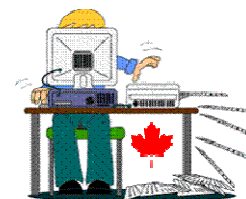


Media Watch...

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

As a public health approach to palliative care gathers pace, it is important that “community” or “social capital” is not viewed as a universal solution to the mounting public health crisis.

‘Social networks, social capital and end-of-life care for people with dementia: A realist review’ (p.9), in *BMJ Open*.

Canada

British Columbia hospice may face penalties if it fails to make medically-assisted death available by deadline

BRITISH COLUMBIA | *The Globe & Mail* – 11 December 2019 – A hospice society that refuses to provide medical assistance in dying (MAiD) at its facility in violation of local rules has been given ... [notice] ... to submit plans for compliance. [Provincial] Health Minister Adrian Dix said the Delta Hospice Society, which operates the Irene Thomas Hospice in Ladner, may face penalties if it fails to do so. Fraser Health’s policy on MAiD sets out expectations for addressing a capable patient’s request for information about the end-of-life procedure, and connections to providers. Individuals and faith-based organizations can choose not to participate in medically assisted deaths, but still must facilitate connections. The policy came into effect in September 2016 and

covers all facilities Fraser Health owns or operates. Irene Thomas Hospice is not faith-based. According to the hospice’s most recent annual report, Fraser Health is by far its biggest funder, contributing about \$1.5-million of \$3-million for the fiscal year ending 31 March 2018. <https://tgam.ca/2Ejx54u>

Specialist Publications

‘Conscientious objection and moral distress: A relational ethics case study of medical assistance in dying in Canada’ (p.13), in *Journal of Medical Ethics*.

Noted in Media Watch 2 December 2019 (#642, p.1):

- CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION (CHPCA) & CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS (CSPCP) | Online – 27 November 2019 – ‘**Joint statement regarding palliative care and medical assistance in dying.**’ The CHPCA and the CSPCP seek to clarify the relationship of hospice palliative care (HPC) and medical assistance in dying (MAiD). Healthcare articles and the general media continue to conflate and thus misrepresent these two fundamentally different practices. MAiD is not part of HPC; it is not an “extension” of palliative care nor is it one of the tools “in the palliative care basket.”; National and international HPC organizations are unified in the position that MAiD is not part of the practice of hospice. **Download/view at:** <http://bit.ly/33mmlad>

U.S.A.

Clarity, honesty matter most in critical care talks with patients

CALIFORNIA | Stanford Medicine News Center – 13 December 2019 – In new research using linguistic theory to examine the root causes of doctor-patient miscues, Stanford University biomedical ethicists raise alarms about whether a patient who is unclear about a prognosis, or about the implications of treatments being offered, can truly give doctors consent to treat them. David Magnus, PhD, is studying why common words physicians use to explain challenging medical concepts – such as “treatable” or “comfort care” – often mean different things to patients than they do to doctors. The director of the Stanford Center for Biomedical Ethics, Magnus said he recognizes the challenge of delivering bad news, and of delivering it clearly and honestly. In research published [recently] ... Magnus [*et al*] stressed the gap between patient

and physician experience and culture may lead to misunderstandings, even when physicians try to be clear and avoid using medical terminology.¹ <https://stan.md/2PJfkkE>

Specialist Publications

‘Assessment of variability in end-of-life care delivery in intensive care units in the U.S.’ (p.11), in *JAMA Open Network*.

‘Clinicians’ perspectives on the duty to inform patients about medical aid-in-dying’ (p.13), in *AJOB Empirical Bioethics*.

1. ‘Treatability statements in serious illness: The gap between what is said and what is heard,’ *Cambridge Quarterly of Healthcare Ethics*, 2019;28(3):394-404. [Noted in 22 July 2019 issue of Media Watch (#623, p.8)] **Abstract (w. list of references):** <http://bit.ly/32yCzU9>

More Americans are dying at home than in hospitals

THE NEW YORK TIMES | Online – 11 December 2019 – For the first time over a half century, more people in the U.S. are dying at home than in hospitals, a remarkable turnabout in Americans’ view of a so-called “good death.” In 2017, 29.8% of deaths by natural causes occurred in hospitals, and 30.7% at home, researchers report...¹ The gap may be small, but it had been narrowing for years, and the researchers believe dying at home will continue to become more common. The last time Americans died at home at the current rate was the middle of the last century, according Dr. Haider J. Warraich, a cardiologist at the Veterans Affairs Boston Healthcare System and a co-author of the new research. In Boston in 1912, about two-thirds of residents died at home, he said. By the 1950s, the majority of Americans died in hospitals, and by the 1970s, at least two-thirds did. <https://nyti.ms/38B6qOP>

1. ‘Changes in the place of death in the U.S.,’ *New England Journal of Medicine*, 2019;381(24):2369-2370. **Access article at:** <http://bit.ly/35fjbfL>

Noted in Media Watch 14 October 2019 (#635, p.4):

- MASSACHUSETTS | Reuters – 7 October 2019 – **‘More U.S. heart disease patients may be choosing to die at home.’** Fewer U.S. patients with cardiovascular disease are dying in hospitals and more of them are dying at home, a new analysis suggests.¹ Between 2003 and 2017, among the more than 12 million Americans who died of cardiovascular disease, the proportion dying at home rose from 23% to 31%... When investigating how to improve people’s last days and hours, researchers have focused on hospital care because most people died there... To take a closer look at how people die in the U.S., researchers [at the Harvard Medical School] merged data from the National Center for Health Statistics and the Centers for Disease Control & Prevention. <https://reut.rs/2lxx0wD>

1. ‘Trends in place of death for individuals with cardiovascular disease in the U.S.,’ *Journal of the American College of Cardiology*, 7 October 2019. **First page view:** <http://bit.ly/31VRzL0>

N.B. Selected articles reflecting trends in end-of-life care in the U.S. noted in 23 September 2019 issue of Media Watch (#632, p.3).

California's palliative care rule a potential foundation for national model

CALIFORNIA | *Hospice News* – 9 December 2019 – California is the first state in the nation to require Medicaid plans to provide palliative care (PC) coverage. Other states have passed legislation designed to spur public and clinician awareness of PC and to promote utilization, but have stopped short of requiring Medicaid or other programs to cover it. As of December 2018, 27 states have laws on their books designed to promote PC... Though details of the legislation vary among the states, they each serve the goal of bringing PC to more patients with serious, chronic, or life-limiting conditions. A number of states have enacted similar laws during 2019 and several states are considering comparable bills. “My hope is that other states will follow in the footsteps of California, because it has transformed California. The fact that there’s a law that says Medicaid patients in California with serious illness must have access to PC brought all the players out of the woodwork,” Diane Meier, executive director of the Center to Advance Palliative Care told *Hospice News*. “All the health insurance companies that manage Medicaid had to figure out how to develop a network, how to find the clinicians that do this, how to contract with them to take care of patients. We don’t have those laws in the other 49 states, and we don’t have a federal law requiring that either, but what we learned from California is that it’s very effective.” <http://bit.ly/348HUAZ>

Why palliative care needs to become more accessible in the U.S., around Globe

HOME HEALTH CARE NEWS | Online – 9 December 2019 – The U.S. is advanced in its access to palliative care (PC), but there’s still a lot of room to grow for home health providers, according to a recent report...¹ The report says that the burden of serious health-related suffering will almost double by 2060, due to a rapidly increasing elder population and the prevalence of chronic health conditions. Because of that, an emphasis on PC needs to be made as demand goes up, even for countries leading in the industry like the U.S. More and more patients prefer to age in place, and there’s a large community of people who could benefit from PC to avoid spending their last days in pain or discomfort. Considering over 20% of the U.S. population will be over 65 by 2030, palliative, in-home care could be a catalyst for reduced spending. Of those that would benefit from PC in the U.S., 60% don’t receive it, according to another report...² <http://bit.ly/2LCus1O>

1. ‘Mapping levels of palliative care development in 198 countries: The situation in 2017,’ *Journal of Pain & Symptom Management*, published online 21 November 2019. [Noted in 25 November 2019 issue of *Media Watch* (#641, p.12)] **Full text:** <http://bit.ly/2s1eAin>
2. ‘Care Redesign Survey: The power of palliative care,’ *NEJM Catalyst*, published online 6 June 2019. [Noted in 10 June 2019 issue of *Media Watch* (#617, p.10)] **Download/view at:** <http://bit.ly/2XwdpTb>

Machine learning could improve end-of-life communication

VERMONT | *Health IT Analytics* – 9 December 2019 – Machine learning tools could analyze conversations between providers and patients about palliative care (PC), leading to improved communication around serious illness and end-of-life treatment, according to a study conducted at the University of Vermont’s (UVM) Conversation Lab.¹ Discussions about treatment options and prognoses amid serious, life-threatening illnesses are a delicate balance for nurses and doctors. Providers are communicating with people who don’t know what the future holds, and these conversations are very difficult to navigate. Researchers at UVM wanted to understand the types of conversations patients and providers have around serious illness. The team set out to identify common features of these conversations and determine if they have common storylines. Researchers used machine learning techniques to analyze 354 transcripts of PC conversations collected by the Palliative Care Communication Research Initiative, involving 231 patients in New York and California. They broke each conversation into ten parts with an equal number of words in each, and examined how the frequency and distribution of words referring to time, illness terminology, sentiment, and words indicating possibility and desirability changed between each decile. Conversations tended to progress from talking about the past to talking about the future, and from happier to sadder sentiments. <http://bit.ly/36ngs41>

1. ‘Story arcs in serious illness: Natural language processing features of palliative care conversations,’ *Patient Education & Counseling*, published online 9 December 2019: **Abstract:** <http://bit.ly/2RAYb3E>

International

A scoping survey of bereavement services in Wales

WALES | End-of-Life Care Board, Welsh Government – 13 December 2019 – A number of gaps and challenges were identified in the survey. Many of these were similar to those identified in surveys of U.K. and European palliative care providers, which included the non-prioritisation of bereavement support at an organisational level, inadequate training of staff/volunteers, limited formal risk assessment practices or adherence to formal policies or guidelines and limited access to specialist mental health support for onward referral of more complex cases. Lack of funding was the most commonly identified barrier for service providers in this survey. Other problems included those relating to the accessibility of services such as unclear referral pathways, restrictive eligibility criteria and rurality. There were also issues impacting upon service delivery such as access to training and trained staff/volunteers, access to appropriate facilities, and the non-prioritisation and lack of a framework for bereavement care within organisations. The fact that available bereavement service standards were rarely mentioned by providers when asked about service assessment, also raises questions over the status and implementation of established standards amongst bereavement care providers in Wales. The finding that nearly half of all services were funded by charities, and only a half were externally assessed, would also indicate lack of priori-

tisation or frameworks at regional and national levels. **Download/view at:** <http://bit.ly/36z6Fb3>

Specialist Publications

'Patterns of religiosity, death anxiety, and hope in a population of community-dwelling palliative care patients in New Zealand. What gives hope if religion can't?' (p.6), in *American Journal of Hospice & Palliative Medicine*.

'Why can't Japanese people decide? Withdrawal of ventilatory support in end-of-life scenarios and their indecisiveness' (p.7), in *Asian Bioethics Review*.

'The impact of population ageing on end-of-life care in Scotland: Projections of place of death and recommendations for future service provision' (p.8), in *BMC Palliative Care*.

'The dying parent and dependent children: A nationwide survey of hospice and community palliative care support services' (p.9), in *BMJ Supportive & Palliative Care*.

'The association between palliative care team consultation and hospital costs for patients with advanced cancer: An observational study in 12 Dutch hospitals' (p.11), in *European Journal of Cancer Care*.

State fails dismally with “end-of-life care”: Not even supplying bare minimum

PORTUGAL | *Portugal Resident* – 12 December 2019 – The majority of palliative (end-of-life) care teams within the Portuguese national health service do not even supply the “bare minimums” defined by the State. This is the dismal bottom line of the latest annual report published by the Portuguese Observatory on Palliative Care, which says there has been a definite “regression” in the implementation of the national strategy laid down to alleviate or avoid suffering in those with incurable illnesses. The document talks of “worrying signs” with many districts offering care that is “very below what is minimally acceptable.” The report’s coordinator Manuel Luís Capelas claims the national plan is “failing” in a sector focused on people “in intense suffering.” Bearing in mind the needs of Portuguese patients, the palliative care sector is light on 430 doctors, 2,141 nurses, 178 psychologists and 173 “social assistants.” <http://bit.ly/38xOh4h>

Cont. next page



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- PORTUGAL | *The Portugal News* (Lagoa) – 24 January 2018 – ‘**Study finds “great need” for more palliative care for adults, children.**’ Portugal has a “great need” for more palliative care (PC), “both for adults and for children,” according to a major study. “71% of deaths in adults and 33% of deaths in children are due to illnesses that are recognised as requiring PC.” Although these estimates are in line with figures from other European countries, Portugal “lacks capacity to respond, above all for children.” The study “shows that it is urgent to assess the sustainability of the current model of healthcare and social support to meet these needs...” Cancer, for example, “is responsible for an ever greater proportion of deaths with palliative needs (34% in adults and 38% in children).” <http://bit.ly/36vjdK>

1. ‘End-of-life decision-making in palliative care and recommendations of the Council of Europe: Qualitative secondary analysis of interviews and observation field notes,’ *Journal of Palliative Medicine*, published online 3 January 2018. [Noted in 8 January 2018 issue of Media Watch (#545, p.15)] **Abstract:** <http://bit.ly/36vrtAs>

Minors’ ombudsman to monitor palliative care provision to children in Russian regions

RUSSIA | Russian Legal Information Agency (Moscow) – 12 December 2019 – Children’s ombudsman Anna Kuznetsova and the St. Petersburg children’s hospice will monitor the efficiency of palliative care (PC) in Russian regions... The monitoring is to be conducted as part of a special project launched by the child rights commissioner and the St. Petersburg children’s palliative organization. A special report based on the monitoring results will be prepared for the President and PC policy intervention proposals will be developed... In March, President of Russia Vladimir Putin signed the law specifying the concept of PC that involves a package of measures including medical treatment, after care and psychological actions aimed to improve the quality of terminally ill patients’ living and is oriented to the amelioration of pain. The law confirms the right of terminal patients to pain relief including drug preparations and medical devices. Such assistance is to be rendered on an outpatient basis and at hospitals by specially trained health workers. Palliative patients are also to receive social and psychosocial support as well as religious care, according to the law. <http://bit.ly/35rZO2U>

N.B. Selected articles on PC in Russia noted in 18 February 2019 issue of Media watch (#602, p.5).

Patients who plan their death end up living longer, study finds

DENMARK | *The Daily Telegraph* (London, England) – 10 December 2019 – People who plan their death end up living longer, research suggests.¹ The study of terminally ill patients found that those who discussed their preferences for end-of-life care with doctors actually lived for longer than other patients. The research ... compared two groups of patients, all of whom were terminally ill. It found that those involved in “advance care planning” – setting out whether they would want treatment to prolong life, or where to spend their last days – had significantly longer survival. The Danish study of 202 terminally ill patients found that 73% of those with advance care plans were alive a year later. This compared with 57% of those who had not taken

such steps. The differences were particularly marked among patients with diseases other than cancer. Researchers said patients who had conversations with their doctors about the fact they were dying might be more likely to reject high-risk treatments. <http://bit.ly/2YNAuCl>

Specialist Publications

‘Preventing unwanted situations and gaining trust: A qualitative study of older people and families’ experiences with advance care planning in the daily practice of primary care’ (p.8), in *Family Practice*.

1. ‘Advance care planning and longer survival in the terminally ill: A randomised controlled trial unexpected finding,’ *BMJ Supportive & Palliative Care*, published online 10 December 2019. **Full text:** <http://bit.ly/346KCqx>



Would this article be of interest to a colleague?

Specialist Publications

What do future hospice patients expect of hospice care? Expectations of patients in the palliative phase who might be in need of hospice care in the future: A qualitative exploration

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 9 December 2019 – Little is known about expectations of patients who might be in need of hospice care (HC). Participants [in this qualitative study from The Netherlands] expected hospice admission only when the burden became unbearable and a home death cannot be reached. Participants expected a homely atmosphere, where one can continue the life lived at home as much as possible. Participants supposed empathic professional caregivers, capable of providing appropriate care. The general practitioner is expected to stay involved in the care process due to the mutual trust. Medical and daily care are required to be provided by competent professionals, where volunteers are expected to provide supportive care. All caregivers are supposed to provide a listening ear and “being there” for participants. Social care and spiritual care are generally pro-

jected to be private matters, unless it is requested. Patients in the palliative phase who might be in need of HC have specific expectations. Perceptions of HC in the public domain should be nuanced in response to these expectations, and information provision on HC should be improved. **Abstract (w. list of references):** <http://bit.ly/2Pu192A>

Publishing Matters

‘Predatory journals: No definition, no defence’ (p.14), in *Nature*.

‘Do journals contribute to the international publication of research in their field?: A bibliometric analysis of palliative care journal data’ (p.14), in *Palliative Medicine*.

Noted in Media Watch 11 November 2019 (#639, p.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 November 2019 – **‘Examining the knowledge, awareness, and perceptions of palliative care in the general public over time: A scoping literature review.’** The majority of studies reported the public having poor knowledge and awareness of palliative care (PC) over the past 16 years. Top characteristics associated with increased levels of knowledge and/or awareness of PC included women, age 40+, experience with a close friend and/or relative requiring PC, and working in healthcare and/or PC. Participants commonly received information about PC from the media, having a close friend or relative requiring PC, and working in a healthcare setting. **Abstract:** <http://bit.ly/2PTjKa4>

N.B. Additional articles on public awareness, knowledge, and perceptions of PC noted in this issue of Media Watch.

Patterns of religiosity, death anxiety, and hope in a population of community-dwelling palliative care patients in New Zealand. What gives hope if religion can’t?

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 9 December 2019 – Early studies show religious faith helps relieve death anxiety, but later work suggests this may only be the case in societies which are generally religious. Very little research has been conducted on this topic in New Zealand, from which recent censuses indicate is an increasingly secular country. If religion is not an important source of hope for dying, it is important to explore what factors do help relieve existential anxiety and to consider their clinical relevance. This study confirmed that organized religion was not a major support factor. Yet several people who declared themselves non-religious scored highly for intrinsic religiosity and were among the most hopeful participants. This could suggest that spirituality may be more relevant than organized religion in relieving existential distress. The main source of hope for most participants was joyful memories and meaningful relationships. Fear of being a burden and of causing family suffering were the most significant causes of distress. **Abstract (w. list of references):** <http://bit.ly/2s9COr1>

N.B. Selected articles on religious coping in the context of end-of-life care noted in 11 March 2019 issue of Media Watch (#605, p.8).

Why can't Japanese people decide? Withdrawal of ventilatory support in end-of-life scenarios and their indecisiveness

ASIAN BIOETHICS REVIEW | Online – 4 December 2019 – According to a recently updated survey on end-of-life care (EoLC) conducted by Japan's Ministry of Health, Labour & Welfare in 2017, the collective intention regarding EoLC has not yet reached a consensus. Within the general public, 66% approved of the idea of preparing written advance directives (ADs) that describe the type of medical care or treatment they wish to receive (or not) if they were to become unable to make a decision. However, 91.3% of these had not actually written out any ADs. In other words, while many Japanese think that it would be good to express their intentions about the end of their lives, most have not actually put this into action. Even when the sample population was limited to elderly over 60 years of age, 85% did not have anything in writing, despite agreeing that this would be a good idea. These results are fairly consistent with those from a survey conducted in 2013. **Abstract (w. list of references):** <http://bit.ly/2YrGHU8>

Noted in Media Watch 7 October 2019 (#634, p.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 29 September 2019 – '**Attitudes and other factors influencing end-of-life discussion by physicians, nurses, and care staff: A nationwide survey in Japan.**' The authors analyzed responses from 1,012 physicians, 1,824 nurses, and 749 care staff. The number of responders who considered they had adequate end-for-life (EoL) discussion with patients near death was 281 (27.8%), 324 (17.8%), and 139 (18.6%), respectively. Participation in a nationwide education program and caring for at least one dying patient per month were factors that showed a significant association with adequate EoL discussion and identification of the proxy decision-maker. **Abstract:** <http://bit.ly/2n6LnjU>

Telehealth in palliative care is being described but not evaluated: a systematic review

BMC PALLIATIVE CARE | Online – 13 December 2019 – This review demonstrates that a variety of U.K. palliative care (PC) telehealth initiatives continue to be described in the published literature. Since a 2010 review there particularly appears to have been an increase in the number of home tele-monitoring interventions, perhaps because of an improvement in this technology. However, where sufficient detail of the telehealth initiative allowed review against a standard, the majority of interventions did not meet the requirements of a U.K. digital service. Despite the description of telehealth development and implementation, there remains a lack of robust study design and evaluation of these interventions meaning that clear conclusions around the benefit of telehealth in PC cannot be drawn; there is insufficient high quality evidence to comment on any influence on access to emergency or unscheduled care. Further work to evaluate the use of telehealth in PC, and to specifically examine its use in out-of-hours specialist PC provision is recommended. **Full text:** <http://bit.ly/2PJKJmT>

Noted in Media Watch 1 July 2019 (#620, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 25 June 2019 – '**Top ten tips palliative care clinicians should know about telepalliative care.**' While additional data are needed, telepalliative care – the application of telehealth technologies to palliative care (PC) – may help address important challenges inherent to our specialty, such as geography and clinician staffing; the burden of traveling to brick-and-mortar clinics for patients who are symptomatic and/or functionally limited; and, the timely assessment and management of symptoms. This article, created by experts in telehealth and PC, provides a review of the current evidence for telepalliative care and potential applications and practical tips for using the technology. **Abstract:** <http://bit.ly/2iLiOM6>

N.B. selected articles on telehealth in PC noted in 9 December 2019 issue of Media Watch (#643, p.13)



Media Watch: Access Online

Updated 12.09.2019

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.15.

“Whatever happens, happens” challenges of end-of-life communication from the perspective of older adults and family caregivers: A qualitative study

BMC PALLIATIVE CARE | Online – 12 December 2019 – This study identified four challenges of engaging in end-of-life (EoL) communication from the perspective of older adults with advanced heart failure and family caregivers. These findings provide useful clinical insights that can inform approaches to integrate EoL communication into serious illness care. The findings highlight a need for EoL communication to begin earlier in the course of illness to better support patients and caregivers during a period of decline as well as for communication to occur iteratively for those who may not be ready to engage. Future research is needed to explore and test alternative communication approaches that effectively unravel the challenges of illness among older adults with serious illness and their caregivers earlier in the illness trajectory. **Full text:** <http://bit.ly/36AM1Yj>

Related

- *FAMILY PRACTICE* | Online – 9 December 2019 – ‘**Preventing unwanted situations and gaining trust: A qualitative study of older people and families’ experiences with advance care planning in the daily practice of primary care.**’ Older people and their family’s lacking trust, or negative thoughts regarding GPs’ time and interest in advance care planning (ACP), appears to make them less open to ACP. A vicious circle may exist in which people, who lack this trust, will be less open to ACP and will less likely gain trust by participating in it. A lack of clarity about who is responsible for documentation, transfer and follow-up, and what can be expected from ACP, seemed to leave older people and their families with the belief that their wishes would be granted. **Full text:** <http://bit.ly/2E8VpGa>

The impact of population ageing on end-of-life care in Scotland: Projections of place of death and recommendations for future service provision

BMC PALLIATIVE CARE | Online – 12 December 2019 – The authors’ projections show that if current Scottish trends continue, the need for end-of-life care will rise over the next 20 years, particularly in home and care home settings. By 2040 community settings could feasibly account for nearly two-thirds of all deaths, and hospital could fall to approximately one-third. These findings align with those projected in England & Wales. However, if community support and capacity does not radically increase, these current trends will not be sustained. If care home capacity remains at 2016 levels, hospital deaths could increase by 9.2% by 2040. If home deaths also remain at 2016 levels, hospital deaths could increase by 30.5%, representing 56.4% of all deaths by 2040. This means that most people would die in hospital, and at higher levels than was observed in 2004. There is growing evidence to support the effectiveness of home based palliative care. **Full text:** <http://bit.ly/2qKez24>

Noted in Media Watch 2 July 2018 (#570, p.9):

- *INTERNATIONAL JOURNAL OF POPULATION DATA SCIENCE* | Online – 11 June 2018 – ‘**End-of-life care in Scotland: Trends in the population in need of palliative care.**’ This paper provides estimates of how many people require palliative care (PC) in Scotland and describes changes in the composition of this sub-population. What are their living arrangements? How have their medical conditions, health service use, and health trajectories changed? While a recent paper suggests that PC need in England & Wales has increased from 72.5% in 2006 to 74.9% in 2014,¹ the share of people with a PC need among all deaths in Scotland has decreased from 80.6% to 78.3% in the period of this study. **Abstract:** <https://goo.gl/s29y1X>

1. ‘How many people will need palliative care in 2040? Past trends, future projections and implications for services,’ *BMC Medicine*, published online 18 May 2017. [Noted in 22 May 2017 issue of Media Watch (#513, p.11)] **Full text:** <https://goo.gl/TP7U92>

N.B. Selected articles on palliative and end-of-life care in Scotland noted in this issue of Media Watch.

Social networks, social capital and end-of-life care for people with dementia: A realist review

BMJ OPEN | Online – 11 December 2019 – A total of 40 context-mechanism-outcome configurations help explain how social capital may influence end-of-life (EoL) care for people with dementia. Such influence was identified within five key areas: 1) Socially orientating a person with dementia following diagnosis; 2) Transitions in the physical environment of care; 3) How the caregiving experience is viewed by those directly involved with it; 4) Transition of a person with dementia into the fourth age; and, 5) The decision-making processes underpinning such processes. Comparatively few interventions and/or EoL policies are designed to address the complexities highlighted by the multiple contexts and mechanisms identified in this review. As a public health approach to palliative care gathers pace, it is important that “community” or “social capital” is not viewed as a universal solution to the mounting public health crisis. This study highlights the need to take a more dispassionate approach, studying its potential in all its complexity in order to further understand what works for whom and in what circumstances. **Full text:** <http://bit.ly/2PBr8VX>

The dying parent and dependent children: A nationwide survey of hospice and community palliative care support services

BMJ SUPPORTIVE & PALLIATIVE CARE | Inprint – Accessed 13 December 2019 – Annually, across the world a substantial number of dependent children experience the death of a parent through life-limiting illness. Without support, this has long-term implications for children’s emotional, social and physical well-being, impacting on health and social care services globally. Limited information exists on how service providers are meeting family needs when a parent with dependent children is dying. 197 hospices [in the U.K.] were invited to participate [in the web-based survey]. Response rate was 66%. More types of support were provided after, than before, parental death. 22% of hospices reported no formal processes for asking or documenting the presence of dependent children. Volunteers were an under-used resource before parental death. Four themes characterised challenges in delivering support for families: 1) Emotional difficulties for families; 2) Practical and social difficulties for families; 3) Funding/resources; and, 4) Staff training/numbers. Family needs are not consistently being met when a parent is dying. Areas for development include: enhanced systems to record when patients have dependent children; flexible approaches to support vulnerable families; staff training to help communication with families and management of their own fears of making the situation worse. Effective educational interventions and service developments to better support staff, parents, and children are needed. **Abstract:** <http://bit.ly/2srneXz>

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 December 2019 – ‘**Addressing child custody concerns of parents with life-limiting illness.**’ Custody concerns are a major source of psychosocial distress among single parents with life-limiting illness. Although children are increasingly living in diverse household structures, the current healthcare system is not designed to meet the unique needs of single parents or non-traditional families. Patients with unaddressed custody concerns can experience psychological suffering during treatment and at the end of life. Lack of clarity and resolution regarding guardianship may also result in additional hardship for their grieving children. **Abstract:** <http://bit.ly/2P87rWG>



Prison Hospice: Backgrounder

Updated 12.15.2019

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>

Photo: Lori Waselchuk. Philadelphia, PA

Heart failure in adult congenital heart disease: From advanced therapies to end-of-life care

CANADIAN JOURNAL OF CARDIOLOGY, 2019;35(12):1723-1739. There is mounting recognition that some of the most urgent problems of adult congenital heart disease (ACHD) are the prevention, diagnosis, and management of heart failure (HF). Recent expert consensus and position statements not only emphasize a specific and pressing need to tackle heart failure (HF in ACHD (ACHD-HF) but also highlight the difficulty of doing so given a current sparsity of data. Some of the challenges are addressed by this review. The authors are from 3 different centres; each centre has an established sub-speciality ACHD-HF clinic and is able to provide heart transplant, multi-organ transplant, and mechanical support for patients with ACHD. Appropriate care of this complex population requires multidisciplinary ACHD-HF teams evaluate all possible treatment options. The risks and benefits of non-transplant ACHD surgery, percutaneous structural and electrophysiological intervention, and ongoing conservative management must be considered alongside those of transplant strategies. In the authors' approach, advanced care planning and palliative care coexist with the consideration of advanced therapies. An ethos of shared decision-making, guided by the patient's values and preferences, strengthens clinical care, but requires investment of time as well as skilled communication. In this review, the authors offer practical real-world advice for managing these patients, supported by scientific data where it exists. **Full text:** <http://bit.ly/356tUsF>

N.B. Selected articles on end-of-life care in heart failure noted in 2 December 2019 issue of Media Watch (#642, p.14).

Making advance directives visual: Introducing young adults to advance care planning with video-recorded advance directives

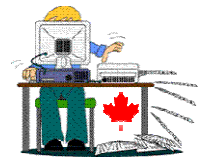
CREATIVE NURSING, 2019;25(4):e44-e51. Currently, young adults are not the intended audience for advance care planning (ACP). A quality improvement project engaged 36 college-age adults in structured group ACP discussions and evaluated the perceived value of a self-recorded advance directive (AD). Findings from a pre- and post-intervention survey suggested that young adults welcomed a conversation about end-of-life care (EoLC); they wished for more information and expressed that a video-recorded AD stimulated thoughts about their own definition of quality of life (QoL). Participants' improved self-perception of comfort, confidence, certainty, and knowledge regarding the ACP process and EoLC indicated young adults may be a willing and eager population for the expansion of ACP. In addition to directing ACP to a younger audience, a personal video-recorded AD may complement the current ACP process and aid individuals in defining their QoL. **Abstract:** <http://bit.ly/2sZmJ7L>

Noted in Media Watch 14 October 2019 (#635, p.11):

- *LIVERPOOL LAW REVIEW* | Online – 5 October 2019 – ‘**Video advance directives: A turning point for advance decision-making? A consideration of their roles and implications for law and practice.**’ While video advance directives (ADs) have several advantages over written ADs, they suffer from issues regarding validity and the opportunity to review the decision, in addition to practical questions on storage, security and accessibility. Despite these weakness, they complement written ADs in their supplementary roles, as such there are opportunities to investigate other ways in which video ADs can assist advance care planning processes and consequently for hospitals to offer training and support to healthcare professionals in facing these concerns. **Full text:** <http://bit.ly/31TtEMi>

[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>



The association between palliative care team consultation and hospital costs for patients with advanced cancer: An observational study in 12 Dutch hospitals

EUROPEAN JOURNAL OF CANCER CARE | Online – 11 December 2019 – This is the first observational study to assess the association between palliative care team (PCT) consultation and hospital care in Dutch hospitals. At baseline, patients with PCT consultation had a significantly worse prognosis and performance status. They also more often had an unplanned hospitalisation, which probably explains why they more often received CT-scans and urine tests. Patients with PCT consultation also more often had no more options for anti-tumour therapy at admission, which explains why chemotherapy during follow-up was less common in this group. The authors found no significant differences in hospital length of stay, medication use, ICU admission, tube feeding or artificial respiration between patients who did and who did not receive PCT consultation. When controlling for baseline differences, we did not find a statistically significant association between PCT consultation and hospital costs. When restricted to patients who received PCT within 3 days of hospital admission, the authors also found a non-significant trend towards lower hospital costs for patients who received PCT consultation. **Full text:** <http://bit.ly/2PefhOz>

Assessment of variability in end-of-life care delivery in intensive care units in the U.S.

JAMA OPEN NETWORK | Online – 11 December 2019 – Overall, 1 of 5 decedents in the U.S. is admitted to an intensive care unit (ICU) before death. This study describes structures, processes, and variability of end-of-life care (EoLC) delivered in ICUs. EoLC delivery varied substantially, and the patterns of care observed suggest that units can be characterized as higher and lower performing. To achieve optimal care for patients who die in an ICU, future research should target unit-level variation and disseminate the successes of higher-performing units. **Full text:** <http://bit.ly/2YKNWGP>

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. Selected articles on EoLC in ICU noted in 7 October 2019 issue of Media Watch (#634, p.9).

Defining the boundaries of palliative care in pediatric oncology

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 12 December 2019 – While palliative care (PC) continues to be integrated into pediatric oncological care, only a minority of patients with cancer receive a formal PC consult. The authors sought to describe oncologists’ current understanding of PC and how primary PC is provided for children with cancer. Seventy-seven participants with diverse training backgrounds (30 attending physicians, 21 nurses, 18 fellows, 5 nurse practitioners, and 2 child life specialists) completed an interview. Approximately 75% provided a modern definition of PC (e.g., not limited to end-of-life care); all participants acknowledged primary PC skills as part of their daily clinical activities. However, participants expressed wide variation in the comfort and time spent performing primary PC tasks (i.e., symptom management, addressing mental health and psychosocial needs) and over half reported that patients’ PC needs are not adequately met. Additionally, some reported confusion about the benefits of PC consultation, despite acknowledging that PC needs to be better integrated into the care of pediatric oncology patients. The findings of this study demonstrate that while most pediatric oncologists accept a modern definition of PC in theory, how to integrate PC in pediatric oncology practice is less understood. Formalized training and standardization of practice surrounding identification of PC needs in patients who may require secondary or tertiary PC services may help to overcome current barriers for PC integration in pediatric oncology. **Abstract (w. link to references):** <http://bit.ly/36CRL3P>

The quality of guidelines on the end-of-life care: A systematic quality appraisal using AGREE II instrument

SUPPORTIVE CARE IN CANCER | Online – 13 December 2019 – The present study was conducted to assess the quality of guidelines available on end-of-life care (EoLC) in patients with cancer using Appraisal of Guidelines for Research & Evaluation (AGREE II). Eight guidelines were included in this study. Five of the guidelines were developed based on evidence and two by consensus and one provided no information about its method of development. The highest mean score (82.77%) pertained to “clarity of presentation” and the lowest to “editorial independence” (44.80%). Based on the AGREE II results, three guidelines were “strongly recommended,” four were “recommended with modifications,” and one was “not recommended.” Despite the variations in the quality and strength of the recommendations, a number of guidelines are currently available on EoLC. Health team members should be aware of this variability. **Abstract (w. list of references):** <http://bit.ly/2YJB4AZ>

Resilience in palliative healthcare professionals: A systematic review

SUPPORTIVE CARE IN CANCER | Online – 6 December 2019 – Exposure to end-of-life and chronic illness on a daily basis may put palliative healthcare professionals’ well-being at risk. Resilience may represent a protective factor against stressful and demanding challenges. Twelve articles were assessed for eligibility and, finally, 6 studies met all the inclusion criteria. Of these, four researches were observational and two interventional pilot studies. From the systematic synthesis, palliative care (PC) providers’ resilience revealed to be related to other psychological constructs, including secondary traumatic stress, vicarious posttraumatic growth, death anxiety, burnout, compassion satisfaction, hope and perspective taking. A model on palliative healthcare providers’ experience and the role of resilience is proposed. **Abstract (w. list of references):** <http://bit.ly/36j8Gbr>

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 13 December 2019 – ‘**Resilience in caregivers: A systematic review.**’ Resilience was associated with a positive impact on the quality of life and emotional distress. Communication and social support increase resilient coping strategies. In most selected articles, the sampling strategy used was convenience sampling. Data collection used evaluation scales related to resilience and associated variables for quantitative studies, and semi-structured interviews were used for qualitative studies. Promoting a resilient coping style in caregivers reduces the distress that normally results from illness-related changes in the biopsychosocial and spiritual dimensions. **Abstract:** <http://bit.ly/36syAt6>
- *DEATH STUDIES* | Online – 9 December 2019 – ‘**Compassion fatigue, emotional labor, and emotional display among hospice nurses.**’ The purpose of this study was to investigate relationships between compassion fatigue, emotional labor, and emotional display among hospice nurses (HN). Study participants indicated the emotional labor they utilize is primarily suppressing both positive and negative affect. Compassion fatigue was positively associated with expressing negative emotions, faking negative emotions, negative display rule perceptions and surface acting are negatively associated with suppressing negative emotions. Interventions and policies that foster greater authenticity and support emotional regulation may help reduce compassion fatigue among HN. **Abstract:** <http://bit.ly/2P5xlV>

Noted in Media Watch 2 December 2019 (#642, p.9):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 November 2019 – ‘**Prevalence and predictors of burnout among hospice and palliative care clinicians in the U.S.**’ The authors observed a burnout rate of 38.7%, with higher rates reported by non-physician clinicians. Most burnout stemmed from emotional exhaustion, with depersonalization comprising a minor portion. Factors associated with higher odds of burnout include non-physician clinical roles, working in smaller organizations, working longer hours, being younger than 50 years of age, and working weekends. Higher rated self-management activities to mitigate burnout include participating in interpersonal relationships and taking vacations. **Abstract (w. link to references):** <http://bit.ly/33jZ8L9>

Cont.

Noted in Media Watch 2 September 2019 (#629, p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 26 August 2019 – ‘**Burnout and resilience after a decade in palliative care: What “survivors” have to teach us. A qualitative study of palliative care clinicians with more than 10 years of experience.**’ Four major themes emerged from this qualitative study: 1) Struggling; 2) Changing mindset; 3) Adapting; and, 4) Resilience. Intervening conditions such as self-awareness, reflection, and evolution were also important factors. The core phenomenon of this study was that of “transformational growth” – a process which PC clinicians have to go through before they achieve resilience. The authors also further classified resilience into both personal and collective resilience. **Abstract (w. link to references):** <http://bit.ly/2HxCJIM>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *AJOB EMPIRICAL BIOETHICS* | Online – 12 December 2019 – ‘**Clinicians’ perspectives on the duty to inform patients about medical aid-in-dying.**’ As of 2019, ten jurisdictions in the U.S. have authorized physicians to prescribe a lethal dose of medication to a terminally ill patient for the purpose of hastening death. Relatively little bioethics scholarship has addressed the question of whether physicians have an obligation to inform qualifying patients about aid-in-dying (AID) in permissive jurisdictions and little is known about providers’ actual communication practices with respect to this issue. One hundred and forty-four in-depth, semi-structured interviews were conducted and analyzed using an inductive analytic approach as part of the Vermont Study on Aid-in-Dying. Seventeen respondents, 14 physicians and 3 nurse practitioners, met the inclusion criteria for this sub-study. Eleven respondents indicated that they at least sometimes inform patients about AID. Respondents described multiple factors that influence whether or not they might initiate discussions of AID, including the importance of informing patients of their options for end-of-life care, worries about undue influence, and worries about the potential effects on the patient-provider relationship. For those providers who do initiate discussion of AID at least some of the time, attention to the particulars of each individual patient’s situation and the context of the discussion appear to play a role in shaping communication about AID. While initiating a clinical discussion of AID is undoubtedly challenging, this study provides compelling descriptive evidence that some medical providers who support AID do not unilaterally follow the conventional bioethics wisdom holding that they ought to wait for patients to introduce the topic of AID. Future research should investigate how to approach these discussions so as to minimize ethical worries **Abstract:** <http://bit.ly/36vX195>
- *JOURNAL OF MEDICAL ETHICS* | Online – 6 December 2019 – ‘**Conscientious objection and moral distress: A relational ethics case study of medical assistance in dying in Canada.**’ Conscientious objection has become a divisive topic in recent bioethics publications. Discussion has tended to frame the issue in terms of the rights of the healthcare professional versus the rights of the patient. However, a rights-based approach neglects the relational nature of conscience, and the impact that violating one’s conscience has on the care one provides. Using medical assistance in dying as a case study, the authors suggest that what has been lacking in the discussion of conscientious objection thus far is a recognition and prioritising of the relational nature of ethical decision-making in healthcare and the negative consequences of moral distress that occur when healthcare professionals find themselves in situations in which they feel they cannot provide what they consider to be excellent care. They propose that policies that respect the relational conscience could benefit healthcare institutions by minimising the negative impact of moral distress, improving communication among team members and fostering a culture of ethical awareness. Constructive responses to moral distress including relational cultivation of moral resilience are urged. **Abstract:** <http://bit.ly/2Rxp03Z>



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Publishing Matters

Predatory journals: No definition, no defence

NATURE | Online – 11 December 2019 – Since the term “predatory publishers” was coined in 2010, hundreds of scholarly articles, including 38 research papers, have been written warning about them. Scientific societies and publishers ... have helped to establish the ‘Think. Check. Submit.’ campaign to guide authors. But it is not enough. More than ninety checklists exist to help identify predatory journals using characteristics such as sloppy presentation or titles that include words such as “international.” This is an overwhelming number for authors. Only three of the lists were developed using research evidence. Paywalled lists of quality journals and predatory journals show that there is an appetite for clear, authoritative guidance. But these lists are inconsistent and sometimes out of reach... A journal’s membership of agencies such as the Committee on Publication Ethics (COPE), curated indexes

such as Web of Science, or being listed in the Directory of Open Access Journals, is insufficient to guarantee quality. Predatory journals have found ways to penetrate these lists, and new journals have to publish for at least a year before they can apply for indexing. **Full text:** <https://go.nature.com/2sihi34>

Leading scholars and publishers from ten countries agreed a definition of predatory publishing that can protect scholarship:

Predatory journals and publishers are entities that prioritize self-interest at the expense of scholarship and are characterized by false or misleading information, deviation from best editorial and publication practices, a lack of transparency, and/or the use of aggressive and indiscriminate solicitation practices.

N.B. ‘Think. Check. Submit.’ Campaign website: <http://bit.ly/2t44jm1>

Do journals contribute to the international publication of research in their field?: A bibliometric analysis of palliative care journal data

PALLIATIVE MEDICINE | Inprint – Accessed 13 December 2019 – Research is important internationally, impacting on health service provision and patient benefit. Journals play an important dissemination role, but there may be geographical bias, potentially affecting access to evidence. Publishers, editors and authors are concentrated in North America or Europe. North American authors are more present in North American journals, and European authors in European journals. This polarised approach, if replicated across readerships, may lead to research waste, duplication, and be suboptimal for healthcare development. **Abstract:** <http://bit.ly/2Pgahcj>

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

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