

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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Exploring and supporting patients religious and spiritual beliefs may be as important as other physical and pharmacological clinical interventions in palliative care, as addressing psychosocial and spiritual concerns with end-of-life patients is critical in facilitating a peaceful end to life.

'The use of forgiveness facilitation in palliative care: A scoping review' (p.7), in *JBI Evidence Synthesis*.

Canada

Not scared of dying but of dying scared

HEALTHY DEBATE | Online – 16 June 2020 – COVID-19 has shone a bright light on a flawed system in need of dramatic reform, and on a workforce that must be better supported and empowered to provide meaningful end-of-life (EoL) care. This is not to place blame at the feet of our underpaid and undervalued care workers. These workers are cycling in and out of and in-between long-term care (LTC) settings without proper resources, training and educational supports. This workforce, much like the residents that they care for in an ageist society, has been largely ignored. While COVID-19 has brought this issue into focus, the lack of EoL support in LTC has been an ongoing injustice. Research by the pan-Canadian research team, SALTY (Seniors – Adding Life to Years), has detailed what many working at the intersections of palliative care (PC) and LTC have known for decades; most Canadians who go into LTC facilities die there. Previously, the majority of deaths took place in hospital, however more recently we have seen deaths increasing at LTC settings, further emphasizing the importance of integrat-

ing PC approaches. There are, thankfully, some deaths occurring in LTC that are well managed by staff and are peaceful for residents. These care facilities adhere to best EoL practices that pay close attention to residents and support them where they are in their EoL trajectory. This, sadly, is not the norm. At times, deaths

COVID-19: End-of-Life Care

'Symptom management and end-of-life care of residents with COVID-19 in long-term care homes' (p.8), in *Canadian Family Physician*.

Specialist Publications

'A scoping research literature review to identify contemporary evidence on the incidence, causes, and impacts of end-of-life intra-family conflict' (p.6), in *Health Communication*.

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occur with symptoms like pain and breathlessness going unmanaged, with no advance care plans in place and little sense of what is most important to residents as they make the transition EoL. Right now, there is an immediate need for provinces and territories, with federal oversight, to help front-line workers provide EoL care to residents infected with COVID-19... <https://bit.ly/37F4bJS>

N.B. SALTY (Seniors – Adding Life to Years) website: <https://bit.ly/37zP3xE>

Noted in Media Watch 8 June 2020 (#669, p.1):

- ONTARIO | *St. Catharines Standard* – 5 June 2020 – **‘Miscommunication can lead to unwanted deathbed outcomes in long-term care homes, studies show.’** End-of-life (EoL) care communication breakdowns can put long-term care residents at risk for “overtreatment,” two new studies from McMaster and Queen’s Universities show.^{1,2} The latter study on clinician barriers included a survey asking doctors what their top barriers were to productive “goals-of-care” EoL discussions. The other study included a survey of “substitute decision-makers,” such as residents’ family members. It looked at how the decision-maker’s knowledge of the care their loved one wanted at EoL jived with what was documented as being what they wanted. The survey found a disconnect between the two. <https://bit.ly/3dFP59w>

1. ‘The impact of prior advance care planning documentation on end-of-life care provision in long-term care,’ *Canadian Geriatrics Journal*, 2020;23(2):172-183. **Full text:** <https://bit.ly/2Ud9RFP>

2. ‘A multicenter study to identify clinician barriers to participating in goals-of-care discussions in long-term care,’ *Journal of Post-Acute & Long-Term Care Medicine*, published online 28 October 2019. [Noted in 11 November 2019 issue of Media Watch (#639, p.11)] **Full text:** <http://bit.ly/2Nc27jW>

Noted in Media Watch 18 May 2020 (#666, p.14):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 15 May 2020 – **‘The relationship between caregivers’ perceptions of end-of-life care in long-term care and a good resident death.’** 78 participants whose relative or friend died in one of five long-term care (LTC) homes in Canada completed questionnaires on their perceptions of end-of-life (EoL) care and perceptions of a good resident death. Findings confirm the critical role staff in LTC play in supporting caregivers’ perceptions of a good resident death. By keeping caregivers informed about expectations at the EoL, staff can enhance caregivers’ perceptions of a good death. By addressing spiritual issues staff may improve caregivers’ perceptions residents were at peace when they died. **Abstract (w. list of references):** <https://bit.ly/3cDyBOz>

N.B. Additional articles on EoL care in LTC homes noted in 27 April 2020 issue of Media Watch (#663, p.8).

[U.S.A.](#)

The pandemic broke end-of-life care

MASSACHUSETTS | *The Atlantic* – 16 June 2020 – When the coronavirus came to Boston, doctors at Brigham & Women’s Hospital noticed how silent certain floors became. Any patients who could be discharged were discharged. Any one who could stay away stayed away. “The hospital had this eerie quiet,” says Jane deLima Thomas, the director of palliative care (PC) at Brigham & Women’s Hospital and Dana-Farber Cancer Institute. But in the intensive care units (ICUs) set up for COVID-19, machines beeped and whirred in room after room of the sickest patients. Those patients were sedated, intubated, and isolated. Many of them would die. PC is

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[COVID-19: End-of-Life Care](#)

‘Recommendations to leverage the palliative nursing role during COVID-19 and future public health crises’ (p.8), in *Journal of Hospice & Palliative Nursing*.

‘The creation of a psychiatry-palliative care liaison team: Utilizing psychiatrists to extend palliative care delivery and access during the COVID-19 crisis’ (p.8), in *Journal of Pain & Symptom Management*.

‘Proactive identification of palliative care needs among patients with COVID-19 in the ICU’ (p.8), in *Journal of Pain & Symptom Management*.

about providing comfort – physical and emotional – to patients who are seriously ill, including those who may be close to death. Before the pandemic, deLima Thomas’s team worked with patients with kidney disease or cancer or heart failure, but this spring, they all switched to COVID-19. They embedded themselves in the ICUs. PC is a field especially invested in the power of a hug, a steadying hand, and a smile. In other words, PC is made especially difficult by a virus that spreads through human contact. The first day the PC doctors walked into the ICUs, Thomas says, “we felt like tourists.” They were dressed in business casual, while their ICU colleagues raced around in scrubs and masks. But the PC team – which includes physicians, nurses, chaplains, and social workers – found ways to integrate themselves. <https://bit.ly/37Cdfj2>

Hospitals should not be able to strip away dying patients’ decisions

NEW JERSEY | NJ.com – 16 June 2020 – During this deadly coronavirus crisis, we should be educating and empowering patients about the importance of end-of-life care (EoLC) planning. Instead, the Centers for Medicare & Medicaid Services (CMS) recently issued a waiver that could strip away EoLC decision-making from dying patients and their loved ones and unilaterally hands it over to hospital administrators, who are overwhelmed with the COVID-19 surge.¹ This waiver has escaped public notice in the tidal wave of news and policy prescriptions about this crisis. Specifically, CMS issued a waiver to the Patient Self-Determination Act requires that hospitals provide information to patients about their policies regarding whether they will honor a patient’s advance directive. This waiver sets a dangerous precedent toward reversing the past three decades of public policy in which patients have been demanding – and receiving – a greater voice in their EoLC, starting with the adoption of the Patient Self Determination Act in 1990. It is also at odds with the administration’s focus on modernizing healthcare, by allowing patients to play a more active role in their medical care, including increased patient access to health information. The harsh reality of COVID-19 is that in some areas of the country there is a shortage of healthcare resources. As a result, hospitals and health systems are developing policies to determine how to allocate resources if they are not available for everybody. The fact that older Americans or people with other life-threatening conditions will unilaterally be denied treatment because there is a scarcity of resources is uncomfortable at best, and unconscionable to most people. <https://bit.ly/2YEEEg1>



1. ‘COVID-19 Emergency Declaration Blanket Waivers & Flexibilities for Healthcare Providers,’ Centers for Medicare & Medicaid Services, June 2020. **Download/view at:** <https://go.cms.gov/30N8l19>

The time is right for a community-based palliative care benefit

HOSPICE NEWS | Online – 15 June 2020 – Stakeholders in the hospice space and beyond have recognized the need for community-based palliative care (PC), delivered in the home, and the time has come for the federal government to do the same. Efforts have been underway among healthcare providers, state governments, advocacy groups and payers, among others, to make community-based PC more accessible to patients and families. These are worthy efforts that hold genuine promise for expanding the availability of palliative services, but by their very nature they will not have the reach and impact of a coordinated, national program established by the U.S. Center for Medicare & Medicaid Services that would be akin to the Medicare Hospice Benefit. Hospices are uniquely positioned to provide this care, evidenced by how many of those providers are already engaged in PC. The Center to Advance Palliative Care reported last year that at least half of the in-home PC providers in the U.S. are hospices.¹ One hindrance to a national program is the lack of a standardized definition for PC. <https://bit.ly/3hvCacn>

1. ‘Mapping community palliative care: A snapshot,’ Center to Advance Palliative Care, New York City, New York, December 2019. [Noted in 23 December 2019 issue of Media Watch (#645, p.3)] **Download/view at:** <http://bit.ly/2tswrzB>

International

Families could be called on for Covid-19 end-of-life care

U.K. | *The Daily Mirror* (London) – 19 June 2020 – Families could soon be on the “frontline.” They may be called on to give drugs to relatives dying in community settings during the pandemic. Ben Bowers and colleagues at Cambridge University outlined their role in this startling new strategy in the *British Medical Journal* [sic].¹ They emphasise caregivers worldwide should be thinking about how drugs can be given when patients are dying from COVID-19 or other conditions at home or in care homes. Quite a lot will have to change to make sure people get adequate end-of-life symptom relief. National Institute for Health & Care Excellence rapid guidance on managing Covid-19 symptoms in the community stresses the importance of prescribing drugs in advance for pain relief, nausea and vomiting, agitation and excess phlegm.² Family caregivers (FCGs) are being approached to consider giving end-of-life drugs when community nurses and doctors aren’t available. FCGs willing to take on this role will be trained and supported with ac-

cess to 24-hour phone advice. Although FCGs commonly do this in rural Australia, it’s rare in the U.K. <https://bit.ly/2YUImSZ>

Specialist Publications

‘Standards of human rights to palliative care: Gaps and trends’ (p.7), in *International Journal of Human Rights in Healthcare*.

‘Spanish and Portuguese societies of internal medicine consensus guideline about best practice in end-of-life care’ (p.11), in *Revista Clínica Española*.

‘First steps: Health and social care professionals beginning to address the palliative and end of life care needs of people with diverse gender identities and sexual orientations in Lebanon’ (p.11), in *Sexualities*.

1. ‘Anticipatory prescribing in community end-of-life care in the U.K. and Ireland during the COVID-19 pandemic: Online survey,’ *BMJ Supportive & Palliative Care*, published online 16 June 2020. **Full text:** <https://bit.ly/2YADDWg>
2. ‘COVID-19 rapid guideline: managing symptoms (including at the end of life) in the community,’ National Institute for Health & Care Excellence, April 2020. [Noted in 27 April 2020 issue of Media Watch (#663, p.6)] **Download/view at:** <https://bit.ly/2RUoKLM>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND | *New Zealand Herald* (Auckland) – 17 June 2020 – ‘**High Court judge says hospices won’t have to provide assisted dying if Kiwis vote for euthanasia.**’ A High Court judge says hospices will not be forced to provide assisted dying services if New Zealanders vote to legalise voluntary euthanasia at this year’s general election. The decision by Justice Jillian Mallon ... also says aspects of the End of Life Choice Act are causing confusion among health providers and Kiwis generally. Hospice New Zealand had asked the court to rule on several questions, including whether organisations can conscientiously object to providing assisted dying, before Kiwis are asked in September to decide on what side of this debate they stand. <https://bit.ly/30SmREI>



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Specialist Publications

Improving care experiences for patients and caregivers at end of life: A systematic review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 19 June 2020 – End-of-life care (EoLC) is increasing as the U.S. population ages. Approaches to providing high-quality EoLC vary across setting, diseases, and populations. Several data collection tools measure patient and/or caregiver care experiences at end of life and can be used for quality improvement. Previous reviews examined palliative care (PC) improvements or available measures but none explicitly on improving care experiences. Articles examined PC experiences across settings; none studied hospice care experiences. Patients and/or caregivers assessed overall care experiences, clinician-staff interactions, provider communication, respect and trust, timeliness of care, spiritual support, caregiver knowledge of care plans, or bereavement support. Efforts aimed at improving EoLC experiences are limited and show mixed results. Research on strategies for improving EoLC experiences should go beyond overall care experiences to include specific aspects of palliative and hospice care experiences. **Abstract (w. list of references):** <https://bit.ly/3hBHNFY>

Facilitators and barriers to general practitioner and general practice nurse participation in end-of-life care: Systematic review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 19 June 2020 – While primary care practitioners have a natural role to play in end-of-life care (EoLC), significant barriers exist to improved general practitioner (GP) and general practice nurse (GPN) involvement in palliative care (PC). More work is required on the role of GPNs. From 6,209 journal articles, sixty-two reviewed papers reported the GP's and GPN's role in EoLC or PC practice. Six themes emerged: 1) Patient factors; 2) Personal GP factors; 3) General practice factors; 4) Relational factors; 5) Co-ordination of care; and, 6) Availability of services. Three specific settings were identified: 1) Aged care facilities; 2) Out-of-hours care; and, 3) Resource-constrained settings (rural, and low-income and middle-income countries). Most GPs provide EoLC to some extent, with greater professional experience leading to increased comfort in performing this form of care. The organisation of primary care at practice, local and national level impose numerous structural barriers that impede more significant involvement. There are potential gaps in service provision where GPNs may provide significant input, but there is a paucity of studies describing GPN routine involvement in EoLC. **Abstract:** <https://bit.ly/2YOCA58>

The roles, responsibilities and practices of healthcare assistants in out-of-hours community palliative care: A systematic scoping review

PALLIATIVE MEDICINE | Online – 15 June 2020 – Access to community palliative care (PC) “out-of-hours” – defined as care provided after the normal hours of work – is advocated globally. Healthcare assistants, who provide care under the direction of a qualified professional, are increasingly employed to help deliver such care, yet there is a little understanding regarding their role, responsibilities or contribution. The authors’ literature search yielded six papers using quantitative, qualitative and mixed methods. Results highlighted a lack of recognition of the role and contribution of healthcare assistants. A concurrent theme was that healthcare assistants continually monitored and responded to patient’s and family’s physical and emotional needs; there was also self-reported evidence indicating patient and family benefit, such as maintaining a sense of normality and support to remain at home. This review highlighted a dearth of evidence relating to the healthcare assistant role in out-of-hours PC. Limited evidence suggests they play a role, but that it is hidden and undervalued. Such invisibility will have a significant impact on the planning and delivery of out-of-hours PC. **Abstract (w. list of references):** <https://bit.ly/2CcHS2V>

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Closing the Gap Between Knowledge & Technology

<http://bit.ly/2DANDFB>

Noted in Media Watch 6 April 2020 (#660, p.10):

- *PULSE* | Online – 30 March 2020 – ‘**End-of-life care during COVID-19: Tips for GPs.**’ The aims of a COVID-19 palliative care plan in primary care are to: 1) Continue to support non-COVID-19 patients at the end of life in the community; 2) Anticipate the discharge of, and provide care to dying patients with COVID-19 in their preferred place of care; 3) Support families and communities who may need enhanced support including bereavement; and, 4) Play a part in supporting local health economies and specialist colleagues and to ensure a safe approach for staff by minimising the risk of infection during home visits when absolutely essential. The key message is: Think ahead – be proactive: create, update, and share more advance care plans for vulnerable patients. **Full text:** <https://bit.ly/3aviPUW>

Noted in Media Watch 3 February 2020 (#651, p.7):

- *FAMILY PRACTICE* | Online – 29 January 2020 – ‘**General practitioners’ provision of end-of-life care and associations with dying at home: A registry-based longitudinal study.**’ 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. **Full text:** <http://bit.ly/2Sdqu90>

N.B. Selected articles on the role of GPs in palliative and EoLC noted in 24 February 2020 issue of Media Watch (#654, p.5).

Increasing advance care planning in the secondary care setting: A quality improvement project

FUTURE HEALTHCARE JOURNAL, 2020;7(2):137-142. This quality improvement project demonstrates a simple and successful strategy for improving advance care planning (ACP) in the hospital setting. The project could be applied to many hospital departments or community settings. If these strategies are employed across primary and secondary care, more patients would be able to express their preferences regarding goals of treatment and so receive individualised care. Suggested next steps include establishing mandatory training in ACP communication skills for all healthcare professionals (HCPs) and training for online systems for communicating information... Through local campaigns, patients should be encouraged to ask HCPs to have these discussions and feel empowered to take control of the remainder of their lives. In summary, the simple interventions used in this project increased ACP within the secondary care setting, embedded it within geriatric ward practice and ensured more patients were provided with the opportunity to have their preferences at the end of life achieved. **Full text:** <https://bit.ly/3dhiYf8>

A scoping research literature review to identify contemporary evidence on the incidence, causes, and impacts of end-of-life intra-family conflict

HEALTH COMMUNICATION | Online – 10 June 2020 – When someone is terminally ill, it is often a very stressful time for the dying person and their family. It would not be unusual for intra-family conflict, involving one or more family members and even the dying person, to occur. However, this type of conflict has not been identified as an end-of-life (EoL) issue needing to be noticed and addressed or prevented when possible. This lack of attention could be because it is not known how common or how impactful this type of conflict is. A scoping research literature review was conducted for available 2004-2019 evidence on the incidence or prevalence of intra-family conflict, factors contributing to it or causing it, and the outcomes or impact of it. A search for published peer-review articles identified 18 research reports for a scoping review. The 18 studies, all conducted in developed countries, revealed intra-family conflict is often present; and with a range of harmful effects for the dying person, the family as a whole or individual family members, and other persons and organizations. The identified factors contributing to or predisposing intra-family conflict were grouped into three categories: 1) Family disagreements over curative treatment and/or EoL care and decisions; 2) Previous family conflict and other family dynamic matters; and, 3) The dying process itself. The evidence identified through this scoping review, although relatively minimal, should be useful for planning future research and for raising awareness of EoL intra-family conflict to improve social services and palliative programs or services. **Abstract:** <https://bit.ly/3hunc6n>

Standards of human rights to palliative care: Gaps and trends

INTERNATIONAL JOURNAL OF HUMAN RIGHTS IN HEALTHCARE | Online – 20 May 2020 – The authors investigated key milestones in the development of standards of human rights to healthcare, in particular in the context of addressing palliative care (PC), relevant efforts of advocacy in the past decade, and future areas of growth. Analysis of human rights and its standards in the context of PC was provided through the lens of freedom from ill treatment and torture, the right to healthcare, and older persons' and children's rights. Findings highlight significant developments in this area, which include the following: 1) First treaty of human rights, which explained the right to PC; 2) First resolution on PC by World Health Assembly; 3) Special rapporteur's report focussed on the denial of pain; and, 4) Addressing the issue of controlled medicine availability in a special session of the United Nations General Assembly. Human rights standards and their development in the context of PC have been most significant in relation to freedom from ill treatment and torture, right to healthcare, and older persons' rights. Further work is required in context of children's rights, and treaty bodies of human rights need to consistently address state obligations towards PC. **Abstract:** <https://bit.ly/2zvchi4>

End-of-life care in schizophrenia: A systematic review

INTERNATIONAL PSYCHOGERIATRICS | Online – 19 June 2020 – Schizophrenia is a severe and persistent mental illness with profound effects on patients, families, and communities. It causes immense suffering on personal, emotional, and socioeconomic levels. Individuals with schizophrenia have poorer health outcomes and die 10-20 years younger than the general population. Economic costs associated with schizophrenia are substantial and comprise 2.5% of healthcare expenditures worldwide. Despite psycho-socioeconomic impacts, individuals with schizophrenia are subject to inequitable care, particularly at end of life (EoL). A systematic review was conducted to examine disparities in EoL care in schizophrenia and identify factors that can be targeted to enhance EoL care in this vulnerable population. The search identified 123 articles; 33 met criteria: 13 case reports, 12 retrospective studies, 5 literature reviews, and 3 prospective studies. Articles were divided into major themes including healthcare disparities, ethics, and palliative care (PC). PC was the most frequent theme comprising >50% of the articles, and there was considerable thematic overlap with ethics and PC. Increased awareness of potential healthcare disparities in this population, creative approaches in multidisciplinary care, and provision of adequate palliative services and resources can enhance EoL care in schizophrenia. **Abstract (w. list of references):** <https://bit.ly/2Cjd3JE>

N.B. Additional articles on palliative and EoL care for people living with schizophrenia noted in 11 November 2019 issue of Media Watch (#639, p.12).

The use of forgiveness facilitation in palliative care: A scoping review

JBI EVIDENCE SYNTHESIS | Online – 8 June 2020 – Spiritual beliefs often include reconciliation and forgiveness, which are critical to patients and families in palliative care (PC). Forgiveness facilitation can represent a valuable response as a multidisciplinary and non-pharmacological intervention to reduce suffering. A total of 23 articles were included in this review. The results suggest a growing interest in forgiveness facilitation in PC in different spiritual and religious traditions. Most studies are based on a psychological perspective. Several activities related to the intervention have been identified, but few details or characteristics are described. Social workers, nurses, doctors, and psychologists were most identified as healthcare staff involved in forgiveness facilitation. The outcomes related to the intervention are mental, physical, and relational well-being; quality of life, decision-making and communication; self-esteem and hope; depression, anger, and anxiety; and, inner peace. Forgiveness facilitation is critical in PC and is grounded in a multidisciplinary approach, but further evidence is needed to inform clinical implementation. These results open new perspectives for research and training on palliative healthcare staff. **Full text (click on pdf icon):** <https://bit.ly/2N4RLBL>

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Noted in Media Watch 12 August 2019 (#626, p.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 August 2019 – ‘**Forgiveness and reconciliation processes in dying patients with cancer.**’ Existing forgiveness models and interventions focus on coping in life, yet no study has examined forgiveness and reconciliation (F/R) processes until death. Three interdisciplinary units at a major Swiss hospital observed 50 dying patients with cancer experiencing severe conflicts with relatives, themselves, and/or with fate/God. Forgiveness and reconciliation processes oscillate between five phases: 1) Denial; 2) Crisis; 3) Experience of hope; 4) Decision; and, 5) Finding F/R. Understanding F/R processes, empathy, hope, and a neutral third party may support patients in seeking forgiveness. **Abstract:** <http://bit.ly/2YMNxSP>

N.B. Additional articles on forgiveness facilitation in PC noted in 23 October 2017 issue of Media Watch (#535, p.10).

Recommendations to leverage the palliative nursing role during COVID-19 and future public health crises

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 5 June 2020 – With the daily number of confirmed COVID-19 cases and associated deaths rising exponentially, social fabrics on a global scale are being worn by panic, uncertainty, fear, and other consequences of the healthcare crisis. Comprising more than half of the global healthcare workforce and the highest proportion of direct patient care time than any other health professional, nurses are at the forefront of this crisis. Throughout the evolving COVID-19 pandemic, palliative nurses will increasingly exercise their expertise in symptom management, ethics, communication, and end-of-life care, among other crucial skills. The literature addressing the palliative care response to COVID-19 has surged, and yet, there is a critical gap regarding the unique contributions of palliative nurses and their essential role in mitigating the sequelae of this crisis. The authors provide recommendations for palliative nurses and other healthcare stakeholders to ensure their optimal value is realized and to promote their well-being and resilience during COVID-19 and, by extension, in anticipation of future public health crises. **Full text (click on pdf icon):** <https://bit.ly/2UHTSja>

Related:

- *CANADIAN FAMILY PHYSICIAN*, 2020;66(6):404-406. ‘**Symptom management and end-of-life care of residents with COVID-19 in long-term care homes.**’ Those living and working in long-term care homes (LTCHs) are at great risk and have considerable needs during the COVID-19 pandemic. The care challenges for residents of LTCHs who test positive for COVID-19 are numerous. They include the need to provide palliative care in place with potentially fewer opportunities for transfer to other facilities. Therefore, a framework that can be used in LTCHs for symptom management including end-of-life care (EoLC) is needed. The authors present such a framework, with considerations for respiratory symptom management and provision of palliative and EoLC in long-term care. **Full text:** <https://bit.ly/2Y0nrym>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 13 June 2020 – ‘**The creation of a psychiatry-palliative care liaison team: Utilizing psychiatrists to extend palliative care delivery and access during the COVID-19 crisis.**’ As the pandemic continues, new epicenters and multiple waves of infection remain possible. With new surges in cases, sudden increases in demand for high acuity palliative care (PC) service threaten to overwhelm existing specialist PC workforce. Collaboration with psychiatry to meet these workforce needs is attractive because psychiatrists are more likely to be available than other potential collaborators like emergency medicine physicians, hospitalists, or intensivists who will be called upon to manage COVID-19 in their respective settings. **Full text:** <https://bit.ly/30Kadrl>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 13 June 2020 – ‘**Proactive identification of palliative care needs among patients with COVID-19 in the ICU.**’ The palliative care (PC) needs of patients with COVID-19 and their families are profound and may not be adequately identified or addressed by traditional consultant referral systems. Given the potentially prolonged duration of the pandemic and the possibility of future patient surges, PC teams should consider implementing a process of proactive screening and outreach to settings in their hospital with high need. If successful, such processes could extend beyond COVID-19, generating a new standard of practice and a small silver lining to the pandemic. **Full text:** <https://bit.ly/2MYyahI>

Lessons learned: Identifying items felt to be critical to leading a pediatric palliative care program in the current era of program development

JOURNAL OF PALLIATIVE MEDICINE | Online – 16 June 2020 – The experience of starting and growing a pediatric palliative care program (PPCP) has changed over the last 10 years as rapid increases of patient volume have amplified challenges related to staffing, funding, standards of practice, team resilience, moral injury, and burnout. These challenges have stretched new directors' leadership skills, yet, guidance in the literature on identifying and managing these challenges is limited. A convenience sample of 15 PPCP directors who assumed their duties within the last 10 years were first asked: "What do you wish you had known before starting or taking over leadership of a PPCP?" Responses were grouped into themes based on similarity of content. Participants ranked these themes based on importance, and an online discussion further elucidated the top ten themes. Thirteen directors responded... Their responses generated 51 distinct items, grouped into 17 themes. Themes ranked as most important included "Learn how to manage, not just lead," "Negotiate everything before you sign anything," and "Balance patient volume with scope of practice." These themes regarding challenges and oppor-

tunities PPCP directors encountered in the current era of program growth can be used as a guide for program development, a self-assessment tool for program directors, a needs-assessment for program leadership, and a blueprint for educational offerings for PPCP directors. **Abstract:** <https://bit.ly/2YPufxV>

Palliative care for young adults with life-limiting conditions: Public health recommendations

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 19 June 2020 – Through a three-phase patient engagement strategy, participants in this study generated 64 recommendations for change and determined that improvements to programming, improvements to funding and creating a continuum of care were their most important priorities. This research demonstrates the unique perspectives and experiences of these young adults and offers recommendations to improve services to enhance their health and well-being. Further, these young adults were integral in the development of recommendations for system changes to match their unique developmental needs. **Full text:** <https://bit.ly/2ClIdaV3>

A randomised Phase II trial testing the acceptability and feasibility of a narrative approach to public health communication to increase community engagement with palliative care

PALLIATIVE MEDICINE | Online – 19 June 2020 – Communities have limited understanding of palliative care (PC), creating barriers to informed choice around consideration of a full range of care options in the event of serious illness. Few empirically tested interventions are available to educate community about PC, and ultimately improve timely access to these services. In this study, a narrative approach to public health communication was found to be acceptable to community members... Exploratory data suggested it immediately improved attitudes towards possible access to PC in the event of serious illness, with the narrative detailing a description of the evidence delivered by a healthcare professional appearing to be the most promising strategy. This study provides preliminary data to inform a future, longitudinal trial evaluating effectiveness and ultimately other evidence-based, public health approaches to improve community engagement with PC. **Abstract (w. list of references):** <https://bit.ly/3fJsgSD>

[Barry R. Ashpole](#)

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://bit.ly/2RPJy9b>



The palliative care needs of adults with intellectual disabilities and their access to palliative care services: A systematic review

PALLIATIVE MEDICINE | Online – 17 June 2020 – This review highlights the specific problems in providing equitable palliative care for adults with intellectual disabilities, but there is a lack of research into strategies to improve practice. This should be prioritised using methods that include people with intellectual disabilities and families. A total of 52 studies were identified, all of which were conducted in high-income countries, the majority in the U.K. From a total of 2,970 participants across all studies, only 1% were people with intellectual disabilities and 1.3% were family members; the majority (97%) were health/social care professionals. Identified needs included physical needs, psychosocial and spiritual needs, and information and communication needs. Barriers and facilitators were associated with education (e.g., staff knowledge, training and experience), communication (e.g., staff skill in assessing and addressing needs of people with communication difficulties), collaboration (e.g., importance of sustained multidisciplinary approach), and, health and social care delivery (e.g., staffing levels, funding and management support). **Abstract (w. list of references):** <https://bit.ly/2CaEISs>

Noted in Media Watch 8 June 2020 (#669, p.8):

- *JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES* | Online – 31 May 2020 – ‘Last months of life of people with intellectual disabilities: A U.K. population-based study of death and dying in intellectual disability community services.’ This study reiterates that the agenda to improve quality of care and experience of people in intellectual disability services must embrace a notion of care “to the end of life.” A failure to do so may ultimately lead only to poor experiences and unnecessary disadvantage at the end of life. Death appears not to be a common event within intellectual disability services but as this population continues to age, and if “ageing in place” becomes increasingly successful, death will only come to have a greater presence. **Full text:** <https://bit.ly/36NZ49S>

N.B. Additional articles on palliative and end-of-life care for patients living with intellectual and developmental disabilities noted in this issue of Media Watch.

Communication and shared decision-making with patients with limited health literacy; helpful strategies, barriers and suggestions for improvement reported by hospital-based palliative care providers

PLOS ONE | Online – 19 June 2020 – This study provides first insights into the experiences of healthcare professionals (HCPs), indicating directions for further research on communication, shared decision-making (SDM) and limited health literacy (LHL) in hospital-based palliative care. HCPs experienced several barriers in effective communication with patients with LHL. As the concept of LHL was unknown to most of the interviewed HCPs, more knowledge and awareness of LHL should be created. Furthermore, HCPs should receive training to recognize LHL, to adjust their communication to LHL-patients, and to facilitate patients to engage in SDM. Hospitals should look into increasing the length of consultations with patients with LHL, and support the development and implementation of new forms of training and existing and new visual educational materials. **Full text:** <https://bit.ly/2Bpcr4Z>

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Prison Hospice: Backgrounder

Updated 06.15.2020

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

Noted in Media Watch 6 March 2017 (#502, p.7):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2016;18(6):544-549. **'The impact of health literacy on palliative care outcomes.'** Limited health literacy is a recognized health problem often leading to poorer health outcomes. Healthcare professionals, including nurses, are responsible for delivering health information in a clear and understandable way. Yet nurses may overestimate patients' health literacy and miss opportunities to help patients understand and then incorporate medical information. Health outcomes may improve when nurses recognize potential barriers to health literacy and use evidence-based interventions. A review of current research regarding health literacy is provided to assist nurses with communication strategies in their delivery of palliative care. **Abstract:** <http://bit.ly/2sG50SP>

Noted in Media Watch 6 February 2017 (#498, p.16):

- *PRACTICAL RADIATION ONCOLOGY* | Online – 27 January 2017 – **'Online palliative care and oncology patient education resources through Google: Do they meet national health literacy recommendations?'** The authors assessed the readability levels of online palliative care (PC) patient education resources using readability algorithms widely accepted in the medical literature. Ten terms were individually searched: PC, hospice, advance directive, cancer pain management, treatment of metastatic disease, treatment of brain metastasis, treatment of bone metastasis, palliative radiation therapy, palliative chemotherapy, and end-of-life care. Most PC education articles readily available on Google are written above national health literacy recommendations. **Abstract:** <http://bit.ly/2QjROkr>

Spanish and Portuguese societies of internal medicine consensus guideline about best practice in end-of-life care

REVISTA CLÍNICA ESPAÑOLA | Online – 11 June 2020 – A steering committee of 12 Spanish and Portuguese experts proposed 37 recommendations. A two rounds Delphi method was performed, with participation of 105 panelists including internists, other clinicians, nurses, patients, lawyers, bioethicists, health managers, politicians and journalists. The authors sent a questionnaire with 5 Likert-type answers for each recommendation. Strong consensus was defined when > 95% answers were completely agree or > 90% were agree or completely agree; and weak consensus when > 90% answers were completely agree or > 80% were agree or completely agree. The panel addressed 7 specific areas for 37 recommendations spanning: identification of patients; knowledge of the disease, values and preferences of the patient; information; patient's needs; support and care; palliative sedation, and, after death care. The panel formulated and provided the rationale for recommendations on good clinical practice rules for caring end-of-life patients. **Abstract:** <https://bit.ly/2MZNeAy>

N.B. Article available in English and Spanish.

First steps: Health and social care professionals beginning to address the palliative and end of life care needs of people with diverse gender identities and sexual orientations in Lebanon

SEXUALITIES | Online – 15 June 2020 – The available evidence demonstrates that lesbian, gay, bisexual, and transgender (LGBT) people face challenges when accessing palliative care (PC) services, and receive suboptimal care at the end of life (EoL). This is mainly attributed to assumed heterosexuality, lack of knowledge and understanding of LGBT issues and specific healthcare needs, discrimination, homophobia, and transphobia. In Lebanon, legal and institutional support for LGBT individuals is minimal, and PC provision remains scarce and fragmented. This compounds the impact of social stigma and marginalisation, and results in unrecognised palliative and EoL care needs for the LGBT individual. This short commentary discusses the development of an LGBT PC workshop in Lebanon, which was the first initiative of its kind in the Middle East and North Africa (MENA) region. It also explores how this initiative has led to further developments, and how these efforts can be replicated in other countries in the MENA region. **Abstract (w. list of references):** <https://bit.ly/3ew4cCV>

N.B. Additional articles on palliative and EoL care for LGBT people noted 2 May 2020 issue of Media Watch (#667, p.4).

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

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

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3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
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.

Search Back Issues of Media Watch @ <http://bit.ly/2ThijkC>

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3cT7i1O>

[Scroll down to 'Media Watch']

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>]

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?']

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

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTP://BIT.LY/300WMRT>

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

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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