

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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The global development of palliative care (PC) is intriguing because it illustrates that PC is flourishing in contexts that markedly differ from the context in which Cicely Saunders began reflecting upon the care needs of terminally ill patients.

'The universality of palliative care philosophy: A case study from India' (p.13), in *Revista Latinoamericana de Bioética*.

U.S.A.

Medicare Advantage beneficiaries disenroll at end of life, driving up costs

HOSPICE NEWS | Online – 30 July 2021 – Medicare Advantage beneficiaries in the last year of life transition to fee-for-service coverage at least twice as often as those who are expected to live longer. Healthcare costs associated with those patients were an estimated \$422 million higher in 2016 than they would have been if they had stayed with their Medicare Advantage plans, according to a new report from the Government Accountability Office (GAO).¹ In 2017, the added costs exceeded \$490 million. GAO analyzed Medicare disenrollment and mortality data for 2015 through 2018 and used claims data to estimate the relative costs between MA and fee-for-service. The agency excluded hospice payments from its comparison. Because payment for hospices almost always goes through the dedicated Medicare benefit, disenrollment wouldn't shift dollars away from MA and into fee-for-service. "MA

plans are prohibited from limiting coverage based on beneficiary health status, and disproportionate disenrollment by MA beneficiaries in the last year of life may indicate potential issues with their care," the GAO indicated in its report. "Stakeholders told GAO that, among other reasons, beneficiaries in the last year of life may disenroll because of potential limitations accessing specialized care under MA." <https://bit.ly/3lgRcY2>

Specialist Publications

'New developments in end-of-life teaching for Roman Catholic healthcare: The implications of *Samaritanus Bonus* ("The Good Samaritan")' (p.3), in *American Journal of Hospice & Palliative Medicine*.

1. 'Medicare Advantage: Beneficiary disenrollments to fee-for-service in last year of life increase Medicare spending,' Government Accountability Office, July 2021. **Download at:** <https://bit.ly/2V7NO71>



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International

Older people felt “cancelled” during COVID-19

IRELAND | Irish Hospice Foundation (Dublin) – 28 July 2021 – Older people have expressed the heightened challenges they faced during COVID-19 and called for a post-pandemic focus on regaining their positive role in society – according to a new hard-hitting review... The review draws together seven leading older persons organisations to capture the experiences of older people during COVID-19, the impact it had on their lives – and what now needs to happen to address this. ‘Telling It Like It Is’ was released by the Alliance of Age, who are working collaboratively to concentrate a shared focus on progressing policy, services and resources with older people. This is the Alliance’s first publication and is an unfiltered account of older people’s lived experiences during COVID-19, as told in conversations, surveys and focus groups involving thousands of older people across the country. The analysis explains

how many of the events that happened during the COVID-19 crisis affected older people disproportionately. **Download Alliance of Age review at:** <https://bit.ly/3i93M9x>

Dying, death and bereavement

COVID-19 raised issues about where it’s safe to live and die, the quality of end-of-life (EoL) care, human dignity in dying and how best to support grief. Fear of dying and death fuelled the stresses older people experienced during the pandemic, particularly deep concern that their wishes, choices and beliefs would not be respected and that they would die alone. Those who lost loved ones experienced a largely hidden anguish of not knowing how a loved one died, whether their EoL wishes were honoured and their dying dignified.

Hospices in England face a huge struggle to match National Health Service pay

U.K. (England) | politics.comm.uk – 26 July 2021 – Throughout the pandemic, the hospice and end-of-life (EoL) sector has stepped up to the mark to support the National Health Service (NHS) with vital care as the numbers of occupied beds in ICUs up-and-down the country increased dramatically. As people stayed at home, fearing exposure to the virus, the number of excess deaths at home also rose. Nurses and practitioners from hospices were there to deliver critical support, from supporting people at the EoL in their own homes with pain relief and symptom control, to providing emotional and bereavement support to families and loved ones. We’ve seen the hospice sector play a vital role in the country’s response alongside the NHS... Yet, as the government announced they are to give NHS workers in England a 3% pay increase, it was apparent that hospices had been forgotten by those in Westminster. Charitably-funded hospices in England now face a huge struggle to match the NHS pay increase as they compete to recruit and retain the same staff. Right now, this salary top up – which could be as much as £25 million per

year – will need to be met by selling second hand clothes, and by generous people running marathons and selling cakes. This wouldn’t happen in maternity services when people are brought into the world, so why should it happen when people die? <https://bit.ly/3f0sGX6>

Specialist Publications

‘Inequities of palliative care availability and access to opioids in low- and middle-income countries’ (p.12), in *Palliative Medicine*.

‘Experiences, challenges and perspectives for ensuring end-of-life patient care: A national online survey with general practitioners in Germany’ (p.12), in *Plos One*.

‘Heidi’s legacy: Community palliative care at work in regional Australia’ (p.13), in *Social Work in Health Care*.

Specialist Publications

New developments in end-of-life teaching for Roman Catholic healthcare: The implications of *Samaritanus Bonus* (“The Good Samaritan”)

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 29 July 2021 – The Vatican’s chief doctrinal body, the Congregation for the Doctrine of the Faith, recently released *Samaritanus Bonus* (“The Good Samaritan”), a letter focused on ethical obligations surrounding the care of patients who are critically ill or nearing the end of life (EoL). Historically, similar documents have had significant implications insofar as all Catholic healthcare institutions, including those within the U.S., are bound to provide services in accordance with Catholic teaching. Furthermore, Catholic healthcare has widespread institutional influence by virtue of the high market-share in over a third of U.S. counties. Analogous to the influence of Catholic healthcare over access to reproductive healthcare, binding doctrinal state-

ments such as this have the potential to significantly impact treatment decisions for patients approaching EoL. A complete review of the letter is beyond the scope of this article; rather, the authors highlight two key areas which may contribute to increased conflict between Catholic healthcare and secular society. **First page view (w. references):** <https://bit.ly/3ib3m2B>

Publishing Matters

‘Using updated PubMed: New features and functions to enhance literature searches’ (p.14), in *Journal of the American Medical Association*.

N.B. Additional articles on Catholic perspectives on EoL care noted in Media Watch 7 September 2020 (#682, p.2).

Primary-level palliative care national capacity: Pallium Canada

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 27 July 2021 – Pallium Canada provides a case study on developing primary-level palliative care (PC) at a national level. It has developed infrastructure, processes, products, strategies and tools to advance the PC approach across different care settings, professions and communities. It has also championed interprofessional learning and the development of compassionate communities across Canada. The work to date, while impactful at local and some provincial levels, still requires considerable spread and scale-up efforts if primary-level PC is to be fully integrated in the healthcare system. Education, while necessary, is alone insufficient. Multipronged approaches that combine education of healthcare professionals and the community, with other strategies such as policies, processes, funding and resources, are required. Linking education with quality improvement approaches holds potential. **Full text:** <https://bit.ly/3BSzWOK>

Related:

- *PROCEEDINGS OF THE INTERNATIONAL SYMPOSIUM ON HUMAN FACTORS & ERGONOMICS IN HEALTH CARE*, 2021;10(1):324-330. ‘**Can we use design approaches to increase comfort and reduce suffering at end of life: A focused literature review.**’ End-of-life (EoL) care is often a difficult period for all involved: the person who is dying, their family and friends, and care providers. A review and analysis of the literature on design for EoL care led to identifying common themes that may influence EoL experience, design categories which aim to support EoL care, and continuing challenges that may undermine EoL experience. An additional review researched impacts of the COVID-19 pandemic on EoL experiences. Results of both reviews are presented... **Abstract (w. references):** <https://bit.ly/3iWXNDU>

How to talk with the family of a dying patient: Anger to understanding, rage to compassion, loss to acceptance

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 26 July 2021 – Informing families about the impending or actual death of their relatives is one of the most challenging and complex tasks a physician may face. This article describes goal-setting and provides five roles/recommendations for conducting the encounter with patient families regarding the imminent or actual death of their relatives. Importantly, the encounter should be family-centred, and the physician should be highly attentive to family needs. The following roles should be applied based on family needs and should not be sequential as numbered. The first and basic role is to inform the family at the earliest possible time and as often as possible. The second goal of the physician is to convey to the family that their relative received the needed therapy during his hospitalisation or in the community. The third goal is to help the family reach acceptance of the death of their relative and leave the hospital having moved beyond anger and bargaining. The fourth goal of the physician during the encounters is to reduce or alleviate guilt by stating that nothing could have changed the course of the disease and that all efforts were made to save the patient. The fifth role is to try and help the family as a single entity and maintain their unity during this stressful situation. **Full text:** <https://bit.ly/3xgyRN7>

Related:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 26 July 2021 – ‘**Healthcare interpreters and difficult conversations: A survey.**’ The aims of this survey were to assess the impacts of difficult conversations such as discussions involving explanation of a serious diagnosis, goals-of-care or death or dying and to discover interpreters’ opinions on ways to improve these conversations. Interpreters surveyed were not experiencing burn-out or secondary traumatic stress and had moderate or high compassion satisfaction scores. Recommended is further training and evidence-based guidelines for medical staff and healthcare interpreters in the facilitation of difficult conversations and pre-briefing and debriefing for interpreters. **Abstract:** <https://bit.ly/3BLrCjp>

N.B. Search back issues of Media Watch for additional articles on “interpreters” in the context of end-of-life care at: <http://bit.ly/2ThijkC>

Status, demand and practice models of palliative day-care clinics and day hospices: A scoping review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 26 July 2021 – Past research suggests that patients highly value palliative and hospice day-care for a variety of reasons. While few (or no) guidelines or recommendations have been reported in the literature, palliative day-care clinics and day hospices have nonetheless found ways to provide care to patients to the best of their abilities. Future studies should aim at identifying and applying tools to more fully analyse the extent of care and outcomes within palliative and hospice day-care services for patients with severe illnesses. Furthermore, research should seek to identify patients with the most to gain from palliative and hospice day-care, including those who have been under-represented within both research and practice. It will be necessary to uncover why these groups have been under-represented, to consider their experiences and to explore how palliative and hospice day-care could benefit a wider range of patient groups. Finally, adaptation of admission criteria would help to ensure that care is provided to the patients who are likely to benefit the most. **Full text:** <https://bit.ly/3y64qtX>

Noted in Media Watch 18 January 2021 (700, p.6):

- *BMC PALLIATIVE CARE* | Online – 12 January 2021 – ‘**Challenges for palliative care day services: A focus group study.**’ Palliative care (PC) day services reflect the holistic nature of PC in aiming to improve the quality of life of patients and their family caregivers complementing mainstream PC.¹ The challenge is to recognise needs that may be addressed via day-services and then to refer patients immediately and integrate day-services into care plans early, even alongside other models of curative intent or life-prolonging treatment. The lack of standardisation has resulted in variations in function, delivery, model of care and staffing. Research indicates a lack of consensus on the model and variable outcome measures makes replication or application to specific patient groups challenging. **Full text:** <http://bit.ly/38CMuNt>

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1. 'The strengths and challenges of palliative day-care centers: Qualitative study with the professionals involved,' *Journal of Palliative Care*, published online 3 October 2017. [Noted in Media Watch 9 October 2017 (#533, p.13)] **Abstract (w. references):** <http://bit.ly/3nxldis>

Anxiety during the COVID-19 pandemic in hospital staff: Systematic review plus meta-analysis

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 26 July 2021 – This study is an up-to-date systematic review and meta-analysis reporting the anxiety prevalence and the impact of various contributing factors among hospital staff with a view of identifying possible interventions to address the complications of this disorder. There were 46 articles included, and to the best of the authors' knowledge, this is the first study examining anxiety prevalence in different job groups of hospital staff working in different geographical locations. Results revealed that the overall estimated prevalence of anxiety among hospital staff in this review was 26.1%... The difference might be due to the variability of sample size, data collection and analysis techniques. Another possible reason might be variation in infrastructure provided by different healthcare systems resulting in different levels of focus on mental well-being and psychological support of healthcare workers (HCWs). Despite some differences in the value of anxiety prevalence reported in the literature, it is clear that a great number of HCWs worldwide suffer from moderate symptoms of anxiety. The literature has proved that the COVID-19 pandemic has caused serious mental, physical and emotional problems among hospital staff who are at a higher risk of contracting the infection or even passing on the disease to others. **Full text:** <https://bit.ly/3ibfLDP>

Palliative care is increasing, but curative care is growing even faster in the last months of life

BRITISH JOURNAL OF GENERAL PRACTICE | Online – 15 July 2021 – The introduction of early palliative care (PC) might be hoped to moderate the medicalisation of dying and the increasingly frequent medical and surgical treatment that patients generally receive in the last months of life. Indeed the old concept of an abrupt change from curative to PC when a person is terminally ill and imminently dying is giving way gradually to the better concept of a phased introduction of PC from diagnosis of a life-threatening illness... By 2018, general practitioners in Scotland recognised 69% of their patients for a PC approach by the time they died, calling it "anticipatory care." This "primary PC" was associated with more frequent care planning, more patients dying in their place of choice and less hospital admissions. However while integrated PC delivery is gradually increasing throughout the last year of life, disease modifying and potentially curative care and unplanned care is not decreasing. It is instead increasing greatly especially in the last three months of life. **Full text:** <https://bit.ly/3f84zG6>

An exploratory investigation into the roles of critical care response teams in end-of-life care

CRITICAL CARE RESEARCH & PRACTICE | Online – 23 July 2021 – The results from this study describe for the first time the perspectives of critical care response team (CCRT) members on their role in providing quality end-of-life care (EoLC) in two large Canadian university hospitals. CCRTs integrate experience from all team members and use this collective wisdom to act as a consultative resource to other members of a patient's circle-of-care. CCRTs provide a unique expertise in evaluating the utility of intensive care treatments; however, team members at times struggle to integrate their expertise into the advance care planning (ACP) system of the hospital, leading to duplication, role confusion, and discontinuity. Since the data collection period for this study, no institutional changes to the CCRT base model or EoLC processes have been implemented. The authors' data highlight the potential for enhancement of overall hospital practice and protocols for ACP, documentation, and transitions to palliative medicine service, which would serve to complement the role of CCRT. Future studies could build on these findings by surveying members across various regions and specialties to determine differences in perspectives between providers and organizations. **Full text:** <https://bit.ly/3i4LuGw>



Palliative Care Network

Palliative Care for Everyone, Everywhere

Closing the Gap Between
Knowledge & Technology
<http://bit.ly/2DANDFB>

Prescribing practices, patterns, and potential harms in patients receiving palliative care: A systematic scoping review

EXPLORATORY RESEARCH IN CLINICAL & SOCIAL PHARMACY | Online – 23 July 2021 – This scoping review provides a broad overview of observational studies examining prescribing in palliative care (PC). The review shows that many patients with PC needs receive considerable numbers of medications, including preventative medications that may provide limited or no therapeutic benefit closer to death. A limited number of studies examined the appropriateness of prescribing or the potential for harm. Future research should look to include assessments of prescribing appropriateness using tools that have been developed specifically to guide prescribing in PC. This should also include assessments of the appropriateness of medications to relieve common symptoms experienced by PC populations towards the end of life. **Full text:** <https://bit.ly/2UYnmfQ>

“No place like home?”: A qualitative study of the experience of sense of place among cancer patients near the end of life

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 29 July 2021 – Only a few studies have examined the end-of-life (EoL) experience in the context of the place of living and receiving care. Sense of place consists of emotional bonds, values, meaning, and symbols attached to a place. This study aimed to explore the experience of a sense of place among individuals at the EoL receiving care at home via home-hospice or in a hospital. Three main themes emerged: 1) “This is me stuck inside my body” – the sick body and the body as a place, focused on the experience of estrangement with and disappointment from the body; 2) “In fantasy, everyone wants to be at home and die at home, but life isn't a fantasy” – the sense of home versus the hospital, focused on the sense of place towards home and hospital; and, 3) “I don't want to meet anyone or to be anywhere” – a lack of sense of place, focused on detachment from physical and social environments and loss of sense of place. The findings demonstrate the complexity of relations with the body as the centre of experience and with the care setting. In conclusion, professional awareness of experiences of sense of place is most relevant to psychosocial interventions with patients near the EoL and their families. Interventions focused on improving patients' sense of place should be developed to increase their peace and quality of life and death. Educating families about the various experiences related to the sense of place may foster better understanding and empathy for the person at the EoL and allow a more positive experience of separation and bereavement after death. **Abstract:** <https://bit.ly/3i8YuLk>

Early palliative care consultation in the burn unit: A quality improvement initiative to increase utilization

JOURNAL OF BURN CARE & RESEARCH | Online – 24 July 2021 – Despite significant morbidity and mortality for major burns, palliative care consultation (PCC) is underutilized in this population. The purpose of this study is to examine the impact of a protocol using recommended “triggers” for PCC at a single academic burn center. This is a retrospective review of patient deaths over a four-year period. Use of life-sustaining treatments, comfort care (de-escalation of one or more life-sustaining treatments) and do not attempt resuscitation orders were determined. Use of PCC was compared during periods before and after a protocol establishing recommended triggers for early PCC was instituted in 2019. A total of 33 patient deaths were reviewed. Many patients had life-sustaining interventions such as intubation, dialysis, or cardiopulmonary resuscitation, often prior to admission. The authors found that while there was increasing use of PCC overall after developing a protocol of recommended triggers for consultation, many patients who met criteria at admission did not receive early PCC. Further research is needed to elucidate reasons why providers may be resistant to PCC. **Abstract:** <https://bit.ly/3iOVUcz>

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Would the *Journal of Burn Care & Research* be of interest to a colleague?

Noted in Media Watch 2 December 2019 (#642, p.9):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 13 November 2019 – ‘**The role of palliative care in burns: A scoping review.**’ Palliative care is used synonymously with comfort and end-of-life care in burns literature. Comfort care (CC) is mostly initiated when active treatment is withheld (early deaths) or withdrawn (late deaths), limiting its overall benefits to burn patients, their families and healthcare professionals. Futility decisions are usually complex and challenging, particularly for patients in the late death category and it is unclear if these decisions result in timely commencement of CC measures. Two CC pathways were identified but it remained unclear how these pathways evaluated “good death” or supported the family... **Abstract (w. references):** <http://bit.ly/351C0aO>
- *PALLIATIVE MEDICINE* | Online – 12 July 2019 – ‘**Do patients, families, and healthcare teams benefit from the integration of palliative care in burn intensive care units? Results from a systematic review with narrative synthesis.**’ Findings suggest that there may be benefits from integrating palliative care (PC) in burn units, specifically in terms of patients’ comfort, decision-making processes, and family care. Multidisciplinary teams may experience lower levels of burden as result of integrating PC in burn units. This review reflects the challenging setting of burn intensive care units. Evidence from these articles suggests that the integration of PC in burn intensive care units improves patients’ comfort, decision-making process, and family care. **Abstract (w. references):** <http://bit.ly/35L38Gu>

The interface of emergency and palliative care

JOURNAL OF GERIATRIC EMERGENCY MEDICINE, 2021;2(4). The SARS-CoV-2 pandemic has taught emergency medicine providers that palliative care (PC) and goals-of-care discussions should be at the forefront of most critically ill emergency department (ED) patient presentations. The authors summarize three articles that discuss the interfacing of palliative and emergency medicine.^{1,2,3} As discussed in this article, randomized studies have demonstrated that integration of PC into the ED increases the frequency of PC consults and improves a patient’s self-reported quality of life. **Full text:** <https://bit.ly/3rFqHwj>

1. ‘Prognosis after emergency department intubation to inform shared decision-making,’ *Journal of the American Geriatric Society*, 2018;66(7):1377-1381. **Abstract:** <https://bit.ly/3iQpbn9>
2. ‘Palliative care in the emergency department: A survey assessment of patient and provider perspective,’ *Palliative Medicine*, 2020;34(9):1279-1285. **Abstract (w. references):** <https://bit.ly/3l6sj0K>
3. ‘Emergency department admission triggers for palliative consultation may decrease length of stay and cost,’ *Journal of Palliative Medicine*, 2021;24(4):554-560. **Abstract:** <https://bit.ly/3iRUZrS>

Noted in Media Watch 12 July 2021 (#725, p.10):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 8 July 2021 – ‘**Palliative care in the emergency department: A qualitative study exploring barriers, facilitators, desired clinician qualities, and future directions.**’ Palliative care (PC) providers perceived as successful in their work in the emergency department (ED) were described as autonomous, competent, flexible, fast, and fluent in ED language and culture. Barriers included the ED environment, lack of access to PC providers at all times, the ED perception of PC, and the lack of a supporting financial model. Facilitators to ED-PC integration included proactive identification of patients who would benefit from PC, ED-focused PC education and tools, PC presence in the ED, and data supporting ED-PC. **Abstract (w. references):** <https://bit.ly/3e1f0KJ>

Noted in Media Watch 7 June 2021 (#720, p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 1 June 2021 – ‘**Increasing awareness of palliative medicine with the emergency department: A quality improvement project.**’ This article highlights a quality improvement project initiated to address knowledge gaps in palliative medicine (PM) with emergency department (ED) staff... The PM staff held an in-service training with the ED staff which focused on defining PM and the importance of early consults when the patient presents in the ED. PM staff also highlighted the differences between PM and hospice care, when and how to initiate a consult for PM, as well as how to contact the PM division. After this educational intervention PM consults increased three-fold. **Abstract (w. references):** <https://bit.ly/3ySPf8e>

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Noted in Media Watch 15 March 2021 (#708, p.8):

- *JOURNAL OF THE AMERICAN COLLEGE OF EMERGENCY PHYSICIANS* | Online – 2 March 2021 – ‘**Understanding patients’ end-of-life goals of care in the emergency department.**’ The emergency department (ED) may be the first and only time a patient has an opportunity to discuss their goals-of-care (GoC) with a physician. A recent review article highlights the current lack of literature on GoC discussions in EDs and emphasizes that more research is needed on all aspects related to GoC in EDs, including conversation content and impact on patients and their families.¹ Improving EoLC in the ED is considered a top research priority in the field of emergency medicine and work to improve GoC discussions with patients will be important to achieving this goal.² **Full text:** <https://bit.ly/3c7PPo0>
 1. ‘Goals-of-care discussions for adult patients nearing end of life in emergency departments: A systematic review,’ *Emergency Medicine Australasia*, published online 1 May 2019. [Noted in Media Watch 6 May 2019 (#613, p.7)] **Abstract:** <http://bit.ly/2vwqFdR>
 2. ‘An emergency medicine research priority setting partnership to establish the top 10 research priorities in emergency medicine,’ *Emergency Medicine Journal*, 2017;34(7):454-456. **Full text:** <http://bit.ly/3enyWbK>

Being a bereavement-conscious hospice and palliative care clinician

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2021;23(4):293-295. Quality bereavement care begins before the death of a patient. Because family members so often struggle with distress surrounding the patients end-of-life (EoL) experience, palliative and hospice nurses can be intentional with patient care in a way that minimizes the potential for regret, guilt, and rumination about the patient’s suffering. That is, nurses can play a critical role in the provision of *bereavement-conscious patient care*. This includes, for example, provision of education about the death process and reassurances about how the patient’s suffering is being addressed. It also includes engaging family in EoL conversations that help them prepare for the possibility of loss and joining in with them in decision-making. Investigations designed to improve advance care planning ... can be construed as bereavement care studies. Another example of bereavement-conscious patient care would be the careful timing of a terminal extubation, so that the medical team can be at the bedside to honor the patient and so the family can say goodbye and be present for the patient’s death. **First page view:** <https://bit.ly/2VbaGCn>

Related:

- *DEATH STUDIES* | Online – 24 July 2021 – ‘**Counselor preparedness to counsel grieving clients: Insights and implications.**’ Research suggests that counselors are not receiving adequate training in grief counseling. Eleven counselors shared their training and experiences counseling clients grieving a death-related loss. Five themes emerged: 1) Personal dynamics of the counselor; 2) Missing preparation and desired training; 3) Perceived counselor responsibilities; 4) The client-counselor relationship; and, 5) Revolving systemic factors – were identified to capture the experiences influencing their perceived preparedness for counseling this population. The findings highlight the need to infuse grief and loss into course curricula and supervision to promote foundational understanding. **Abstract:** <https://bit.ly/3zAOgtc>

A review of web-based COVID-19 resources for palliative care clinicians, patients, and their caregivers

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2021;23(4):316-322. Palliative and end-of-life care has been pushed to the forefront of medical care during the pandemic caused by ... COVID-19. Palliative care (PC) organizations have responded to the growing demand for the rapid dissemination of research, clinical guidance, and instructions for care to clinicians, patients with COVID-19, and their caregivers by creating COVID-19 resource Web pages. Here, end users can access resources that can be updated in real time. These Web pages, however, can be variable in what resources they offer and for whom they are designed for (e.g., clinicians, patients, caregivers). Therefore, this project was conducted to consolidate these resources via summary tables of specific contents available through each Web page grouped by PC domains (e.g., care discussion and planning, communication, symptom management, care access) and to

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identify the target audience. This environmental scan was conducted by compiling a comprehensive list of COVID-19 resource Web pages of PC organizations generated by reviewing previously published research studies and consulting with PC research experts. Snowballing techniques were used to identify resource Web pages not captured in the initial scan. Among the eligible resource Web pages, most ... had specific target audiences and care settings, whereas the rest presented information targeted to all audiences. Although 11 Web pages offered resources that addressed all 4 domains, only one Web page conveyed all 12 sub-domains. **Abstract:** <https://bit.ly/3l4Z2Ua>

Optimizing the global nursing workforce to ensure universal palliative care access and alleviate serious health-related suffering worldwide

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 28 July 2021 – Palliative care (PC) access is fundamental to the highest attainable standard of health and a core component of universal health coverage. Forging universal PC access is insurmountable without strategically optimizing the nursing workforce and integrating palliative nursing into health systems at all levels. The COVID-19 pandemic has underscored both the critical need for accessible PC to alleviate serious health-related suffering and the key role of nurses to achieve this goal. Nurses working across settings provide a considerable untapped resource that can be leveraged to advance PC access and PC program development. Best practice models demonstrate promising approaches and outcomes related to education and training, policy and advocacy, and academic-practice partnerships. An estimated 28 million nurses account for 59% of the international healthcare workforce and deliver up to 90% of primary health services. It has been well-documented that nurses are

often the first or only healthcare provider available in many parts of the world. Strategic investments in international and interdisciplinary collaboration, as well as policy changes and the safe expansion of high-quality nursing care, can optimize the efforts of the global nursing workforce to mitigate serious health-related suffering. **Abstract (w. references):** <https://bit.ly/3x999d7>

Extract from *Journal of Pain & Symptom Management* article

Achieving universal PC access is a global social justice priority. Nurses are critical to strategically realizing this vision. Health system leaders, interdisciplinary partners, and policy makers must support nurses to practice to the full extent of their education and licensure to provide high-quality PC services for populations worldwide.

Evaluation of the caring ahead: Preparing for end of life with dementia questionnaire

JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE | Online – 21 July 2021 – Family caregivers (FCGs) of persons with dementia rarely feel prepared for end of life (EoL) although preparedness predicts outcomes in bereavement. The 'Caring Ahead: Preparing for End-of-Life With Dementia' questionnaire was developed to measure family caregiver death preparedness. The aim of this study was to evaluate questionnaire psychometrics and refine the 'Caring Ahead...' questionnaire. Data were collected by mail from 134 English-speaking FCGs of persons with dementia recruited from more than 50 congregate living facilities in Canada. Thirty-two participants completed a test-retest. A 4-factor model with 20 items emerged through exploratory factor analysis with principal factors extraction and promax rotation. The revised questionnaire includes 4 factor subscales: 1) Actions (7 items); 2) Dementia knowledge (5 items); 3) Communication (4 items); and, 4) Emotions and support needs (4 items). Lower levels of preparedness were reported for "knowing what the dying process with dementia may be like" and "discussing EoL care and preferences with healthcare providers." Preliminary evidence for validity and reliability of the refined 20-item Caring Ahead questionnaire suggests the questionnaire may be useful to clinicians and researchers seeking to assess caregivers' feelings of preparedness, identify specific areas for intervention, and evaluate the effectiveness of caregiver interventions. **Abstract (w. references):** <https://bit.ly/3zAMb0m>

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Related:

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 31 July 2021 – ‘**Quality indicators for dementia and older people nearing the end of life: A systematic review.**’ The authors provide a shortlist of 71 quality indicators (Qis) for older people and people with dementia nearing the end of life that are robust, which can be applicable across care settings and measurable using routinely collected electronic datasets and applied across care settings. Future research should focus on testing and developing psychometric rigor of existing QIs and implementation of robust QIs into practice, to guide understanding of quality of care provided to these populations, to identify unmet needs, and to improve service provision. **Full text:** <https://bit.ly/3xftHRn>

N.B. Search back issues of Media Watch for additional articles on EoL care for people living with “dementia” at: <http://bit.ly/2ThijkC>

“When I heard the word palliative”: Obscuring and clarifying factors affecting the stigma around palliative care referral in oncology

JCO ONCOLOGY PRACTICE | Online – 26 July 2021 – Palliative care (PC) can help patients with cancer manage symptoms and achieve a greater quality of life. However, there are many barriers to patients with cancer receiving referrals to PC, including the stigmatizing association of PC with end of life (EoL). This study explores factors that obscure or clarify the stigma around PC referrals and its associations with EoL in cancer care. Interviews with 44 participants revealed both obscuring and clarifying factors surrounding the association of PC as EoL. Prognostic uncertainty, confusion about PC’s role, and social network influence all perpetuated an inaccurate and stigmatizing association of PC with EoL. Contrarily, familiarity with PC, prognostic confidence, and clear referral communication helped delineate PC as distinct from EoL. To reduce the stigmatizing association of PC with EoL, referring clinicians should clearly communicate prognosis, PC’s role, and the reason for referral within the context of each patient and his or her unique cancer trajectory. The oncology team plays a vital role in framing the messaging surrounding referrals to PC. **Abstract:** <https://bit.ly/3y8Rfsp>

Related:

- *JCO ONCOLOGY PRACTICE* | Online – 29 July 2021 – “‘**I’m being forced to make decisions I have never had to make before**’”: **Oncologists’ experiences of caring for seriously ill persons with poor prognoses and the dilemmas created by COVID-19.**’ This study offers an in-depth exploration of the problems faced by oncologists as a result of the COVID-19 pandemic and how they navigated them. Optimal decision-making for seriously ill persons with cancer during the COVID-19 pandemic must include open acknowledgment of the ethical challenges involved, the emotions experienced by both patients and their oncologists, and the urgent need to integrate technology with compassionate communication in determining patient preferences. **Full text:** <https://bit.ly/3BWHdMmP>



[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>



Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.15.

Parental death during adolescence: A review of the literature

OMEGA – JOURNAL OF DEATH & DYING | Online – 29 July 2021 – While extensive research exists on parental loss in childhood and the related psychological interventions, little has been done in the adolescent population. Adolescence is a particular phase of life characterized by a singular psychological, emotional, neurological, and endocrinological development, paralleled by the process of self-affirmation and an opening toward social relationships. This complex neuropsychological phase should thus be understood independently from children and adults. The objective of this work was to review the literature studying the impacts of parental loss in adolescents. The current review identified a wide range of behavioral and emotional responses to parental death in adolescence, including depression, suicidal ideations, anxiety, insomnia, addiction and impaired function at school and home. The role of peers, school life, and family and social environment are important for the recovery from loss. More studies are required to better understand the different psychological trajectories in adolescence after parental death and tailor mental health interventions accordingly. **Full text:** <https://bit.ly/37bPIGe>

Young adults understanding and readiness to engage with palliative care: Extending the reach of palliative care through a public health approach: A qualitative study

BMC PALLIATIVE CARE | Online – 28 July 2021 – This study is the first study to explore in-depth how young adults perceive palliative care (PC) and identify what factors affect their understanding and engagement. Influenced by a prevalent culture that placed PC out of their reach and relevance unless directly affected, young adults in this study had a limited understanding of PC. They related what they had seen, heard and experienced in their families, community and on study placement which revealed a much narrower scope of PC than advocated in global policy and academia. The family as the context of experiences was significant in participant accounts, dictating the level of understanding and potential for engagement. At the intrapersonal and interpersonal levels, the study findings have the potential to inform the practice of PC, highlighting how experiences, especially within families, impact young adults' understanding of PC. **Full text:** <https://bit.ly/3ln7T47>

N.B. See literature review at 'The Crossroads of Grief: Understanding Grief & Diversity,' published by the Children & Youth Grief Network, Ontario Canada.' In particular, 'Children's Understanding of Death & Dying' (p.5), 'Parental Illness, Dying & Death' (p.13), and 'Death of a Parent (p.30) at: <http://bit.ly/2OB4Y6C>

Impact of the COVID-19 pandemic on end-of-life care delivery in care homes: A mixed method systematic review

PALLIATIVE MEDICINE | Online – 30 July 2021 – This review has provided the first comprehensive overview of the impact of the COVID-19 pandemic on end-of-life (EoL) care delivery in care homes. From analysis of the literature, four themes were identified: 1) The importance of advance care planning (ACP); 2) Increased responsibilities and expectations; 3) Emotional trauma and fear; and. 4) Professional pride and resilience. The results presented in this review highlight the significant challenges as well as the opportunities which have emerged during the pandemic. Thus, the review provides a valuable collation of current evidence to inform immediate and future policy, practice and research. Challenges with ACP are not new. Research has long highlighted that engagement in ACP has not been consistent across the care home sector. Nor is the problem confined to care homes, having also been identified in the acute care sector. The effect of the pandemic has been to exacerbate an already existing problem in the EoL care of people who reside in care homes. The problem is significant because it has been established that ACP can improve care quality, reduce unnecessary admissions to hospital at the EoL, and lower stress and anxiety for all involved. **Full text:** <https://bit.ly/3fbb6zA>



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

Related:

- *BMC PALLIATIVE CARE* | Online – 28 July 2021 – ‘Using a self-directed workbook to support advance care planning with long term care home residents.’ The findings of this study suggest that self-directed advance care planning workbooks can elicit long-term care residents’ reflections on a range of care preferences important to end-of-life (EoL) planning. This study’s workbook encouraged reflections on preferred decisional-roles, treatment directions, familial/friend involvement, post-mortem planning, interpersonal communication, and spiritual preferences. The authors findings further suggest that if clarified and communicated, workbook reflections may inform the provision of EoL care that is aligned with residents’ values and preferences. **Full text:** <https://bit.ly/3xdRhha>

Inequities of palliative care availability and access to opioids in low- and middle-income countries

PALLIATIVE MEDICINE | Online – 26 July 2021 – In 2021, palliative care (PC) provision for people living in low- and middle-income countries remains woefully inadequate; and the number of people who will die with unnecessary suffering is projected to increase significantly in coming decades. Gross inequities in access to opioids and PC availability exist throughout the world. A secondary analysis of PC provision across Europe highlights inequities between high-income countries and low- and middle-income countries.¹ High-income countries and those within Western Europe achieved major increases in home-based, inpatient and hospital support PC between 2005 and 2019; while low- and middle-income countries across the region showed little increase in specialised PC provision.¹ These inequities are also underscored in a survey of PC service development for non-communicable diseases across World Health Organisation Member States.² The survey revealed large disparities across country income levels for PC funding and integration in primary and community care; a mere 4% of low-income countries and 13% of lower middle-income countries have home-based or community PC services, compared to 70% of high-income countries. **Full text:** <https://bit.ly/3rCSY6D>



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1. ‘Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years,’ *Palliative Medicine*, published online 10 June 2020. [Noted in Media Watch 15 June 2020 (#670, p.11)] **Full text:** <https://bit.ly/2UwwuFd>
2. ‘National palliative care capacities around the world: Results from the World Health Organization Non-communicable Disease Country Capacity Survey,’ *Palliative Medicine*, published online 10 July 2017. [Noted in Media Watch 10 July 2017 (#520, p.15)] **Abstract (w. references):** <https://bit.ly/3cnVbv3>

Experiences, challenges and perspectives for ensuring end-of-life patient care: A national online survey with general practitioners in Germany

PLOS ONE | Online – 27 July 2021 – The COVID-19 pandemic is posing major challenges for healthcare systems. In Germany, one such challenge has been that adequate palliative care (PC) for the severely ill and dying (with and without COVID-19), as well as their loved ones, has not been available at all times and in all settings. The pandemic has underlined the significance of the contribution of general practitioners (GPs) to the care of severely ill and dying patients. 410 GPs responded to an online survey: 61.5% indicated that the quality of their patients’ end-of-life care (EoLC) was maintained throughout the pandemic; 36.8% reported a decrease in quality compared to pre-pandemic times. Of the GPs who made home visits to severely ill and dying patients, 61.4% reported a stable number of visits, 28.5% reported fewer visits. 62.7% of the GPs reported increased telephone contact and reduced personal contact with patients; 36.1% offered video consultations in lieu of face-to-face contact. The GPs reported that relatives were restricted (48.5%) or prohibited from visiting (33.4%) patients in nursing homes. They observed a fear of loneliness among patients in nursing homes (91.9%), private homes (87.3%) and hospitals (86.1%). The findings of this study may support the development of a national strategy for PC during a pandemic. To address EoLC issues appropriately, GPs and PC specialists should be involved in COVID-19 task forces on the micro, meso, and macro levels of healthcare. **Full text:** <https://bit.ly/3y9WUy9>

Cont. next page

Related:

- *AMERICAN JOURNAL OF MANAGED CARE*, 2021;27(7):e215-e217. 'Reimagining the inpatient palliative care consult: Lessons from COVID-19.' Over the past several months in epicenters of the COVID-19 pandemic, PC providers have responded to the increased need for palliative care (PC) services through innovative digital programs including telepalliative care programs. The authors explore how PC innovations during COVID-19 could transform the PC consult to address workforce shortages and expand access to PC services during and beyond the pandemic. They propose a 3-pronged strategy of bolstering inpatient telepalliative care services, expanding electronic consults, and increasing training and educational tools for providers... **Full text:** <https://bit.ly/3wDjgXI>

The universality of palliative care philosophy: A case study from India

REVISTA LATINOAMERICANA DE BIOÉTICA, 2021;21(1):99-112. The modern hospice movement, which is the origin of what is now known as palliative care (PC), derived strong inspiration from Christianity. Given this original Christian inspiration, the global spread of PC even to countries where Christianity is only a minority religion may look surprising. In line with the theory of the "secularization of hospice," it could be argued that PC has spread globally because its underlying philosophy has become secular, allowing it to become universal. However, given the continuing importance of religion in many areas of PC, we could wonder how secular contemporary PC really is. This article argues that the universality of PC philosophy resides in its susceptibility to contextualization. PC has become a global success story because people all over the world committed to PC's principles and ideas have contextualized these and developed models of PC delivery and even philosophy that are adapted to the local socio-economic and cultural-religious contexts.

This article analyzes PC in India to illustrate this point, describing contextualized models of PC delivery and showing that PC physicians and nurses in India draw inspiration from their local context and religiosity. **Full text:** <https://bit.ly/3zEFqdO>

Extract from *Revista Latinoamericana de Bioética* article

A possible explanation for the global expansion of PC may be found in the theory of the "secularization of hospice." Several scholars have argued that simultaneously with its global expansion, PC has gradually moved away from the original Christian inspiration and has become more secular. Following this theory, we could argue that the original PC philosophy, which was steeped in Christianity, has become universal through a process of secularization in which it was separated from its original Christian foundations.

N.B. English language article.

Heidi's legacy: Community palliative care at work in regional Australia

SOCIAL WORK IN HEALTH CARE | Online – 26 July 2021 – Advances in the management of chronic diseases, combined with an aging population, have escalated the prevalence of people with life-limiting conditions and demand for palliative care. In Australia, this has prompted calls for change in policy frameworks, service systems and funding models that underpin care. The complex social, cultural and policy transformation required to enact these changes has been problematic. The authors report on qualitative research into a unique, Australian community PC program reflecting these aspirational changes. The research examined the program design and its implementation through the perspectives of program staff and volunteers. **Abstract:** <https://bit.ly/3zJ7pc6>



Publishing Matters

Using updated PubMed: New features and functions to enhance literature searches

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 26 July 2021 – PubMed is a widely available web-based resource that supports the search and retrieval of literature from the U.S. National Library of Medicine's MEDLINE database. The recent 2021 update has enhanced



PubMed's built-in functions and added new features that facilitate identification of COVID-19 articles and preprints. With a 3-step search process, these PubMed updates could help clinicians conduct efficient literature searches to answer clinical questions regarding therapy, diagnosis, etiology, or prognosis for almost any specific disease. However, the retrieved research evidence must always be critically appraised with formal rules of evidence to identify clinically sound studies. After critical appraisal, clinically sound studies should be used in a conscientious, explicit, and judicious fashion to guide clinical decisions that are aligned with clinician judgment and patient values and preferences. **Full text:** <https://bit.ly/375W61r>

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Something Missed or Overlooked?

IF YOU ARE AWARE OF A CURRENT REPORT, ARTICLE, ETC., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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