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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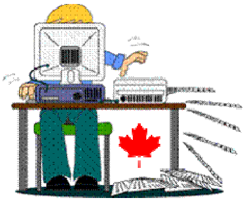

Compiled & Annotated by Barry R. Ashpole

> **So, patients and their families do want honest, timely, clear conversations, and we need to ensure that they understand and accept what we've explained. But we also need to be honest about uncertainty.**
>
> 'What to say when patients are "sick enough to die"' (p.8), in *British Medical Journal*.

U.S.A.

University of West Florida professor explores use of DNR tattoos

FLORIDA | WUWF Radio News (Pensacola) – 17 October 2019 – A growing number of Americans are turning to tattoos to inform medical personnel of their desire not to be resuscitated. This creates a predicament for medical staff: How do they know when a tattoo accurately represents a patient's wishes? Dr. Brian Elzweig [of the University of West Florida College of Business] ... argues that "do not resuscitate" tattoos can be useful to patients and regulated in a way that would provide clarity for medical personnel.[1] "The burden that medical professionals carry in making split-second, irrevocable decisions is too great to allow for inaccessible and unreliable guidance," Elzweig says.... "DNR tattoos, if codified, standardized and properly executed, could ameliorate this burden by allowing a person's self-determined wishes to be met." http://bit.ly/2qkwL1D

Specialist Publications

'Trends and factors associated with place of death for individuals with dementia in the U.S.' (p.12), in *Journal of the American Geriatrics Society*.

'Older patients with severe traumatic brain injury: National variability in palliative care' (p.14), in *Journal of Surgical Research*.

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1. '"Do not resuscitate" tattoos: Adequate evidence of a patient's intent to die?' *Oregon Law Review*, published online 19 June 2019. [Noted in 3 June 2019 issue of Media Watch (#616, p.11)] **Abstract:** http://bit.ly/2MSqtxP

N.B. Additional articles on DNR tattoos noted in 17 December 2018 issue of Media Watch (#594, p.8).

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Five obstacles to home-based healthcare, and how to overcome them

HARVARD BUSINESS REVIEW | Online – 17 October 2019 – An increasing number of new and established organizations are launching and scaling models to move primary, acute, and palliative care to the home. For frail and vulnerable patients, home-based care can forestall the need for more expensive care in hospitals and other institutional settings. As an example, early results from Independence at Home, a five-year Medicare demonstration to test the effectiveness of home-based primary care, showed that all participating programs reduced emergency department visits, hospitalizations, and 30-day readmissions for home-bound patients, saving an average of $2,700 per beneficiary per year and increasing patient and caregiver satisfaction.[1] http://bit.ly/2MIQVda

1. 'Home-based primary care: Beyond extension of the Independence at Home Demonstration,' *Journal of the American Geriatrics Society*, 2018;66(4):812-817. **Abstract**: http://bit.ly/2Mn6ybi

N.B. 'Independence at Home Demonstration,' Innovation Center, Centers for Medicare & Medicaid Services: http://bit.ly/2MNGp4B

Engaging faith groups supports hospice outreach

HOSPICE NEWS | Online – 17 October 2019 – Hospices that engage with religious leaders and faith communities can boost their public outreach to bring patients into hospice earlier, promote advance care planning as well as increasing market share among unserved populations. Hospices nationwide work with faith communities to educate the public about the benefits of hospice care and to provide spiritual care to patients and families. They can also help resolve patient and family concerns that ending curative treatment could conflict with the tenets of their religion. Religious groups also often hold fundraisers to collect donations for hospices in their communities and encourage volunteerism. http://bit.ly/2IW51Ha

When it comes to cancer, fighting words might be the wrong approach

CALIFORNIA | *USC News* (University of Southern California) – 16 October 2019 – When it comes to cancer and other serious diseases, we often rely on words of aggression and tenacity. Patients are "fighters," and those who experience remission or return to good health are "survivors." Obituaries are filled with references to people "losing their battle" with an illness or "fighting until the very end." Researchers at the University of Southern California designed a study to test the "war on cancer" metaphor. The research team asked about 1,000 people to read a story about a cancer patient that framed the disease either as a "journey" or as a "battle" or "war." They hypothesized that aggressive language might prompt participants to be more vigilant about preventing cancer and regularly check for warning signs that they might have the disease. Instead, they found people who read the "battle" or "war" version of the story perceived cancer as difficult and painful to treat.[1] They also felt like they couldn't control the disease or do anything to stop it from occurring. http://bit.ly/31oWP8E

1. 'Battle metaphors undermine cancer treatment and prevention and do not increase vigilance,' *Health Communication*, published online 9 September 2019. **Abstract:** http://bit.ly/2oFwTsp

N.B. Additional articles on the use of metaphors in relation to "combating" life-limiting or life-threatening illness, notably in cancer, noted in 27 May 2019 issue of Media Watch (#615, p.3).

Five trends that reveal the hospice opportunity in senior housing

SENIOR HOUSING NEWS | Online – 14 October 2019 – Joanne Ford knows all too well the challenges hospice faces in senior living."One of the barriers for people making referrals to hospice from assisted living (AL) facilities is … 'We don't want people to see hospice in our building – please don't wear your name tag here,'" says Ford, vice president of the AL division of Tidewell Hospice out of Sarasota, Florida. Tidewell delivers hospice services to residents in 174 AL facilities, with an overall average daily census of

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more than 1,100. "We actually have corporate entities that tell their folks, 'Don't refer to hospice. We don't want that image in this building,'" Ford says. She spoke with *Senior Housing News* for a recent deep-dive report exploring the pressing need for senior living providers to formulate hospice strategies, and the significant benefits they could see from doing so. That trepidation is fading. Utilization of hospice – a spate of end-of-life services for the terminally ill geared toward a person's physical and spiritual wellbeing – is rising in the U.S., particularly in AL. http://bit.ly/2VMq1FK

Noted in Media Watch 26 November 2018 (#591, p.10);

- *JOURNAL OF AGING*, 2018;47(12):72-83. **'Contours of "here": Phenomenology of space for assisted living residents approaching end of life.'** This study investigates how assisted living residents who are approaching end of life (EoL) navigate and experience space. Findings show that participants experience a neutral theme of shrinking space, negative themes of confinement and vulnerability, and positive themes of safety and intimacy. Findings have implications for interventions to improve place integration in assisted living and enhance residents' quality of life at EoL, including developing strategies to promote small meaningful journeys within context of shrinking life space. **Abstract:** http://bit.ly/31mARTH

Noted in Media Watch 7 April 2014 (#352, p.10):

- *JOURNAL OF AGING STUDIES*, 2014;30(4):1-13. **'"This is our last stop.": Negotiating end-of-life transitions in assisted living.'** The authors present a model for how end-of-life (EoL) care transitions are negotiated in assisted living (AL) that depicts the range of multi-level intersecting factors that shape EoL processes and events in AL. These vary across and within settings depending on multiple influences, including, notably, the dying trajectories and care arrangements of residents at EoL, the prevalence of death and dying in a facility, and the attitudes and responses of individuals and facilities toward EoL processes and events (including how deaths were communicated and formally acknowledged), and the impact of death and dying on the residents and staff. **Abstract:** http://bit.ly/2BdR57b

International

An eloquent judgment

U.K. (England & Wales) | *The Irish Medical Times* (Dublin, Ireland) – 17 October 2019 – Modern medicine creates a raft of ethical, moral, legal, and philosophical challenges. Doctors, like lawyers, are trained to look for certainty, for logical outcomes and for justification of treatment. However, MB was more than the sum of his various conditions. His treatment could not be approached purely from the perspective of medical logic. His own aspirations as to how he wished to live the remainder of his life had to be taken into consideration. Giving his decision in the case, Mr. Justice Hayden [of the England & Wales Court of Protection] said that it had been possible to put together a home care plan that was very significantly beyond the ordinary. That required enormous ingenuity, determination and creative thinking. It was a triumph of professional collaboration. In that regard, he paid particular tribute to the lead clinician, the palliative care (PC) consultant, and the case manager. While the lead clinician's instinct as a doctor was that MB's death could best be managed in a hospital setting, he was prepared to look creatively at a transitional plan and a return home. He accepted the role of Responsible Clinician in the event that MB moved to live at home. Also integral to the plan was the PC consultant who had "battled through the bureaucratic maze" to a situation where she was now in a position to be responsible for overseeing MB's PC in the community. http://bit.ly/2Mr6o2Y

Specialist Publications

'Palliative care: An essential facet of universal health coverage' (p.15), in *The Lancet Global Health*.

'The opinion of the Italian Committee for Bioethics "Bioethical reflections on medically assisted suicide"' (p.18), in *Medicina E Morale*.

End of life care for adults: Service delivery

U.K. | National Institute for Health & Care Excellence (NICE) – 16 October 2019 – The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian. All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines & Healthcare products Regulatory Agency... Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties. **Download/view at:** http://bit.ly/33Ecjar

Whangārei health professionals to help at world's largest refugee settlement in Bangladesh

NEW ZEALAND | *New Zealand Herald* (Auckland) – 15 October 2019 – For Walter Nasarek, it will be his second time to Bangladesh on medical duties but the sheer scale of providing palliative care (PC) to community health field workers in the world's largest refugee settlement isn't lost on him. The staff member at North Haven Hospice in Whangārei, together with palliative medicine specialist Dr. Kees Lodder, flew out on Sunday for two and a half weeks to help other health professionals at the refugee camp in Cox's Bazar, southeast Bangladesh. The camps are spread over more than 14km and house more than 1 million Rohingya refugees displaced from Burma. Both will volunteer their time training those working for agencies such as Red Cross and Doctors Without Borders, and educate them on PC pathways for helping the sick. Nasarek, originally from Germany, did leprosy work with his wife for seven years in Bangladesh in the 1970s, and said his heart still bled for people in the impoverished country. He read … about PalCHASE, the Palliative Care in Humanitarian Aid Situations & Emergencies network, calling for volunteers to spend two weeks helping train community health field-workers in the refugee camps. He and Lodder will be joined by a doctor from Portugal and a counsellor from Zimbabwe before four PC specialists arrive in January. "In humanitarian crisis situations, the focus goes on managing acute illnesses and vaccination programmes to stop epidemics, etc. Unfortunately, the forgotten are people with chronic illnesses and terminal illnesses who need PC, as well as the elderly and disabled," Nasarek said. http://bit.ly/2MIHACi

Specialist Publications

'Palliative care in humanitarian crises…' (p.8), in *British Medical Journal*.

Noted in Media Watch 26 August 2019 (#628, p.5):

- BANGLADESH | *The New Humanitarian* (Geneva, Switzerland) – Accessed 19 August 2019 – **'The healer: In Rohingya camps, a local response reaches untreated refugees.'** There are nearly 100 non-governmental organizations, United Nations' agencies, or government bodies working on the massive refugee response in Bangladesh's Rohingya camps. But only one – a tiny local organisation – is focused on the neglected field of palliative care (PC). The Dhaka-based Fasiuddin Khan Research Foundation treats people with life-threatening or severe chronic illnesses in their homes – finding hard-to-reach patients who can't access hospitals or clinics in the sprawling camps. Proponents say it's the first PC programme in any humanitarian response. http://bit.ly/2TK0ziZ

N.B. Fasiuddin Khan Research Foundation: http://bit.ly/2BdyrMP

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Noted in Media Watch 2 April 2018 (#557, p.5):

- BANGLADESH | IRIN Association – 28 March 2018 – **'Caring for the chronically ill in Bangladesh's Rohingya camps.'** Dr. Farzana Khan founded the Bangladesh-based Fasiuddin Khan Research Foundation that set up a programme that helps Sanjida and 200 other severely ill patients. Advocates of palliative care (PC) say it's the first programme to offer dedicated help for people with chronic or life-threatening illnesses during a humanitarian response. "There's absolutely no reason why PC can't be there as part of the health system," said Joan Marston, co-founder of PalCHASE (Palliative Care in Humanitarian Aid Situations & Emergencies Network), a U.K.-based organisation that advocates for such assistance to be included in responses to disasters and conflict. http://bit.ly/2IVnx2w

N.B. Palliative Care in Humanitarian Aid Situations & Emergencies Network: http://bit.ly/2BdY1RI

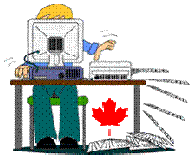
U.K. in end-of-life care crisis as 100,000 people die each year without dignity

U.K. | *The Daily Mirror* (London) – 12 October 2019 – Doctors warn Britain is in the grip of an end-of-life care crisis which subjects 100,000 people a year to an undignified death. Campaigners say the National Health Service (NHS) is battling a shortage of 3,500 nurses needed to support people dying at home. Funding problems, meanwhile, forced the closure of a string of hospices which comfort and care for the terminally ill. And around 80% of hospices which rely on charity will fall into the red next year, says Hospices UK.[1] Dr. Amy Proffitt, vice-president of the Association of Palliative Medicine, warned there are just 60 palliative care consultants – and a shortage of junior doctors training to specialise in the area. Dr. Proffitt, a consultant at St. Christopher's Hospital in South London, said: "We wouldn't run maternity services like this but are happy to allow the dying to rely on charity. Something has to change. We've 100,000 people a year who can't access a hospice bed or even get the right care at home from specialist nurses." Most hospices are funded by charities but some NHS units remain. An extra £25 million funding was announced by the Government in August – a "drop in the ocean," said Dr. Proffitt.[2] The average adults hospice receives 30% of funds from health budgets and the rest through charities, donation and fundraisers, according to Hospice UK.[3] For children's hospices the State provides 22% of funds. http://bit.ly/31bGvIz

1. 'Eight in ten charitable hospices planning a deficit budget this financial year,' Hospice UK, September 2019. [Noted in 14 October 2019 issue of Media Watch (#635, p.7)] http://bit.ly/2obgnA9

2. '£25 million for hospices won't go far,' *British Medical Journal*, 18 September 2019. [Noted in 23 September 2019 issue of Media Watch (#632, p.8)] **Full text:** http://bit.ly/2lW27cS

3. 'U.K. hospices face funding crisis as one in three forced to cut end-of-life services,' ITV News, 7 May 2019. [Noted in 20 May 2019 issue of Media Watch (#614, p.6)] http://bit.ly/3071bSA



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

IPCRC.NET International Palliative Care Resource Center

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

Specialist Publications

Survey of paediatricians caring for children with life-limiting conditions found that they were involved in advance care planning

ACTA PAEDIATRICA | Online – 18 October 2019 – Paediatricians from six Dutch university hospitals completed a survey … which investigated experiences with advance care planning (ACP) in their most recent case of a deceased child and with ACP in general. ACP themes were discussed with parents in all cases. Topics common to many cases were diagnosis, life expectancy, care goals, the parent's fears and code status. ACP conversations occurred with children in 23% of cases. The joy in living was the most frequent topic. The frequency of ACP conversations was insufficient according to 49% of respondents. In 60% it was stated ACP has to result in a documented code status. Paediatricians reported having ACP conversations mainly with parents focusing on medical issues. There was limited insight into the child's preferences for care and treatment. **Abstract:** http://bit.ly/2J5cyDy

Publishing Matters

'Predatory and exploitative behaviour in academic publishing: An assessment' (p.19), in *Journal of Academic Librarianship*.

Noted in Media Watch 2 April 2018 (#557, p.12):

- *ARCHIVES OF DISEASE IN CHILDHOOD: EDUCATION & PRACTICE* | Online – 24 March 2018 – **'Fifteen-minute consultation: Developing an advance care plan in partnership with the child and family.'** When performed well, the process provides all those involved with the opportunity to talk honestly about the future allowing children and their families to retain autonomy and to influence how they are looked after. While this may represent a difficult area of practice for healthcare professionals, both staff and families appear to benefit when the process is fully informed and the child and family are actively involved. **Full text:** http://bit.ly/2BoXNax

Noted in Media Watch 8 October 2018 (#584, p.7):

- *ARCHIVES OF DISEASE IN CHILDHOOD: EDUCATION & PRACTICE* | Online – 28 September 2018 – **'Fifteen-minute consultation: Not the whole story – considering children's spirituality and advance care planning.'** In a society of diverse views, faiths and beliefs, what can paediatric palliative care contribute to our understanding of children's spirituality? The authors explore how developments in advance care planning are addressing these issues. Since children's spirituality is elusive and rarely explored in practice, they clarify understanding of it with examples and offer suggestions for hearing the voice of the child amid the needs of parents and professionals. **Abstract:** http://bit.ly/2Otj1fj

Cultural humility: A way to reduce lesbian, gay, bisexual, transgender, and queer or questioning health disparities at the end of life

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 13 October 2019 – Sexual and gender minorities experience disparities throughout the life course. These are especially detrimental at the end-of-life (EoL) and can include disenfranchised grief, homophobia and transphobia from medical staff, and forced outing. The best healthcare training approach to ameliorate health disparities is debated. Cultural competency trainings for clinicians have been commonly proposed by major medical institutions and certifying bodies to ameliorate lesbian, gay, bisexual, transgender, and queer or questioning (LGBTQ) health disparities. However, cultural competency trainings have limitations, including: 1) False competence; 2) Measurement issues; and, 3) Ecological fallacy (i.e., assuming individuals conform to the norms of their cultural group). The purpose of this commentary is to describe the limitations of cultural competency training and argue for healthcare systems to implement cultural humility trainings as a way to reduce LGBTQ health disparities at the EoL. The strengths of cultural humility training include focus on: 1) Individuals instead of their cultural groups; 2) Self-reflection; and, 3) Active listening. While there are

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challenges to implementing cultural humility trainings in the healthcare system, the authors assert that these trainings align with the aims of healthcare systems and can be an essential tool in reducing LGBTQ health disparities. They suggest practical components of successful cultural humility trainings including leadership buy-in, appropriate outcome measurements, multiple training sessions, and fostering a safe reflection space. **Abstract:** http://bit.ly/2plG9BA

Related

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 10 September 2019 – **'Silent illumination: A case study exploring the spiritual needs of a transgender-identified elder receiving hospice care.'** This is a case study of a hospice volunteer who used skillful means as an artist to help a transgender-identified woman express her spirituality in the last six months of her life. Four themes emerged related to the expression of spirituality by lesbian, gay, bisexual, transgender, and queer (LGBTQ) elders at end of life: 1) The human element in advocacy for spiritual care; 2) The importance of safe spaces for reflection and meditation; 3) The importance of skillful means to work with LGBTQ people; and, 4) Acknowledgement of gender identity as a spiritual need. **Abstract:** http://bit.ly/2lSjuuY

N.B. Additional articles on EoL care for LGBTQ people noted in 2 September 2019 issue of Media Watch (#629, p.8).

Associations between home deaths and end-of-life nursing care trajectories for community-dwelling people: A population-based registry study

BMC HEALTH SERVICES RESEARCH | Online – 15 October 2019 – In this retrospective longitudinal study, the authors' estimates show a low number of potentially planned home deaths in Norway. Trajectories of home nursing hours and probability of skilled nursing facility stays indicated possible effective palliative home nursing for some, but also missed opportunities of staying at home longer at the end of life (EoL). Continuity of care seems to be an important factor in providing home nursing and dying at home. Transitions from home need further research to ascertain if current policies maximize time spent at home and increase the likelihood of home deaths. Future studies should also investigate how family physicians follow up patients at the EoL and whether they can contribute to an increased number of planned home deaths. **Full text:** http://bit.ly/2MfKL5s

Related

- *PAIN MANAGEMENT NURSING* | Online – 15 October 2019 – **'Cancer pain social processes and pain management in home hospice care.'** Preliminary categories of social processes were identified [in this study]: 1) Pain meaning; 2) Working toward comfort; and, 3) Bridging pain. Six sub-categories were identified: 1) Perceiving pain and discomfort; 2) Knowing what to do; 3) Planning activities; 4) Negotiating a pain plan; 5) Talking about pain; and, 6) Being together in pain. This study moved the management approach of pain from a dichotomous realm of nurse-patient, to the more naturalistic realm for home hospice of nurse-patient-caregiver. **Abstract (w. link to references):** http://bit.ly/32Fp9p3

End-of-life care in intellectual disability: A retrospective cross-sectional study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 16 October 2019 – The authors report on a population-based survey on the end-of-life care (EoLC) for adults with intellectual disability (ID). They note some positive experiences and highlight a number of areas for improvement. Health and social services seem to be enabling people with ID to stay in their usual residence at the end of their lives but may not have been offered enough support at the actual time of death or give sufficient encouragement to care providers to involve people with ID in care planning where there is a capacity to do so. Since the population of people with ID is ageing (despite being markedly younger than the general population), multi-morbidity associated with age and frailty means that their EoLC needs are likely to increase in complexity over time. Care facilities and their staff must be supported and equipped to provide the complex care that these people need as they approach the end of their lives. **Full text:** http://bit.ly/31shqcc

N.B. Additional articles on palliative and end-of-life care for people living with intellectual and developmental disabilities noted in 6 May 2019 issue of Media Watch (#613, p.6).

What to say when patients are "sick enough to die"

BRITISH MEDICAL JOURNAL | Online – 16 October 2019 – First, patients' families are far more likely to be distressed by clinical teams not explaining how sick their loved ones are, and not saying that they're dying, than by doctors openly discussing the issue and involving them in decisions. Some people won't welcome unexpected conversations about dying, however sensitively handled – but they'll be in a minority. Most people value discussion and involvement. The National Survey of Bereaved People and the National Audit of End-of-Life Care in Hospital [*sic*] make that clear, as does the Royal College of Physicians' 'Talking About Dying.'[1,2,3] Communication failings and insufficient information are a major cause of bad experiences.[4] Second, although we should communicate sensitively, vague euphemisms don't work. Unless you say very clearly that someone is dying, or at very high risk, patients and families are left in limbo. If doctors are resolved to have these difficult conversations we can't equivocate or eschew plain language. Third, it's not enough to have the conversation once. To be clear and direct you need to go back and have it as many times as needed for people to come to terms with what can be shocking news.[5] Finally, while our language should be direct and unequivocal, that doesn't mean that we should be more confident in predicting imminent death than the evidence allows. Early warning scores for physiologically deteriorating patients, or scores such as APACHE for those with sepsis or intensive care needs, have strong correlations with risk of death and good predictive validity, but peer reviewed analyses of big datasets show that they're not infallible. Besides, they depend on individual context: how much intervention we give and for how long. **Full text:** http://bit.ly/31nZqzM

1. 'National Survey of Bereaved People (VOICES): England, 2015: Quality of care delivered in the last 3 months of life for adults who died in England,' Office for National Statistics, April 2016. [Noted in 25 April 2016 issue of Media Watch (#459, p.9)] **Download/view at:** http://bit.ly/2qfpvUJ

2. 'National Audit of Care at the End of Life: 2018-2019 Report,' Healthcare Quality Improvement Partnership, July 2019. [Noted in 15 July 2019 issue of Media Watch (#622, p.6)] **Download/view at:** http://bit.ly/2LhXa9J

3. 'Talking about dying: How to begin honest conversations about what lies ahead,' Royal College of Physicians, October 2018. [Noted in 22 October 2018 issue of Media Watch (#586, p.3)] **Download/view at:** http://bit.ly/33zMok9

4. 'One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life,' Leadership Alliance for the Care of Dying People, June 2014. [Noted in 30 June 2014 issue of Media Watch (#364, p.7)] **Download/view at:** http://bit.ly/33Cx5HE

5. 'The Second Conversation Project: Improving training in end-of-life care communication among junior doctors,' *Future Healthcare Journal*, 2019;6(2):129-136. [Noted in 24 June 2019 issue of Media Watch (#619, p.7)] **Full text:** http://bit.ly/2IqdP8t

Palliative care in humanitarian crises…

BRITISH MEDICAL JOURNAL | Online – 14 October 2019 – Recently there has been renewed interest in how to best integrate palliative care (PC) into aid efforts during humanitarian crises. The range of people who would stand to benefit from this is broad. It includes people with life limiting and complex chronic conditions who may have benefitted from PC even before a disaster. Then there are those with potentially life limiting conditions that are a result of the crisis. This may include people with chronic illness who have lost access to life saving medical care (for example, dialysis or cancer chemotherapy). It also applies to people with serious injuries who are unable to reach life-saving care or whose injuries may be beyond the abilities of any healthcare intervention to save. Likewise, there are those who, in the midst of communicable disease outbreaks with high mortality, like Ebola, face a high likelihood of serious symptom burden and death. Finally, PC may include support for family members and for medical providers who are struggling with the burden of care and loss. The recognition that PC may have an important role in relief efforts is long overdue, but is gradually starting to gain traction. **Full text:** http://bit.ly/2MfqIEg

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Noted in Media Watch 9 September 2019 (#630, p.9)

- *MEDICAL JOURNAL OF AUSTRALIA*, 2019;211(5):201-203. **'Integrating palliative care and symptom relief into responses to humanitarian crises.'** The medical and moral imperative that palliative care (PC) be integrated into standard responses to humanitarian crises (HC) can be fulfilled by basic training and an essential set of medicines, equipment, social support and protocols. Humanitarian crises often cause both extensive loss of life and widespread suffering. Yet HC response virtually never fully integrates PC, the discipline devoted to preventing and relieving suffering. Recently, the World Health Organization recognised the necessity of integrating PC and symptom relief into responses to HC of all types and published a guide to this integration. **Abstract:** http://bit.ly/2ZGvFcJ

What place for an ethics committee in a comprehensive cancer centre? For an ethics embodied in real life

BULLETIN DU CANCER | Online – 5 October 2019 – The Ethics Committee of Gustave Roussy cancer center [Villejuif, Paris] is devoted to both reflection and action. The group has 40 members, professionals, patients and outside experts. These meet in plenary meetings or in specific working sessions and intervene at the request of any professional faced with ethical questions in the care. This Ethics Committee has voluntarily a double vocation: on one hand, a reflective group on major issues of ethics in health and its involvement in hospital life; on the other hand, a working group embedded in the daily lives of the care. The themes addressed at the meetings (plenary sessions, annual meetings) include shared-decision making, advance directives, refusal of care, religious aspects, or biomedical research… Daily activity centered on the care revolves around several times a week meetings, in various services, "Supportive Collegial Meetings" such as proposed in the 3rd French Cancer Plan; these include nursing staff members, oncologists, intensive and palliative care specialists, psychologist, around difficult medical and/or ethical situations. In case of situation requiring an urgent discussion, a referral to the Ethics Committee brings together within 24 hours four to five members of the Committee and the care team.. Its double polarity aims to reconcile "philosophical time" for the ethics process, and the connection with the routine issues raised by patients, their families and caregivers. **Abstract:** http://bit.ly/32f8hFj

Extract from *Bulletin du Cancer* article

…the Ethics Committee helped develop Aid to Decision Making Form upon care gradation for hospitalized cancer patients. Through these interventions on a daily basis, assistance of professionals, reflexive vocation or even delivery of training, the Ethics Committee contributes to an acculturation around anticipation and collegiality in the care.

N.B. French language article.

Navigating power dynamics in engaging communities in end-of-life issues: Lessons learned from developing community-based intergenerational arts initiatives about death and loss

DEATH STUDIES | Online – 11 October 2019 – Lack of community engagement in end-of-life (EoL) issues and age-segregation in Swedish society motivated the authors to develop Studio DöBra, a community-based intergenerational arts initiative to support community engagement in EoL issues and develop intergenerational meeting places. Representatives from several community organizations formed a project group … to develop Studio DöBra. Based on analysis of exploratory interviews with professionals involved in other, similar initiatives and data from Studio DöBra development, the authors discuss challenges related to power dynamics in developing initiatives to engage communities in EoL issues, and how these can inform the development of similar initiatives. **Full text:** http://bit.ly/31a3IdW

N.B. The term DöBra is a Swedish pun which literally means dying well, but figuratively means "awesome."

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Noted in Media Watch 11 March 2019 (#605, p.13):

- *BMC PALLIATIVE CARE* | Online – 7 March 2019 – **'Discussing end-of-life wishes – the impact of community interventions?'** Well-designed awareness-raising and educational events, delivered in a sensitive manner, can prompt the public to consider end-of-life preferences and discuss these with the people closest to them, and may increase recipient's confidence in having those conversations. These types of intervention have the potential to reach beyond the immediate recipients, as attendees talk to others about issues, or even host their own similar events. The events evaluated in this study appeared to be relevant and effective for all age groups, but were most relevant and effective for those aged 45 to 74. Further research might identify interventions more suitable for younger and older age groups, and those who would not be reached by events like these. **Full text:** http://bit.ly/2XP8soK

Complicated grief therapy for clinicians: An evidence-based protocol for mental health practice

DEPRESSION & ANXIETY | Online – 17 October 2019 – A significant minority of bereaved persons experience intense, prolonged and disabling grief symptoms associated with considerable morbidity and mortality... Individuals with complicated grief require more formal interventions. The authors describe a compassionate and evidence-based approach to bereavement-care that can be provided in varied mental health settings. For individuals struggling with acute grief, clinicians can help by providing recognition and acceptance of the grief, eliciting and compassionately listening to their narratives of their relationship with the deceased and the death, and regularly "checking in" regarding their grief experiences. For bereaved persons who are experiencing complicated grief, the authors recommend an evidence-based approach to bereavement-care, complicated grief therapy (CGT), that involves helping the individual accept and cope with the loss while simultaneously assisting them with adaptation to life without the deceased. They describe ways of implementing CGT's seven core themes: 1) Understanding and accepting grief; 2) Managing painful emotions; 3) Planning for a meaningful future; 4) Strengthening ongoing relationships; 5) Telling the story of the death; 6) Learning to live with reminders; and, 7) Establishing an enduring connection with memories of the person who died. **Abstract:** http://bit.ly/33HIE0c

Related

- *DEATH STUDIES* | Online – 14 October 2019 – **'The Coping Assessment for Bereavement & Loss Experiences: Development and initial validation.'** The authors present the development and validation of the 'Coping Assessment for Bereavement & Loss Experiences,' the first instrument designed to assess a range of potentially constructive strategies for coping with grief following the death of a loved one. Exploratory and confirmatory factor analysis with an international sample of bereaved adults yielded a six-factor, 28-item structure. Use of this validated, clinically useful, self-report tool can inform clinicians and researchers in evaluating bereavement coping, and in developing interventions designed to increase the number and broaden the types of coping strategies used to facilitate healing following loss. **Abstract:** http://bit.ly/2B9qAj9

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE* | Online – 12 October 2019 – **'A brief psychodynamic and person-centered approach to address anticipatory loss in acute care settings.'** Palliative care addresses the biopsychosocial and spiritual distress of people with critical and chronic illness. Depending on the trajectory of an illness, a social worker in an acute care setting may have a limited number of opportunities to engage in meaningful interaction with an emotionally distressed patient. The social worker is often faced with providing care to a patient who is having the dual experience of maintaining hope for medical improvement and anticipating loss. This article offers therapeutic practice skills needed by social workers to address the experience of anticipatory loss in an acute care setting. **Abstract:** http://bit.ly/2BdDmwZ

- *SOCIAL SCIENCE & MEDICINE* | Online – 12 October 2019 – **'Disadvantaged and disenfranchised in bereavement: A scoping review of social and structural inequity following expected death.'** Studies highlighted unequal social status in bereavement related to gender, class, sexuality, ethnicity and age, with structural inequity experienced in interactions with institutions and social networks. The experience of bereavement itself may be accompanied by exposure to disenfranchising systems and processes. Findings point to the need for consideration of socio-ecological approaches within and beyond specialist palliative care, involving development of more responsive social policy, coordinated advocacy, and systemic capacity building regarding experiences of grief, to better support populations positioned as structurally vulnerable in bereavement. **Abstract:** http://bit.ly/33pYH2p

Facing the large variety of life-limiting conditions in children

EUROPEAN JOURNAL OF PEDIATRICS | Online – 17 October 2019 – Life-limiting conditions in children in specialized pediatric palliative care (PC) are manifold. The Together for Short Lives (TfSL) association established four disease categories, which represent the most common illness trajectories. Better understanding the PC needs and symptoms of children within these TfSL groups will result in improved anticipation of clinical problems and tailored care. During this retrospective single-center cohort study, 198 children, adolescents, and young adults (CAYAs) were in pediatric PC. Mean age at referral was 8.7 years, mean duration of care 355 days. One hundred six (53.5%) CAYAs died during the study period. Sixty-five (32.8%) CAYAs were assigned to TfSL-1, 13 (6.6%) to TfSL-2, 49 (24.7%) to TfSL-3, and 71 (35.9%) to TfSL-4. Home visits were conducted on average every 9.6 days in TfSL-1, 18.9 days in TfSL-2, 31.7 days in TfSL-3, and 31.8 days in TfSL-4 (p value < 0.01). Intensity of PC significantly differed between the TfSL groups. Neurological and gastrointestinal symptoms were most prominent across all TfSL groups. Symptom cluster analysis showed distinct clusters in TfSL-1 (cluster 1, fatigue/lack of appetite/nausea/somnolence; cluster 2, dyspnea/fear/myoclonus/seizures/spasticity) and TfSL-3/4 (cluster 1, spasticity; cluster 2, all other symptoms). **Abstract (w. list of references):** http://bit.ly/2P124Jm

> **N.B.** 'Categories of life-limiting and life-threatening conditions,' Together for Short Lives. **Download/view at:** http://bit.ly/2VUF5B7
>
> **Related**
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> - *PEDIATRIC BLOOD & CANCER* | Online – 14 October 2019 – **'Palliative care utilization in hospitalized children with cancer.'** The authors analyzed the 2005-2011 National Inpatient Sample, a representative, cross-sectional sample of U.S. hospital admissions. 4.4% of [10,960] hospitalizations included PC involvement. In regression models invoking stepwise variable selection, a shorter length of stay, solid cancer, and older age were associated with PC use. PC utilization was also associated with lower overall and daily hospital costs. These results have significant implications for public health resource allocation and the delivery of pediatric PC as high-value care. Future research should focus on the development of new tools to help physicians assess when PC is appropriate for their patients. **Abstract:** http://bit.ly/2VKzXzk

Institute-based sustainable palliative care program: A unique initiative of "cancer treatment center program"

INDIAN JOURNAL OF PALLIATIVE CARE, 2019; 25(4):485-486. The Indian healthcare system, like elsewhere, is built on an acute care paradigm, and is ill equipped to deal with the onslaught of chronic life-limiting diseases. In India, about 5.4 million people a year are estimated to require palliative care (PC) services, with the highest number being the terminally ill elderly. Every year, 9.8 million people die in India, most of them with unbearable pain and suffering, of which 60% are expected to benefit from PC. Despite PC being available in India since the 1980s, and the National Program for Palliative Care being initiated in 2012, <2% of India's population have access to PC, with <4% having access to morphine. The efforts of non-governmental organizations and few committed individuals have birthed many community-driven initiatives that provide flexible, cost-effective, PC. Specialist PC services have been given the required thrust with the introduction of postgraduate programs in PC in tertiary care centers. Yet, despite three decades of presence in the country, coverage of PC services remains patchy and incomplete, with some regions

Cont.

having better access to PC services than others. Improving access to PC in the geopolitical milieu of India is a Herculean task. The World Health Organization has established a public health strategy to effectively integrate PC into the existing healthcare systems. This includes four components: 1) Development of appropriate governmental policies and programs,; 2) Improved and continued availability of essential pain medications; 3) Education of healthcare workers and public; and, 4) Implementation of PC services at all levels of the society. **Full text:** http://bit.ly/2BjfpEA

N.B. Additional articles on PC in India noted in 6 July 2019 issue of Media Watch (#620, pp.9-10).

Stopping dialysis, good deaths, and social justice

JAMA NETWORK OPEN | Online – 11 October 2019 – A major challenge, one not unique to dialysis, is knowing when it is the right time to stop pursuing these aggressive, organ-replacement therapies and instead pursue an aggressive approach focused on high-quality palliative and end-of-life (EoL) care. Richards *et al* conducted an elegant analysis of multiple data sets to explore the association of stopping dialysis and receipt of hospice services with EoL care measures, such as quality of care (QoC).[1] Overall, they found that only 28% of patients stopped dialysis prior to death. Of those, 58% received hospice services. Of the remaining 72% of patients who continued dialysis, only 18% received hospice services prior to death. Compared with patients who continued dialysis, families of patients who chose to stop dialysis were more likely to rate the quality of EoL care as excellent (46% vs 56%). Of patients who continued dialysis, choosing to receive hospice services was associated with a markedly higher proportion of family members rating the QoC as excellent at the EoL compared with those who did not receive hospice services (61% vs 40%). **Full text:** http://bit.ly/2MELlsq

1. 'Association of family ratings of quality of end-of-life care with stopping dialysis treatment and receipt of hospice services,' *JAMA Network Open*, 2019;2(10):e1913115. **Full text:** http://bit.ly/35BhkCE

Trends and factors associated with place of death for individuals with dementia in the U.S.

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 14 October 2019 – In this study, place of death [for people living with Alzheimer's disease-related dementias] was categorized as hospital, home, nursing facility, hospice facility, and other. Aggregate data included age, race, Hispanic ethnicity, sex, urbanization, and census division. Individual-level predictors included age, race, Hispanic ethnicity, sex, marital status, and education. From 2003 to 2017, nursing facility and hospital deaths declined from 65.7% and 12.7% to 55.0% and 8.0% while home and hospice facility deaths increased from 13.6% and .2% to 21.9% and 6.2%, respectively. Odds of hospital and hospice facility deaths declined with age while odds of nursing facility deaths increased with age. Male sex was associated with higher odds of hospital or hospice facility death and lower odds of home or nursing facility death. Non-white race, Hispanic ethnicity, and being married were associated with increased odds of hospital or home death and reduced odds of nursing facility death. More education was associated with higher odds of home or in a hospice facility death and reduced odds of death in a nursing facility or hospital. Significant disparities in place of death by urban-rural status were also noted. **Abstract:** http://bit.ly/2oFH7ZC

N.B. Selected articles on palliative and end-of-life care for people living with dementia noted in 29 July 2019 issue of Media Watch (#624, p.13).

Related

- *ZEITSCHRIFT FUR GERONTOLOGIE UND GERIATRIE* | Online – 14 October 2019 – **'Advance care planning in the context of dementia.'** Since 2015, Germany's Hospice and Palliative Care Act has defined the entitlement of nursing home residents to preventive planning in the final phase of their lives. Nevertheless, the advance care planning (ACP) concept has not yet been sufficiently researched in Germany. The deficient evidence on this topic appears to be even more considerable in connection with dementia. The necessity of such a discussion increases exponentially when dementia is diagnosed, not only for the person affected but also for their relatives and other caregivers and companions. **Full text:** http://bit.ly/2MuXmSA

  N.B. German language article.

A brief video intervention to improve medical students' attitudes toward prisoners

JOURNAL OF CONTEMPORARY MEDICAL EDUCATION, 2019;9(2):46-52. Implicit biases against prisoners may negatively impact the quality of care prisoners receive. The inclination to stigmatize prisoners as morally deviant or corrupt, fear of prisoners and other factors can be seen as a justification for lack of equivalent compassion and suboptimal medical care. Healthcare professionals and trainees working in the hospital setting need to be cognizant of their implicit biases toward prisoners and have tools for tackling these perceptions. Introducing medical students to prisoners via a video that depicted them as fellow human beings, without excusing their actions, can lead to attitudinal adjustments more in line with the Hippocratic ideals to which the medical students should be aspiring. Unlike other interventions, a video, such as the one used in this study, can be easily incorporated into medical school training in order to positively impact attitudes toward prisoners. This study is a first step in exploring medical students' attitudes toward prisoners and the effectiveness of video material in shifting attitudes and behaviors toward prisoner care. Next steps include finding ways of optimizing the effectiveness of video interventions and comparing their effects to other interventions, such as prisoner panels. Video interventions grounded in concepts of equivalence, compassion, and consciousness-raising could also be used to promote care of other marginalized or vulnerable populations. **Full text:** http://bit.ly/2OSFeDL

> **N.B.** Click on pdf icon to access full text. 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

Worth living or worth dying? The views of the general public about allowing disabled children to die

JOURNAL OF MEDICAL ETHICS | Online – 15 October 2019 – Decisions about withdrawal of life support for infants have given rise to legal battles between physicians and parents creating intense media attention. It is unclear how we should evaluate when life is no longer worth living for an infant. Public attitudes towards treatment withdrawal and the role of parents in situations of disagreement have not previously been assessed. An online survey was conducted with a sample of the U.K. public to assess public views about the benefit of life in hypothetical cases similar to real cases heard by the U.K. courts (e.g., Charlie Gard, Alfie Evans). The authors then evaluated these public views in comparison with existing ethical frameworks for decision-making. One hundred and thirty participants completed the survey. The majority (94%) agreed that an infant's life may have no benefit when well-being falls below a critical level. Decisions to withdraw treatment were positively associated with the importance of use of medical resources, the infant's ability to have emotional relationships, and mental abilities. Up to 50% of participants in each case believed it was permissible to either continue or withdraw treatment. Despite the controversy, the findings of this survey indicate that in the most severe cases, most people agree that life is not worth living for a profoundly disabled infant. The survey [to the authors' knowledge the first to examine public intuitions towards quality of life and treatment withdrawal decisions in paediatrics] found wide acceptance of at least the permissibility of withdrawal of treatment across a range of cases, though also a reluctance to overrule parents' decisions. These findings may be useful when constructing guidelines for clinical practice. **Full text:** http://bit.ly/2Bf1HTh

Noted in Media Watch 22 April 2019 (#611, p.3):

- *ARCHIVES OF DISEASE IN CHILDREN* | Online – 18 April 2019 – '**Achieving consensus: Advice for paediatricians and other health professionals on prevention, recognition and management of conflict in paediatric practice,**' Conflict is damaging, stressful and emotionally challenging for all involved. Taking the correct early steps may prevent early disagreements reaching conflict. If conflict is reached, families must continue to be supported even if there is a breakdown of trust between families and clinicians. As the voice of the child and what is in their best interest remains paramount, the families' wishes and needs must also be taken into consideration. **Full text:** http://bit.ly/2T4Zwd6

Doing theology in medical decision-making

JOURNAL OF MEDICAL ETHICS | Online – 14 October 2019 – Religious considerations in medical decision-making have enjoyed newfound attention in recent years, challenging the assumption that the domains of biological and spiritual flourishing can be cleanly separated in clinical practice. A surprising majority of patients desire their physicians to engage their religious and spiritual concerns, yet most never receive such attention, particularly in cases near the end of life where such attention seems most warranted. As physicians Aparna Sajja and Christina Puchalski recently wrote … modern medical training is "falling short of preparing physicians to help patients with the metaphysical needs of their illness."[1,2] It would seem then that both patients and physicians might challenge the conclusions proffered by philosophers Jake Greenblum and Ryan Hubbard … in which they claim that physicians ought not to engage religious reasoning for medical decisions.[3] Their conclusion relies on two core arguments: a "public reason" argument and a "fiduciary argument," both of which contend that theology and religious considerations have no place in medical reasoning. **Introduction:** http://bit.ly/2INc05h

1. 'Training physicians as healers,' *American Medical Association Journal of Ethics*, 2018;20(7):E655-663. **Full text:** http://bit.ly/31i90Em

2. 'Religion and spirituality in healthcare practice,' *American Medical Association Journal of Ethics*, 2019;20(7):E607-E674. [Noted in 9 July 2018 issue of Media Watch (#571, p.7)] **Journal contents page:** http://bit.ly/32fDw36

3. 'Responding to religious patients: Why physicians have no business doing theology,' *Journal of Medical Ethics*, 20 June 2019. **Abstract:** http://bit.ly/2MGAMVT

Older patients with severe traumatic brain injury: National variability in palliative care

JOURNAL OF SURGICAL RESEARCH | Online – 10 October 2019 – Older patients with traumatic brain injury (TBI) have higher mortality and morbidity than their younger counterparts. Palliative care (PC) is recommended for all patients with a serious or life-limiting illness. However, its adoption for trauma patients has been variable across the U.S. Of 5,733 patients [i.e., the patient population studied], 78% died in hospital with a median length of stay (LoS) of one day, and 85% of the survivors were discharged to facilities. The overall PC rate was 35%. Almost 40% of deaths received PC, with nearly half within 48 hours of admission. PC was used in 26% who had neurosurgical procedures, compared with 35% who were non-operatively managed. PC was associated with less intensity of care in the entire population. For survivors, those with PC had significantly shorter LoS, compared with those without PC. Despite high mortality, only one-third of older patients with severe TBI received PC. PC was associated with decreased use of life support and lower intensity of care. **Abstract (w. link to references):** http://bit.ly/2IQb3ct

Top ten tips palliative care clinicians should know when caring for patients with brain cancer

JOURNAL OF PALLIATIVE MEDICINE | Online – 15 October 2019 – The diagnosis of an aggressive, primary brain tumor is life altering for those affected and too often portends a poor prognosis. Despite decades of research, neither a cure nor even a therapy that reliably and dramatically prolongs survival has been found. Fortunately, there are a number of treatments that may prolong the life of select brain tumor patients although the symptom burden can sometimes be high. This article brings together neuro-oncologists, neurologists, and palliative care physicians to help shine a light on these diseases, their genetics, treatment options, and the symptoms likely to be encountered both from the underlying illness and its treatment. **Abstract:** http://bit.ly/2OTk7RM

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Noted in Media Watch 7 October 2019 (#634, p.11):

- *NEUROCRITICAL CARE* | Online – 29 August 2019 – **'Palliative care in the neuro-ICU: Perceptions, practice patterns, and preferences of neurointensivists.'** The authors surveyed members of the [U.S.] Neurocritical Care Society to explore current practice patterns, perceptions, and preferences regarding integration of palliative care (PC) in the neurological ICU. PC consultations are utilized infrequently by the majority of the respondents. The most common indication for a palliative consultation was to discuss goals-of-care and make treatment decisions. A large majority either agreed or strongly agreed that PC services were utilized in the management of difficult cases apart from discussions regarding withdrawal of life sustaining therapy. **Abstract (w. list of references):** http://bit.ly/2mQ0zln

Palliative care: An essential facet of universal health coverage

THE LANCET GLOBAL HEALTH, 2019;7(11):PE1488. Katherine Sleeman *et al* use the concept and methodology of the *Lancet* Commission on Global Access to Palliative Care & Pain Relief to project the need for palliative care (PC) to 2060, contributing to scant literature on this topic.[1,2] Their findings reinforce the Commission's call-for-action by showing that the burden of serious health-related suffering (SHS) will almost double, with the fastest increase in low-income countries, and overall among older people and those with dementia. The Commission report included a research agenda that is steadily moving forward. A group of authors of the Commission report are generating updated estimates of SHS and access to pain relief medication. The initial calculations in the report were based on mortality data from the World Health Organization Global Health Estimates for 2015 combined with limited evidence on disease-specific prevalence, while SHS 2.0 uses 2017 mortality and prevalence data from the Institute for Health Metrics & Evaluation. Further, SHS 2.0 includes an historical time series going back to 1990. These new data required a revised methodology for estimating non-decedent SHS to incorporate the country-specific, IHME over-time prevalence data. SHS 2.0 will be the first update to the 2017 *Lancet* Commission report. SHS 2.0 data from 1990 to 2017, matched with time series data on access to opioid medications from the International Narcotics Control Board, are being applied to develop country-specific, health system performance indicators of access to PC as an essential facet of universal health coverage. Although inexpensive, off-patent, injectable and immediate-release oral morphine is only one component of the essential PC package put forward by the Commission, it is a salient tracer of overall access that can be tracked over time. The next step is to expand the access indicator to include the rest of the essential package. **Full text:** http://bit.ly/2Bfj9ak

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. [Noted in 10 June 2019 issue of Media Watch (#617, p.11)] **Full text:** http://bit.ly/30BUwA2

2. 'Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,' *The Lancet*, 12 October 2018. [Noted in 16 October 2017 issue of Media Watch (#534, p.14)] **Full text:** http://bit.ly/2Ww8Cku

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

- *THE LANCET*, 2019;394(10199):621-622. **'Defining primary palliative care for universal health coverage.'** Primary care-led management of chronic diseases, including palliative care (PC), is essential to deliver cost-effective universal health coverage that does not impose financial hardship on people with non-communicable diseases. PC for all is only achievable if all members of the health workforce who care for people with life-limiting illnesses deliver it – in all health systems, irrespective of a country's income status. People are mostly at home for their last years of life, so primary care teams provide much of their PC. The PC delivered by primary care teams is well developed and promoted in some higher-income countries, but much less so in low-income and middle-income countries, although the 2018 WHO guidelines are an encouraging start. **Full text**: http://bit.ly/2ZmyDry

N.B. See 'Palliative Care and Universal Health Coverage Fact Sheet,' developed by the Worldwide Hospice Palliative Care Alliance, the International Association of Hospice & Palliative Care and the International Childrens' Palliative Care Network. The information is based on the findings of the *Lancet* Commission Report on Palliative Care & Pain Relief. **Download/view at:** http://bit.ly/2ZroKsM

Perceptions of and attitudes toward death, dying, grief, and the finitude of life: A representative survey among the general public in Germany

OMEGA – JOURNAL OF DEATH & DYING | Online – 15 October 2019 – Some end-of-life (EoL) aspects have become a significant political and social issue such as elderly care and euthanasia. But hardly anything is known about how the general public in Germany thinks about death and dying more generally. Therefore, the authors conducted a representative online survey regarding 21 EoL aspects. The findings revealed that the general public is open to engaging with topics of death, dying, and grief and that death education might even be promoted for children. Most participants appraised dealing with the finitude of life as part of a good life, but few have contemplated death and dying themselves so far. Attitudes and perceptions were related to age, subjective health, religious denomination, and gender. The survey provides useful implications for community palliative care, death education, and communication with dying people. **Abstract:** http://bit.ly/2Bd1aRX

End-of-life care and place of death in adults with serious mental illness: A systematic review and narrative synthesis

PALLIATIVE MEDICINE | Online – 14 October 2019 – People with serious mental illness have greater mortality risk than the general population. They experience healthcare inequalities throughout life; it is not clear if this persists to end of life (EoL). After full-text screening, 23 studies were included. The authors found studies reporting hospital admissions, emergency department care, palliative care, and general practitioner (GP) visits at EoL. They found conflicting evidence for the association between serious mental illness and EoL care, although different patient groups, settings and measures were used across studies. People with serious mental illness were more likely to die in care homes than the general population. There were no patterns for other places of death. The evidence was sparse and heterogeneous, demonstrating variability in patterns and reporting of healthcare use and with little consensus on where people with serious mental illness are likely to die. Given that people with serious mental illness have increased mortality risk, this gap in the knowledge around EoL care outcomes is concerning; this area of research needs further development. **Abstract:** http://bit.ly/32h2RcP

Noted in Media Watch 25 March 2019 (#607, p.13):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 19 March 2019 – '**A scoping review of palliative care for persons with severe persistent mental illness.**' This review reveals a highly vulnerable population with complex needs that are not reliably being met by the healthcare system and providers. Research in this area must continue to develop using rigorous qualitative and quantitative study designs, and interventions should be developed and tested based on existing knowledge to inform care. The voices of people with severe persistent mental illness (SPMI) in need of palliative care must be represented in future studies to address gaps. To expand a body of literature addressing mainly individuals, system perspectives and socio-cultural analysis can bring much to contextualizing the experience of living with SPMI in the palliative phase of care. **Abstract (w. list of references):** http://bit.ly/2TVvgnN

Implementing advance care planning in routine nursing home care: The development of the theory-based ACP+ program

PLOS ONE | Online – 17 October 2019 – ACP+ … consists of multiple components, activities and materials that need to be implemented together in a stepwise manner over the course of eight months with the help of an external trainer. Its thorough development process and the standardized description in this paper aim to prevent implementation failure in real practice and increase transparency, comparison with other interventions and replication in the future. The program is currently under evaluation as part of a cluster randomized controlled trial. **Full text:** http://bit.ly/31mGuS9

Would this article be of interest to a colleague?

Mind the gap: Patients' experiences and perceptions of goal setting in palliative care

PROGRESS IN PALLIATIVE CARE | Online – 13 October 2019 – Palliative care (PC) aims to support people to live actively until death. A rehabilitative approach which includes goal setting could be an important way of achieving this. Goal setting is well established in best practice guidelines for PC. However little is known about how the process of goal setting actually happens in practice, especially from patients' points of view. Participants [in this study] understood and valued goal setting but did not always share their goals with hospice staff. These were often participants' own personal activity-based goals that they worked on in parallel, but not always in partnership with hospice professionals. Participants were able to adapt their goals as their situation changed. The authors' findings revealed a gap between the goals that participants identified and worked towards compared with those that participants perceived the professionals focussed on. Opportunities were missed for patients and professionals to work together to achieve goals. **Abstract:** http://bit.ly/31jnHXX

The right time for palliative care in heart failure: A review of critical moments for palliative care intervention

REVISTA ESPAÑOLA DE CARDIOLOGÍA | Online – 11 October 2019 – Despite guideline recommendations, cardiologists refer to palliative care (PC) at rates much lower than other specialties and very late in the course of the disease, often in the final 3 days of life. One reason for delayed referral is that prognostication is challenging in patients with heart failure (HF), making it unclear when and how the limited resources of specialist PC will be most beneficial. It might be more prudent to consider PC referrals at critical moments in the trajectory of patients with HF. These include: 1) The development of poor prognostic signs in the outpatient setting; 2) Hospitalization or intensive care unit admission; and, 3) At the time of evaluation for certain procedures, such as left ventricular assist device placement and ablation for refractory ventricular arrhythmias, among others. In this review, the authors also summarize the results of clinical trials evaluating palliative interventions in these settings. **Abstract:** http://bit.ly/2VM4eh4

> **N.B.** English language article. Additional articles on palliative and end-of-life care for patients living with heart failure noted in 14 October 2019 issue of Media Watch (#635, p.4).

Uncertainty in illness in family caregivers of palliative care patients and associated factors

REVISTA LATINO-AMERICANA DE ENFERMAGEM | Online – 14 October 2019 – Caring for a patient in palliative care is a complex situation that poses a challenge for the family caregiver (FCG). The results of this study show high levels of uncertainty in illness in FGGs of patients in PC. In addition, these levels of uncertainty are associated, in a slight but significant way, with the condition of the patient who is cared for and the symptoms presented by him, the length of service as a caregiver and the support that the caregiver perceives coming from health professionals, family and religion. These findings provide evidence on the importance of the nursing professional in identifying the needs and assisting the FCG of the patient in PC; the strengthening of the family support network of this patient-caregiver dyad; and, the need to recognize the value of religious or spiritual support groups. All this to avoid the appearance or to modulate the uncertainty in caregivers about the patient's illness and to improve the health care provided to this population. **Full text:** http://bit.ly/2px1Tuk

> **N.B.** Click on pdf icons to access the full texts of the English, Portuguese or Spanish language versions of the article. Selected articles on the role and the importance of the FCG as a member of the palliative care team noted in the September issue of the newsletter of the International Association for Hospice & Palliative Care: http://bit.ly/2lJANOL

Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.20.

Palliative care in rural areas: It's possible!

REVUE DE L'INFIRMIÈRE, 2019;68(254):33-35. Many rural areas, far from hospitals, are seeing a decline in the number of general practitioners, making it more difficult for patients in these regions to access care. However, there are relevant solutions, as illustrated by the Dousopal network in Normandy, which, teaming up with home care providers, contributes to organising palliative care support for all, in optimal conditions. **Summary:** http://bit.ly/2OTp6lt

> **N.B.** French language article. Selected articles on the provision and delivery of palliative care in rural areas are noted in past issues of Media Watch: in the U.S. (#634, p.2); in Canada (#632, p.12); and, in Australia (#631, p.5). Dousopal soins palliatifs à domicile website: http://bit.ly/2MdSyR2

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *MEDICINA E MORALE* | Online – 15 October 2019 – **'The opinion of the Italian Committee for Bioethics "Bioethical reflections on medically assisted suicide."'** In July 2019 the Italian Committee for Bioethics approved and published an Opinion entitled "Bioethical reflections on medically assisted suicide."[1] This article, after a brief presentation of the institutional history of this document, seeks answers to some bioethical questions touched by the Opinion. What emerges is a critical reading that goes beyond individual questions (and especially the legal and juridical profiles involved), and refers to the need for a new meditation on the meaning of bioethics and its relationship with philosophical anthropology and identity issues. **Abstract:** http://bit.ly/2J87dvs

    1. 'Bioethical reflections on medically assisted suicide,' Italian Committee for Bioethics, July 2019. **Download/view at:** http://bit.ly/33LTHpe

- *MEDICINA E MORALE* | Online – 15 October 2019 – **'The false analogy between refusal-renunciation of treatments and physician-assisted suicide. Bioethical considerations about the Constitutional Court Ordinance No. 207/2018.'** This paper provides some bioethical considerations that are particularly lacking within Ordinance n. 207/2018 issued by the Constitutional Court. With reference to the case of Fabiano Antoniani … who requested and subsequently committed assisted suicide …, the ordinance deals with the dubious constitutional illegitimacy of Article 580 of the Italian Criminal Code. On the one hand, this paper brings attention to the Constitutional Court's thesis that criminal provision on assisted suicide is not incompatible with the Constitution. On the other hand, it criticizes how the Court justifies medical aid to suicide – albeit in relation to certain exceptional situations. This justification is based on the erroneous assumption that there are not significant differences between refusal-renunciation of treatments and physician-assisted suicide. On the basis of this assumption, the Court has come up with the highly questionable proposal of modifying the recent law… **Abstract:** http://bit.ly/2VUNJQ9

    Noted in Media Watch 30 September 2019 (#633, p.5):

    - ITALY | *The Guardian* (London, England) – 25 September 2019 – **'Assisting a suicide is not always a crime, rules Italian court.'** Italy's constitutional court has ruled it was not always a crime to help someone in "intolerable suffering" kill themselves, opening the way for a change of law in the Catholic country. Parliament is now expected to debate the matter, which was highlighted by the Milan trial of an activist who helped a tetraplegic man die in Switzerland. Anyone who "facilitates the suicidal intention … of a patient kept alive by life-support treatments and suffering from an irreversible pathology" should not be punished under certain conditions, the top court ruled. The court was asked to rule on the case of Fabiano Antoniani, known as DJ Fabo, a music producer, traveller and motocross driver left tetraplegic and blind by a 2014 traffic accident. http://bit.ly/2lmZd0Y

Media Watch: Behind the Scenes
http://bit.ly/2MwRRAU

Publishing Matters

Predatory and exploitative behaviour in academic publishing: An assessment

JOURNAL OF ACADEMIC LIBRARIANSHIP, 2019;45(6). The issue of "predatory" publishing continues to affect many scholars around the world who publish. When one reads the fairly vast literature surrounding "predatory" publishing, there is an erroneous tendency to continue pivoting around Jeffrey Beall's blacklists of "predatory" open access journals and publishers. However, to be "predatory" involves much more than defining a handful of select behaviours, and it is becoming increasingly important to start defining, or curtailing, the lexicon to avoid referring to any journal or publisher that might display one of the following qualities (exploitative, deceptive, excessive, unscrupulous, abusive, advantageous, manipulative, profit-seeking, or others) as synonymously meaning "predatory." This paper focuses mainly on the oft-interchangeable terms "predatory" and "exploitation," and explores the morality of predatory and exploitative actions by applying a deontological ethics approach which implies that certain actions are wrong even if they achieve good consequences, with the understanding that because a predatory entity aims to exploit others, these actions would be considered morally wrong from a deontologist's perspective. In articulating their argument, the authors attempt to expand the conversation around this important topic, with the hope that it might bring additional clarity to the issue of what might constitute a "predatory" journal or publisher. **Abstract:** http://bit.ly/2P2kER7

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