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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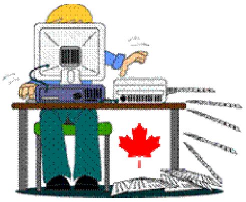

Compiled & Annotated by Barry R. Ashpole

Whilst advance care planning (ACP) is intended to reduce inequalities in end-of-life care, the implementation of ACP is itself inequitable.

'How should end-of-life advance care planning discussions be conducted according to patients and informal carers? A qualitative review of reviews' (p.8) in *Journal of Pain & Symptom Management*, published online 17 April 2019.

Canada

Planning for death, when life is a struggle – project helps marginalized populations prepare for a dignified end

BRITISH COLUMBIA | *The Globe & Mail* (Victoria) – 19 April 2019 – A group of front-line workers and palliative-care (PC) experts have joined forces in Victoria to help those most at risk of an untimely death to make effective end-of-life (EoL) plans. They are adapting the principles of PC – from pain management to emotional support for those who are dying – to the needs of vulnerable and marginalized populations. Kelli Stajduhar, a professor of nursing with the University of Victoria's Institute on Aging, is leading the project. Professor Stajduhar has worked in PC for three decades and her research has exposed how poorly the most vulnerable populations are served at the end of their lives. Few Canadians have good EoL planning in place, she said, but usually family members can help advocate for their loved ones. However, being part of a tight-knit street family carries no legal weight. "They are not typically listened to by the healthcare system," Stajduhar said. "So, people are screwed." The project has two parts. One is reaching out to Victoria's street community population, getting people to sit down and make an advanced care plan for their death and to answer questions such as: If you are nearing death, who can speak for you? Do you want to be at home, on the street or in a hospital? At what point do you want to stop life-prolonging medical interventions? The other is ensuring those plans are recognized by those who deliver EoL care. Prof. Stajduhar's team is engaging healthcare workers in acute-care settings, as well as those who run supportive housing and shelter workers. The group is testing and piloting the tools as they go. https://tgam.ca/2UtZsT9

Specialist Publications

'Provision of comprehensive, culturally competent palliative care in the Qikiqtaaluk region of Nunavut: Healthcare providers' perspectives' (p.6), in *Canadian Family Physician.*

Cont.

Noted in Media Watch 5 November 2018 (#588, p.1):

- BRITISH COLUMBIA | CTV News (Victoria) – 1 November 2018 – **'Study finds homeless, vulnerable, finally get care when at death's door.'** The lives of 25 homeless or marginally housed people in Victoria only started to get better when they were close to death, says a University of Victoria study.[1] Researchers followed the people for two years during the study, which concluded many of them received the best healthcare available only when they had reached the end of their lives. People living on the streets are in a world of unmet needs, multiple losses, persistent grief and trauma. The study recommends better training throughout the healthcare system to inform providers about the barriers to care endured by marginalized people, including end-of-life support. http://bit.ly/2ULKCwB

1. 'Too Little, Too Late: How we fail vulnerable Canadians as they die and what to do about it,' Institute on Aging & Lifelong Health, November 2018. **Download/view at:** http://bit.ly/2Ilg47D

N.B. Additional articles on palliative and end-of-life care for the homeless in Canada noted in 30 this issue of Media Watch.

Workplaces launch help for employees struggling with caring for elder relatives

ONTARIO | *The Globe & Mail* (Toronto) – 14 April 2019 – Employing 25 staffers, the Ottawa Art Gallery has instituted a work environment that respects constraints around parental care. The gallery offers flexible hours, telecommuting and negotiable short-term paid leaves, replacing sick days with "wellness days" for maintaining mental health and self-care. The gallery joins a handful of other employers across the country beginning to embrace cultural change around caregiving by providing family care days, job-protected leave, virtual workshops and referral services, among other supports. These workplaces represent a paradigm shift: They recognize that eldercare can seriously disrupt people's day jobs and contribute to productivity loss if not addressed head on. Some six million Canadians – or about 35% of the country's work force – are balancing their careers with caregiving duties, according to a 2015 report from the federal government. Many are struggling to do both: Forty three per cent of employees arrived to work late or had to leave early, 15% slashed their weekly hours and 10% passed up a promotion or new job, according to the latest data available from Statistics Canada. https://tgam.ca/2v7scHm

U.S.A.

Wall Street Journal editorial debates hospice fraud case

HOSPICE NEWS (Chicago, Illinois) | Online – 18 April 2019 – A major fraud case centered around live hospice discharges is being argued not only in 11th Circuit Court of Appeals, but in the editorial pages of the *Wall Street Journal*.[1] Kyle Clark and Andrew George, trial lawyers for the Washington-based law firm of Baker Botts published a recent editorial … on the case *U.S. vs. AseraCare*. Arguments in the *U.S. vs. Aseracare* have tried to untangle the complex question of whether the live discharges were the result of deliberate fraud or occurred because of the inherent difficulty of predicting a patient's life expectancy. "The decision could ratify a trend of criminalizing medical judgments and jailing doctors based on disagreements with other doctors," Clark and George wrote… Much of the case indeed hinges on disagreements among physicians. A physician witness for the government reviewed 233 patient records and found that most of the patients should have been found ineligible for the Medicare Hospice Benefit. http://bit.ly/2KQ5jD2

Specialist Publications

'Informal caregivers' perceptions of needs from hospice providers: An integrative review' (p.4), in *American Journal of Hospice & Palliative Medicine*.

'Federal right-to-try: Where is it going?' (p.7), in *The Hastings Report*.

1. 'Medicare's hospice rules could make your doctor a criminal,' *Wall Street Journal*, 21 March 2019. https://on.wsj.com/2HO9VXa

Centers for Disease Control & Prevention clarifies opioid prescribing guideline following concerns

CENTERS FOR DISEASE CONTROL & PREVENTION (CDC) | Online – 17 April 2019 – The chief medical officer of the National Center for Injury Prevention and CDC, [recently] wrote a letter to physicians at the National Comprehensive Cancer Network, the American Society of Clinical Oncology, and the American Society of Hematology, responding to their concerns about the CDC's 'Guideline for Prescribing Opioids for Chronic Pain.' The recommendations were developed to guide primary care physicians in prescribing care to chronic pain patients, not patients with cancer or receiving palliative care or end-of-life care. However, the guidelines would pertain to cancer survivors with chronic pain. **Source:** 'Briefings in Palliative Medicine,' *Journal of Palliative Medicine*, 17 April 2019 issue: http://bit.ly/2Zem1PD

"Talking the talk": Advancing end-of-life conversations

HOSPICE NEWS (Chicago, Illinois) | Online – 16 April 2019 – Identifying patients in need of hospice earlier in the course of their illness is a business and moral imperative for hospice providers. Though conversations about end-of-life care (EoLC) difficult for everyone involved, including clinicians and social workers who facilitate them, they reap substantial benefits for patients, families, payers, and providers. Early conversations are positively associated with family decisions to limit or withdraw life-sustaining treatments, fewer in-hospital deaths, fewer unplanned hospital admissions, shorter hospital stays, family satisfaction with EoLC, and increased odds of receiving strong opioid pain medications in the last 24 hours of life…[1] **Abstract:** http://bit.ly/2V8EEF8

1. 'Association between end-of-life conversations in nursing homes and end-of-life care outcomes: A systematic review and meta-analysis,' *Journal of the American Medical Directors Association*, 2019; 20(3):249-261. **Abstract:** http://bit.ly/2Xjimya

Related

- NEW JERSEY | New Jersey Health Care Quality Institute (Princeton) – 16 April 2019 – **'Most New Jerseyans have considered but not planned for end-of-life wishes.'** Six in 10 New Jerseyans have given a great deal or at least some thought to their wishes for medical care towards the end of their life. But only 47% have actually talked to someone about their wishes, 42% have designated someone to make decisions about their care if they are unable, and just 30% have a written document detailing their wishes. http://bit.ly/2Uki1Jv

International

Doctors face more rows over dying children

U.K. | *The Times* (London) – 18 April 2019 – Doctors are increasingly in conflict with parents of terminally ill children and are being advised on how to deal with them in the wake of several high profile cases. Prompted by the cases of Ashya King, Charlie Gard and Alfie Evans, in which parents and paediatricians faced one another in court, the Royal College of Paediatrics & Child Health has set out guidance on "achieving consensus" with families.[1] "Managing conflicts is becoming an increasing problem, particularly in managing children with complex and life-threatening conditions," Dr. Mike Linney, registrar of the College, said. http://bit.ly/2V3npFv

RCPCH
Royal College of
Paediatrics and Child Health

1. 'Achieving Consensus: Advice for paediatricians and other health professionals on prevention, recognition and management of conflict in paediatric practice,' *Archives of Disease in Children*, published online 18 April 2019. **Full text:** http://bit.ly/2v96faN

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200 hospital patients died while waiting to be discharged in 2018

U.K. (Northern Ireland) | BBC News (Belfast) – 15 April 2019 – A report by the charity Marie Curie also showed delayed discharges resulted in patients spending thousands of extra days in hospital. This was despite the patients being declared ready to go home. The Health & Social Care Board said ensuring all patients were able to either return home or to a community setting was a key priority. Some of the patients had a terminal illness, such as cancer or a respiratory condition. Others may have been approaching the natural end of their lives. Instead of being cared for at home or in the community, the report says 204 people were stuck in hospital and eventually died there. Freedom of Information requests were sent to all of the five local health trusts. While there is no breakdown of types of illness and patient, the data may also include those who at the last minute decided not to go home. https://bbc.in/2Gg5rWG

Assisted (or facilitated) death

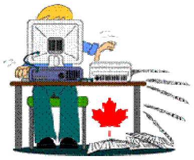
Representative sample of recent news media coverage:

- GERMANY | *Deutsche Welle* (Bonn) – 15 April 2019 – **'Top German court to decide legality of assisted suicide.'** Germany's Federal Constitutional Court will hear oral arguments this week about whether medical associations and physicians should be allowed to aid terminally ill patients in their own deaths. Physician-assisted suicide has been hotly contested in Germany since 2015, when the parliament outlawed the prescribing of life-ending drugs. A federal court case in 2017 deemed assisted suicide legal in extreme cases, but authorities have largely ignored the ruling – pitting political parties and various branches of the government against one another. Authorities distinguish among various forms of assisted suicide and how the government punishes violations. http://bit.ly/2PjLDpL

Specialist Publications

Informal caregivers' perceptions of needs from hospice providers: An integrative review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 16 April 2019 – In the U.S., informal caregivers (ICs) provide care to over 70% of patients at the end of life (EoL). Approximately 500,000 ICs contribute to the EoL care for patients in the U.K.. Hospice care is expanding worldwide to meet the needs of these ICs. Because ICs play an instrumental role in the provision of hospice services, and their perspective of their needs of formal services requires further clarity, the purpose of this review is to synthesize research that elucidates perceptions of ICs regarding their experiences with hospice providers. Four primary themes emerged that describe what ICs perceive as beneficial contributions of hospice providers in aiding their caregiving: providing easy access to desired care, building up the caregiver, forming a relationship, and utilizing culturally relevant interpersonal skills. Particular attention must be paid to ensuring that the IC is acknowledged as an expert part of the team. Clearly explaining available services, creating better ways to ease the IC's transition from caregiving to bereavement, and recruiting minority hospice providers are other important efforts that could improve the caregiving experience. **Abstract:** http://bit.ly/2Iz7jNb



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

Outcomes and cost of patients with terminal cancer admitted to acute care in the final two weeks of life: A retrospective chart review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 16 April 2019 – Research have shown that incorporating palliative care (PC) is integral to optimal end-of-life care, but it is an aspect of medical practice that is often neglected. The current study sought to provide an overview of health outcomes and hospital costs of patients with cancer admitted to The Ottawa Hospital [in Canada] and/or received acute medical services during their final two weeks of life. Cost comparisons and estimates were made between hospital and hospice expenditures. In the cohort of 130 patients studied, 71% of admitted patients did not have advanced care directives and 85% experienced a metastasis, but only 18% had a PC medical doctor. Patients were hospitalized, on average, for 7 days and hospitalization costs exceeded the estimated hospice cost by approximately 2.5 times… Based on their analyses, the authors conclude that these patients would have likely benefited more from hospice care rather than hospitalization. **Abstract:** http://bit.ly/2V7BeCO

Supporting families involved in court cases about life-sustaining treatment: Working as academics, advocates and activists

BIOETHICS | Online – 15 April 2019 – This article explores the links between the roles as academics, advocates, and activists, focusing on the authors research on treatment decisions for patients in vegetative and minimally conscious states. They describe how our work evolved from personal experience through traditional social science research to public engagement activities and then to advocacy and activism. The authors reflect on the challenges they faced in navigating the relationship between their research, advocacy, and activism, and the implications of these challenges for their research ethics and methodology – giving practical examples of how they worked with research participants, wrote up case studies and developed interventions into legal debates. The authors also address the implications of the impact agenda – imposed by the British Research Excellence Framework – for their actions as scholar-activists. Finally, the authors ask how practicing at the borders of academia, advocacy, and activism can inform research – helping to contextualize, sensitize, and engage theory with practice, leading to a more robust analysis of data and its implications, and helping to ensure a dialogue between research, theory, lived experience, front-line practice, law, and public policy. **Abstract:** http://bit.ly/2UEJEIE

Related:

- *PAEDIATRIC RESPIRATORY REVIEWS*, 2019;29(2):1-2. **'Integrating ethics and palliative care concepts into pediatric end of life care and decision-making: A changing landscape?'** The ethical dimensions of clinical dilemmas challenge even the best and most experienced of us to negotiate conflicting values, cultures and religious beliefs and their interplay in decision making; all while adhering to professional standards and setting appropriate medical limits. As medical technology and options continue to evolve, these dilemmas are bound to become even more complex; in the pediatric context, the evolving autonomy of the patient, the sometimes competing interests of more powerful parental voices and the struggle to promote the child's best-interests are additional challenges. **Full text:** http://bit.ly/2vakImU

Essential skills cluster in palliative care

BRITISH JOURNAL OF HEALTHCARE ASSISTANTS | Online – 10 April 2019 – This essay explores palliative care (PC) on an elderly medical ward. It analyses effective aspects in regard to the patient and family or caregivers' needs being met. The paper also revealed problems that arose when looking after a palliative patient. This included staff shortages, insufficient spiritual or religious needs being met, as well as lack of communication between everyone involved in the PC of the person. Multidisciplinary working was a major theme that seemed to have a huge impact on outcomes of preferred care, as results showed referrals and working together got desired outcomes for the patient and the relatives or carers involved. **Abstract:** http://bit.ly/2DdPlfL

Provision of comprehensive, culturally competent palliative care in the Qikiqtaaluk region of Nunavut: Healthcare providers' perspectives

CANADIAN FAMILY PHYSICIAN, 2019;65(4):e163-e169. This study is the first to explore the provision of palliative care (PC) services to Nunavut patients and their families using qualitative research methods. By determining the perspectives of healthcare providers (HCPs), five complex and interwoven themes emerged, creating a framework to guide HCPs in providing comprehensive, culturally competent PC services in the Qikiqtaaluk region of Nunavut. HCPs highlighted the need to develop a PC program within Nunavut that builds upon existing local programs and resources. Further studies examining the perspectives of Nunavummiut and their families, as well as medical interpreters, are needed. The authors hope their study results will help guide PC strategic planning in Nunavut, including program development and educational initiatives for healthcare providers, helping to build local community capacity, provide better care, and improve end-of-life care for patients and their families. **Full text:** http://bit.ly/2GcnVaC

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

Treatment patterns among *de novo* metastatic cancer patients who died within one month of diagnosis

CANCER SPECTRUM | Online – 15 April 2019 – Little is known about patterns of and factors associated with treatment for *de novo* metastatic cancer patients who die soon after diagnosis. The authors examine treatment patterns for patients newly diagnosed with metastatic lung, colorectal, breast, or pancreatic cancer who died within one month of diagnosis. Treatment substantially varied by cancer type, over time, age, insurance, and facility type. Surgery ranged from 0.4% in pancreatic to 28.3% in colorectal cancer (CRC) patients, chemotherapy from 5.8% among CRC to 11% in lung and breast cancer patients, and radiotherapy from 1.3% in pancreatic to 18.7% in lung cancer patients. Use of some treatments (e.g., surgery for CRC and breast cancer) progressively declined between 2004 and 2014. Compared with lung cancer patients treated at NCI-designated cancer centers, those treated at community cancer centers had 48% lower odds of radiation. These variations in treatment warrant more research to better identify patients with imminently fatal *de novo* metastatic cancer who may not benefit from aggressive and expensive therapies. **Abstract:** http://bit.ly/2Di7dpH

Better guidance for surrogates

THE HASTINGS REPORT, 2019;49(2):2. The author of the article, 'Changing the question,' addresses how to help the surrogate deal with a treatment decision.[1] A core insight he offers is that the structure of the surrogate's decision has been misunderstood and the misunderstanding makes the task yet harder. As usually understood, the surrogate is supposed to be guided by the question, what would the patient choose, if the patient were making the choice herself? The author argues that this conception is impossible, and that the surrogate's task is instead to consider the patient's best interests, as illuminated in part by the patient's expressed values and past choices. This understanding leads, he argues, to a different guiding question: what could the patient choose, given her values? **Full text:** http://bit.ly/2GjOaMq

Loved ones with healthcare decision-making power often over-confident

REUTERS | Online – 26 November 2018 – People entrusted with decision-making for incapacitated loved ones tend to believe they know what their loved ones would choose – but the vast majority of surrogate decision-makers in a recent study were wrong about loved ones' wishes.[1,2] https://reut.rs/2Zo1CHA

1. 'Assessment of surrogates' knowledge of patients' treatment goals and confidence in their ability to make surrogate treatment decisions,' *JAMA Internal Medicine*, **Abstract:** http://bit.ly/2ZlAlWk
2. 'Preparing surrogates for complex decision making: The often neglected piece of the advance care planning equation,' *JAMA Internal Medicine*. **Abstract** http://bit.ly/2Zmn4N9

N. B. Reuters report noted in 3 December 2018 issue of Media Watch (#592, p.4).

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1. 'Changing the question,' *The Hastings Report*, 2019;49(2):9-16. **Abstract:** http://bit.ly/2Uo6WXP

Federal right-to-try: Where is it going?

THE HASTINGS REPORT, 2019;49(2):26-36. Policy-makers, bioethicists, and patient advocates have been engaged in a fierce battle about the merits and potential harms of a federal right-to-try law. This debate about access to investigational medical products has raised profound questions about the limits of patient autonomy, appropriate government regulation, medical paternalism, and political rhetoric. For example, do patients have a right to access investigational therapies, as the right-to-try movement asserts? What is government's proper role in regulating and facilitating access to drugs that are still in development? In this review, the authors analyze the history of the right-to-try movement, review the arguments put forth by supporters and opponents of the legislation, and consider the movement's consequences. Two possible scenarios may emerge. One is that the right-to-try pathway may fail to meaningfully increase patient access to investigational products. Alternatively, certain companies may attempt to rely on the federal right-to-try legislation to sell investigational products, taking advantage of the provision that allows for direct costs, as there is currently no clear mechanism for enforcement or monitoring of cost calculations. **Abstract:** http://bit.ly/2GtUIsW

> **N.B.** Additional articles on the issue of "right-to-try" new experimental or investigational drugs noted in 11 March 2019 issue of Media Watch (#605, p.9).

Performance of care for end-of-life cancer patients in Tuscany: The interplay between place of care, aggressive treatments, opioids, and place of death

INTERNATIONAL JOURNAL OF HEALTH PLANNING & MANAGEMENT | Online – 17 April 2019 – Findings on the Tuscany Regional Health System (TRHS) performance related to the provision of end-of-life (EoL) care for cancer patients reveal the supply of EoL services across the 34 health districts, in terms of place of care, treatment offered, and place of death. They show a strong geographical variability despite the existence of national and regional frameworks that regulate the integration of palliative care (PC). Although part of this variability may be affected by patient/family preferences regarding EoL treatments, it seems that there is no significant strategy in the provision of supportive/palliative care. In fact, there are numerous cases where health districts with a good performance for some indicators show a negative performance for the remaining indicators. In addition, only few patients appropriately access the PC nodes of the TRHS: For example, districts with a higher percentage of cancer patients treated in the home still have a higher percentage of patients admitted to the emergency department. On the other hand, being supported in a hospice during the last month of life is positively associated with dying in the hospice and receiving pain medication. Receiving home care in the last month of life is positively associated with dying with the support of home care professionals. **Full text:** http://bit.ly/2ZhYv4b

A scoping review of undocumented immigrants and palliative care: Implications for the Canadian context

JOURNAL OF IMMIGRANT & MINORITY HEALTH | Online – 13 April 2019 – Approximately 30-40 million undocumented immigrants worldwide suffer restricted healthcare. A scoping review was conducted to determine what is known about this population's palliative end-of-life (EoL) care experiences. The authors' search revealed limited peer-reviewed and grey literature on the topic. A total of six articles met inclusion criteria, of which four were case descriptions. Barriers to palliative care (PC) included lack of advanced care planning, lack of health insurance, poverty, fear of deportation, and limited English ability. Undocumented immigrants were more likely to have delayed access to and inadequate palliative EoL care. **Abstract (w. list of references):** http://bit.ly/2V14QkY

Cont. next page

Related

- *WIENER KLINISCHE WOCHENSCHRIFT* | Online – 17 April 2019 – **'Migrate your mind: The role of palliative care in transcultural cancer treatment.'** This qualitative study at the Medical University of Vienna included interviews with 21 staff members from different disciplines in oncology and palliative care (PC) working with patients with various cultural backgrounds at the end of life (EoL). Interviews revealed specific aspects of PC, which fell into four fundamental categories and were all perceived as beneficial in the clinical encounter with migrant clients. This study revealed first insights into possibilities and prospects of transcultural PC for migrants and their relatives. The results might have important implications for the EoL care in this growing population. **Full (English) text:** http://bit.ly/2XiAhVq

N.B. Additional articles on PC for undocumented immigrants noted in 1 April 2019 issue of Media Watch (pp.14-15).

Living donation by individuals with life-limiting conditions

JOURNAL OF LAW, MEDICINE & ETHICS | Online – 17 April 2019 – The traditional living donor was very healthy. However, as the supply-demand gap continues to expand, transplant programs have become more accepting of less healthy donors. This paper focuses on the other extreme, asking whether and when individuals who have life-limiting conditions should be considered for living organ donation. The authors discuss ethical issues raised by: 1) Donation by individuals with progressive severe debilitating disease for whom there is no ameliorative therapy; and, 2) Donation by individuals who are imminently dying or would die by the donation process itself. **Abstract:** http://bit.ly/2V4EPBn

N.B. See commentary on 'Living organ donation near and at the end of life: Drawing and re-drawing the boundaries around permissible practices in organ donation,' *Journal of Law, Medicine & Ethics*, published online 17 April 2019. **First page view:** http://bit.ly/2ICCYgx

How should end-of-life advance care planning discussions be conducted according to patients and informal carers? A qualitative review of reviews

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 17 April 2019 – The authors have synthesised over a decade's worth of literature reviews on patient and carer perceptions of advance care planning (ACP). Whilst ACP is intended to reduce inequalities in end-of-life care, the implementation of ACP is itself inequitable. The authors conclude patients and carers perceive many benefits from ACP discussions, but these may differ from the dominant narratives about ACP in health policy and may move away from the narratives of randomized control trials and standardisation in research and practice. Their review suggests that researchers and clinicians need to adjust their approaches as current practices are not aligned enough with patient and carer preferences. Future research may need to test implementation strategies of ACP interventions to resolve the tension between standardisation and flexibility and elucidate how benefits from both might be realised. **Full text:** http://bit.ly/2GlO8Uo

Participation in online research examining end-of-life experiences: Is it beneficial, burdensome, or both for parents bereaved by childhood cancer?

JOURNAL OF PEDIATRIC ONCOLOGY NURSING | Online – 12 April 2019 – The this study examines the perceived benefit and burden of parents participating in a survey exploring their perceptions of their child's end-of-life (EoL) and bereavement experiences. Less burden was perceived by younger and female parents [i.e., study participants], parents of younger children, those who had felt prepared to meet their children's emotional needs at EoL, and those not using bereavement services at the time of the survey. With the increasing use of social media as a source for bereaved parents to receive and provide emotional support, it is important for clinicians and researchers to understand the perceived benefits and risks of participating in research about EoL experiences via online recruitment. The authors findings suggest that the benefit and burden of online research participation may vary for bereaved parents, but further research is necessary to replicate the findings and explore ways to optimize the use of this approach. **Abstract:** http://bit.ly/2VfBek0

Barriers and facilitators to preparedness for death: Experiences of family caregivers of elders with dementia

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 18 April 2019 – Less is known about how caregivers prepare (or do not) for the death of a family member with dementia. In this study, four primary themes were identified as barriers: 1) Hindrances to information; 2) Barriers to hospice; 3) Ineffective attempts to comfort; and, 4) The nature of death with dementia. Six themes were identified as facilitators: 1) Religious/spiritual beliefs; 2) Caregiver initiative; 3) Prior experience; 4) Bearing witness to decline; 5) Professionals alerting caregiver (of what to expect of impending death); and, 6) Culture and legacy of family caregiving. The results support an increased role of social work in addressing caregivers' awareness of impending death and helping prepare them for the death of an elder with dementia. **Abstract:** http://bit.ly/2vd3vcw

N.B. Additional articles on palliative and end-of-life care for people living with Alzheimer's and other forms of dementia noted in 8 April 2019 issue of Media Watch (#609, p.7).

Physicians' perspectives on palliative care for patients with end-stage liver disease: A national survey study

LIVER TRANSPLANTATION | Online – 9 April 2018 – Although most hepatologists' and gastroenterologists' [recruited from the American Association for the Study of Liver Diseases membership directory] believe that patients with end-stage liver disease (ESLD) should have access to palliative care (PC), they reported rarely collaborating with PC and had substantial concerns about patients' perceptions of PC. Interventions are needed to overcome misperceptions of PC and promote collaboration with PC clinicians for patients with ESLD. **Abstract:** http://bit.ly/2lj4nVE

N.B. Additional articles on PC and end-stage liver disease noted in 1 April 2019 issue of Media Watch (#608, p.8).

Social representations associated with the words "palliative care" among the general public

MÉDECINE PALLIATIVE | Online – 17 April 2019 – There are no common representations of palliative care (PC) between patients and caregivers, and the co-building of a shared vision is a determining factor in the success of care. The objective of this study was to explore the social representations associated to the words "palliative care" among the general population. The interviewees said they did not know the subject. PC was focused on patients described as being in a precarious physical state, not able to communicate and dependent. For the majority of interviewees, PC was provided just before the death. Their goal was physical and psychological well-being, global care, but also the consideration of close relatives. Nurses and nursing auxiliaries were easily imagined as being in contact with patients, but it was more difficult for physicians, who were less concerned according to interviewed people. Emotions were often negative (fear, anguish, sadness). Representations were rich and heterogeneous, based on personal experiences. Representations are close from the PC's definition of the Société française d'accompagnement et de soins palliatifs, but with nuances. These results open up possibilities for thinking on the means and the need to inform patients and their families about the purpose and objectives of PC. **Abstract:** http://bit.ly/2UvN1WV

N.B. French language article.

Assessing for post-traumatic stress disorder in terminally ill patients

NEW SOCIAL WORKER | Online – Accessed 18 April 2019 – Social workers working with such patients in geriatric, hospice, and palliative care settings may encounter challenges for patients that run counter to conventional end-of-life (EoL) goals, such as effective symptom management, good communication, and a peaceful death. Identifying such patients can be difficult. Symptoms of post-traumatic stress are often misattributed to personality or disease-related factors. Patients may be unaware that they are experiencing posttraumatic stress or may be reluctant to disclose this because of the fear of stigma, stoicism, or a preference to avoid painful memories. Limited energy and cognitive changes may hamper a patient's ability to provide information. Symptom management concerns or other EoL goals may take priority. Although information may emerge during conversations about concerns or coping, there may be issues related to privacy or trust that render assessment through direct inquiry problematic. Standard post-traumatic stress disorder (PTSD) assessment tools may send the wrong message to some patients who are sensitive to psychiatric labels or perceived inferences that they are being judged as having a psychiatric disorder. Social workers familiar with the many validated measures of assessing for PTSD may be able to adapt these with patients who are receptive, but what about patients with cognitive impairment, high levels of distrust, or who prefer to avoid the topic? **Full text:** http://bit.ly/2VRLgoI

Challenges and facilitators in providing effective end-of-life care in intensive care units

NURSING STANDARD | Online – 15 April 2019 – While intensive care is one of the fastest-growing healthcare specialties as a result of technological and scientific advances, a significant proportion of patients admitted to an ICU in the U.K. will not survive their ICU stay. Therefore, it is important to examine ways to enhance practice in this area and the factors that might affect the care provided to patients and their families. Ten articles were included in this literature review, which identified various challenges and facilitators in providing effective end-of-life care (EoLC) in ICUs. The main themes identified were: communication, family involvement, personal factors and the ICU environment. All of the studies identified several important challenges related to communication, such as time constraints, disagreements among healthcare professionals, and a lack of knowledge among healthcare professionals about how to conduct challenging conversations with patients and families. Future developments in practice should consider the role of effective multidisciplinary team-working in EoLC. **Abstract:** http://bit.ly/2PdiNak

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 14 April 2019 – **'The timing of family meetings in the medical ICU.'** Of the 131 patients who met the authors' inclusion criteria in the 12-month study period, the median time from admission to family meeting (FM) was 4 days. Fewer than half of patients had a documented FM within 72 hours of admission, with substantial interphysician variability in meeting rates ranging from 28% to 63%. Patients with FMs within 72 hours were 30 times more likely to die within 72 hours. Of the 55 patients who died in the ICU, 49% had their first FM within 1 day of death. This suggests for some physicians, FMs may primarily be used to negotiate withdrawal of life support rather than to support the patient and family. **Abstract:** http://bit.ly/2PeQfgF

Noted in Media Watch 1 April 2019 (#608, p.9):

- *INTENSIVE CARE MEDICINE* | Online – 25 March 2019 – **'Focus on ethics and palliative care in the intensive care unit.'** This editorial highlights papers on prognostic and palliative care strategies for critically ill patients and their families that were published in *Intensive Care Medicine* and other journals in the last two years, including five original research papers, one systematic review, one pragmatic review, six "what's new," two "understanding the disease," and one editorial. The past several decades of critical care research have led to numerous treatment and technological advances resulting in improved ICU survival, but interventions to improve patient- and family-centered care have not kept pace. **Full text:** http://bit.ly/2CAVyBN

    1. 'Ten key points about ICU palliative care,' *Intensive Care Medicine*, 2017;43(1):83-85. **Introduction (w. list of references):** http://bit.ly/2YuRPz1

Cont.

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

Assessing quality of life in palliative care settings: Head-to-head comparison of four patient-reported outcome measures

SUPPORTIVE CARE IN CANCER | Online – 16 April 2019 – No patient-reported outcome measures (PROMS) was clearly superior, confirming that choosing the best PROM requires careful consideration of the research goals, patient population, and the domains of assessing health-related quality of life targeted by the intervention being investigated. FACIT-Pal had better internal consistency than QLQ-C15-PAL and FACT-G7. FACIT scales had better test-retest reliability than QLQ-C15-PAL. Four scales demonstrated sensitivity to Australia-modified Karnofsky performance status: QLQ-PAL-15 Physical Functioning and Global QOL, FACT-G Functional Wellbeing and FACIT-Pal Trial Outcome Index. Nine scales demonstrated responsiveness: three in the ketamine trial population (QLQ-C15-PAL Pain, FACIT-Pal-14, FACT-G7), six in the octreotide trial population. **Abstract (w. list of references):** http://bit.ly/2KFf4DT

Access to palliative care services in prison: Who cares?

WHITIREIA NURSING & HEALTH JOURNAL | Online – Accessed 15 April 2019 – The Aotearoa New Zealand prison system houses a growing number of chronically ill prisoners and, coupled with an ageing prison population, the need for end-of-life care is evident. There are significant barriers restricting the provision of palliative care (PC) for this most vulnerable group, including delays in physical and psychological assessments, restricted access to medications and regulations preventing timely interventions to alleviate suffering. Ethical considerations of "custody versus care" and negative public attitudes contribute further barriers against the provision of equitable care for the dying prisoner. Currently in New Zealand, compassionate release or admission into a purpose-built high-dependency unit are the only options available for the terminally ill prisoner. However, PC is not a "one size fits all" concept, and more work needs to be done in this area. At a Ministry of Health level, the development of a future action plan has commenced, focusing on improving the delivery of PC across the board, thus providing an opportunity for stakeholders to speak out and effect change. By reviewing what is already working overseas, and considering this in the New Zealand prison context, there is an opportunity to ensure that prisoners and their families are both acknowledged and included as part of this process. For prisoners with a life-limiting illness, having access to a level of care without prejudice is both achievable and necessary while still ensuring public safety and justice. **Abstract:** http://bit.ly/2ZhScxE

> **N.B.** A compilation of selected articles, reports, etc., on PC in the prison system noted in past issues of the weekly report is posted on the Palliative Care Network website. **Download/view at:** http://bit.ly/2RdegnL

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BRITISH JOURNAL OF PSYCHOTHERAPY* | Online – 17 April 2019 – '**"How can anyone live like that?" Exploring the conscious and unconscious implications for disabled people of any change in assisted suicide law.**' This paper explores the issue of assisted suicide in relation to disabled people from a psychosocial perspective. The implications, particularly the unconscious implications, for disabled people and for the psychosocial dynamics around disability if assisted suicide was

Cont.

made lawful in the U.K. are explored. Assisted suicide is the subject of persistent attempts at legal change and while not, in theory, specific to disabled people, the issue brings some of the psychosocial dynamics around impairment and disability into focus, illuminating the attitudes and emotions with which disabled people must try to live. Psychoanalytic ideas in relation to trauma, loss, mourning and containment are drawn upon with particular reference to the work of Freud, Klein, Bion and more contemporary thinkers such as Garland, Sinason and Rustin. The paper draws on three texts by disabled people in order to explore emotional responses to profound impairment. Attachment theory helps in considering varying narrative styles. Disability studies literature and legal, social and political contextual issues inform the psychosocial perspective applied in the paper. **Abstract:** http://bit.ly/2UOIKTS

- *SOCIOLOGY OF HEALTH & ILLNESS* | Online – 4 April 2019 – **'Expanded definitions of the "good death"? Race, ethnicity and medical aid in dying.'** The range of end-of-life (EoL) options is expanding across North America. Specifically, medical aid in dying (AID), or the process by which a patient with a terminal illness may request medical assistance with hastening death, has recently become legal in eight jurisdictions in the U.S. and all of Canada. Debates about AID often rely on cultural constructions that define some deaths as "good" and others as "bad." While research has found commonalities in how patients, family members and healthcare providers define good and bad deaths, these constructions likely vary across social groups. Because of this, the extent to which AID is seen as a route to the good death also likely varies across social groups. The authors analyse qualitative data from six focus groups across three racial and ethnic groups: African American, Latino and white Californians, just after a medical AID law was passed. They find that definitions of the "good death" are nuanced within and between groups, suggesting that different groups evaluate medical AID in part through complex ideas about dying. These findings further conversations about racial and ethnic differences in choices about EoL options. **Abstract:** http://bit.ly/2Vbk6vM

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

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Something Missed or Overlooked?

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

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