

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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Pediatric clinicians are urged, when communicating with parents during end-of-life care situations, to be empathetic, warm, and compassionate. These recommendations generally do not include practical suggestions and have little evidence that parents value specific communication techniques.

'Techniques to communicate better with parents during end-of-life scenarios in neonatology' (p.12), in *Pediatrics*.

Canada

Medical aid in dying should be extended to people with mental illness, report says

THE NATIONAL | Online – 30 January 2020 – As Canada is set to extend medical aid in dying to people who are not necessarily about to die naturally anyway, an expert panel of clinicians and ethicists is recommending the new law not exclude people whose only medical condition is a mental disorder. "There is no reason to believe that suffering from mental disorders in some cases is not as intolerable and deserving of relief as suffering from physical disorders," reads the new report from the Institute for Research on Public Policy,¹ by a panel of eight professors of medicine, law, sociology, psychiatry and nursing from across Canada. They recommend the new laws, which the federal government is considering in response to a Quebec court ruling, not exclude people who have only mental illness. The experts also suggest a new requirement be imposed that a decision to accept medical aid [*sic*] in dying (MAiD) be "well-considered," which is to say "well thought out and not impulsive," but not necessarily a "good" decision in the judgment of the assessor, and with no requirement for a settled intention to die immediately. The re-

Extract from the Institute for Research on Public Policy report

Just as better access to palliative care is no justification for denying access to MAiD in individual cases, so improved mental health services and social supports generally speaking are not in and of themselves justification for denying access to MAiD to all individuals with MD-SUMC [i.e., mental disorder is the sole underlying medical condition]. One does not preclude the other...

Specialist Publications

'Does early palliative identification improve the use of palliative care services?' (p.13), in *Plos One*.

'Attitudes and expectations regarding bereavement support for patients, family members, and friends: Findings from a survey of MAiD providers' (p.13), in *BC Medical Journal*.

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port calls for clear regulatory standards for nurses and doctors, more professional training, and a federal consultation service to run for at least five years, with all cases of people without lethal conditions accepting medical aid in dying being sent to a “post hoc peer review process.” The advice comes as a federal public consultation period ended this week, seeking guidance in advance of a full review of the MAiD law this summer. <http://bit.ly/2SavV11>

1. ‘MAiD Legislation at a Crossroads: Persons with Mental Disorders as Their Sole Underlying Medical Condition,’ Institute For Research on Public Policy, Montreal, Quebec, January 2020. **Download/view at:** <http://bit.ly/38UxkJL>

[U.S.A.](#)

End of life and hospice care

MASSACHUSETTS | WACI (Cape, Coast & Islands National Public Radio Station) – 30 January 2020 – The *New England Journal of Medicine* reported that for the first time since the early 20th Century, home has become the most common place of death among Americans dying of natural causes, while deaths in nursing homes and hospitals are in decline. National Public Radio’s ‘On The Point’ talks with hospice professionals and end-of-life care givers about the realities of dying at home, what hospice care does and doesn’t provide, and efforts to create a community home for the living and dying in Provincetown. <http://bit.ly/2UbksSq>

[Specialist Publications](#)

‘**Examination and analysis of after-hours calls in hospice**’ (p.5), in *American Journal of Hospice & Palliative Medicine*.

‘**Trends in contracting and common ownership between hospice agencies and nursing homes**’ (p.10), in *Medical Care*.

Noted in Media Watch 6 January 2020 (#647, p.9):

- *MEDICAL ANTHROPOLOGY* | Online – 23 December 2019 – ‘**Meaningful deaths: Home health workers’ mediation of deaths at home.**’ After several generations in the U.S. in which medicalized deaths have become normal, more people are seeking to die at home. However, home deaths lead to emotional uncertainty and practical confusion, in which kin lack a cultural script. In this article the author draws on interviews with patients’ kin and their African immigrant home health workers, and show that the care workers helped create a more meaningful death through their knowledge of death, familiarity with the physical processes of death, and their presence, which they used to create pathways for their patients and their kin. **Abstract:** <http://bit.ly/37nlzSq>

Noted in Media Watch 16 December 2019 (#644, p.2):

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

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

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Noted in Media Watch 5 November 2018 (#588, p.8):

- *JOURNAL OF HOUSING FOR THE ELDERLY* | Online – 25 October 2018 – ‘**The motivations and consequences of dying at home: Family caregiver perspectives.**’ Five family caregivers participated in semi-structured interviews about their experiences witnessing and supporting the end-of-life process of an older family member who died at home. Their stories paint a vivid picture about the motivations and consequences of the experience, including themes such as caregivers’ immense feelings of uncertainty regarding their caregiving abilities and decision-making, the significance of the home environment as a symbol of comfort and security, the influence of family and social networks, and “dying well” as a social justice issue. **Abstract:** <http://bit.ly/2UrFwVh>

Population health models can help hospices admit patients earlier

HOSPICE NEWS | Online – 27 January 2020 – Organizations are experimenting with population health principles to engage patients further upstream and move them into hospice earlier, if appropriate and concordant with the patient’s wishes and goals. This can contribute to improved quality of life for patients as well as cost savings for healthcare providers. Population health is in most contexts a term used to describe the health outcomes of a group of individuals, including the distribution of such outcomes within the group, according to the University of Wisconsin’s Department of Population Health Sciences. Such groups can consist of the population of a certain geographic area, a demographic, or a group of particular types of patients, such as cancer patients or patients enrolled in hospice. Application of population health principles to palliative and hospice care through the use of predictive models can improve the quality of care, reduce hospitalizations and slash healthcare costs. A September 2019 study ... followed 204 members of a Medicare Advantage plan in an Ohio health system who were enrolled in a community-based palliative care program.¹ The patients, who were identified through population health analytics, saw a 20% reduction in total medical costs, nearly 40% reduction in intensive care unit admissions, a 33% drop in hospital admissions, and 12% reduction in hospital lengths of stay. <http://bit.ly/2RVjh6J>

1. ‘Effects of a population health community-based palliative care program on cost and utilization,’ *Journal of Palliative Medicine*, 2019;22(9):1075-1081. **Full text:** <http://bit.ly/2vll2Iz>

International

Community pharmacy paediatric palliative care pilot launched in Scotland

U.K. (Scotland) | *The Pharmaceutical Journal* – 31 January 2020 – A 12-month pilot of a community pharmacy-led palliative care (PC) service specifically targeted at children has launched in Scotland. The service, thought to be the first of its kind in the U.K., was launched ... by Children’s Hospices Across Scotland, a charity that provides support to families with children with life-shortening conditions, and National Health Service Forth Valley, and will aim to improve treatment for babies, children and young adults with life-shortening conditions. It is an extension of the existing Community Pharmacy Palliative Care Network, which currently only delivers services for adults. The 14 community pharmacies in the network will hold a core stock of paediatric PC medicines to improve timely access for patients, as well as deliver paediatric PC medicines advice to patients and healthcare professionals. <http://bit.ly/2vHBXzw>

Specialist Publications

‘**Unmet needs of patients with cancer in their last year of life as described by caregivers in a developing world setting: A qualitative study**’ (p.6), in *BMC Palliative Care*.

‘**Need for palliative care education in India: Can online palliative care education bridge these needs?**’ (p.7), in *Indian Journal of Palliative Care*.

‘**How cancer supportive and palliative care is developed: Comparing the policy-making process in three countries from three continents**’ (p.8), in *Indian Journal of Palliative Care*

‘**The past is present: Death systems among the Indigenous Sámi in Northern Scandinavia today**’ (p.10), in *Mortality*.

“We must act now to save our hospices – or children will go without care”

U.K. | *The Daily Mirror* – 30 January 2020 – One of many hospices across the country threatened with closure as Britain faces an end-of-life care crisis, Acorns’ shortage of National Health Service (NHS) funding means it is increasingly reliant on donations and charity shops. It needs to raise £2 million to continue to support families across the Black Country. As part of its long-term plan, NHS England has pledged to raise funding for children’s hospices to £25 million in 2023-2024, and the Conservative Party pledged to “support our precious hospices” in its election manifesto. But hospice and healthcare charity Sue Ryder says this is a “sticking plaster” and that “warm words do not begin to address the underlying problems”. A report [*sic*] from Together For Short Lives, a group which represents hospice users, warns of a “children’s palliative care (PC) workforce crisis.”¹ It says services are at “breaking point” because of a growing shortage of PC doctors and nurses. The report shows there are just 15 children’s PC consultants in the U.K. when there should be 40 to 60. <http://bit.ly/2GCXwU9>

1. ‘Open letter delivered to Secretary of State,’ Together for Short Lives, January 2020. **Download/view** at: <http://bit.ly/2OgFIT3>

Noted in Media Watch 8 July 2019 (#621, p.2):

- U.K. (England) | Third Sector (Twickenham) – 2 July 2019 – ‘**Charity succeeds in battle to ring-fence National Health Service funding for children’s hospices.**’ National Health Service (NHS) England promised last year funding for children’s hospices would more than double from £12 million to £25 million by 2023-2024, dependent on clinical commissioning groups providing additional match funding to the government’s £7 million investment. But Together for Short Lives last month accused NHS England of reneging on its promise to properly fund children’s hospices by making the money available to non-palliative care, too. Following the charity’s intervention, NHS England said it would provide the full £25 million itself without input from Clinical Commissioning Groups. <http://bit.ly/2NtiZoM>

N.B. Recent news media coverage on funding childrens’ hospices in England noted in this issue of Media Watch.

Parents Matter: A new report on mental health support for parents of a seriously ill child

U.K. | Rainbow Trust Children’s Charity – 29 January 2020 – ‘Parents Matter – The impact on parents’ mental health when a child has a life-threatening illness’ shares parents’ stories of managing their mental health, and their advice to other parents in the same situation. The report sets out how regular practical and emotional support can help parents develop their own coping strategies by providing regular time off from caring and by easing the burden on the family as a whole. In the last 18 months, more than a fifth of families referred to the Rainbow Trust had mental health concerns cited as a reason for needing support. The report encourages everyone to be aware of parents’ mental health needs when a child has a life-threatening or terminal condition. It provides a checklist for health and social care professionals to follow when working with parents of a seriously ill child, as well as parents’ tips for other parents in the same situation. In a recent survey of 2,002 parents with a

child under 18 shows that half of parents (51%) believe the greatest impact on their mental health would be their child dying or being diagnosed with a terminal or life-threatening illness. The survey also reveals that 65% of parents would have no idea how to cope if their child became seriously ill. **Download/view at:** <http://bit.ly/318dgYL>

Specialist Publications

‘**Identifying key elements for paediatric advance care planning with parents, healthcare providers and stakeholders: A qualitative study**’ (p.11), in *Palliative Medicine*.

‘**Techniques to communicate better with parents during end-of-life scenarios in neonatology**’ (p.12), in *Pediatrics*.

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Noted in Media Watch 31 December 2018 (#595, p.7):

- U.K. (England) | *Charity Today News* – 21 December 2018 – ‘**Charity finds the needs of siblings of seriously ill children are ignored by government.**’ Siblings of seriously ill children risk being left with a long-term negative impact on their mental health and education unless there is more funding to support them, a report by Rainbow Trust Children’s Charity warns.¹ Demand for sibling support is increasing, and the mental health and educational attainment of brothers and sisters of seriously ill children can be affected by their situation. More than 70% of children’s hospices, who responded to a 2018 Rainbow Trust survey of sibling support in England, said the demand for sibling support has increased over the last three years but only a third said that they can “always” meet demand. <http://bit.ly/3aT10B3>

1. ‘See us, Hear us, Notice us: The case for supporting siblings of seriously ill children,’ Rainbow Trust Children’s Charity, December 2018. **Download/view at:** <http://bit.ly/2GzXbkY>

A house for the end of life

U.K. | BBC Radio 4 – Accessed 27 January 2020 – BBC’s Susan Marling looks at work architects are doing now to dramatically enhance small healthcare buildings – especially Maggie centres which are for cancer sufferers and hospices for people with life-shortening diseases. Many of these buildings are inspirational. They show the power of good design and beautiful gardens in lifting the human spirit and restoring to the patient a sense of dignity and individuality. <https://bbc.in/2U2Gqa1>

Partnership working improves end-of-life care for people in South East Essex

U.K. (England) | *The Leigh Times* (Leigh-on-Sea, Essex) – 25 January 2020 – A partnership between National Health Service (NHS) Castle Point and Rochford Clinical Commissioning Group (CCG), NHS Southend CCG and Essex Partnership University Trust (EPUT) is improving end-of-life care (EoLC) for people in South East Essex. The 2018-2019 Care Quality Commission (CQC) rating for EoLC was rated as “requires improvement” which led to the Community Palliative Care Specialist Nurses Team and the Palliative Care Service Register Team integrating to become the EPUT Community Palliative Care Service and working together towards improving the EoLC for people in South East Essex. The objectives focused on improving identification of patients at the end of their life, empowering patients to achieve their preferred place of death or care, to strengthen community partnerships, and to integrate better to improve the quality of patient EoLC. The integration of the teams now means that more patients are identified as being [at] end of life. Those patients are now located on one central register, which can also be accessed by GPs to deliver more joined-up, safe and high quality EoLC. <http://bit.ly/36uOPpo>

Specialist Publications

Examination and analysis of after-hours calls in hospice

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 30 January 2020 – To ensure safe and effective care at home, most hospice agencies provide 24-hour call services to patients and their families. However, responding to such calls can be very extensive since so many calls occur after hours when staff are fewer. By understanding why these calls are made, we might be able to reduce the number of avoidable after-hours calls. This descriptive retrospective chart review study was conducted using data from 9 patient care teams within a single hospice agency. During the 6-month study period, the hospice agency received 1,596 after-hours calls. The number of calls averaged 10.3 per night. Common clinical-related calls included consultations about the shortness of breath (10.2%) and pain (9.5%). A total of 37.7% of the calls were non-clinical, non-emergency in nature, including requests for supplies (29.6%) and medication refills (8.1%). There were statistically significant differences between teams in the numbers of supply request calls, medication refill request calls, and calls associated with clinical-related issues. Also, there was a statistically significant difference in the after-hours calls across teams that resulted in dispatching staff to a home. These findings suggest that many after-hours calls would be more appropriately addressed during regular daytime hours. There are significant across-team differences that are not yet well understood. Further studies are needed to determine how to reduce the number of after-hours calls. **Abstract:** <http://bit.ly/2RIUm7p>

Unmet needs of patients with cancer in their last year of life as described by caregivers in a developing world setting: A qualitative study

BMC PALLIATIVE CARE | Online – 24 January 2020 – Inadequate communication was cited by about half the participants as a major unmet need. In studies of end-of-life care, this is consistently ranked as a critical need. Poor communication was distressing to caregivers in this study. As seen in other work, this lack of consistent communication can contribute to an increased burden of care and to adverse bereavement experiences. The “information giving behaviours” which foster effective communication were found lacking. In this study, both communication skills and opportunities for information sharing were deficient. Health professionals’ inadequacy in communicating may have contributed to their avoiding difficult conversations. Limited visiting hours contributed, denying families access to wards when doctors were around. This reluctance to share information suggests a failure to recognize the pivotal role of the caregiver as part of the unit of care and the wider health system. Families need to be valued for their critical role in caregiving. Community based interventions built on lay persons have been highly effective in places such as Kerala. Trinidad & Tobago might benefit from an approach that focuses on valuing the caregiver, putting interventions in place to train and educate the caregiver and on harnessing community resources to improve quality of care. **Full text:** <http://bit.ly/38RnWh5>



Extracts from *BMC Palliative Care* article

Caribbean literature on end-of-life care (EoLC) is lacking, but literature from other low resource settings has identified several barriers to good EoLC. Some of the critical issues cited are the absence of national policies on palliative care (PC) and lack of integration of PC into mainstream healthcare.

There is need for systemic interventions to improve the care of those dying from cancer in Trinidad & Tobago. Stakeholders need to commit to PC as a public health priority, implementing education, planning services, and mobilizing community resources.

Noted in Media Watch 25 January 2016 (#446, p.8):

- *BMC PALLIATIVE CARE* | Online – 22 January 2016 – ‘**The needs, models of care, interventions and outcomes of palliative care in the Caribbean: A systematic review of the evidence.**’ This review has revealed that the peer reviewed literature offers little evidence on palliative care (PC) needs of the Caribbean population. The available evidence was broadly divided into healthcare practitioner’s needs, patients’ needs and healthcare institutional needs. They included patients’ needs for access to analgesia, preferred place of care/death and multi-dimensional aspects of support needed for patients and their caregivers. Healthcare practitioners spoke about their need for health policy and education in PC. **Full text:** <http://bit.ly/2TZdS19>

Communicating death with humor: Humor types and functions in death over dinner conversations

DEATH STUDIES | Online – 29 January 2020 – Using death-over-dinner conversations, the authors examined 83 family and/or friend groups comprising 424 participants to understand how humor is used when talking about death and dying. Thematic analysis revealed that family and friends used six types of humor in their conversations about death: 1) Entertainment humor; 2) Gallows humor; 3) Tension-relieving humor; 4) Confused/awkward laughter; 5) Group humor/narrative chaining; and, 6) Self-deprecating humor. The authors discuss the benefits and drawbacks of the use of humor when discussing uncomfortable topics, practical applications related to humor and death, as well as possibilities for future research. **Abstract:** <http://bit.ly/2RZDgRN>

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Of related interest:

Noted in Media Watch 28 May 2018 (#565, p.9):

- *FRONTIERS IN PSYCHOLOGY* | Online – 15 May 2018 – ‘**Humor assessment and interventions in palliative care: A systematic review.**’ The central goal of palliative care (PC) is to optimize the quality of life of patients suffering from life-limiting illnesses, which includes psychosocial and spiritual wellbeing. Research has demonstrated positive correlations between humor and laughter with life satisfaction and other aspects of wellbeing, and physiological symptoms can be improved by humorous *stimuli*. Findings showed that humor had a positive effect on patients, their relatives, and professional caregivers. Overall, however, research on humor assessment and interventions in PC has remained limited in terms of quantity and quality. **Abstract:** <http://bit.ly/2O8Ydso>

Noted in Media Watch 2 April 2018 (#557, p.8)

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 27 March 2018 – ‘**The use of humor in palliative care: A systematic literature review.**’ Humor plays an unquestionable role in palliative care (PC), but its use needs training and appropriate use. A total of 156 studies were identified, which were then filtered in pairs by means of an established hierarchy, selecting studies that discussed the use of humor specifically in PC from all perspectives and designs and finally published in English, French, Portuguese or Spanish. Five main topics were identified: 1) Definition of humor; 2) Use and functions of humor in PC; 3) How to use humor; 4) When not to use humor; and, 5) Humor before and after the diagnosis of terminal illness. **Abstract (w. list of references):** <http://bit.ly/3aWMCqj>

End-of-life care in Norway

General practitioners’ provision of end-of-life care and associations with dying at home: a registry-based longitudinal study

FAMILY PRACTICE | Online – 29 January 2020 – This population-based analyses showed that GP home visits and interdisciplinary collaboration increased the odds that people died at home. People leaving their home for GP consultations or out-of-hours contacts or those who were hospitalized were less likely to die at home. Overall, 9.2% received home visits during the last 4 weeks of life, of which a third died at home. Only 6.6% additionally had GPs involved in interdisciplinary collaboration. Over a third of people were hospitalized during the last week of life. These findings are important for clinicians and policy-makers. Norwegian policies are shifting towards care at home at the end of life (EoL) and possibly home death, but the potential for GPs and primary care to deliver this care is currently not utilized. There is a need for a population-based strategy for EoL care in primary care with a patient-centred approach. **Full text:** <http://bit.ly/2Sdgu90>

Need for palliative care education in India: Can online palliative care education bridge these needs?

INDIAN JOURNAL OF PALLIATIVE CARE, 2020;26(1):1-3. According to the 2015 Quality of Death Index report, the palliative care (PC) provision in India is poor due to a low-demand and low-supply situation.¹ Low demand is because both the public and healthcare providers have limited knowledge about PC. In the last two decades, there have been many short and long PC training programs offered by many institutes across India. However, their penetration has been marginal and it has not contributed toward generalized sensitization of healthcare providers on PC. Moreover, the 2014 Global Atlas of Palliative Care has shown that there is 1 trained PC physician for one million population in India.² Lack of sensitization and awareness about PC among the healthcare providers has resulted in poor quality of life, higher healthcare costs, and inappropriate treatment at the end of life. Therefore, there is a pressing need for mass PC sensitization of healthcare providers. A scoping search of Indian literature showed that there are only 11 studies that have explored the PC education need in India. In a study conducted at AIIMS Delhi among postgraduate students, out of 186 respondents, 56% had not received any basic training in PC. In

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a similar study conducted among pediatric postgraduates at Chennai, out of 180 postgraduates studied, 88% had never received any training in any aspect of PC. In another study conducted among the medical students, only 9.2% of the students were aware about PC. A similar study conducted among all health-care undergraduate students showed awareness of only 11%. These findings were corroborated by two studies which showed low incidence of PC awareness among pharmacy and nursing students. The two studies conducted at Mumbai showed poor PC awareness among primary healthcare providers, and they significantly lacked skills and knowledge to provide PC. A survey conducted in India about the acceptance of online PC education in India showed that 89% responded affirmatively for online learning. **Full text:** <http://bit.ly/37zU5ZX>

1. '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit (commissioned by the Lien Foundation of Singapore), October 2015. [Noted in 12 October 2015 issue of Media Watch (#431, p.6)] **Download/view at:** <http://bit.ly/30YoDkI>
2. 'Global Atlas of Palliative Care at the End of Life,' World Health Organisation and Worldwide Palliative Care Alliance, January 2014. [Noted in 3 February 2014 issue of Media Watch (#343, p.5)] **Download/view at:** <http://bit.ly/2tZah8z>

Related:

- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2020;26(1):116-119. '**Rural elderly and access to palliative care: A public health perspective.**' Most age-related diseases (ARDs) need palliative care (PC) for a fairly long duration. Existing PC centers [in India] are limited in numbers, situated mainly in urban areas and mostly attached to cancer hospitals. Socio-economic vulnerabilities of the elderly, especially in rural areas, are high and access to health is also not optimal. In the coming decades, the number of needy people, as well as the demand for PC will increase. Exponential increment in quantum and quality of PC services is required to deal with the imminent burden. Specific suggestions are made to use existing public health programs to cater to the rural elderly. **Full text:** <http://bit.ly/2RznQ7N>

How cancer supportive and palliative care is developed: Comparing the policymaking process in three countries from three continents

INDIAN JOURNAL OF PALLIATIVE CARE, 2020;26(1):72-79. Several factors are involved in how cancer palliative care (PC) policy is included in policymakers' agenda. First, understanding a necessity as a result of an increase in the number of chronic patients in need of care; second, raising public awareness and acceptance as a result of sensing the physical and non-physical care outcomes, such as physical and financial access; and, third, attracting the attention of policymakers and other providers of financial and non-financial resources, including the private and charity sectors. In the formulation of policies, the main issue is the government's protective role, which in the U.K. includes all supportive duties, while in Malaysia and South Africa the government only fulfills some of these tasks, with the non-governmental sector sometimes taking over them. In the field of policy implementation, it seems that there are three different methods of providing supportive and PC: government and non-government provision of care through collaborative policy-making and planning in the U.K., potent non-government and limited government care provision with a feeble

government policy-making in Malaysia, and non-government care provision through centralized and imperative government policy-making and planning in South Africa. Finally, three types of evaluations are involved, proportional to the systems of care provision: a government and internal evaluation in the U.K., a non-governmental internal evaluation in Malaysia, and a combination of internal and external evaluations in South Africa. **Full text:** <http://bit.ly/2Rx5nst>

Oxford Textbook of
**Palliative
Medicine**

'Communications with the Public,
Politicians, and the News Media,'
Synopsis: <http://bit.ly/2rHIIeI>

“Please keep mom alive one more day.” Clashing directives of a dying patient and her surrogate

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 31 January 2020 – All medical care providers are legally and ethically bound to respect their patients wishes. However, as patients lose decision-making capacity and approach end of life, their families or surrogates, who are confronted with grief, fear, self-doubt, and/or uncertainty, may ask physicians to provide treatment which contradicts the patients' previously-stated wishes. The authors of this article discuss the legal and ethical issues surrounding such requests, and provides guidance for clinicians to ethically and compassionately respond – without compromising their professional and moral obligations to their patients. **Abstract (w. link to references):** <http://bit.ly/2Ui35iW>

Chronic obstructive pulmonary disease: A palliative medicine review of the disease, its therapies and drug interactions

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 28 January 2020 – Despite significant advances in treatment, chronic obstructive pulmonary disease (COPD) remains a chronic and progressive disease that frequently leads to premature mortality. COPD is associated with a constellation of significant symptoms including dyspnea, cough, wheezing, pain, fatigue, anxiety, depression and insomnia, and is associated with increased morbidity. Palliative care (PC) is appropriate to support these patients. However, historically PC has focused on supporting patients with malignant disease, rather than progressive chronic diseases such as COPD. Therapies for COPD often result in functional and symptomatic improvements including health-related quality of life (HRQL), and PC may further improve symptoms and HRQL. Provision of usual PC therapies for this patient population requires understanding the pathogenesis of COPD and common, disease-targeted pharmacotherapies, as well as an approach to balancing life prolonging and HRQL care strategies. This review describes COPD and current targeted therapies and their effects on symptoms, exercise tolerance, HRQL, and survival. It is important to note that medications commonly used for symptom management in PC can interact with COPD medications resulting in increased risk of adverse effects, enhanced toxicity, or changes in clearance of medications. The authors review pharmacologic interactions with, and precautions related to use of COPD therapies in conjunction with commonly used PC medications. **Abstract (w. link to references):** <http://bit.ly/38ZsHFp>

Noted in Media Watch 4 November 2019 (#638, p.16):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 October 2019 – ‘**Early palliative care in chronic obstructive pulmonary disease.**’ Guidelines recommend that pulmonary clinicians involve palliative care (PC) in chronic obstructive pulmonary disease (COPD); however, integration before advanced stage, that is, early PC, is rare. Pulmonary and PC clinicians [i.e., study participants] agreed that early PC could add value to disease-focused COPD care. Perspectives on many barriers and facilitators were shared between specialties along broad educational, clinical, and operational categories. Pulmonary and PC clinicians shared concerns about the misconception that PC was synonymous to end-of-life care. **Abstract:** <http://bit.ly/36cebtj>

N.B. Additional articles on PC for people living with COPD noted in this issue of Media Watch.

Palli@Doc: A single access point to palliative care information

MÉDECINE PALLIATIVE | Online – 31 January 2020 – Documentalists at French national centre on palliative care (PC) and end-of-life (EoL) – Centre National des Soins Palliatifs et de la Fin de Vie – launched ... a project of enrichment of bibliographic database Palli@Doc. This aims to increase the number of referred documents in this database and to cover more disciplines on PC, in order to make Palli@Doc an essential reference in its area. A secondary objective but nevertheless essential was to optimize this documentary task in terms of human resources and time. This article describes the implementation of the project, step by step, from the selection of computer tools cataloging scientific articles to semi-automated watch on PC, EoL death and bereavement. **Abstract:** <http://bit.ly/2UeSzsk>



N.B. French language article. Palli@Doc website: <http://bit.ly/36lqQDk>

Trends [in the U.S.] in contracting and common ownership between hospice agencies and nursing homes

MEDICAL CARE | Online – 23 January 2020 – In recent years, policymakers have paid particular attention to the emergence of a robust for-profit hospice sector and increased hospice use by nursing home residents. Previous research has explored financial incentives for nursing home-hospice use, but there has been limited research on nursing home-hospice partnerships and none on the extent of nursing home-hospice common ownership. Between 2005 and 2015, the number of hospice agencies and nursing homes with common ownership grew substantially, now representing almost 1-in-5 providers in each sector. Relative to individuals using hospice in nursing homes without common ownership, adjusted analyses found that individuals receiving hospice from a commonly owned agency had a greater likelihood of having stays of 90 days or more, having a stay resulting in a live discharge, and having at least 1 registered nurse/licensed practical nurse visit during the last 3 days of life; these individuals also had a lower mean visit hours per day. **Abstract:** <http://bit.ly/2tUXSCA>

Noted in Media Watch 18 September 2017 (#530, p.13):

- *HEALTH AFFAIRS*, 2017;36(9):1547-1555. ‘**Corporate investors increased common ownership in hospitals and the post-acute care and hospice sectors.**’ Historically, the ability to track common investors across the continuum of healthcare providers has been limited. Little is known about common investor ownership structures that exist across healthcare delivery systems and how these linkages have evolved over time. This study provides a description of common investor ownership trends in these sectors. The percentage of acute care hospitals having common investor ties to the post-acute or hospice sectors increased from 24.6% in 2005 to 48.9% in 2015. These changes have important implications for antitrust, payment, and regulatory policies. **Abstract:** <http://bit.ly/37S0uQJ>

The past is present: Death systems among the Indigenous Sámi in Northern Scandinavia today

MORTALITY | Online – 27 January 2020 – Despite growing interest in Indigenous health, the lack of end-of-life (EoL) research about the Sámi people led us to explore experience-based knowledge about EoL issues among the Sámi. The authors describe Sámi death systems and the extent to which [psychologist Robert] Kastenbaum’s conceptualisation of death systems is appropriate to Sámi culture. Kastenbaum’s model of death systems, with functions along a time trajectory from prevention to social consolidation after death, and the components of people, times, places, and symbols/objects, was applied thereafter in an effort to understand the data. The model provides a framework for understanding aspects of the death system that were Sámi-specific, Sámi-relevant as well as what has changed over time. Whereas Kastenbaum differentiated among the components of the death system, the authors analysis indicated these were often so interrelated as to be nearly inseparable among the Sámi. Seasonal changes and relationships to nature instead of calendar time dominated death systems, linking people, places and times. The extended family’s role in enculturation across generations and EoL support was salient. Numerous markers of Sámi culture, both death-specific and those recruited into the death system, strengthened community identity in the EoL. **Full text:** <http://bit.ly/2O5aJn>

N.B. The Sámi people are an indigenous Finno-Ugric people inhabiting Sápmi, which today encompasses large northern parts of Norway and Sweden, northern parts of Finland, and the Kola Peninsula within the Murmansk Oblast of Russia.

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Closing the Gap Between Knowledge & Technology
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Identifying key elements for paediatric advance care planning with parents, healthcare providers and stakeholders: A qualitative study

PALLIATIVE MEDICINE | Online – 27 January 2020 – Although international guidelines recommend discussions about goals-of-care and treatment options for children with severe and life-limiting conditions, there are still few structured models of paediatric advance care planning (ACP). Participants constituted an advisory board and took part in two transdisciplinary workshops. Key elements were discussions, documentation, implementation, timing and participation of children and adolescents. Parents engage in discussions with facilitators and persons of trust to reach a decision. Documentation constitutes the focus of professionals, who endorse brief recommendations for procedures in case of emergencies, supplemented by larger advance directives (ADs). Implementation hindrances include emotional barriers of stakeholders, disagreements between parents and professionals and difficulties with emergency services. Discussion timing should take into account parental readiness. The intervention should be repeated at regular intervals, considering emerging needs and increasing awareness of families over time. Involving children and adolescents in ACP remains a challenge. A paediatric ACP intervention should take into account potential pitfalls and barriers including issues related to timing, potential conflicts between parents and professionals, ambiguity towards written ADs, the role of non-medical carers for paediatric ACP implementation, the need to involve the child and the necessity of an iterative process. **Abstract (w. list of references):** <http://bit.ly/2tXPoe7>

Noted in Media Watch 13 January 2020 (#648, p.4):

- *ACTA PAEDIATRICA* | Online – 9 January 2020 – ‘**Survey of paediatricians found them to be involved in advance care planning: Are we there yet?**’ Adult studies have shown advance care planning (ACP) increased congruence in treatment preferences between patients and medical staff and increased the likelihood patients’ preferences were respected. International guidelines and medical organisations, such as the American Academy of Pediatrics, the Institute of Medicine and the World Health Organization, recommend ACP for adults and children. However, minors have been broadly neglected in existing ACP programmes and ACP research, which implies that they may be denied the possible benefits of ACP that have been reported by adult studies. **Full text:** <http://bit.ly/2NcJWug>
- *JOURNAL OF PAEDIATRICS & CHILD HEALTH* | Online – 3 January 2020 – ‘**Treatment limitation and advance planning: Hospital-wide audit of paediatric death.**’ The authors examine paediatric deaths following withdrawal or withholding of medical treatment (WWMT) from a hospital-wide perspective and identify changes over a 10 year period. 101 deaths occurred in the inpatient setting in 2015-2016. Most followed WWMT and occurred in children with pre-existing chronic conditions. There was a shift to earlier discussions with parents regarding WWMT compared to 10 years prior. There was also increased paediatric palliative care involvement, and a slightly greater proportion of children died outside of intensive care. **Abstract:** <http://bit.ly/2tBbWAV>

CANADIAN
Virtual Hospice  **Portail** CANADIEN EN SOINS
palliatifs

Supporting Grieving or Bereaved Children
<http://bit.ly/2sQ2bLy>



Prison Hospice: Backgrounder

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

Photo: Lori Waselchuk. Philadelphia, PA

Techniques to communicate better with parents during end-of-life scenarios in neonatology

PEDIATRICS | Online – 28 January 2020 – The goal of this study was to identify core behaviors that could be easily taught and emulated. All participants were adequate in their technical and communication skills, and they were Neonatal Resuscitation Program trained and often participated in resuscitations... The evidence regarding how to communicate with families before a critical delivery or when a child becomes unstable is scarce and generally not addressed in resuscitation manuals. A resuscitation team may only have seconds to communicate with parents, but the authors' results show this time can be used effectively. Similarly, there is scarce evidence regarding communication with families during resuscitations. Although parental presence remains controversial, the mother is inevitably physically present at birth ... and the father is often there. The communication scores during the resuscitation were the lowest. Indeed, this task is complex because it requires multitasking by the code leader. Ideally, a provider would be dedicated to do this task. Several institutions have developed specific training guidelines for such a family support role. Realistically, in these rare situations, the additional personnel ... are generally diverted to help with the resuscitation. In this study, it was possible for more than half of

the participants to communicate well, using 6 core behaviors. This took a total time of less than a minute and was feasible while leading a resuscitation. **Full text:** <http://bit.ly/2REsSA1>

Educational perspectives: Palliative care education in neonatal-perinatal medicine fellowship

NEOREVIEWS, 2020;21(2):e72-e79. The American Academy of Pediatrics has set forth recommendations related to pediatric palliative care (PC) for the various pediatric sub-specialties; however, much of the focus is on disease processes and curing or mitigating various illnesses. Given the high preponderance of death in the neonatal period, neonatal-perinatal medicine training programs should be tasked with generating formal PC training. Such training should be geared to providing better care for neonatal patients with a life-limiting or life-altering illness, and better equipping future neonatologists with the tools needed to provide truly comprehensive care for their sickest patients at risk for death and disability. This article reviews the concept of PC in neonates, discusses the paucity of formal education in PC, explores the general trend in PC education, reviews various ways in which PC education can be formalized, and defines metrics of a successful educational program. **Abstract:** <http://bit.ly/36Nzh03>

Noted in Media Watch 16 September 2019 (#631, p.9):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2019;22(9):1149-1153. **'Top ten tips palliative care clinicians should know about caring for children in neonatal and pediatric intensive care units.'** Over the past several years, pediatric critical care units increasingly count on the expert advisement of palliative care (PC) specialists. Given the limited availability of pediatric PC specialists, all PC clinicians may be required to care for pediatric patients and their families. Special considerations in caring for these patients include the relative importance of prognosis, involvement of child life, music and pet therapy, incorporation of parents in end-of-life rituals, care for siblings, use of medical technology, and prolonged duration of stay. **Abstract:** <http://bit.ly/2krWVNH>

Noted in Media Watch 22 July 2019 (#623, p.11):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2019;21(4):333-343. **'Parents' wishes for what they had or had not done and their coping after their infant's or child's neonatal intensive care unit/pediatric intensive care unit/emergency department death.'** Mothers wished they spent more time with the child, chosen different treatments, advocated for care changes, and allowed the child his or her wishes. Fathers wished they had spent more time with the child and gotten care earlier. Mothers wished they had not agreed to child's surgery/treatment, taken her own actions (self-blame), and left the hospital before the death. Fathers wished they had not been so hard on the child, agreed with doctors/treatment, and taken own actions (self-blame). **Abstract:** <http://bit.ly/2GcuKK9>



Would the articles above be of interest to a colleague?

Palliative care in Canada

Does early palliative identification improve the use of palliative care services?

PLOS ONE | Online – 31 January 2020 – In this propensity-score matched cohort study of patients who were likely to die within one year, the authors found that actively identifying patients who may benefit from a palliative care (PC) approach increased the utilization of PC services and community-based care such as home care, physician home visits, and outpatient opioid use. This effect was observed with identification both in a cancer clinic setting and a primary care setting. This effect was also seen in very complex cancer patients including those with lung cancer and glioblastoma. There was also an increase in acute care utilization, namely emergency department encounters and hospitalizations for the intervention group. Earlier access to PC is in line with quality standards for quality care in the province of Ontario. Nevertheless, the most recent data from the Canadian Institute for Health Information shows that in Ontario and Alberta, fewer than 15% receive PC at home.¹ The results of this study are also congruent with other end of life studies. **Full text:** <http://bit.ly/31gyd3N>

1. 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, September 2018. [Noted in 24 September 2018 issue of Media Watch (#582, p.1)] **Download/view at:** <http://bit.ly/2MqmCYO>

Invoking death: How oncologists discuss a deadly outcome

SOCIAL SCIENCE & MEDICINE | Online – Accessed 31 January 2020 – Existing sociological research documents patient and physician reticence to discuss death in the context of a patient's end of life. This study offers a new approach to analyzing how death gets discussed in medical interaction. Using a corpus of 90 video-recorded oncology visits and conversation analytic methods, this analysis reveals that when existing parameters are expanded to look at mentions of death outside of the end-of-life context, physicians do discuss death with their patients. Specifically, the most frequent way physicians invoke death is in a persuasive context during treatment recommendation discussions. When patients demonstrate active or passive resistance to a recommendation, physicians invoke the possibility of the patient's death to push back against this resistance and lobby for treatment. Occasionally, physicians invoke death in instances where resistance is anticipated but never actualized. Similarly, death invocations function for treatment advocacy. Ultimately, this study concludes that physicians in these data invoke death to leverage their professional authority for particular treatment outcomes. **Abstract:** <http://bit.ly/2CJOWko>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BC MEDICAL JOURNAL*, 2020;62(1):18-23. '**Attitudes and expectations regarding bereavement support for patients, family members, and friends: Findings from a survey of MAiD providers.**' The majority of respondents agreed that patients, family members, and friends need bereavement support in the days and weeks before and following an assisted death. While the importance of bereavement support was acknowledged by 13 respondents (72.2%), the same number indicated they have neither the time nor the resources to provide this kind of follow-up. For physicians providing some form of bereavement support, most referred people to resources (community programs, grief counseling, online information) or provided printed information. Notably, 12 respondents believed providing bereavement follow-up to be part of their professional and moral obligation to families. When asked if bereavement was different for an assisted death, 13 respondents said that in their experience it was. Reasons for this included the newness and unfamiliarity of medical assistance in dying and the potential for stigma. Respondents also shared ideas about dedicating and/or designating non-physicians to offer bereavement support, enhancing bereavement services delivered by other groups and organizations, and generating accessible supports from the health authority in the form of printed materials or default follow-up services. **Full text:** <http://bit.ly/36JYJ6x>

Cont.

Noted in Media Watch 4 November 2019 (#638, p.19):

- *CRISIS* | Online – 28 October 2019 – ‘**Grief after euthanasia and physician-assisted suicide: A systematic review.**’ People bereaved by euthanasia/physician assisted suicide (EPAS) generally had similar or lower scores on measures of disordered grief, mental health, and post-traumatic stress compared with those who died naturally. Lack of social support and secrecy may compound their grief. Being involved in the decision-making process and having the feeling of honoring the deceased’s will may facilitate their grief. There is little evidence of increased risk of adverse grief or mental health outcomes in people bereaved by EPAS. **Abstract (w. link to references):** <http://bit.ly/32YuXK9>

Noted in Media Watch 11 March 2019 (#605, p.15):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 1 March 2019 – ‘**Impact of medical assistance in dying on family caregivers.**’ The aim of this article is to explore the experience of medical assistance in dying (MAiD) from the family caregiver perspective, namely their beliefs and opinions about the intervention, how the process of MAiD impacts them, how the intervention shapes their view of their loved one’s quality of death, and the psychosocial outcomes after the passing of their loved one. Beyond the literature, challenges within both the clinical and research realms are discussed and future directions are offered. **Abstract:** <http://bit.ly/2NFkvjY>

Publishing Matters

Journal transparency index will be “alternative” to impact scores

TIMES HIGHER EDUCATION | Online – 29 January 2020 – A new ranking system for academic journals measuring their commitment to research transparency will be launched next month – providing what many believe will be a useful alternative to journal impact scores. Under a new initiative from the Center for Open Science, based in Charlottesville, Virginia, more than 300 scholarly titles in psychology, education and biomedical science will be assessed on 10 measures related to transparency, with their overall result for each category published in a publicly available league table. The centre aims to provide scores for about 1,000 journals within six to eight months of their site’s launch in early February. **Full text:** <http://bit.ly/2RDJ985>

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.

Distribution

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2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
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Cont.

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6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

[Something Missed or Overlooked?](#)

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

[Media Watch: Access on Online](#)

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://bit.ly/2sMI2JY>

[Scroll down to 'Media Watch: The Indigenous Peoples']

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://bit.ly/2ThijkC>

PALLIATIVE CARE NETWORK: <http://bit.ly/2Ujdk2S>

PALLIMED: <http://bit.ly/2ResswM>

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at: <http://bit.ly/2MwRRAU>]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://BIT.LY/2SWDYWP>

[Scroll down to 'e-Library' ('From Around the Region') and 'Media Watch Barry Ashpole']

Australia

PALLIATIVE CARE RESEARCH NETWORK: <http://bit.ly/2E1e6LX>

[Click on e-News (November 2019); scroll down to 'Useful Resources in Palliative Care Research']

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <http://bit.ly/2TboKFX>

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <http://bit.ly/2XC24jA>

HUNGARY | Magyar Hospice Alapítvány: <http://bit.ly/2RqTvYr>

U.K. | Omega, the National Association for End-of-Life Care: <http://bit.ly/2MxVir1>

South America

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

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