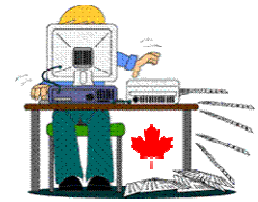


Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

27 April 2020 Edition | Issue #663



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Compiled & Annotated by Barry R. Ashpole

Innovative approaches that involve family members in inpatient care during the COVID-19 pandemic may lead to long-lasting progress in, rather than regression from, the standards of family-centered care the healthcare community has recently achieved.

'Family-centered care during the COVID-19 era' (p.7), in *Journal of Pain & Symptom Management*.

U.S.A.

Hospices tackle telehealth challenges during COVID-19

HOSPICE NEWS | Online – 20 April 2020 – The COVID-19 pandemic has hindered some of the hands-on patient care that hospices deliver. While some hospices were well-positioned to integrate and increase technology utilization into a wider scope of services, others have hit obstacles. When the U.S. Centers for Medicare & Medicaid Services announced temporary waivers on requirements last month, expanding the allowable use of telehealth services was among the flexibilities offered to hospice. The temporary waiver was intended to help support providers in delivering safe care and minimize infection risks to staff and patients during in-person visits. While telehealth keeps patients and families connected with their hospices, providers have had to develop and implement new processes and absorb the associated costs. Hospice care is now infused with technology, which has largely driven improvement, such as improved accuracy in patient records and availability of information for patients, families, and referral part-

ners. Even with these improvements, the hospice industry overall is behind in utilizing technology in operations and administration, patient care and raising end-of-life care awareness, according to some experts. Among the concerns that come with increased telehealth is defining the parameters for when and how the hospice should use it. As the pandemic created an urgent and time-sensitive need for many critical patients, providers were met with the task of designing telehealth programs independently while awaiting more hospice-specific guidelines from federal agencies. <https://bit.ly/3eCGdCg>

COVID-19: End-of-Life Care

'Characteristics and palliative care needs of COVID-19 patients receiving comfort directed care' (p.6), in *Journal of the American Geriatrics Society*.

Cont.

Related:

- *HOSPICE NEWS* | Online – 20 April 2020 – ‘**Cybersecurity a new priority for hospice providers.**’ As hospices begin to offer a wider range of services via telehealth during the COVID-19 pandemic, they may need to get smarter when it comes to cybersecurity. Hospices often rely on popular video-conferencing platforms to conduct telehealth visits with patients, including Zoom, Skype and other systems. Security concerns are starting to arise about the use of these systems... These privacy concerns are critical for hospices to understand in order to prevent data breaches that could cause financial harm, reputational damage or exposure of information protected by the Health Insurance Portability & Accountability Act. <https://bit.ly/2VxucXf>

Noted in Media Watch 20 April 2020 (#662, p.12):

- *JAMA NETWORK OPEN*, 2020;3(4):202583. ‘**Effects of a telehealth early palliative care intervention for family caregivers of persons with advanced heart failure.**’ A nurse-led, early palliative care telehealth intervention did not demonstrate significant differences in quality of life, mood, and burden compared with usual care over sixteen weeks. Pre-specified secondary outcomes including global health and positive aspects of caregiving were also not significantly different at 16 weeks. While the intervention do not demonstrate benefit to these particular outcomes, the results nonetheless reveal essential insights to advancing future intervention testing and to guiding clinical services for heart failure family caregivers. **Full text:** <https://bit.ly/2XEsYeu>

Noted in Media Watch 16 December 2019 (#644, p.7):

- *BMC PALLIATIVE CARE* | Online – 13 December 2019 – ‘**Telehealth in palliative care is being described but not evaluated: A systematic review.**’ This review demonstrates that a variety palliative care (PC) telehealth initiatives continue to be described in the published literature. Since a 2010 review there particularly appears to have been an increase in the number of home tele-monitoring interventions... Despite the description of telehealth development and implementation, there remains a lack of robust study design and evaluation of these interventions meaning that clear conclusions around the benefit of telehealth in PC cannot be drawn; there is insufficient high quality evidence to comment on any influence on access to emergency or unscheduled care. **Full text:** <http://bit.ly/2PJKJmT>

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

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 25 June 2019 – ‘**Top ten tips palliative care clinicians should know about telepalliative care.**’ While additional data are needed, telepalliative care – the application of telehealth technologies to palliative care (PC) – may help address important challenges inherent to our specialty, such as geography and clinician staffing; the burden of traveling to brick-and-mortar clinics for patients who are symptomatic and/or functionally limited; and, the timely assessment and management of symptoms. This article, created by experts in telehealth and PC, provides a review of the current evidence for telepalliative care and potential applications and practical tips for using the technology. **Abstract:** <http://bit.ly/2LiOM6>



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/2RPy9b>

International

Research shows a significant rise in the number of children with life-limiting conditions

U.K. (England) | Together for Short Lives – 23 April 2020 – A new research study shows that the number of children in England with life-limiting or life-threatening conditions has continued to rise over the last 17 years. The Make Every Child Count study, conducted by the University of York, has revealed that the number of children in England with life-limiting or life-threatening conditions increased to 86,625 in 2017-2018 compared to 32,975 in 2001-2002. The new research also reveals that prevalence of life-limiting conditions is by far the greatest in babies under the age of one, and that more young people with life-limiting conditions are living to the age of 19 years. That more seriously ill children are living longer is cause for celebration, however there is an urgent need to make sure that children's palliative care (PC) services are properly planned, funded and delivered to ensure that these children, and their families, can live life to the full. It's hoped that the Make Every Child Count research will make it easier for government, the National Health Service, children's PC providers and others to do this. <https://bit.ly/34WQXqG>

N.B. Link to University of York report imbedded in Together for Short Lives announcement.

“The art of dying well.”: Deathbed etiquette guide offers advice on virtual communication with dying relatives

U.K. (England) | *The Daily Mail* (London) – 20 April 2020 – A stark guide to deathbed etiquette has been released in a bid to aid families hit by the Coronavirus pandemic.¹ The Centre for The Art of Dying Well at St. Mary's University, London, advised relatives unable to be physically with their loved ones to communicate with them virtually, trust in the care of doctors and nurses and not let feelings of guilt take over. The guide also said relatives should speak from the heart, remember to say important last words and reassure them that you “will be ok.” The U.K. has recorded 16,509 deaths from COVID-19 since the outbreak began, the majority of which are in individuals more than 60 years old. <http://dailym.ai/3eyFx0R>

1. 'Deathbed etiquette,' Centre for The Art of Dying Well, St. Mary's University, London. **Download/view at:** <https://bit.ly/3eG2yyY>

Coronavirus: Hospices in Wales to share £6.3 million funding

U.K. (Wales) | BBC News (Cardiff) – 19 April 2020 – Hospices in Wales are to get a £6.3 million package of extra help, the health minister has announced. It aims to fill a gap left by a drop in fund-raising for charities due to the Coronavirus pandemic. There has been a drastic cut in charity events, while fund-raising shops have been forced to close. The funding for the next three months aims to address what the Welsh Government calls the “very serious risk that hospice and end-of-life care (EoLC) services could slip into insolvency.” Hospice and EoLC services help more than 20,000 people in Wales a year, as well as preventing avoidable admissions to hospital. <https://bbc.in/3aotU9g>

Specialist Publications

‘Advances and challenges in European paediatric palliative care’ (p.12), in *Medical Sciences*.

COVID-19: End-of-Life Care

‘Managing COVID-19 symptoms (including at the end of life) in the community: Summary of National Institute for Health & Care Excellence guidelines’ (p.6), in *British Medical Journal*.

‘Administration of end-of-life drugs by family caregivers during COVID-19 pandemic’ (p.7), in *British Medical Journal*.

‘The key role of palliative care in response to the COVID-19 tsunami of suffering’ (p.7), in *The Lancet*.

‘Public health, health systems and palliation planning for COVID-19 on an exponential timeline’ (p.7), in *Medical Journal of Australia*.

‘Between intensive care and palliative care at the time of COVID-19’ (p.7), in *Recenti Progressi in Medicina*.

Specialist Publications

Recommendations relevant to physiatrists in new clinical practice guidelines for quality palliative care

AMERICAN JOURNAL OF PHYSICAL MEDICINE & REHABILITATION, 2020;99(5):444-445. The fourth edition references function, disability, and rehabilitation.¹ Though not explicitly stated in the guidelines, these references broaden the construct of quality palliative care (PC) to include areas that overlap with psychiatry expertise. As such, whether as a formal PC team member, occasional consultant, or lecturer/educator, the physiatrist has meaningful skills and perspective to contribute to the provision of excellent interdisciplinary PC. Several key elements from the guidelines lend themselves to physical medicine and rehabilitation involvement in interdisciplinary PC. For example, to address the guidelines' attention to assessing and addressing functional needs in order to promote quality of life, physiatrists can facilitate thorough assessments of functional status and make recommendations for appropriate and safe equipment, home modifications, and rehabilitation therapies. As another example, the guidelines set forth coordination of care for patients with limited cognition or communication as a standard of PC excellence. The guidelines note that a standard of PC includes the premise that, "patients with disabilities are assumed to have decision-making capacity unless determined otherwise, according to applicable laws."

Full text: <https://bit.ly/2RVIVu4>

1. 'National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care,' National Consensus Project for Quality Palliative Care, 2018. [Noted in 1 April 2019 issue of Media Watch (#608, p.11)] **Download/view 4th edition at:** <http://bit.ly/2uuIDhJ>

Noted in Media Watch 6 January 2020 (#647, p.4):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 30 December 2019 – '**Rehabilitation in palliative care: A qualitative study of team professionals.**' The concept of rehabilitative palliative care (PC) has been advocated to help patients preserve function and independence, through greater patient enablement and self-management. Such an approach requires engagement from all members of the PC team. The objective of this research was to explore hospice-based PC professionals' understanding and perceptions of rehabilitation. Overall, participants in this study clearly articulated the underlying values and benefits of rehabilitative PC. Emphasis was placed on ensuring that rehabilitation was appropriately tailored to each individual patient. **Abstract:** <http://bit.ly/2Qb5BF8>

Noted in Media Watch 28 October 2019 (#633, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 September 2019 – '**Top ten tips palliative care clinicians should know about physical medicine and rehabilitation.**' This article, written by a team of physical medicine and rehabilitation (PM&R) and palliative care (PC) specialists, aims to help the PC team ... expand their toolkit for treating musculoskeletal and neurological symptoms, improve prognostication for patients with brain and spinal cord injuries, and decide when patients may benefit from PM&R consultation and support. There is significant overlap between the populations treated by PM&R and PC. Better integration between these specialties will help patients to maintain independence as well as advance excellent patient-centered care. **Abstract:** <http://bit.ly/2lxH54o>

A palliative care approach in psychiatry: Clinical implications

BMC MEDICAL ETHICS | Online – 19 April 2020 – Traditionally, palliative care (PC) has focused on patients suffering from life-threatening somatic diseases such as cancer or progressive neurological disorders. In contrast, despite the often chronic, severely disabling, and potentially life-threatening nature of psychiatric disorders, there are neither PC units nor clinical guidelines on palliative measures for patients in psychiatry. The authors contribute to the growing literature on a palliative approach in psychiatry and is based on the assumption that a change of perspective from a curative to a palliative approach could help promote patient-centeredness and increase quality of life (QoL) for severely ill patients in psychiatry as

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well as in somatic medicine. They emphasize that many typical interventions for treatment-refractory psychiatric disorders may indeed be of a palliative nature. Furthermore, introducing traditional features of PC, e.g., so-called goals-of-care conversations, could aid even further in ensuring that caregivers, patients, and families agree on which treatment goals are to be prioritized in order to optimize QoL in spite of severe, persistent mental disorder. **Full text:** <https://bit.ly/2RPIAlk>

Noted in Media Watch 6 August 2018 (#575, p.9):

- *AMERICAN MEDICAL JOURNAL OF ETHICS*, 2018;20(8):E717-E723. **‘Four communication skills from psychiatry useful in palliative care and how to teach them.’** In considering the communication skills needed in palliative care (PC), the authors note parallels with psychiatric training. PC has always been interdisciplinary in perspective and practice, as reflected not only in its team approach to care but also in its recruitment of physicians from diverse specialties, including psychiatry. The authors propose that these similarities exist due to the intimacy of the clinical relationship in PC and psychiatry, the affectively charged clinical situation in which care occurs, and the primary role of patient-clinician relationships in decision-making and treatment. **Full text:** <http://bit.ly/2m8nPKA>

Profiles of family caregivers of patients at the end of life at home: A Q-methodological study into family caregiver’ support needs

BMC PALLIATIVE CARE | Online – 21 April 2020 – This study identified four distinct profiles of family caregivers (FCGs) of patients at home at the end of life (EoL): 1) Those who want appreciation and a contact person (profile 1); 2) Those who need supportive relationships (profile 2+ who have supportive relationships and profile 2- who lack supportive relationships); 3) Those who want guidance, information and practical/medical support (profile 3); and, 4) Those who need time off (profile 4). The profiles identified FCGs who shared similar support needs and experiences with caregiving as well as differences between the profiles. Overall, they showed similar characteristics to previously identified caregiver profiles, in that they could be roughly sub-divided into FCGs who can cope well with the care tasks, enjoy sufficient support and manage pretty well (profile 2+), FCGs who can cope with the care but need support in order to carry on with caregiving (profile 1 and 3), FCGs who experience care as demanding and receive little support (profile 2-), and FCGs who experience the care as a burden and can hardly cope with the care that is required but do not ask for respite care (profile 4). FCGs of patients at the EoL have varying support needs and one size does not fit all. The profiles are relevant for HCPs and volunteers in palliative care as they provide an overview of the main support needs among FCGs of patients near the EoL. This knowledge could help HCPs giving support. **Full text:** <https://bit.ly/2xEtIR>

Related:

- *CANADIAN ONCOLOGY NURSING JOURNAL*, 2020;30(2):147-152. **‘Needs of caregivers of patients receiving in-home palliative and end-of-life care.’** The results of this study shed light on the multiple needs of caregivers and the necessity of addressing these needs to facilitate home support and dying at home when this option is chosen by a patient and their caregivers. It is essential to develop a trajectory of care and services that meet these needs and continue during the bereavement period. Nursing support through education about care, medication, management of symptoms, and emotional support helps meet caregivers’ needs in a timely manner, establish a trusting relationship and make home support and dying at home feasible. **Full text (click on pdf icon):** <https://bit.ly/3548IEN>

Advance care plans and hospitalized frail older adults: A systematic review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 17 April 2020 – This review provides evidence for physicians that they could usefully offer advance care planning (ACP) to older hospitalised patients, or assist ACP facilitators to do so. Notably, while a large majority of patients expressed an interest in participating in ACP, experiences of those who had done so were mixed: many patients are “ambivalent” to ACP, simultaneously experiencing benefits and unpleasant feelings. Clinicians need to be aware that 13%-23% of older patients would prefer not to participate in ACP, and that patients may have limited re-

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collection of ACP conversations held in hospital. Furthermore, there is evidence in other patient groups of a “hospitalisation dip,” where patients initially prefer less aggressive treatment following a hospital admission but revert to wanting more life-sustaining treatments over time. Clinicians could usefully consider arranging a post-discharge review of ACP discussions and documents made in hospital. At an organisational level, this review provides some evidence that hospitals should seek to support ACP practice and that hospital-level factors may account for a significant amount of variation in ACP rates. Further evidence is needed on the best way to increase ACP but multi-component interventions including ACP facilitators, healthcare professional and patient education and standardised documentation have been successful in some sites. This review provides evidence to endorse

this, while also demonstrating that there remain considerable areas of uncertainty. **Full text:** <https://bit.ly/2XMMCVv>

Extract from *BMJ Supportive & Palliative Care* article

Patients with frailty have been identified as having palliative care needs at similar levels to people with cancer, but differences in attitudes towards dying and talking about death have been noted between frail patients and those with cancer or organ failure, in part related to unpredictability of death and dying.

N.B. Selected articles on palliative and end-of-life care for the frail elderly noted in 17 February 2020 issue of Media Watch (#653, pp.11-12)

Related:

- *HEALTH COMMUNICATION* | Online – 20 April 2020 – ‘**Benefit, barrier, and self-efficacy messages in advance care planning education materials.**’ Fewer than 30% of patients engage in advance care planning (ACP) and little is known about specific messages relevant to health behavior change in ACP education materials. This study examined both manifest and latent message content in ACP education materials, focusing specifically on benefit, barrier, and self-efficacy messages. Education materials lack unique, specific benefit, barrier, and self-efficacy messages, which may lower patients’ motivation and self-efficacy with regard to ACP. Recommendations for designing ACP education materials in medical organizations are made. **Abstract:** <https://bit.ly/34V2yGX>

Managing COVID-19 symptoms (including at the end of life) in the community: Summary of National Institute for Health & Care Excellence guidelines

BRITISH MEDICAL JOURNAL | Online – 20 April 2020 – Although much focus has been on assessing the severity of COVID-19, general practitioners and other community based clinicians also need a working knowledge of symptom management. Symptoms of cough, fever, and breathlessness can be highly distressing even in those who do not have severe disease. Also, treatments for symptoms in severe COVID-19 will be needed for patients whose advance care plan or advance decision to refuse treatment includes a decision not to escalate treatment beyond home based care. This article summarises key points from the National Institute for Health & Care Excellence COVID-19 rapid guideline on managing symptoms (including at the end of life) in the community.¹ The guideline is part of a series of rapid guidelines on COVID-19, developed in collaboration with National Health Service England... **Full text:** <https://bit.ly/2VLw9hx>

Characteristics and palliative care needs of COVID-19 patients receiving comfort directed care

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 24 April 2020 – The first known COVID-19 related hospitalization in New York City was reported at Columbia University Irving Medical Center/NewYork-Presbyterian Hospital. Since then, the rapid increase in the number of patients with COVID-19 associated with acute respiratory distress syndrome and high rates of mortality have highlighted the critical need for high-quality end-of-life (EoL) care. On 31 March 2020, an 8-bed palliative care unit (PCU) was established ... for patients with COVID-19 whose surrogates opted to initiate or continue life-sustaining therapies. To the authors’ knowledge, this is the first report describing COVID-19 patients receiving comfort directed-care. This case series aims to describe the characteristics and palliative care needs in patients admitted to the PCU at Columbia University Irving Medical Center/NewYork-Presbyterian Hospital to inform other clinicians caring for this population at the EoL. **First page view:** <https://bit.ly/2xb89fK>

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1. 'COVID-19 rapid guideline: Managing symptoms (including at the end of life) in the community,' National Institute for Health & Care Excellence, 2020. **Download/view at:** <https://bit.ly/2RUoKLM>

Related:

- *BRITISH MEDICAL JOURNAL* | Online – 24 April 2020 – '**Administration of end-of-life drugs by family caregivers during COVID-19 pandemic.**' Although family caregivers (FCGs) commonly administer anticipatory medications in rural Australia, it is rare in the U.K. and many other countries. This is a big ask. FCGs may feel under pressure to undertake tasks for which they do not feel prepared or confident. They may feel a tension between their emotional involvement and this clinical task. Clinicians often worry that they may have hastened death if a patient dies shortly after drug administration. This anxiety may be even greater for FCGs, with some worrying that it amounts to euthanasia. **Full text:** <https://bit.ly/2x3Fau7>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 22 April 2020 – '**Family-centered care during the COVID-19 era.**' Internet-based solutions can facilitate the routine, predictable and structured communication central to family-centered care. But the reliance on technology may compromise patient privacy and exacerbate racial, socio-economic and geographic disparities for populations that lack access to reliable internet access, devices or technological literacy. The authors provide a toolbox of strategies for supporting family-centered inpatient care during physical distancing responsive to the current clinical climate. Innovations in the implementation of family involvement during hospitalizations may lead to long-term progress in the delivery of family-centered care. **Full text:** <https://bit.ly/3eLvXYw>
- *THE LANCET* | Online – 22 April 2020 – '**The key role of palliative care in response to the COVID-19 tsunami of suffering.**' During the COVID-19 pandemic, access to essential palliative care (PC) at end-of-life, including bereavement support, will be limited in the face of high demands in all countries. There will be increased isolation and suffering for PC patients and those who are bereaved. Strict physical distancing regulations to slow disease transmission mean that patients who die from COVID-19 will usually be without loved ones by their side, who in turn will be unable to say goodbye or undertake traditional grieving rituals. Providers of PC, including private hospices, will require additional human and financial resources. **Full text:** <https://bit.ly/3cHDMg1>
- *MEDICAL JOURNAL OF AUSTRALIA* | Online – 1 April 2020 – '**Public health, health systems and palliation planning for COVID-19 on an exponential timeline.**' While the potential for mass mortality is sometimes considered in major disaster plans, the issue of mass palliation is often neglected. Provision of equitable, compassionate, safe and dignified end-of-life care to COVID-19 cases unable to be offered lifesaving critical care is fundamental to ensuring the integrity of the Australian social fabric, and moral and mental welfare of potentially large swathes of the population. Up to 40% of the elderly in some age brackets live alone, complicating how to achieve what is necessary and right. **Full text:** <https://bit.ly/2KotpBs>
- *RECENTI PROGRESSI IN MEDICINA*, 2020;111(4):223-230. '**Between intensive care and palliative care at the time of COVID-19.**' The shortage of intensive care units (ICU) beds and ventilators for the treatment of patients with severe respiratory failure produces angst in the clinicians/intensivists who have to decide which patients admit to ICU and in which patients to implement palliative care. They have to apply specific clinical and ethical criteria, in emergency conditions. Proportionality and appropriateness criteria should be integrated with equity, equality, utility criteria, widening the distributive justice concept from the right of the patient to receive all available therapies to a right resources allocation during shortage, guided by public health ethic. **Full text:** <https://bit.ly/2VUn4mD>

N.B. Italian language article.



Resources relevant to Palliative Care and COVID-19

The International Association for Hospice & Palliative Care has compiled a list of resources relevant to palliative care and COVID-19 published by academia, civil society organizations, member states and special agencies of the United Nations, with links to all of the websites and documents listed. <https://bit.ly/2QQ1q1t>

Five-year risk of admission to long-term care home and death for older adults given a new diagnosis of dementia: A population-based retrospective cohort study

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2020;192(16):E422-E430. Among community-dwelling older adults with newly identified dementia in Ontario, the majority died or were admitted to a long-term care (LTC) home within 5 years. This information may be helpful for discussions on prognosis and need for admission to LTC. The global prevalence of dementia is increasing as the population ages and is expected to triple by 2050. Although there are exceptions, dementia is associated with a limited life expectancy. Because of the progressive course of cognitive decline, dementia is also a major contributing factor to the placement of individuals in LTC homes ... and in Canada's largest province, Ontario, more than 70% of residents of LTC homes have dementia. Despite the high prevalence of dementia before death, clinicians often do not discuss mortality prognosis after a new diagnosis of dementia, which may be partly because of discomfort with discussing death and dying and exacerbated by a

lack of resources to support those discussions. This study examined the association between a newly documented diagnosis of dementia and the risk of admission to a LTC home and death at 5 years. This information may be used by healthcare providers in their discussions about survival with patients with dementia and their families. **Full text:** <https://bit.ly/3cvRqTk>

Extract from *Canadian Medical Association Journal* article

Studies consistently find that individuals with dementia are far less likely to receive palliative care than individuals with other diseases, which reflects suboptimal end-of-life care for patients and may lead to families being unprepared for their loved one's death.

N.B. Selected articles on palliative and end-of-life care for people living with dementia noted in the 20 April 2020 issue of Media Watch (#662, p.10)

Associations between length of stay in long-term care facilities and end-of-life care. Analysis of the PACE Cross-Sectional Study

ENVIRONMENTAL RESEARCH & PUBLIC HEALTH | Online – 16 April 2020 – This is the first study of which the research team is aware that focuses specifically on the relationship between length of stay in a long-term care facility (LTCF) and end-of-life care (EoLC). A strength of the data used in this analysis is their representativeness of a large sample of LTCFs across six European countries [i.e., Belgium, England, Finland, The Netherlands and Poland]. Longer lengths of stay were associated with higher scores of quality of care in the last month of life and on the personhood, closure and preparatory tasks subscales. Longer lengths of stay were also associated with higher scores of comfort in the last week of life, on all sub-scales except the dying symptoms subscale. Associations between longer lengths of stay and quality of EoLC occurred earlier than in comfort in the last week of life, with significantly higher scores identified from 3 months compared to 1 year. A slight but statistically significant association was identified with fewer hospital admissions and resident deaths in hospital when length of stay was longer. **Full text:** <https://bit.ly/2xSGLU7>



Noted in Media Watch 2 March 2020 (#655, p.10):

- *JOURNAL OF POST ACUTE & LONG-TERM CARE MEDICINE* | Online – 27 February 2020 – ‘**Palliative care implementation in long-term care facilities: European Association for Palliative Care White Paper.**’ This is the first study the authors are aware of that has formulated recommendations on strategies for implementation of palliative care (PC) interventions in long-term care facilities (LTCFs) based on international research with experts. The recommendations aim to guide how PC can be introduced, embedded and sustained in LTCFs. The authors offer a framework of recommendations at each level in which strategies can be implemented and outlines the processes involved, although the authors acknowledge that change is unlikely to be linear. **Full text:** <http://bit.ly/2wicpcg>

N.B. Additional articles on end-of-life and PC in LTCFs noted in this issue of Media Watch.

Hope, loneliness and sense of coherence among bereaved parents

ENVIRONMENTAL RESEARCH & PUBLIC HEALTH | Online – 18 April 2020 – The results of this study underscore the significant links between hope, personal coherence, and loneliness among parents in bereaved families. These components constitute a complex mosaic of factors related to vulnerability, risk, and resilience that significantly impact parents' ability to cope even in the face of the severe adversity that has befallen them. This multifaceted examination is of great importance when translating research findings into practical goals and methods of intervention that may eventually become part of the toolbox of those who care for bereaved families. Identifying both the risks and strengths of the parents will help define specific goals that are tailored to the family's growth. The authors recommend the adoption of therapeutic approaches developed within the hope theory framework in formulating interventions and building "communities of hope" in an effort to reduce the agony of bereaved parents and boost their personal and family empowerment. **Full text:** <https://bit.ly/2znk6Q1>

Identifying core principles of palliative care consultation in surgical patients and potential knowledge gaps for surgeons

JOURNAL OF AMERICAN THE AMERICAN COLLEGE OF SURGEONS | Online – 17 April 2020 – Previous studies demonstrated that surgeons tend to underuse palliative care (PC) in comparison with medical services. Furthermore, little is known about the specific use of PC services among surgical oncology practices. Therefore, the authors designed and performed this study to evaluate the use of PC in cancer patients undergoing major oncologic surgery. Surgical patients were less likely to undergo PC consultation for assistance with symptom management and more likely to undergo consultation for assistance with end-of-life (EoL) discussions than were medical oncology patients. Advanced care planning and EoL discussions should be an area of focus in PC education for surgeons. **Abstract:** <https://bit.ly/3cBMNgM>

Identifying Core Principles of Palliative Care Consultation in Surgical Patients and Potential Knowledge Gaps for Surgeons			
Inpatient Palliative Care Consultations			
Surgical Oncology Patients		Medical Oncology Patients	
62%	Consult for pain control	97%	
32%	Consult for Advanced Care Planning	13%	
15%	Transfer to inpatient Palliative Care	2%	
7%	Code Status changed to DNR	30%	

“To live until you die could actually include being intimate and having sex.”: A focus group study on nurses' experiences of their work with sexuality in palliative care

JOURNAL OF CLINICAL NURSING | Online – 22 April 2020 – Nurses [i.e., study participants] experience that sexuality has an indistinct place in their work, “sexuality” is a word difficult to use, and differing views are held on whether it is relevant to address sexuality, and if so, when? Although they have experiences involving patient and partner sexuality, which is viewed as sexuality in transformation during the palliative care (PC) process, nurses seldom explicitly address patient or partner sexuality. Despite the lack of knowledge, routines and organizational support, they acknowledge the importance of addressing sexuality in PC, as they express that they want to do right. Nurses appear to follow differing cultural, interpersonal and intrapsychic scripts on sexuality rather than knowledge-based guidelines. This underlines the importance of managers who safeguard the adherence to existing PC guidelines where sexuality is already included. It is important to be aware of norms to avoid excluding patients and partners that differ from the nurses themselves as well as from societal norms on sexuality. **Abstract:** <https://bit.ly/2XWFDJA>

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Noted in Media Watch 28 October 2019 (#637, p.5):

- *ACTA MÉDICA PORTUGUESA*, 2019;32(10):625-627. ‘**How prepared are we to address sexuality in palliative care?**’ Sexuality, as one of the determinants of quality of life (QoL), includes different subjective dimensions related to identity, communication and intimacy. Sexuality “is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.” In this sense, WHO considers intimacy as an important element of the expression of sexuality. This includes individual satisfaction with his/her affective, loving, and sexual relationships. For many patients, sexual health is an essential component of their QoL, providing a sense of normality and closeness within the couple. **Full text:** <http://bit.ly/2BvpQ8s>

N.B. Click on ‘Select Language’ to access full text in either English or Portuguese.

Overlooking the landscape of palliative care in cystic fibrosis

JOURNAL OF CYSTIC FIBROSIS | Online – 16 April 2020 – Palliative care (PC) is a comprehensive and holistic approach to the care of patients and families aimed at improving quality of life and reducing symptom burden in the face of illness. Increasingly, evidence demonstrates that implementation of PC throughout the course of serious illness can improve outcomes. As a result, PC programs have expanded across healthcare centers, but issues surrounding awareness, optimal timing and implementation of these programs to cater to the needs of specific populations remain unclear. **Abstract (w. link to references):** <https://bit.ly/3cAVRwm>

N.B. Additional articles on the PC needs of people living with cystic fibrosis noted in 30 March 2020 issue of Media Watch (#659, p.5).

Meaningful futility: Requests for resuscitation against medical recommendation

JOURNAL OF MEDICAL ETHICS | Online – 24 April 2020 – “Futility” is a contentious term that has eluded clear definition, with proposed descriptions either too strict or too vague to encompass the many facets of medical care. Requests for futile care are often surrogates for requests of a more existential character, covering the whole range of personal, emotional, cultural and spiritual needs. Physicians and other practitioners can use requests for futile care as a valuable opportunity to connect with their patients at a deeper level than the mere biomedical diagnosis. Current debate around Canada’s changing regulatory and legal framework highlights challenges in appropriately balancing the benefits and burdens created by requests for futile care. **Full text:** <https://bit.ly/2VXevYj>

Creating a seat at the table: How family meetings elucidate the palliative care social work role

JOURNAL OF PALLIATIVE MEDICINE | Online – 23 April 2020 – Palliative care social workers (PCSWs) play a crucial role in optimizing communication and family-centered care for seriously ill patients. However, PCSWs often struggle to demonstrate and receive open acknowledgment of their essential skill set within medical teams. This case discussion focuses on the care of patients and families surrounding family meetings to highlight the crucial role of the PCSW in: 1) Preparing the family; 2) Participating in the provider meeting; 3) Participating in the family meeting; and, 4) Following up after the meeting. The aim is to illuminate how the PCSWs can demonstrate their unique and essential skill set to medical teams and as a means of furthering the work of psychosocial clinicians throughout medical systems. As the medical model continues to shift toward family-centered care, it is crucial for medical teams to optimize their partnership with patients and families. PCSWs can offer a trauma-informed bio-psycho-social-spiritual lens that is instructed by continuity of care and exemplary clinical and rapport-building skills. PCSWs can play a critical role in optimizing communication, support, collaboration, and family-centered whole-person care. **Abstract:** <https://bit.ly/353MYZi>

Cont.

Noted in Media Watch 30 May 2020 (#659, p.12):

- *SOCIAL WORK IN HEALTH CARE* | Online – 18 March 2020 – ‘**Hospice social workers’ perception of being valued by the interdisciplinary team and the association with job satisfaction.**’ This study examined the degree to which hospice social workers feel valued by other members of the interdisciplinary team... A non-probability sample of 203 hospice social workers completed an online survey assessing job satisfaction, perception of feeling valued by each of the professionals on the interdisciplinary hospice team, interdependence of team members, and professional and personal characteristics. The final regression model for intrinsic job satisfaction included feeling valued by doctors and by other social workers and interdisciplinary interdependence. **Abstract:** <https://bit.ly/3aa9Xnf>

Noted in Media Watch 25 March 2019 (#607, p.12):

- *SOCIAL WORK IN HEALTH CARE* | Online – 19 March 2019 – ‘**Sitting with silence: Hospital social work interventions for dying patients and their families.**’ Controversy around hospital end-of-life (EoL) care highlights the vulnerability of dying patients and their families. Little is known about how social workers provide support and intervention at the EoL in the hospital. Eight hospital social workers provided qualitative descriptions of their clinical practice for adult patients and their families. Highlighting a theoretical orientation towards a person-in-environment approach, social workers develop unique interventions to contribute to multidisciplinary care. Findings emphasize the need to prepare social work students and clinicians for the reality of working with EoL issues. **Abstract:** <http://bit.ly/2Y9jcyC>

N.B. Additional articles on the role of social workers in EoL care noted in this issue of Media Watch.

Burnout and self-care for palliative care practitioners

MEDICAL CLINICS, 2020;104(3):561-572. Burnout is common in physicians who care for patients with serious illness, with rates greater than 60% in some studies. Risk factors for burnout include working on small teams and/or in small organizations, working longer hours and weekends, being younger than 50 years, burdensome documentation requirements, and regulatory issues. Personal factors that can protect against burnout include mindfulness, exercise, healthy sleep patterns, avoiding substance abuse, and having adequate leisure time. Institutional and work factors that can buffer against burnout include working on adequately staffed teams, having a manageable workload, and minimally burdensome electronic health record documentation. **First page view:** <https://bit.ly/2KoVCs4>



Noted in Media Watch 16 March 2020 (#657, p.13):

- *PROGRESS IN PALLIATIVE CARE* | Online – 14 March 2020 – ‘**Reflections on the integration of a narrative medicine and mindfulness program in hospice and palliative care.**’ By 2060, almost 25% (98 million) of the population in the U.S. is expected to be aged 65 or older. Healthcare professionals (HCPs) who provide hospice and palliative care (PC) are over-tasked and demonstrate symptoms of burnout. Narrative medicine and mindfulness interventions create meaningful connections with patients, improve the delivery of patient-centered care, and enhance the health of the caregivers. HCPs in hospice and PC settings were invited to participate in a study to evaluate the impact of narrative medicine or mindfulness on measures of burnout and empathy. **Abstract:** <http://bit.ly/2TOxjJo>

Cont.

Noted in Media Watch 2 March 2020 (#655, p.5):

- *BMC PALLIATIVE CARE* | Online – 25 February 2020 – ‘**Compassion fatigue, watching patients suffering and emotional display rules among hospice professionals: A daily diary study.**’ Emotionally demanding jobs entail a higher frequency and intensity of daily interactions with patients and families that in turn requires regular use of emotional labour regulation. Emotional connections are a vital component of the therapeutic relationship in the hospice context, expressing their feelings when healing suffering is a fundamental part of this relationship. The authors found that burnout moderated the within-person relationship between seeing patients suffering, and daily emotion work display such that this relationship was stronger for those high in burnout. **Full text:** <http://bit.ly/2PseJUV>

N.B. Additional articles on compassion fatigue and the well-being and resilience practices in hospice and palliative care noted in 27 January 2020 issue of Media Watch (#650, p.7).

Advances and challenges in European paediatric palliative care

MEDICAL SCIENCES | Online – 17 April 2020 – Advances in both public health and medical interventions have resulted in a reduction in childhood mortality worldwide over the last few decades; however, children still have life-threatening conditions that require palliative care (PC). Children’s PC is a specialty that differs from PC for adults in many ways. The authors discuss some of the challenges, and some of the recent advances in paediatric PC. Developing responsive services requires good epidemiological data, as well as a clarity on services currently available and a robust definition of the group of children who would benefit from PC. Once a child is diagnosed with a life-limiting condition or life-limiting illness, parents face a number of complex and difficult decisions; not only about care and treatment, but also about the place of care and ultimately, place of death. The best way to address the needs of children requiring PC and their families is complex and requires further research and the routine collection of high-quality data. Although research in children’s PC has dramatically increased, there is still a

dearth of evidence on key components of PC notably decision-making, communication and pain and symptom management specifically as it relates to children. This evidence is required in order to ensure that the care that these children and their families require is delivered. **Full text:** <https://bit.ly/3bqg2N7>

Extract from *Medical Sciences* article

A new definition of palliative care (PC) put forward by the International Association of Hospice & Palliative Care combines adult and paediatric PC; however, this development may be less useful for research, clinical practice, service development and delivery, and hamper lobbying and advocating specifically on behalf of children. It has not been endorsed by the European Association of Palliative Care, nor by several other regional, national and international PC organisations.

1. ‘Consensus-Based Definition of Palliative Care,’ International Association of Hospice & Palliative Care. **Download/view at:** <https://bit.ly/2VGyXwF>

N.B. See key notes on paediatric PC development in some European countries in ‘European Association for Palliative Care Atlas of Palliative Care in Europe 2019’ (Chapter 2, Integration of Palliative Care & Paediatrics, pp.54-55). [Noted in 27 May 2019 issue of Media Watch (#615, p.4)] **Download/view at:** <http://bit.ly/2whaYrF>

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 20 April 2020 – ‘**Strengths, gaps, and opportunities: Results of a state-wide community needs assessment of pediatric palliative care and hospice resources.**’ Key themes identified: 1) Defining and providing pediatric palliative care (PPC); 2) The environment for PPC in Georgia; 3) Coordination and collaboration; and, 4) The future of PPC in Georgia. Recommendations to improve PPC services in Georgia were categorized by feasibility and importance. This assessment provides the foundation for next steps in coordinated efforts between hospital-based clinicians, state hospice and palliative care organizations, and state policymakers to ultimately expand PPC... **Abstract (w. link to references):** <https://bit.ly/2KmyzOD>

Cont.

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 April 2020 – ‘**A pilot study of the effects of COMPLETE: A communication plan early through end of life, on end-of-life outcomes in children with cancer.**’ Most children with cancer die in hospital settings, without hospice, and many suffer from high-intensity medical interventions and pain at end of life (EoL). The authors examine the effects of COMPLETE ... to increase hospice enrollment in children with cancer at EoL. COMPLETE resulted in increased hospice enrollment in children with cancer at EoL compared with historical controls. In pre/post analysis COMPLETE decreased child pain while supporting hope and reducing uncertainty in their parents. **Abstract (w. link to references):** <https://bit.ly/3cwkgTD>

RADboud indicators for Palliative Care Needs in Parkinson’s Disease

A tool to support healthcare professionals in timely identifying palliative care needs of people with Parkinson’s disease

PLOS ONE | Online – 21 April 2020 – An important new finding from this study is that healthcare professionals (HCPs) suggest two important marking moments in a Parkinson’s disease (PD) trajectory: 1) The ultimate moment to initiate advance care planning (ACP); and, 2) The start of the actual palliative phase. Differentiating these two moments might help professionals to discuss needs and wishes of palliative care (PC) with a person with PD before he or she loses decisional capacity. Recognizing a palliative phase can contribute to evaluate appropriate care goals that are in line with the actual (medical) situation of a person with PD. Participants emphasized that the process of ACP should start earlier, even before the palliative phase. But this might also be due to the fact that ACP was not seen as part of PC by HCPs. Many HCPs emphasized the need for ACP as cognitive problems may already be present even at an earlier stage of PD trajectory. Many of patients with PD will eventually develop dementia. Therefore, professionals emphasized that the process of ACP should be separated from the palliative phase in order to avoid that a person with PD can no longer be involved due to a lack of decision-making capacity and communication problems. The suggested indicators that could contribute to specify both marking moments included dysphagia, dementia, weight loss, and falls, among other things. The indicators were either PD-specific symptoms or general indicators such as recurrent hospital admissions and more support needed for activities of daily living. Some of these indicators have also been described in earlier studies as triggers to initiate PC in PD. **Full text:** <https://bit.ly/3an6jG8>

N.B. Additional articles on PC for patients living with PD noted in 17 February 2020 issue of Media Watch (#653, p.10).



Closing the Gap Between Knowledge & Technology
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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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International



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