are allowed a natural death without attempted CPR across a variety of settings (community, skilled nursing facilities, emergency medical services, and hospice). Few patients (6%) who select "comfort measures only" die in the hospital, whereas more (22%) who choose "limited interventions," and still more (34%) without a POLST form, die in the hospital… **Full text:** http://bit.ly/2K3SCST

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Noted in Media Watch 9 April 2018 (#558, p.9):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 6 April 2018 – **'National standards and state variation in Physician Orders for Life-Sustaining Treatment forms.'** The National POLST Paradigm Task Force maintains consensus-based standards for POLST programs to determine whether a state POLST program is developing, endorsed or mature. There is variability in adherence to required and optional standards as well as challenges in interpreting and applying existing standards. Although there may be legal and logistical barriers to the existence of a national POLST form, standardization remains an important goal to support patient-centered care. **Abstract:** http://bit.ly/2HUwFTy

Noted in Media Watch 1 January 2018 (#539, p.12):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 December 2017 – **'Respecting Choices® and related models of advance care planning: A systematic review of published evidence.'** The authors found that there is a low level of evidence that Respecting Choices® (RC) and derivative models increase the incidence and prevalence of advance directive and Physician Orders for Life-Sustaining Treatment (POLST) completion. The evidence is mixed, inconclusive and too poor in quality to determine whether RC and derivative models change the consistency of treatment with wishes and overall health-care utilization in the end of life. **Abstract:** http://bit.ly/2Ew5GwH

Self-perceived burden to others as a moral emotion in wishes to die. A conceptual analysis

BIOETHICS, 2019;33(4):439-447. Patients at the end of their life who express a wish to die sometimes explain their wish as the desire not to be a burden to others. This feeling needs to be investigated as an emotion with an intrinsically dialogical structure. Using a phenomenological approach, two key meanings of the feeling of being a burden to others as a reason for a wish to die are identified. First, it is an existential suffering insofar as it contains the perception of a plight so desperate that it can only be relieved by the end of the patient's existence. Second, it is an empathic concern that implies caring about those who bear the burden of caring for the person at the end of their life. It is therefore a moral emotion, encompassing a series of difficulties, including the subjective perception of a stark imbalance between giving and taking, the adequacy of the representation of the caregiver burden in the patient's mind, and the danger of diminishing the worth of one's life out of shame or self-denigration. The sense of being a burden implies the belief the caregiver feels burdened, and the fear that this burden could become unbearable. **Abstract:** http://bit.ly/2wrq2Db

bioethics

Special Issue: Being a burden to others and wishes to die – an ethically complicated relation.

Journal contents page: http://bit.ly/2W22ljH

N.B. Additional articles on wishes to hasten death noted in 4 February 2019 issue of Media Watch, #600, p.15.

End-of-life care in New Zealand

End of life care for long-term care residents with dementia, chronic illness and cancer: Prospective staff survey

BMC GERIATRICS | Online – 22 May 2019 – This study found that New Zealand ranks highly in overall long-term care (LTC) end-of-life care (EoLC) in comparison to other countries. The authors also found that symptom management needs in the last week of life do not vary by diagnosis overall, although subgroup analysis found residents with dementia and chronic illness experience higher physical distress over a longer period of time before death than residents with cancer. Residents with advanced physical and cognitive frailty often require LTC for complex geriatric issues which need to be integrated with palliative

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care (PC) principles in the months and possibly years before they die. It is essential that those working in LTC facilities recognise PC philosophy and practice as an integral part of their work and that the model of care acknowledges the demands associated with LTC EoLC. It is also crucial that specialist PC providers work collaboratively with, and become more skilled in gerontology and complex geriatric syndromes. Now, and into the future, the oldest old will make up the majority of all deaths, and a significant proportion of people will die in LTC. It is therefore essential that gerontology and PC approaches are integrated to assure high quality end of life care in LTC settings. **Full text:** http://bit.ly/2VHGVUg

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 21 May 2019 – **'Advance directives in European long-term care facilities: A cross-sectional survey.'** The presence of any written advance directive (AD) varied substantially among residents within and between six European countries studied [i.e., Belgium, Finland, Italy, The Netherlands, Poland and the U.K.]. This study's results indicate that timing for end-of-life care discussion and advance care planning with a resident is at its best when a resident has the ability to express himself or herself. Residents living in nursing or care homes where a physician was available 24 hours a day and 7 days a week were less likely to have written AD compared with facilities where physician was not available in the facility. **Full text:** http://bit.ly/2JWrVzw

Can artificial intelligence predict the end of Life … and do we really want to know?

CYBERPSYCHOLOGY, BEHAVIOR & SOCIAL NETWORKING, 2019;22(5):297-299. A new algorithm developed by researchers at Stanford University has the ability to predict the time of death within 3-12 months for a hospital patient. The process claims to be 90% accurate, and hospital admissions in the future may be able to screen health records with artificial intelligence (AI) to determine a patient's need for palliative care before death. According to additional studies by the university, it's estimated that 80% of Americans prefer to die at home, but only 20% see that wish fulfilled. In reality, 80% of those facing death pass away in a combination of hospital and nursing home settings. So, a calculated prediction may be able to grant the terminally ill a final wish rather than prolonging a painful process. Although one may consider death a final resting place, the mental effects that one undergoes are anything but. Elisabeth Kübler-Ross explains the five stages of death ... as a series of psychological steps that lead to accepting m mortality. However, could AI alleviate the struggle by offering an acceleration that preserves mental health in the face of mortality, or doe knowing one's time of death place extra strain on their ability to cope? **First page view:** http://bit.ly/2WfqgMb

Meeting in a "free-zone": Clinical ethical support in integrated heart-failure and palliative care

EUROPEAN JOURNAL OF CARDIOVASCULAR NURSING | Online – 15 May 2019 – Integrating heart-failure and palliative care (PC) combines expertise from two cultures, life-saving cardiology and PC, and involves ethically difficult situations that have to be considered from various perspectives. The authors found no studies describing experiences of clinical ethical support (CES) in integrated cardiology and PC teams. In this study, participants in CES was found to offer possibilities for meeting in an ethical "free-zone" where the participants could relate to each other beyond their various professional roles and specialties. The trust within the team seemed to increase and the participants were confident enough to express their points of view. Together they developed an integrated understanding, and acquired more knowledge and a comprehensive view of the ethically difficult situation of concern. The CES sessions were considered a means of becoming better prepared to deal with ethical care issues and developing action strategies to apply in practice, from shared standpoints. **Abstract:** http://bit.ly/2WUplhc

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Back Issues of Media Watch
http://bit.ly/2ThijkC

Noted in Media Watch 20 May 2019 (#614, p.11):

- *JAMA NETWORK OPEN*, 2019;2(5):e192356. **'Improving primary and specialist palliative care in cardiovascular disease.'** There are not enough palliative care (PC) specialists to see all the patients with serious cardiovascular disease (CVD) who may benefit from PC, so it is critical to develop capacity and competency in primary (i.e., basic) PC and refer appropriate patients to specialist PC teams. A 2017 review proposed key primary and specialist roles in PC for patients with heart failure.[1] Leveraging the skills of affiliate healthcare professionals (e.g., nurses, social workers, chaplains) and engaging patients and caregivers using technology are approaches to improve primary PC in CVD. **Full text:** http://bit.ly/309VhjF

  1. 'Primary palliative care for heart failure: What is it? How do we implement it?' *Heart Failure Review*, 2017;22(5):611-620. **Abstract (w. list of references):** http://bit.ly/2LJVB5g

N.B. Additional articles on PC for patients living with heart failure noted in 4 March 2019 issue of Media Watch, #604, p.8.

Parental experiences and coping strategies when caring for a child receiving paediatric palliative care: A qualitative study

EUROPEAN JOURNAL OF PEDIATRICS | Online – 19 May 2019 – This study [from The Netherlands] reports in detail about the most prominent parental experiences when caring for a child with a life-limiting or life-threatening diseases (LLD/LTD), both malignant and non-malignant, at home. It also investigates parents coping strategies in adjusting to the situation. Parenting and caring for a child with a LLD/LTD require continuous management of anxiety and loss. At the same time, parents work towards a new normality and gradually take control to arrange the best care for their child and family. Some parents manage this process well, while for other parents this process is a major burden and they need adequate support from healthcare professionals (HCPs). In order to provide support and guidance geared towards specific families from the start of the disease trajectory, HCPs need to understand parents' anxiety, grief, relationship with their child and coping strategies. **Full text:** http://bit.ly/2VMgAZU

Extract

Prominent experiences were: continuous management of anxiety of child loss, feelings of uncertainty, tension with end-of-life decision making and engagement with professionals. Parents experienced unique significance to their child, reinforcing a meaningful parent-child relationship.

Relevant coping strategies were: suppressing emotions, seeking support, taking control to arrange optimal care and adapting to the ongoing changes.

Related

- *JOURNAL OF HUMANISTIC PSYCHOLOGY* | Online – 16 May 2019 – **'Hospital clown narratives in pediatric palliative care.'** The authors show several narrative categories from a clown's perspective: "tragic metamorphosis," "meditating on the mystery," "an ultimate poetic atmosphere," "interconnectedness and interrelatedness of all things," "an emotional catalyst," "the deep need to say goodbye," "ethical guidance values." The authors interpret the narratives categories according to humanistic/existential framework as the theoretical base. The clown addresses those aspects of healing that are not well developed in modern Western medicine, the treatment of the whole person. The clown embraces human nature as physical, emotional, cognitive, and spiritual. **Abstract:** http://bit.ly/2JxozUg

How to talk with dying patients and their families after disasters and humanitarian crises: A review of available tools and guides for disaster responders

INTERNATIONAL JOURNAL OF HUMANITARIAN ACTION | Online – 22 May 2019 – In responding to those affected by sudden onset disasters and chronic humanitarian crises, disaster responders and humanitarian aid workers will face the challenge of caring for dying patients. While medical intervention may

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be severely limited or constrained, bearing witness by listening and being able to compassionately communicate with such victims and their families is an important skill. This review examines the current literature on communication training and palliative care (PC) skills for disaster workers and offers a menu of communication tools including guidelines developed for administering PC in non-disaster settings that can be used by both disaster responders and humanitarian aid workers. **Full text:** http://bit.ly/2X9mtNu

Noted in Media Watch 20 May 2019 (#614, p.15):

- *PREHOSPITAL & DISASTER MEDICINE* | Online – 6 May 2019 – **'Palliative care training for work in an austere environment after a natural disaster.'** Challenges to the care of the dying during a disaster include a loss of medical infrastructure and scarce medical or physical resources. Palliative care (PC) training for non-PC specialists can be instructive for the development of PC training for medical care responders after disasters. Applying standards, identifying goals-of-care for the expectant patient, communication to the patient and family members, if available, can help reduce suffering of this group of devastatingly vulnerable patients. **Abstract:** http://bit.ly/2HeVGIY

N.B. Additional article on integrating PC and symptom relief into responses to humanitarian emergencies and crises noted in 14 January 2019 issue of Media Watch, #597, p.5.

Surrogate decision making for incarcerated patients

JAMA INTERNAL MEDICINE | Online – 20 May 2019 – When patients are too ill to make their own healthcare decisions and lack a previously designated decision maker, identifying the appropriate surrogate can be a complex process. For example, clinicians may use surrogacy ladders … which are delineated in state statutes [in the U.S.]. Although patients with incapacitating illness are inherently vulnerable, there are additional considerations for people who are incarcerated, and these may not be addressed in state laws. The authors discuss the selection of surrogates for incarcerated patients and who should or should not serve in this role. **Abstract:** http://bit.ly/2JSqi5O

Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report can be downloaded/ viewed on the Palliative Care Network website at: http://bit.ly/2RdegnL

Updated 05.20.2019

Photo: Lori Waselchuk

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 beginning on p.16.

Communicating bad news: Insights for the design of consumer health technologies

JMIR HUMAN FACTORS, 2019;6(2):e8885. As people increasingly receive personal health information through technology, there is increased importance for this information to be communicated with empathy and consideration for the patient's experience of consuming it. Although technology enables people to have more frequent and faster access to their health information, it could also cause unnecessary anxiety, distress, or confusion because of the sensitive and complex nature of the information and its potential to provide information that could be considered bad news. The authors describe qualitative results combining an analysis of the clinical guidelines for sharing bad health news with patients and interviews on clinicians' specific strategies to communicate bad news and the emotional and informational support that patients and their family members seek. Specific strategies clinicians use included preparing for the patients' visit, anticipating patients' feelings, building a partnership of trust with patients, acknowledging patients' physical and emotional discomfort, setting up a scene where patients can process the information, helping patients build resilience and giving hope, matching the level of information to the patients' level of understanding, communicating face-to-face, if possible, and using non-verbal means. Patient and family member experiences included internal turmoil and emotional distress when receiving bad news and emotional and informational support that patients and family members seek. The results from this study identify specific strategies for health information technologies to better promote empathic communication when they communicate concerning health news. **Full text:** http://bit.ly/2JusfGu

Summary of recommendations for communicating bad news

One person only should be responsible for breaking bad news

The patient has a legal and moral right to information

Primary responsibility is to the individual patient

Give accurate and reliable information

Ask people how much they want to know

Prepare the patient for the possibility of bad news as early as possible

Avoid giving the results of each test individually, if several tests are being performed

Tell the patient his or her diagnosis as soon as it is certain

Ensure privacy and make the patient feel comfortable

Ideally, family and significant others should be present

If possible, arrange for another health professional to be present

Inform the patient's general practitioner and other medical advisers of the level of development of patient's understanding

Use eye contact and body language to convey warmth, sympathy, encouragement, or reassurance to the patient

Employ a trained health interpreter if language differences exist

Be sensitive to the person's culture, race, religious beliefs, and social background

Acknowledge your own shortcomings and emotional difficulties in breaking bad news

Words matter: The language of family caregiving

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 23 May 2019 – One area that has received less attention than it deserves is the language used to describe family caregiving. Every day, at least 43.5 million individuals in the U.S. assume caregiving responsibilities for a spouse, family member, or friend who needs help because of limitations in their physical, mental, or cognitive functioning. Although many people require care, age-related needs are the single most common problem requiring help from caregivers. To distinguish family caregivers from paid care providers such as home care workers, the term "informal caregiver" is commonly used. The authors argue that this term is a poor choice of words that disrespectfully frames the family caregiving role and has counterproductive consequences. The term "informal caregiver" originated in the 1980s when caregiving became a major topic for research. It was used to reflect the understanding that family caregivers were relied on mainly for emotional support

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and for basic assistance with household tasks and personal care. Indeed, the term “informal” suggests “casual, unstructured, unofficial care – pleasant but not essential”; today's caregivers would tell you they find this term invalidating and that there is absolutely nothing “informal” or unessential about the care they provide. These caregivers, most of whom are women, provide approximately 80% of direct home and community care services, an unpaid contribution valued at $375 billion U.S. dollars annually. On average, caregivers spend nearly 25 hours a week providing care, and about one-quarter (23%) provide 41 or more hours of care a week. **Full text:** http://bit.ly/2YJ7om7

Timing of palliative care: When to call for a palliative care consult

JOURNAL OF SURGICAL ONCOLOGY | Online – 18 May 2019 – Palliative care (PC), unlike hospice, can be utilized concurrently with disease-modifying or curative therapies. Some of the benefits of PC include improved quality of life, less end-of-life treatment, and decreased medical costs. Furthermore, PC can help guide treatment decisions to be in line with patients' physical, psychological, and spiritual needs. On the basis of these benefits, the authors advocate for PC involvement early in the course of advanced malignancy and other terminal diagnoses. **Abstract:** http://bit.ly/2VyVmtF

Noted in Media Watch 1 April 2019 (#608, p.12):

- *JOURNAL OF SURGICAL ONCOLOGY* | Online – 20 March 2019 – **‘Evidence for integration of palliative care into surgical oncology practice and education.’** High-quality data support multiple clinical benefits of integrating palliative care (PC) into routine oncology care. Though these data come largely from the medical oncology literature, data from surgical oncology populations support similar associations between PC integration and improved clinical outcomes, all without compromise in survival. The authors review data ... with a focus on surgical populations and recommendations for incorporating PC into surgical oncology. **Abstract:** http://bit.ly/2YpqHlb

Global palliative care: From need to action

THE LANCET GLOBAL HEALTH | Online – 22 May 2019 – Katherine Sleeman and colleagues report the first worldwide projection of the future global burden of serious health-related suffering.[1] The calculation followed the methods used by the Lancet Commission on Palliative Care & Pain Relief assessing global palliative care need. Combining these methods with World Health Organization's revised global and regional projections of mortality up to 2060, the authors estimate the global burden of serious health-related suffering requiring PC by world regions and age groups for 20 health conditions. The vision of the future delivered by this article is alarming: “By 2060, an estimated 48 million people (47% of all deaths globally) will die each year with serious health-related suffering, and 83% of these deaths will occur in low-income and middle-income countries.” These numbers indicate that 130,000 people worldwide will die every day with serious health-related suffering by 2060, the equivalent to twice the size of a Super Bowl stadium. The real burden of serious health-related suffering is even greater because the authors' calculations are based on mortality data and do not include the burden of people living with serious health-related suffering who do not die in a given period. **Full text:** http://bit.ly/2K0SxPJ

1. ‘The escalating global burden of serious health-related suffering: Projections to 2060 by world regions, age groups, and health conditions,’ *The Lancet Global Health*, published online 22 May 2019. Full text: http://bit.ly/30BUwA2

Noted in Media Watch 22 May 2017 (#513, p.11):

- *BMC MEDICINE* | Online – 18 May 2017 – **‘How many people will need palliative care in 2040? Past trends, future projections and implications for services.’** By 2040, annual deaths in England & Wales are projected to rise by 25.4% (from 501,424 in 2014 to 628,659). If age- and sex-specific proportions with palliative care (PC) needs remain the same as in 2014, the number of people requiring PC will grow by 25% (from 375,398 to 469,305 people/year). However, if the upward trend observed from 2006 to 2014 continues, the increase will be of 42.4% (161,842 more people/year, total 537,240). Healthcare systems must adapt to the age-related growth in deaths from chronic illness by focusing on integration and boosting of PC across health and social care disciplines. **Full text:** http://bit.ly/2IHcYCi

Improving critical care for Americans with terminal illness

THE LANCET RESPIRATORY MEDICINE | Online – 20 May 2019 – Use of intensive care unit (ICU) resources in the U.S. outpaces that of other countries. This increased use is not accompanied by superior clinical outcomes and is at times discordant with patient preferences. For more than three decades, both medical professionals and the public have worried that patients may receive non-beneficial care in U.S. ICUs during their final months of life. Some of these patients wish to avoid severe cognitive and physical impairments, and protracted deaths in the hospital setting. Recognising when intensive care admission will not restore a person's health, and helping patients and families embrace goals related to symptom relief, interpersonal connection, or spiritual fulfilment are central challenges of critical care practice in the U.S. This series of articles identifies major drivers of ICU resource use in the U.S. and reviews trials from the past decade to better understand the interventions designed to address these challenges. **Executive summary:** http://bit.ly/2M1BXCd

Noted in Media Watch 11 March 2019 (#605, p.9):

- *INTENSIVE CARE MEDICINE* | Online – 7 March 2019 – **'Eight things we would never do regarding end-of-life care in the ICU.'** As intensivists from three distinct regions of the world [i.e., the U.S., France, Israel] with different cultural backgrounds, the authors believe it relevant in this rapidly emerging period of healthcare to share thoughts among clinicians providing end-of-life care (EoLC) in the intensive care unit. This article presents the authors' vision of eight top-tier concepts that should be embraced to usher in the best EoLC for all patients. The authors realize that not everyone will agree with these points and anticipate that our "eight things" will stimulate healthy discussion and debate. **Abstract (w. list of references):** http://bit.ly/2XHEB1L

N.B. Additional articles on EoLC in the ICU noted in 22 April 2019 issue of Media Watch, #611, pp.10-11.

Redesigning the evidence synthesis in palliative care: The realist review

MÉDECINE PALLIATIVE | Online – 22 May 2019 – Evidence-based medicine is an ideal that challenges palliative care (PC) practice, especially because the knowledge synthesis is highly difficult in this field. Despite the fact that systematic reviews offer a rigorous synthesis of the evidence, they face limits of their evaluative objectives. They do not offer an overall understanding of why and how a complex intervention is efficient in a specific context. Initially developed in social sciences, the realist review might be a more accurate solution to address issues specific to PC. **Abstract:** http://bit.ly/2HXaOe9

N.B. French language article.

Towards a "social anthropology" of end of life moral deliberation: A study of Australian Salvation Army officers

STUDIES IN CHRISTIAN ETHNICS | In print – Accessed 19 May 2019 – A research project by the Schools of Theology & Psychology of Australia's Charles Sturt University surveyed a large sample of Salvation Army officers. This paper considers survey responses to two questions relating to end-of-life (EoL) care: the use of pain medications that may shorten life, and the cessation of fluid and food intake. The results of the analyses are evaluated in terms of Michael Banner's proposal that moral theology should more assiduously converse with "patient ethnographic study," which the survey instantiates to some extent. Banner's proposal and the results of the survey are contrasted to Peter Singer's analytical moral philosophical dictums on EoL care. The results are also compared to a meta-study by Rodríguez-Prat and van Leeuwen of fourteen ethnographic studies of those who wish to hasten death at the EoL. The authors conclude that respondents exemplify a form of moral reasoning that: is embedded within Christian spirituality; counters the assumptions of Singer's approach; contrasts the diminishment of "meaning" at the EoL, as seen in Rodríguez-Prat and van Leeuwen; and, deserves further respectful ethnographic study. **Abstract:** http://bit.ly/2VK9kxP

Are cancer helplines effective in supporting caregivers? A systematic review

SUPPORTIVE CARE IN CANCER | Online – 16 May 2019 – Forty-five publications met the inclusion criteria for this review. Forty-one papers reported on the proportion of caregivers accessing cancer helplines. Twenty-six studies described demographic and clinical characteristics of caregivers and eight reported on call characteristics. Reasons for contacting the service were stated in 21 studies and caregiver satisfaction with the helpline service was assessed in 12 articles. Fourteen studies investigated specific topics of interest (e.g., prevalence of sleep problems, distress screening, or clinical trial participation). Two randomized controlled trials examined the efficacy of cancer helplines in improving caregiver outcomes, with findings showing interventions to be effective in reducing distress and unmet needs, and in increasing positive adjustment. There is limited scientific evidence regarding the efficacy of cancer helplines to improve caregivers' health and well-being. **Full text:** http://bit.ly/30Ag1kX

Noted in Media Watch 28 January 2019 (#599, p.2):

- *JOURNAL OF ONCOLOGY PRACTICE*, 2018;14(12):731-736. **'Patients with cancer and social media: Harness benefits, avoid drawbacks.'** Social media (SM) platforms such as Facebook, Instagram, Twitter, and online cancer support groups are an emerging source of social support. The purpose of this article is to describe five potential benefits and five potential drawbacks patients may experience while using SM and to encourage oncologists to become aware of these, to guide patients in using SM to their benefit. This review also provides specific care practice behaviors that oncologists can apply during care delivery to guide patients' SM use, to help avoid the potential drawbacks, and harness the potential benefits. **Abstract:** http://bit.ly/2VQ2A1b

Noted in Media Watch 16 October 2017 (#534, p.16):

- *SUPPORTIVE CARE IN CANCER* | Online – 9 October 2017 – **'Palliative care content on cancer center websites.'** Cancer center homepages rarely mention palliative care (PC) services. While the majority of centers have web pages with PC content, they sometimes omit information about early use of care. The authors conducted a content analysis of 62 National Cancer Institute designated cancer center websites. 10% had no webpage with PC information for patients. Among centers with information for patients, the majority (96%) defined palliative or supportive care, but 30% did not discuss delivery of PC alongside curative treatment, and 14% did not mention provision of care early in the disease process. **Abstract (inc. list of references):** http://bit.ly/2wb8RWg

Assisted (or facilitated) death

Representative sample of recent journal articles:

- CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS | Online – 17 May 2019 – **'Key messages: Palliative care and medical assistance in dying (MAiD).'** In June 2016, the Federal Government [in Canada] enacted Bill C-14 legalizing assisted death under certain circumstances and adopted the term "medical assistance in dying." 'Medical assistance in dying' (MAiD) includes both euthanasia and assisted suicide, whereby under Canadian law eligible patients may have their lives intentionally ended through either the direct administration, typically injection (euthanasia), or self-ingestion (assisted suicide) of a lethal dose of drugs prescribed by a physician or nurse practitioner. The vast majority of MAiD procedures in Canada are provided through euthanasia. The term "medical assistance in dying" continues to cause confusion with respect to the role of palliative care (PC). PC provides medical assistance/aid in dying every day to patients and their families, to help them live as fully as possible until their natural death. The goal of this Key Messages document is to help clarify and define the role of PC within the Canadian context of legalized euthanasia and assisted suicide, these latter practices hereafter referred to as "MAiD." **Download/view at:** http://bit.ly/2QdIGre

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Something Missed or Overlooked?

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

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