

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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A team leader, reflecting on shadowing as an activity, said of her colleagues: “It gives them a thirst for quality improvements, that they can engage in and make to improve patient experience.”

“As soon as you’ve been there, it makes it personal”: The experience of healthcare staff shadowing patients at the end of life’ (p.8), in *Health Expectations*.

With this issue of Media Watch, the weekly report begins its 14th year of publication.

U.S.A.

A conversation game may reduce disparity in end-of-life care for African Americans

PENNSYLVANIA | *MedicalXPress* – 23 July 2020 – A Penn State College of Medicine research team found that playing a simple conversation game may encourage African Americans to make plans for their end-of-life (EoL) care. Researchers say the game may be a useful tool in addressing the disparities in EoL care in African American communities. After playing the game, 98% of participants in a recent study engaged in some form of advanced care planning (ACP), including conversations about care preferences with family members and completing or updating advanced directives, where an individual outlines their preferences for EoL medical care.¹ Less than 25% of African Americans have advance care directives according to prior research. That means African Americans are less likely to receive EoL care aligned with their preferences, such as hospice services. Although ACP has doubled to approximately 60% of the general population, the disparity remains in African American communities. The conversation game is called “Hello” and involves a series of

open-ended discussion questions where players in groups of three to six answer questions that are designed to stimulate conversations about preferences for EoL care. <https://bit.ly/2OR6cu0>

Specialist Publications

“‘Palliative pandemic plan’: Triage and symptoms algorithm as a strategy to decrease providers’ exposure, while trying to increase teams availability and guidance for goals of care and symptoms control’ (p.4), in *American Journal of Hospice & Palliative Medicine*.

‘Understanding nursing home staff attitudes toward death and dying: A survey’ (p.5), in *American Journal of Nursing*.

‘Regional variation in use of end-of-life care at hospitals, intensive care units, and hospices among older adults with chronic illness in the U.S., 2010 to 2016’ (p.9), in *JAMA Network*.

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1. 'Association of participation in an end-of-life conversation game with advance care planning behavior and perspectives among African American individuals,' *JAMA Network Open*, 2020;3(5):e204315. **Full text:** <https://bit.ly/3jC3jvd>

N.B. Selected articles on disparities and barriers in the provision and delivery of EoL care for racial/ethnic minorities in the U.S. noted in Media Watch 8 June 2020 (#669, p.5).

Public perception limits expansion of advance care planning

HOSPICE NEWS | Online – 21 July 2020 – Public perceptions of advance care planning (ACP), as well as a lack of understanding of the nature of hospice and palliative care, have many reluctant to pursue these options, according to a new study...¹ ACP has been shown to have a significant impact on the quality and experience of life's final stages, yet broaching these conversations with patients and families involves breaking down walls of nescience around end-of-life care (EoLC). Advocates nationwide are calling for improved strategies to bring the conversation of death into a new light and shift the culture of dying in America. Said Anthony Back, MD, co-director of the Cambia Palliative Care Center of Excellence and one of the study's authors. "We did a big scenario-planning exercise, and then ended up coming to two big factors that weren't getting enough attention, one of which was public engagement. We decided to focus this study on public messaging and how it is being done for all aspects of serious illness care to learn what this information could show us and what we should be doing differently. We had the sense that we were kind of at a plateau in terms of public engagement, and in fact the research from this study really showed that. We wanted to create a bigger influence in the public's acceptance of palliative and hospice care." <https://bit.ly/3fLRbWe>

1. 'Public perceptions of advance care planning, palliative care, and hospice: A scoping review,' *Journal of Palliative Medicine*, published online 2 July 2020. [Noted in Media Watch 6 July 2020 (#673, p.11)] **Abstract:** <https://bit.ly/3gl24yf>

International

Parents' agony after Great Ormond Street Hospital decided to let their seriously ill daughter die without consulting them

U.K. (England) | *The Daily Mail* (London) – 24 July 2020 – Great Ormond Street Hospital has been blasted by a High Court judge over its role in the death of a nine-year-girl in their care. The hospital's ethics committee was slammed for not consulting her parents when they advised that the girl's end-of-life care should be managed, rather than her condition treated. Last night the hospital said the family were spoken to straight after the meeting to inform them of what was discussed. But her parents said the committee meeting set in motion a "tsunami of medical consequences" that meant their daughter was "left to die needlessly, bereft of available medical treatment." In a statement they said: "Without either our knowledge or our involvement the Trust's Ethics Committee determined that she should no longer be given active treatment. The determination by the Ethics Committee meant simply that our daughter would be allowed to die. Its decision was made behind closed doors and based on what was subsequently shown to

be a wholly inadequate medical diagnosis about our daughter." Ms. Justice Russell said members of the ethics committee at Great Ormond Street Hospital, in London, decided that medics should focus on providing the nine-year-old girl with palliative care to maximise her comfort and quality of life prior to death. The judge ... called for guidance on "patient/family participation" in such discussions. <http://dailym.ai/32VS8la>

Specialist Publications

'Estimating the prevalence of life-limiting conditions in Queensland for children and young people aged 0-21 years using health administration data' (p.5), in *Australian Health Review*.

'Caring for children with life-limiting illness in Bloemfontein, South Africa: Challenging the assumptions of the "good death"' (p.10), in *Omega – Journal of Death & Dying*.

Special “cuddle beds” to be installed at West Berkshire Community Hospital ... to improve the quality of end-of-life care

U.K. (England) | *Newbury Today* – 22 July 2020 – Newbury Cancer Care is planning to install a “cuddle bed” in two of the four Rainbow Rooms in West Berkshire Community Hospital. The rooms, funded and maintained by the charity, have given great comfort to many families who have had loved ones seriously ill or even coming towards the end of life (EoL). But now, a new dimension is being planned. The cuddle beds have been requested by families and nursing staff to improve the quality of EoL care. These beds have the same footprint as a standard ward bed, but offer the opportunity to expand to a double bed, allowing a partner or family members to lie next to and cuddle their loved ones. <https://bit.ly/3fRVHTh>

Specialist Publications

Humor in healthcare

AMA JOURNAL OF ETHICS, 2020;22(7):E571-644. According to philosophers of humor, our experiences of “funny” can release nervous tension, express our feelings of superiority over others, or reveal our struggles to assimilate something unexpected. Comedy is the art of creating funny, and studying when and why things are funny is a part of value theory called aesthetics. Like ethics, aesthetics helps us interrogate what we value and what we see as worth the risk to get a benefit from humor. To some, not much is funny about illness and injury. To others, there seems to be a lot to joke about.

This tension is the focus of this issue. **Download journal contents page at:** <https://bit.ly/3fUVXRy>

Publishing Matters

‘Trends in published palliative care research: A 15-year review’ (p.11), in *American Journal of Hospice & Palliative Medicine*.

‘Fake journals in the age of fake news: The dangers of predatory publishing’ (p.11), in *Healthy Debate*.

Noted in Media Watch 3 February 2020 (#651, p.6):

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

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

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



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“Palliative pandemic plan”: Triage and symptoms algorithm as a strategy to decrease providers’ exposure, while trying to increase teams availability and guidance for goals of care and symptoms control

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 21 July 2020 – As the spread of **COVID-19** continues worldwide, healthcare systems are facing increased demand with concurrent healthcare provider shortages. This increase in patient demand and potential for provider shortages is particularly apparent for palliative medicine, where there are already shortages in the provision of this care. In response to the developing pandemic, the authors’ Geriatrics & Palliative (GAP) Medicine team formulated a 2-team approach which includes triage algorithms for palliative consults as well as acute symptomatic management for both patients diagnosed with or under investigation for COVID-19. These algorithms provided a delineated set of guidelines to triage patients in need of palliative services and included provisions for acute symptoms management and the protection of both the patient care team and the families of patients with COVID-19. These guidelines helped with streamlining care in times of crisis, providing care to those in need, supporting frontline staff with primary-level palliative care, and minimizing the GAP team’s risk of infection and burnout during the rapidly changing pandemic response. **Full text:** <https://bit.ly/32GfVel>

Related:

- *HEALTH SECURITY* | Online – 20 July 2020 – **‘Working upstream in advance care planning in pandemic palliative care.’** Patients who have had the chance to engage in thoughtful, iterative discussions about their values with sufficient guidance, may approach the end of life with more autonomy, dignity, and peace. As a result, their families have reported fewer grief-related complications. Preexisting advanced directives may not be sufficient to ensure goal-concordant care during the **COVID-19** pandemic. Pandemic-specific palliative care (PC) calls for upstream reiteration of goals by skilled providers surrounding specific topics, including intubation and hospitalization. Automatic triggers for PC consultations remain an area of potential exploration. **Full text:** <https://bit.ly/2EiOpKm>
- *JOURNAL OF MEDICAL EDUCATION & CURRICULAR DEVELOPMENT* | Online – 10 July 2020 – **‘Breaking bad news training in the COVID-19 era and beyond.’** COVID-19 has disrupted the *status quo* for healthcare education. As a result, redeployed doctors and nurses are caring for patients at the end of their lives and breaking bad news with little experience or training. In this article, the authors aim to understand why redeployed doctors and nurses feel unprepared to break bad news through a content analysis of their training curricula. As digital learning has come to the forefront in healthcare education during this time, relevant digital resources for breaking bad news training are suggested. **Full text:** <https://bit.ly/2OUadOg>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 July 2020 – **‘Dying from Covid-19: Loneliness, end-of-life discussions and support for patients and their families in nursing homes and hospitals. A national register study.’** The current study revealed some important differences both when comparing patients deceased from Covid-19 with deaths in similar patient groups during 2019, and when comparing Covid-19 deaths at nursing homes with deaths at hospitals. In the former comparison, the greatest difference was for the variable “dying with someone present.” In 2019, the figure was 83%, whereas the figure for all Covid-19 patients was only 59%. When comparing nursing homes and hospitals, the figures were 61% and 55%, respectively. **Full text:** <https://bit.ly/2BvcXP7>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 24 July 2020 – **‘Global palliative care education in the time of COVID-19.’** With the rising need for global palliative care (PC) skills, both abroad and at home owing to the current pandemic, the field of PC must respond by building our future workforce, in reciprocal partnership with international programs. As a specialty, we are poised to provide expertise to our colleagues and health systems in how to prepare for these events, as well as how to provide high quality and creative care when they do occur. We have much to learn from our international colleagues, many of whom are already well versed in practicing compassionate PC amidst resource constraints and during humanitarian emergencies. **Full text:** <https://bit.ly/2WPKvPi>

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- *NEW ENGLAND JOURNAL OF MEDICINE*, 2020;383(7):306-307. '**Pandemic as teacher – forcing clinicians to inhabit the experience of serious illness.**' Just as COVID-19 causes physiological dysfunction in patients, so, too, is it causing systemic dysfunction in households, institutions, cities, and nations. As a result, clinicians have been forced to inhabit some of the harsh realities of serious illness, including uncertainty, loss of control and challenge to identity. Therein lies a rare opportunity ... to pause in the midst of the chaos and gain a deeper understanding of our patients' experiences with illness. Doing so could conceivably have long-term salutary effects, such as deepening our empathy, changing our practice habits, and improving our systems of care. **Full text:** <https://bit.ly/3jECAOy>

Understanding nursing home staff attitudes toward death and dying: A survey

AMERICAN JOURNAL OF NURSING | Online – 9 July 2020 – Nearly 70% of nursing home residents are eligible for palliative care (PC), yet few receive formal PC outside of hospice. Nursing home staff [i.e., study participants] generally reported feeling comfortable caring for the dying, but half believed the end of life (EoL) is a time of great suffering. Pain control (63%), loneliness (52%), and depression (48%) were the most important issues identified with regard to these patients, and there was ambivalence about the use of strong pain medications and the utility of feeding tubes at the EoL. Top priorities identified for improving PC included greater family involvement (43%), education and training in pain control (50%) and in management of other symptoms (37%), and use of a PC team (35%) at their facility. There is a need for more PC training and education, which should be built on current staff knowledge, skills, and attitudes toward. **Abstract:** <https://bit.ly/2WDjU8c>

Estimating the prevalence of life-limiting conditions in Queensland for children and young people aged 0-21 years using health administration data

AUSTRALIAN HEALTH REVIEW | Online – 20 July 2020 – Data from the U.K. indicate that the prevalence of life-limiting conditions among children and young people is increasing. However, such data are not available for the Australian population. Because prevalence data can be affected by population characteristics, it is important to establish country-specific epidemiological data rather than extrapolating data from other countries. Country-specific data can inform health planners and policy makers of the scale of the problem within a geographical and demographic context. This is essential for Australia given the diverse geographical and demographic characteristics and specific needs of Aboriginal and Torres Strait Islander peoples. This study is the first to provide an estimate of the prevalence of life-limiting conditions in children and young people aged 0-21 years in Queensland. Estimates include the prevalence of life-limiting conditions in children and young people who identify as being of Aboriginal and/or Torres Strait Islander descent. The prevalence of life-limiting conditions in Queensland is greater than previously thought. There is a need to grow both a generalist and specialist paediatric palliative care workforce in response to this increasing prevalence. The estimates of prevalence proportions from this study provide the foundation on which future health service activities can be built because they provide country-specific clinical and demographic characteristics. **Abstract (w. list of references):** <https://bit.ly/39he7ue>

Noted in Media Watch 11 November 2019 (#639, p.13):

- *ADVANCES IN MEDICAL EDUCATION & PRACTICE* | Online – 7 November 2019 – '**Perspectives of health professionals and educators on the outcomes of a national education project in pediatric palliative care: The Quality of Care Collaborative Australia.**' Demand for generalist health professional knowledge and skills in pediatric palliative care (PPC) is growing in response to heightened recognition of the benefits of a palliative approach across the neonatal, pediatric, adolescent and young adult lifespan. This study contributes to a growing body of knowledge on innovative and responsive mechanisms for enhancing workforce capability in PPC and provides additional evidence to support funding of dedicated educator roles in specialist PPC services. **Full text:** <http://bit.ly/2CnA2Ak>



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

Living and dying with incurable cancer: A qualitative study on older patients' life values and healthcare professionals' responsiveness

BMC PALLIATIVE CARE | Online – 20 July 2020 – Anticipatory fears of loss of, e.g., the body, the mind, and social contacts play an important role in the lives of every patient, including older adults living with incurable cancer. This study shows that these fears are usually influenced by previous experiences with cancer in their social network. Healthcare professionals (HCPs) acknowledge that these fears should be explored, but exploration is not a simple task as patients can be reluctant or yet unable to share these often-slumbering fears. The literature suggests that the origin and impact of these fears can be explored through guided dialogues with patients, in which they might find their way back out of their burdensome thoughts. Although HCPs are willing to aim for such dialogue, they expressed some barriers, e.g., older people being less assertive and less in need of being in charge. This is also reported in a literature review about life values of older adults living with incurable cancer, however, not expressed by patient participants in this study. Other barriers expressed were patients and HCPs both experiencing lack of time for reflection and slow decision-making processes, and cancer being an intangible phenomenon. This study describes the kind of lives older adults living with incurable cancer hope to live and keep on living for as long as possible. **Full text:** <https://bit.ly/2BlzH4c>

Frailty and palliative care

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 24 July 2020 – Frailty is a syndrome evident when a threshold number of regulatory systems required to maintain human body homeostasis are compromised by intercurrent and chronic diseases and physiological ageing. As a result, someone with frailty becomes vulnerable to adverse outcomes when exposed to stressors like an acute illness or treatment(s). Frailty can also have significant personal impact, including care dependence and loneliness. Many different concepts of frailty exist and consequently prevalence data shows huge variation. It is not simply present or absent but a spectrum that encompasses cognitive, functional, psychosocial and somatic domains. With greater vulnerability, seemingly insignificant stressors like a urinary tract infection can cause significant incremental morbidity, like delirium or functional decline and ultimately death. Frailty may fluctuate, but over time patients usually exhibit slowly progressive decline, sometimes interspersed with disease episodes or exacerbations and (partial) recovery, with only a slight acceleration of decline as death approaches. People with frailty have physical, psychosocial and support needs amenable to palliative interventions, but studies reveal they are less likely to access palliative care (PC) than those with advanced cancer. We will focus on two questions. First, why is PC relevant to patients with frailty and what hinders them from receiving it? Second, why is awareness of frailty and its components relevant for provision of PC? **Introductory paragraphs:** <https://bit.ly/3jHh37W>

N.B. Selected articles on frailty and PC noted in Media Watch 11 May 2020 (#665, p.4).

Teach me about death

BRITISH MEDICAL JOURNAL | Online – 22 July 2020 – Medicine has come on leaps and bounds and, as a result, in the U.K. we have become what has been called a “death free generation.” Many people are largely unaffected by deaths from war, childbirth, or infection and can live for decades without experiencing the death of a loved one. It has almost become an expectation that we will all live well into old age. However, death is inevitable and plays some part in every clinical specialty. Public health figures indicate that 46.9% of people in England will die in hospital, making death an important part of hospital life that both medical students and doctors will be exposed to and required to address. Junior doctors, who commonly staff inpatient wards, are likely to be involved in prognosis counselling and end-of-life (EoL) conversations with patients, carers, and loved ones from the very beginning of their careers. However, medical schools aren't preparing us for the reality of having these conversations. A U.K. survey of medical schools found that on average only 20 hours of the curriculum were dedicated to palliative care, with a

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large proportion of these occurring in the later years of training.¹ A study by the Royal College of Physicians of Edinburgh admitted that it was “unrealistic” to expect any graduating medical student to be fully prepared for palliative medicine.² Yet this failure to equip junior doctors with adequate knowledge of EoL care risks patients and their loved ones being left without the support they require. **Full text:** <https://bit.ly/3hsjJQW>

1. ‘Preparation for palliative care: teaching about death, dying and bereavement in U.K. medical schools 2000-2001,’ *Medical Education*, published online 31 May 2002. **Abstract:** <https://bit.ly/32MtlG9>
2. ‘Are newly qualified doctors prepared to provide supportive and end-of-life care? A survey of Foundation Year 1 doctors and consultants,’ *Journal of the Royal College of Physicians of Edinburgh*, 2013;43(1):24-28. **Abstract:** <https://bit.ly/2BuJYLu>

Related:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 21 July 2020 – ‘**From European Association for Palliative Care recommendations to a blended, standardized, free-to-access undergraduate curriculum in palliative medicine: The EDUPALL Project.**’ As the changing demographic profile of Europe’s population results in increased need and increased demand for palliative care services, the EDUPALL curriculum is a first step in ensuring that “tomorrow’s” doctors are prepared to meet that need. The curriculum is based on the updated European Association for Palliative Care recommendations of 2013... The overarching aim of the EDUPALL project is the development of a universally adaptable and applicable curriculum, freely available in multiple languages. **Full text:** <https://bit.ly/2WFdkhx>
N.B. EDUPALL is an ERASMUS+ funded international collaborative project to develop and pilot an undergraduate program for training in palliative medicine.
- *PALLIATIVE MEDICINE IN PRACTICE*, 2020;14(2):81-88. ‘**Postgraduate palliative care education and curricular issues in Central Asia, Eastern and South-Eastern Europe: Results from a quantitative study.**’ Across the World Health Organization (WHO) European region, the provision of palliative care (PC) training for healthcare professionals is inconsistent and the main barrier to increasing access to PC. The WHO recommends all healthcare professionals should get basic training on PC. This study looks at PC developments focusing on the postgraduate PC education and curricular issues in Central-Asia, Eastern and South-Eastern Europe, in regions, where the struggle to introduce PC services is a matter of paramount importance. **Download full text (click on pdf icon) at:** <https://bit.ly/399qCbb>

Supportive and palliative care of adults with respiratory problems experiencing structural vulnerability from homelessness, prison or other criminal justice system involvement

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 20 July 2020 – This review identifies the current prevalence of potentially life-limiting respiratory conditions among those who have experienced homelessness, incarceration or had criminal justice involvement, and current developments in, and barriers to, delivery of supportive and palliative respiratory care to these populations. These structurally vulnerable populations are known to be growing, their health behaviours more risky, and their morbidity and mortality higher, with evidence of accelerated ageing. Most studies identified investigated prevalence of respiratory conditions, which were found to be high. Only one study directly explored supportive and palliative care (in a prison population) and none considered or addressed palliative and end-of-life (EoL) needs of these populations, or mechanisms to address them. There was an absence of qualitative work and studies of the impact on, or role of, family, friends or informal networks. There is a need for evidence-based interventions to reduce the risk of communicable respiratory conditions and a greater understanding of disease trajectories and management for these vulnerable populations, including provision of accessible appropriate supportive, palliative and EoL care. **Abstract:** <https://bit.ly/2EgjnCR>



Would the article above be of interest to a colleague?

“As soon as you've been there, it makes it personal”: The experience of healthcare staff shadowing patients at the end of life

HEALTH EXPECTATIONS | Online – 19 July 2020 – The authors uncover the nature of the most challenging aspects of the work of shadowing for healthcare staff, which proved to be emotional, rather than practical, professional, logistical or ethical. The emotions felt by shadowers in response to their experience of being with patients in this way were complex, and at the heart was the way that new perspectives afforded were “unusual.” Participants in this study found they were accompanying patients, seeing the familiar from unfamiliar vantage points, which created new emotional responses to the patients and what they were experiencing. They appeared at times to be taking on informally a role which was different from that of observer. The physical and emotional closeness that comes with shadowing seemed to open up varying relational spaces and opportunities for an emergent meaning-making and knowledge that would not have been available in other ways. For example, the satisfaction expressed through providing companionship to a patient who was lonely or bored. Such “relational goods” are not things, ideas or services, they are emergent and have a “sui generis reality” (i.e., a unique dynamic): they are productive, have benefits and cannot be appropriated by any one single individual. Emotional investments that arise in relational moments could subsequently play a part in motivating participants to make changes for their patients for the better, including engaging in their projects in a way not usually seen in quality improvement, which if managed appropriately could be effective for service improvement. A team leader, reflecting on shadowing as an activity, said of her colleagues: “It gives them a thirst for quality improvements, that they can engage in and make to improve patient experience.” **Full text:** <https://bit.ly/2ZLJ5r7>

Looking behind the fear of becoming a burden

HEC FORUM | Online – 23 July 2020 – As they age, many people are afraid that they might become a burden to their families and friends. In fact, fear of being a burden is one of the most frequently cited reasons for individuals who request physician aid in dying. Why is this fear so prevalent, and what are the issues underlying this concern? The author argues that perceptions of individual autonomy, dependency, and dignity all contribute to the fear of becoming a burden. However, this fear is misplaced; common conceptions of these values should be re-framed and re-examined. Practices that support a more community-centered type of autonomy can be found in dependency and dignity. This article offers some practical examples of how to address common end-of-life situations that may cause anxiety to patients who are worried about being a burden. These practices include discussing expectations, both for care and how the relationship among the participants might change, and modeling respectful caregiving behaviors. Most difficult of all, though, includes cultural and societal attitude changes so that people recognize the good in receiving care and get used to the idea that they do not need to do anything to be valuable. **Abstract (w. list of references):** <https://bit.ly/3fYjH76>



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>

Regional variation in use of end-of-life care at hospitals, intensive care units, and hospices among older adults with chronic illness in the U.S., 2010 to 2016

JAMA NETWORK | Online – 21 July 2020 – Most older adults living with chronic illness prefer palliation of symptoms at home rather than invasive therapies or hospitalization at the end of life (EoL). In the U.S., death occurring at home has become more common than death occurring in the hospital. However, national patterns may overlook important regional variation in EoL care. Additionally, research is lacking on these patterns among the increasing population of older adults with chronic illness. From 2010 through 2016, the rates of hospitalization at the EoL decreased and hospice enrollment increased in nearly all regions in the U.S. Nonetheless, Medicare beneficiaries with chronic illnesses continue to experience marked regional variation in EoL hospitalization, ICU use, and hospice use – these rates varied more than 3-fold across all U.S. regions. Despite a common preference to avoid EoL hospitalization and intensive therapies, the region of residence may remain an important determinant of the site of EoL care. **Full text:** <https://bit.ly/30A5RBw>

Noted in Media Watch 30 September 2019 (#633, p.3):

- CENTRE TO ADVANCE PALLIATIVE CARE & NATIONAL PALLIATIVE CARE RESEARCH CENTRE | Online – 26 September 2019 – ‘**America’s Care of Serious Illness: 2019 State-by-State Report Card on Access to Palliative Care in Our Nation’s Hospitals.**’ The new report demonstrates that access to palliative care (PC) continues to remain variable and depends more upon accidents of geography, whether a hospital is for-profit or non-profit, and hospital size than it does upon the needs of patients living with a serious illness, and their families. The U.S. shows continued growth in the overall number of hospital PC teams: 72% of U.S. hospitals with fifty or more beds report a PC team. This is up from 67% in 2015, 53% in 2008, and 7% in 2001. **Download/view at:** <http://bit.ly/2lrJOWl>

Initiating palliative care referrals in pediatric oncology

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 21 July 2020 – Early palliative care (PC) has been shown to improve the quality of life of children with cancer, yet referral practices by pediatric oncology providers remains inconsistent and few patients receive a formal PC consult. In this study ... more than 75% of participants reported that PC was consulted “too late” and cited communication and systems issues as the top barriers. A majority of participants (85%) stated that a screening tool would be helpful to standardize referral practices to PC. Characteristics such as poor prognosis (88%), symptom management (86%), comorbidities (65%), and psychosocial needs (65%) were commonly reported triggers that should initiate PC consultation. However, when presented with case scenarios that included these characteristics, participants did not consistently identify the PC triggers. Nearly 50% of participants stated they had received some formalized PC training, however only one third of these participants noted completing a PC rotation. Pediatric oncologists are committed to improving the integration of PC for their patients and that standardization of referral practices, through the use of a screening tool, would be of benefit. **Abstract (w. list of references):** <https://bit.ly/39kT4H4>

Factors influencing the integration of a palliative approach in intensive care units: A systematic mixed-methods review

BMC PALLIATIVE CARE | Online – 22 July 2020 – Four key prerequisite factors were identified: 1) Organizational structure in facilitating policies, unappropriated resources, multi-disciplinary team involvement, and knowledge and skills; 2) Work environment, including physical and psychosocial factors; 3) Interpersonal factors/barriers, including family and patients’ involvement in communication and participation; and, 4) Decision-making, e.g., decision and transition, goal conflict, multidisciplinary team communication, and prognostication. Factors hindering the integration of a palliative approach in an intensive care context constitute a complex interplay among organizational structure, the care environment and clinicians’ perceptions and attitudes. While patient and family involvement is an important facilitator of palliative care, it was also recognized as a barrier for clinicians due to challenges in shared goal setting and communication. **Full text:** <https://bit.ly/39lf04Z>

N.B. Selected articles on PC in the ICU noted in Media Watch 27 January 2020 (#650, p.5).

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Noted in Media Watch 16 December 2019 (#644, p.11):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 12 December 2019 – ‘**Defining the boundaries of palliative care in pediatric oncology.**’ The findings of this study demonstrate that while most pediatric oncologists accept a modern definition of palliative care (PC) in theory, how to integrate PC in pediatric oncology practice is less understood. Formalized training and standardization of practice surrounding identification of PC needs in patients who may require secondary or tertiary PC services may help to overcome current barriers for PC integration in pediatric oncology. While PC continues to be integrated into pediatric oncological care, only a minority of patients with cancer receive a formal PC consult. **Abstract (w. link to references):** <http://bit.ly/36CRL3P>

Instability in preference for place of death among patients with symptoms of advanced heart failure

JOURNAL OF POST ACUTE & LONG-TERM CARE MEDICINE | Online – 18 July 2020 – Patient preference for place of death is an important component of advance care planning (ACP). If patients’ preference for place of death changes over time, this questions the value of their documented preference. The authors provide evidence of instability in patients with heart failure preference for place of death, which suggests that ACP documents should be regularly re-evaluated. In this study, 66% of the 282 patients interviewed changed their preference for place of death at least once during the study period with no consistent pattern of change. Correct prognostic understanding at the time of survey reduced the relative risk of change in preference for place of death to home, whereas a higher quality of life score was associated with a lower relative risk of patients changing their preferred place of death to an institution relative to no change in preference. **Abstract (w. list of references):** <https://bit.ly/3jEbl74>

Caring for children with life-limiting illness in Bloemfontein, South Africa: Challenging the assumptions of the “good death”

OMEGA – JOURNAL OF DEATH & DYING | Online – 23 July 2020 – Theories of good death focused on acceptance, control, and meaning-making inform adult palliative care in high-resource settings. As children’s palliative and hospice care (CPHC) develops in resource-limited settings, critical conceptualisations of a “good death” for children across these diverse settings are unknown. Assessed against high-resource setting tenets of “good death” from carer perspectives, results suggest: carer agency is limited; advanced discussion of death does not occur; distress results from multiple burdens; basic survival is prioritised; physical pain is not an emphasised experience; and, carers publicly accept death quickly while private grief continues. Hegemonic conceptions of “good death” for children do not occur in contexts where agency is constrained and discussing death is taboo, limiting open discussion, acceptance, and control of dying experiences. Alternate forms of discourse and “good death” could still occur. Critical, grounded conceptualisations of “good death” in individual resource-limited settings should

occur in advance of CPHC development to effectively relieve expansive suffering in these contexts. **Abstract (w. list of references):** <https://bit.ly/3jOHDwe>

Safety in pediatric hospice and palliative care: A qualitative study

PEDIATRIC QUALITY & SAFETY, 2020;5(4):e328. Patient safety is extensively studied in both adults and pediatric medicine; however, knowledge is limited regarding particular safety events in pediatric hospice and palliative care (HPC). Additionally, pediatric HPC lacks a unified definition of safe care. The use of traditional hospital safety measures for patients receiving HPC could undermine the patient’s goals or dignity, ultimately leading to harm to the patient. Patients’ and families’ unique goals and values must be considered when defining safety for children in this population. Future studies should continue to explore family perspectives of safety in the hospital and ambulatory settings and seek to identify measurable indicators in safety which are truly patient- and family-centered. **Full text:** <https://bit.ly/32OK77G>

Publishing Matters

Trends in published palliative care research: A 15-year review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 24 July 2020 – The authors reviewed every issue of the *Journal of Pain & Symptom Management*, *Journal of Palliative Medicine*, and *American Journal of Hospice & Palliative Medicine* from 2004 through 2018. Studies included were original articles and brief reports. Study type (qualitative, quantitative), author (first and last), gender, and professional degree of the author (first and last) were recorded. 4,881 articles were included in this study. The proportion of quantitative papers significantly increased across 3 time points from 63% to 67% to 78%. The proportion of women first authors increased across all 3 time points (54%, 2004-2008; 57%, 2009-2013; 60%, 2014-2018), and the proportion of women last authors increased across all time points (38%, 2004-2008; 44%, 2009-2013; 46%, 2014-2018). More than 40% of authors were physicians. Published PC studies are increasingly quantitative in design. Gender authorship is female dominant for the first authors and increasingly equal across genders for the last authors. **Abstract (w. list of references):** <https://bit.ly/2WRzLjL>

Fake journals in the age of fake news: The dangers of predatory publishing

HEALTHY DEBATE | Online – 20 July 2020 – The emergence of “predatory journals” has clouded the available health information



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needed for sound, evidence-based advice to support decision-making for patients and the public. Health research has led to improved therapies, new medicines, new surgeries and improved patient safety. Many of these advances have come about through the accumulation and sharing of knowledge between researchers. The process of scientific communication occurs primarily through the publication of research findings in medical journals. This process, however, is being disrupted by a new phenomenon: predatory journals. The Royal Society of London published one of the first academic journals in 1665 as a way for members to share their work. Many of its features continue today, including peer reviews in which independent scientists critically review works prior to publication, and proper archiving that allows researchers to access and build upon existing knowledge... At that time, access to journal publications was limited to scientists and others who paid publishers to read the articles. However, standards are rapidly changing. Many journals are moving toward an open-access model in which readers no longer pay for the articles. This has been perceived as a fair and equitable development since research is often funded by governments and belongs in the public realm. Publishing in these open-access journals can come at a significant cost as some journals charge researchers (or their research institutions) thousands of dollars to publish the research and make it available to the public, which helps the journal recoup costs for editorial and archiving services. Predatory journals have entered this shifting landscape and have found an opportunity to profit.

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

Media Watch: Editorial Practice

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

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[Something Missed or Overlooked?](#)

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

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International



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

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Australia

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

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EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <https://bit.ly/3iZKjXr>

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

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

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South America

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



Media Watch: Behind the Scenes

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