

**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.

7 June 2021 Edition | Issue #720



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Compiled & Annotated by Barry R. Ashpole

**Interventions that predominantly focus on providing clear medical information to surrogates who are unexpectedly facing decisions about the use of life-prolonging treatments have failed to change end-of-life outcomes, such as surrogates' depression, anxiety, post-traumatic stress disorder, and perceptions of the quality of care.**

'Reconceptualizing how to support surrogates making medical decisions for critically ill patients' (p.9), in *Journal of the American Medical Association*.

## Canada

### **Improving the quality of life of our seniors in care is at the centre of new strategy**

ALBERTA | *The Calgary Herald* – 1 June 2021 – The Alberta government released a 217-page report based on a long review into the province's continuing care system, with the stated aim of making the lives of those in care more fulfilling and dignified right until the end.<sup>1</sup> The report makes 42 recommendations to better prepare Alberta for the coming grey wave as baby boomers ... head into old age. The report states that in 2019 ... 13% of the population was over 65 years of age. That's expected to increase to 20% by 2046, but people "over 80 years of age are expected to experience the highest growth with an expected increase of around 225%" over the same time frame, states the report. "Nowhere in Canada have I yet seen recommendations as bold and with such transformative potential as these," said Carole Estabrooks, a professor in the faculty of nursing at the University of Alberta, who was on the 15-member review panel. "The recommendations will go a very long way to eliminating the fear that many Albertans have of one day needing to place their loved one in care and to

eliminating our own individual fears of one day needing those individual services ourselves ... by tackling the most important aspect of any supportive or long-term care (LTC) home – a good quality of life for residents and good end of life." One of the key recommendations is for the province to bolster home care services and keep our elderly out of LTC facilities as long as possible. This is an approach long touted as a best practice by experts in aging. <https://bit.ly/3wPVPKS>

#### **Extract from Alberta Department of Health report**

Alberta will have the fastest growing aging population in Canada over the next ten years and will need a workforce with special training and understanding in continuing care and geriatric services. Knowledge of the aging process, dementia, chronic disease management, and palliative care will also be necessary in the delivery of continuing care services for all types of roles including administration and management, through to front-line and support staff.

1. 'Improving Quality of Life for Residents in Facility-Based Continuing Care,' Alberta Department of Health, April 2021. Download at: <https://bit.ly/3fF72by>

## U.S.A.

### **Most in U.S. have little understanding of palliative care, study finds**

UNITED PRESS INTERNATIONAL | Online – 4 June 2021 – Most surveyed Americans have an inadequate understanding of palliative care (PC), according to a study published in *Cancer Epidemiology, Biomarkers & Prevention*.<sup>1</sup> PC is the improvement of the quality of life for patients and caretakers by addressing the physical, psychological, and logistical challenges associated with a disease or its treatment. Rather than hospice care, which comforts patients who have stopped treatment and are near the end of life (EoL), PC serves as a supplementary treatment by addressing the side effects of treatment. Dr. Motolani Ogunsanya, an assistant professor at The University of Oklahoma Health Sciences Center, led the study for the American Association for Cancer Research. “Despite the known benefits of PC and its endorsement by the American Society of Clinical Oncology and the National Comprehensive Cancer Network, we have not seen an increased uptake of PC by those who need it most,” said Ogunsanya. “A common misconception is that PC is only for EoL care when, in fact, it can begin at any point in the disease course.” The researchers collected data from the National Cancer Institute’s Health Information National Trends Survey from 2018, which included self-reported knowledge of PC. <https://bit.ly/3z0WATo>

1. ‘Predictors of palliative care knowledge: Findings from the Health Information National Trends Survey,’ *Cancer Epidemiology, Biomarkers & Prevention*, published online 4 June 2021. **Abstract:** <https://bit.ly/3vSFt43>

Noted in Media Watch 16 March 2020 (#657, p.9):

- *JOURNAL OF GENERAL INTERNAL MEDICINE* | Online – 10 March 2020 – ‘**Lack of awareness and common misconceptions about palliative care among U.S. adults: Insights from a national survey.**’ Despite recent growth in palliative care (PC) programs, PC remains underutilized. Studies suggest that patients and providers commonly associate PC with end of life, often leading to misconceptions and late referrals. PC knowledge was self-reported in response to: “How would you describe your level of knowledge about PC?” Level of misconceptions was based on a series of factual and attitudinal statements about PC. Among U.S. adults, 28.8% report knowing about PC, but only 12.6% report knowing what PC is and hold no misconceptions. **Abstract (w. list of references):** <http://bit.ly/2TL0taJ>

Noted in Media Watch 12 August 2019 (#626, p.1):

- CENTER TO ADVANCE PALLIATIVE CARE | Online – 8 August 2019 – ‘**Palliative care still relatively unknown among the general public: Shows education for consumers and physicians necessary to make a difference.**’ New opinion research confirms that once educated with the correct definition of palliative care (PC), understanding and favorability greatly increase among consumers and physicians. “All organizations and clinicians must proactively align themselves in defining PC correctly,” said Diane E. Meier, the Center’s director. “With an aging population increasing exponentially, it is more important than ever that both the field of PC and the referring clinicians evolve their rhetoric. The point must always be made that PC is based on need, not prognosis.” <http://bit.ly/2ZXaHXX>



### Barry R. Ashpole

MY INVOLVEMENT IN HOSPICE AND PALLIATIVE CARE DATES FROM 1985. As a communications consultant, I’ve been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I’ve applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://bit.ly/2RPy9b>

## Grand Ronde ends hospice program due to workforce shortage

*HOSPICE NEWS* | Online – 1 June 2021 – Oregon-based Grande Ronde Hospital & Clinics will close its hospice program this month due to staffing shortages. The organization indicated that the COVID-19 pandemic exacerbated industry-wide workforce issues, leading to the decision to close. Many hospice providers have seen staff turnover rise during the pandemic, as have organizations in other healthcare settings. Slightly more than 20% of healthcare workers have considered leaving the field due to stress brought on by the pandemic, and 30% have considered reducing their hours, according to a recent study published in *JAMA Network Open*.<sup>1</sup> More than 35% of hospice leaders surveyed by *Hospice News* earlier this year cited staffing shortages as a top concern for their organizations, along with regaining access to patients in facilities.<sup>2</sup> Staffing shortages have plagued the hospice industry for years. The U.S. has 13.35 hospice and palliative care specialists for every 100,000 adults 65 and older, according to an April 2018 study.<sup>3</sup> The research estimated that by 2040 the patient population will need 10,640 to 24,000 specialists; supply is expected to range between 8,100 and 19,000. <https://bit.ly/3g7sBkd>

1. 'Experiences of a health system's faculty, staff, and trainees' career development, work culture, and child-care needs during the COVID-19 pandemic, *JAMA Network Open*, published online 2 April 2021. **Full text:** <https://bit.ly/3yYc8aD>
2. 'Top hospice worries 2021: Accessing facility-bound patients, staffing,' *Hospice News*, published online 8 February 2021. [Noted in Media Watch 15 February 2021 (#704, p.1)] <http://bit.ly/3p78SDs>
3. 'The growing demand for hospice and palliative medicine physicians: Will the supply keep up?' *Journal of Pain & Symptom Management*, published online 2 February 2018. [Noted in Media Watch 5 February 2018 (#549, p.12)] **Full text:** <http://bit.ly/2CRjxwO>

## Can you trust doctors to honor your end-of-life wishes? Here's what to consider

*THE SAN DIEGO UNION-TRIBUNE* | Online – 1 June 2021 – Is your physician's refusal to honor your wishes good or bad? "Good" means in your "best interest," such as preventing premature dying. "Bad" means forcing you to endure prolonged, and likely increased, suffering with little or no benefit. Are physicians' actions well-meaning or selfish? "Selfish" means refusal benefits your physician as it harms you. Physicians' hubris leads to their desiring that their actions are viewed favorably – while you suffer longer, and more. Many physicians want to view themselves as heroes who sustained your life. But the ethical position of the American Medical Association is clear: "The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail." A comprehensive question for physicians to ask: Are their actions legal, ethical and respectful? You have a claim right to self-determination (what happens to your body) and to avoid suffering.

Claim rights impose a duty on others to act by honoring your rights, so ... physicians should attempt to reduce your suffering and physicians should not violate your bodily integrity. This includes assisted oral feeding and hydrating – if you previously refused it. In addition to being unethical, force feeding may be illegal since battery is a crime. Yet some physicians argue they must consider all available information, strive to do no harm and maximize what they feel is your benefit. Hence, your living will's future success depends on your resolving common conflicts during advance care planning. <https://bit.ly/3paqTTa>

### [Specialist Publications](#)

'Life support preferences in the context of COVID-19: Results from a national U.S. survey' (p.7), in *Medical Decision Making*.

## Aging and dying behind prison bars

STATE OF NEW YORK | *New York Daily News* – 31 May 2021 – Right now, nearly one in four people locked behind bars are 50 and older. Many are stuck there until they die. It's clear how this situation unfolded. For decades, our criminal justice system has dealt out incredibly harsh sentences, but without any evidence that such punishments were necessary or cost-effective. As a result, our prisons have essentially turned into inhumane nursing homes – trapping people who bear no risk to public safety. This isn't just a problem in New York. Nationwide, of the 200,000 people serving life sentences, nearly one-third are 55 or older. Fortunately, momentum is building across the country for reforms that would re-evaluate long sentences for incarcerated people, according to a new report from The Sentencing Project.<sup>1</sup> In New York, lawmakers are considering legislation that would allow many incarcerated people with extreme sentences to be eligible for parole. The share of older New Yorkers behind bars has more than doubled in recent years. In 2007, 11% of the prison population was 50 or older. By 2017, that skyrocketed to 20%. Now, it's 25%, and could go even higher. Elderly incarcerated people like these men have experienced horrible prison conditions and poor healthcare for decades, resulting in serious health problems. In

fact, an incarcerated person's health often matches that of a non-incarcerated person who is 10-15 years older. 55-year-olds in prison have the health of a 65 to 70-year-old. All in all, every year in prison takes an alarming two years off a person's life expectancy... <https://bit.ly/34DIAIK>



Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report, last updated 1 May 2021, can be downloaded at the Palliative Care Network website at: <http://bit.ly/2RdegnL>

Photo: Lori Waselchuk. Philadelphia, PA

1. 'A Second Look at Injustice,' The Sentencing Project, May 2021. Download at: <https://bit.ly/3yREL9b>

## “Time don't heal it”: The “grief pandemic” from COVID-19 will torment Americans for years, experts say

USA TODAY | Online – 30 May 2021 – With nearly 600,000 in the U.S. lost to COVID-19 ... researchers estimate that more than 5 million Americans are in mourning, including more than 43,000 who have lost a parent. The



pandemic – and the political battles and economic devastation that have accompanied it – have inflicted unique forms of torment on mourners, making it harder to move ahead with their lives than with a typical loss, said sociologist Holly Prigerson, co-director of the Cornell Center for Research on End-of-Life Care. The scale and complexity of pandemic-related grief have created a public health burden that could deplete Americans' physical and mental health for years, leading to more depression, substance misuse, suicidal thinking, sleep disturbances, heart disease, cancer, high blood pressure and impaired immune function. “Unequivocally, grief is a public health issue,” said Prigerson, who lost her mother to COVID-19 in January. “You could call it the grief pandemic.” The pandemic has prevented many families from gathering and holding funerals, even after deaths caused by conditions other than COVID-19. Prigerson's research shows that families of patients who die in hospital intensive care units are seven times more likely to develop post-traumatic stress disorder than loved ones of people who die in home hospice. <https://bit.ly/3uCnDkr>



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## International

### Urgent reform of palliative care required for those experiencing homelessness

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 1 June 2021 – Homelessness has traditionally been a bleak picture in Scotland over the years. This has been highlighted in recent months by National Records of Scotland figures which showed there were over 200 estimated deaths of those experiencing homelessness in 2019 in Scotland; the average age of death was just 39 for women and 43 for men. Many people experiencing homelessness often struggle to access the palliative care (PC) support they need because of multiple complex health issues usually comprising a combination of a physical health condition, mental health issues and substance/alcohol dependency. This significantly impacts their quality of life and ability to access the care they need when dying. The frequent overlap between at least one of the above issues and homelessness are usually coupled with challenges faced by public sector and charitable services, where services are often set-up to address “single issues” ... This creates opportunities for people to fall through the cracks, and highlights the need for a collaborative approach between Local Authorities, Health & Social Care Partnerships, multi-disciplinary clinical teams, PC providers, homelessness support organisations (among others) to ensure the right PC support is accessible and reflects individual needs. In a recent report, Marie Curie for urgent reform of PC support for those

experiencing homelessness and terminal illness.<sup>1</sup>  
<https://bit.ly/3fE6qTx>

#### Specialist Publications

**‘Understanding end-of-life care in Australian hospitals’** (p.7), in *Australian Health Review*.

**‘Public-private collaboration in the provision of palliative care for children and adolescents with cancer: A Chilean experience’** (p.8), in *Cancer Reports*.

**‘Palliative care in Latin America: Are we making any progress? Assessing development over time using macro indicators’** (p.10), in *Journal of Pain & Symptom Management*.

**‘Good quality care for patients with cancer dying in hospitals, but information needs not met: Bereaved relatives’ survey within seven countries’** (p.11), in *The Oncologist*.

**‘Are public health measures and individualised care compatible in the face of a pandemic? A national observational study of bereaved relatives’ experiences during the COVID-19 pandemic’** (p.11), in *Palliative Medicine*.

**Dying in the margins: A literature review on end of life in English prisons’** (p.13), in *Religions*.

1. ‘Dying in the cold; being homeless at the end of life in Scotland,’ Marie Curie, May 2021. **Download at:** <https://bit.ly/3uGvGg2>

Noted in Media Watch 10 May 2021 (#716, p.3):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 3 May 2021 – **‘Palliative care for homeless and vulnerably housed people: Scoping review and thematic synthesis.’** Research has been conducted examining a wide range of issues in relation to end-of-life care (EoLC) for homeless and vulnerably housed people, however, a contemporary scoping review of this literature is lacking. Sixty-four studies, involving 2,117 homeless and vulnerably housed people were included, with wide variation in methodology, population and perspective. The thematic synthesis identified three themes around experience, beliefs and wishes, relationships, and EoLC. Discussion highlighted gaps in the evidence base, especially around people experiencing different types of homelessness. **Abstract:** <https://bit.ly/3eUkC9u>

**N.B.** Search back issues of Media Watch for additional articles on palliative and EoLC for the “homeless” at: <http://bit.ly/2ThijkC>



**Palliative Care Network**

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

## Specialist Publications

### **Increasing awareness of palliative medicine with the emergency department: A quality improvement project**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 1 June 2021 – Referrals for palliative medicine (PM) are more advantageous when initiated in the emergency department as this is the first point of contact for seriously ill patients being admitted to the hospital. This article highlights a quality improvement project initiated to address knowledge gaps in PM with emergency department (ED) staff and to increase referrals for PM from the ED. 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. The results showed that after this educational intervention the number of PM consults increased three-fold. Before the educational intervention, monthly averages for PM were 6 and after rose to 18.9 per month. **Abstract (w. references):** <https://bit.ly/3ySPf8e>

#### **Related:**

- *BMC PALLIATIVE CARE* (Research Square) | In print – Accessed 3 June 2021 – **‘The palliative care illusion on acute wards an ethnographic study of the introduction of a palliative care consultation team.’** This study shows the challenges when two different care cultures meet and attempt to work together. Primary team members in acute care settings may provide good end-of-life care, but this study did not confirm that. However, a fusion is possible, but requires efforts from all involved. Cultural routines and thinking are challenged, but can be overcome. The authors suggest that success with a palliative care consultation team on acute wards requires building relationships and create a team feeling among members of the different cultures... **Full text (click on pdf icon):** <https://bit.ly/3wWUOka>

### **Assisting people with their living, not their dying: Health professionals’ perspectives of palliative care and opioids in interstitial lung disease**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 31 May 2021 – While guidelines recommend early specialist palliative care (PC) referral to improve symptoms and quality of life (QoL), few patients living with interstitial lung disease (ILD) access such care towards the end-of-life. This study aimed to explore Australian respiratory clinicians’ perspectives regarding specialist PC and opioids to understand barriers to optimal care and guide clinical practice improvement initiatives. Four themes were identified: 1) Understanding how to improve patient care and support; 2) The need to dispel stigmatized beliefs and misconceptions; 3) The importance of trusted relationships and good communication; and, 4) The challenges of navigating the healthcare system. Participants discussed the need to implement early specialist PC and symptom palliation to alleviate symptoms, provide emotional support and augment QoL. Specialist PC and opioids were believed to improve patients’ QoL, however, many barriers can make accessing such care challenging. To address these issues, multi-disciplinary collaboration, high-quality communication and trusted therapeutic relationships are crucial throughout the ILD illness journey. **Abstract (w. references):** <https://bit.ly/3vPkfE8>

#### Research Matters

**‘What is realist research, when should we consider it, how and why?’** (p.14), in *Archives of Disease in Childhood*.

**‘Views of patients with advanced disease and their relatives on participation in palliative care research’** (p.15), in *BMC Palliative Care*.

**‘Emotional disclosure in palliative care: A scoping review of intervention characteristics and implementation factors’** (p.15), in *Palliative Medicine*.

#### Publishing Matters

**‘Scientific production about palliative care and communication in online journals: A scoping review’** (p.16), in *Revista Brasileira de Enfermagem*.



## Understanding end-of-life care in Australian hospitals

*AUSTRALIAN HEALTH REVIEW* | Online – 2 June 2021 – The majority of Australian patient deaths occur in hospitals whose care needs to align to the Australian Commission on Safety & Quality in Health Care's National Consensus Statement, essential elements of safe and high-quality EoLC.<sup>1</sup> The authors explored end-of-life care (EoLC) in the ward and intensive care unit (ICU) environment in nine Australian hospitals in a retrospective observational study. In total, 1,693 in-hospital deaths, 356 in ICU, were reviewed, including patient demographics, advance care plans (ACPs), life-sustaining treatments, recognition of dying by clinicians and evidence of the palliative approach to patient care. This, the largest Australian study of hospital deaths revealed only 12% of patients have existing ACPs, recognition of death is predominantly within the last 48 hours of life, with 60% receiving investigations and interventions during this time with late symptom relief. Late recognition of dying can expose patients to active interventions and minimises timely palliative care. **Abstract (w. references):** <https://bit.ly/3piNHQz>

1. 'Essential Elements for Safe & High-Quality End-of-Life Care,' Australian Commission on Safety & Quality in Health Care, June 2015. [Noted in Media Watch, 1 June 2015, #412 (p.6)] **Download at:** <https://bit.ly/3fHNIKB>

**N.B.** Selected articles on EoLC in Australia noted in Media Watch 31 May 2021 (#719, p.2). Search back issues of the weekly report for additional articles on EoLC in "Australia" at: <http://bit.ly/2ThijkC>

## The theorisation of "best interests" in bioethical accounts of decision-making

*BMC MEDICAL ETHICS* | Online – 1 June 2021 – The "best interests" principle is a key component of policies concerned with decision-making in every area of medical practice. The principle of informed consent suggests that persons of sound mind may refuse medical treatment because autonomous persons should decide what is best for themselves. However when autonomous persons demand treatment, their demands are ostensibly limited by what is in their best interests. Often when a patient lacks autonomy – from the barriers to communication arising from developmental immaturity in neonatal intensive care, to temporary, anaesthesia-induced, insensibility in operating theatre, to fluctuating capacity due to dementia, to irreversible loss of consciousness at the end of life – a fundamental principle governing decision-making is that a decision be made in a patient's best interests. While, historically, "best interests" can be found in rhetorical use in moral discourse going back to the eighteenth century, even rhetorical claims about best interests will be underpinned by particular theoretical assumptions. Yet the theoretical basis of best interests is unclear, and thus the role of best interests in future policy remains uncertain. This article presents analysis suggesting that the approach taken to best interests in the bioethics literature is often reductive, focusing predominantly on negative interests in a way that suggests concordance with ideology and a potential for frictions in practice. There is more to say about best interests than much of the bioethics literature suggests. **Full text:** <https://bit.ly/3fH3gyx>

### Related:

- *FRONTIERS IN PUBLIC HEALTH* | Online – Accessed 1 June 2021 – '**DNR and COVID-19: The ethical dilemma and suggested solutions.**' While do-not-resuscitate (DNR) decisions are made in advance in certain medical situations, in particular in the setting of poor prognosis ... the discussion of DNR in relation to acute medical conditions, the COVID-19 pandemic in this example, might impose ethical dilemmas to the patient and family, healthcare providers (HCPs) including physicians and nurses, and to the institution. The literature on DNR decisions in the more recent pandemics and outbreaks is scarce. The unprecedented condition of the COVID-19 pandemic leaves healthcare systems worldwide confronting tough decisions. **Full text:** <https://bit.ly/3fC1QoT>
- *MEDICAL DECISION MAKING* | Online – 29 May 2021 – '**Life support preferences in the context of COVID-19: Results from a national U.S. survey.**' Research conducted before the COVID-19 pandemic showed that patients have a stronger desire to receive life support when they are unaware of its potential harms, such as long recovery and long-term or permanent loss of physical or mental function. In addition, COVID-19 introduces the unfortunate consideration of scarcity, where someone must make decisions about who receives life support and who does not. This study was conducted at the height of the first wave of the COVID-19 pandemic in the U.S., when national discussions about life-supporting scarcity were prevalent. **First page view (w. references):** <https://bit.ly/3c1HyTG>

## **Frames and counter-frames giving meaning to palliative care and euthanasia in The Netherlands**

*BMC PALLIATIVE CARE* | Online – 3 June 2021 – Based on the case of palliative care (PC) and euthanasia in The Netherlands, the authors present an analysis of frames and counter-frames used in the ongoing public debate about these two intertwined topics. Each (counter)frame presents a cultural theme that can act as a prism to give meaning to PC and/or euthanasia. Each frame comprehends a different problem definition, consequences and policy options. Typical word choices and metaphors are identified that can evoke these frames and the underlying reasoning. The frames do not belong to a specific stakeholder but a pattern can be seen in their use that is related to interests and ideology. Two frames about PC were constructed: the *Fear of death* frame, which stresses the hopeless “terminality” of PC and the *Heavy burden* frame, in which PC is too big a responsibility for the relatives of the patient. In addition, two counter-frames were constructed: PC as a contributor to *Quality of life* and *Completion*. With regard to euthanasia, five frames were identified that lead to a problematising definition: *Thou shalt not kill*, *Slippery slope*, *Lack of willpower*, *I am not God*, and *Medical progress*. Five counter-frames offer a non-problematising definition of euthanasia in the debate: *Mercy*, *Prevention*, *Triumph of reason*, *Absolute autonomy*, and *Economic utility thinking*. The debate in The Netherlands on euthanasia and PC is characterized by a plurality of angles that goes beyond the bipolar distinction between the pros and cons of euthanasia and PC. Only with an overview of all potential frames in mind can an audience truly make informed decisions. The frame matrix is not only useful for policymakers to know all perspectives when joining public debate, but also to healthcare workers to get into meaningful conversations with their patients and families. **Full text:** <https://bit.ly/3wTI3He>

## **Limitations in health professionals’ knowledge of end-of-life law: A cross-sectional survey**

*BMJ SUPPORTIVE PALLIATIVE CARE* | Online – 2 June 2021 – Insufficient knowledge about end-of-life (EoL) law can impede the provision of safe and high-quality EoL care. Accurate legal knowledge across health professions is critical in palliative and EoL settings given the reliance on multidisciplinary care. Most research has focused on doctors, finding significant knowledge gaps. The limited evidence about other health professions also suggests legal knowledge deficits. An online pre-training survey was completed by participants enrolled in a national training programme on EoL law. The optional survey collected demographic data and measured baseline legal knowledge and attitudes towards EoL law. This study provides new evidence about legal knowledge across a broad range of health professions. While knowledge levels varied somewhat across professions, knowledge gaps were observed in all professional groups. Education and training initiatives to enhance knowledge of EoL law should be tailored to meet the specific needs of each profession. **Abstract:** <https://bit.ly/3cgGATu>

## **Public-private collaboration in the provision of palliative care for children and adolescents with cancer: A Chilean experience**

*CANCER REPORTS* | Online – 29 May 2021 – In Chile, children and adolescents with cancer in need of palliative care (PC) receive services through a collaborative scheme between the hospitals of the public health system and the non-profit civil society organization Fundación Nuestros Hijos (FNH). FNH has designed a program that complements clinical hospital care, adding benefits that allow families to meet their medical and financial needs. One of the most relevant aspects of this alliance is that it encourages the return of children and adolescents to their homes with their parents through strengthening the skills of caregivers and the delivery of medical and social services. The “transition house” is the best example of the two main characteristics of the pediatric PC program: on one side, it represents the effectiveness of the public-private collaboration between the health system and the FNH, where both institutions complement biomedical and psychosocial services. On the other side, the “transition house” enables the practice of the principles of family-centered care, where all PC efforts take into consideration the emotional, financial, and social needs of the family. Regardless of all the advances described, and although the model presented is efficient, it is necessary to make progress in expanding the availability of home care teams and the existence of “transition houses” in other parts of the country, with the aim of bringing services closer to people. This challenge will require the participation of the state, FNH, and other social organizations and all health establishments, particularly those primary care teams in each city. **Full text:** <https://bit.ly/34zNkra>



## Consensus on a conversation aid for shared decision-making with people with intellectual disabilities in the palliative phase

*JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES* | Online – 1 June 2021 – The aim of this study was to develop a consensus-based tool for shared decision-making (SDM) with people with intellectual disabilities in the palliative phase. The authors conducted a two-round Delphi consensus procedure. The components of the tool they developed were considered “relevant” or “highly relevant.” The feedback from the expert panel led to improvements, for instance with respect to terminology. The final conversation aid consists of four themes (“Who are you,” “Illness/End-of-life,” “Making choices,” and “Application”) and has a guiding premise. Every conversation starts with the premise “you are important.” In this way, we try to create a safe environment where people are able to say what really matters to them. Each theme has different components that do not have to be followed in any particular order. To clarify this, the different components have names rather than numbers. In the theme “Who are you” information is collected to find out who the person with intellectual disability trusts, how they want to talk, what they enjoy, how much information they want, and where they feel safe. In the theme “Illness/End-of-life”, information is collected to find out what the person with an intellectual disability knows and wants to know about their illness. The theme “Making choices” investigates if the person with an intellectual disability understood all the information and if they are ready to make a choice. The theme “Application” examines who needs to be informed about the decision that has been made, and investigates whether the decision is still right or needs to be revised. The conversation aid should be used in a flexible way and could be applicable for people with all levels of intellectual disabilities. **Full text:** <https://bit.ly/3ioRFpF>

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

## Nobody wants to talk about dying: Facilitating end-of-life discussions

*JOURNAL OF CONTINUING EDUCATION IN NURSING*, 2021;52(6):287-293. This study investigated the association between nursing staff and end-of-life (EoL) discussions in an assisted living facility. Although mandated, these conversations often are deficient due to healthcare providers’ limited knowledge on advance care documents. Facility staff underwent EoL training to identify their own reservations that prevent involvement with advance directive (AD) completion, to develop AD competency, to recognize the ramifications when ADs are not documented, and to role-play to experience different character viewpoints. Group discussions and interview data were summarized into four main themes: 1) Not qualified to broach the EoL documents; 2) Reluctance to get involved; 3) Right place, right time, and right words; and, 4) Who wants to think about death? Staff acknowledged the value of in-service education to alleviate their uncertainty on the

subject matter, gaining confidence, proficiency, and perspectives with EoL planning. **Abstract:** <https://bit.ly/3hYDKGu>

### Reconceptualizing how to support surrogates making medical decisions for critically ill patients

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2021;325(21):2147-2148. Many clinicians may consider that the best way to support surrogate decision-makers is to focus on providing them the medical information needed to make informed choices, based on the assumption that good decisions will reliably flow from good information. However, this approach has repeatedly failed to influence treatment intensity at the end of life or lessen the psychological distress experienced by surrogates, probably because it overlooks key aspects of what makes the surrogate role so difficult. **Full text:** <https://bit.ly/3wQqBDp>

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Would the *Journal of Continuing Education in Nursing* be of interest to a colleague?

## Related:

- *JOURNAL OF AGING & SOCIAL POLICY* | Online – 3 June 2021 – ‘**End-of-life planning: Normalizing the process.**’ End-of-life (EoL) planning occurs across the U.S. at a frequency of below 50%, suggesting a new approach to encourage action is in order, especially as COVID-19 and other potentially lethal conditions emerge. Utilizing data from a multi-year survey of 2,614 adults in Nebraska, this study examined demographic factors related to completion of EoL planning documents, and identified people with whom EoL wishes could, and had been discussed. Logistic regression estimates indicated more reliance on non-healthcare providers for EoL discussions. This shift with whom people would discuss EoL wishes may afford others an opportunity to encourage EoL discussions. **Abstract:** <https://bit.ly/3chk650>
- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 1 June 2021 – ‘**English and Spanish-speaking vulnerable older adults report many barriers to advance care planning.**’ Barriers must be considered when developing customized advance care planning (ACP) interventions for diverse older adults. English- and Spanish-speaking older adults reported 26 unique barriers to ACP... The most common were: (patient-level) discomfort thinking about ACP (60%), wanting to leave health decisions to “God” (44%); (family/friend-level) not wanting to burden friends/family (33%), assuming friends/family already knew their preferences (31%); (clinician/system-level) assuming doctors already knew their preferences (41%), and mistrust (37%). **Abstract:** <https://bit.ly/3uLMVgk>
- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 1 June 2021 – ‘**The compliance of end-of-life care preferences among older adults and its facilitators and barriers: A scoping review.**’ Key components identified in the compliance of end-of-life care (EoLC) preferences: 1) Supportive policy; 2) Supportive environment; 3) Cultural characteristics; 4) Advance care planning (ACP); 5) The concordance of EoLC preferences between patients and surrogate decision makers; 6) Prognosis awareness; and, 7) Patient’s health status and the type of disease. Facilitators for the compliance of EoLC preferences included enactment of relevant policy, sufficient care institutions, the utilization of ACP, and poor health status. **Abstract (w. references):** <https://bit.ly/3pmAXs6>
- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 2 June 2021 – ‘**Advance care planning among older Canadians amid the COVID-19 pandemic: A focus on sexual orientation.**’ The authors examine the extent to which COVID-19 has influenced advance care planning (ACP) actions and discussions among older adults: those at the greatest risk of COVID-19 illness and death and those most addressed in news and policy decisions. The authors also focus on lesbian, gay, and bisexual (LGB) persons... Specifically, the authors examine the extent of ACP document completion and revision and discussion engagement by older LGB and heterosexual women and men in Canada, both before and since the onset of the COVID-19 pandemic. **Full text:** <https://bit.ly/3z6Wkly>

## Palliative care in Latin America: Are we making any progress? Assessing development over time using macro indicators

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 May 2021 – Monitoring and reporting palliative care (PC) development serves to identify progress as well as remaining challenges for improvement. The authors conducted a secondary analysis of the data collected for the 2012 and 2020 editions of the ‘Atlas of Palliative Care in Latin America’ using indicators on policy, education, access to medicines and service provision.<sup>1,2</sup> The number of countries with a national PC plan increased from 5 (29%) to 9 (53%); percentage of medical schools with PC as an independent subject at the undergraduate level grew from 4.2 to 17.1%; distributed opioid morphine equivalence increased from 6.6 to 7.1 mg/capita; and, number of services increased from 1.5 to 2.6/million. The number of PC services was correlated to the proportion of medical schools which included PC ... but not associated with the existence of a national plan. With the standardization of the indicators, three groups ranked by development were identified. Significant advances in PC development in Latin America have been achieved. **Abstract (w. references):** <https://bit.ly/3vEj1eU>

1. ‘Atlas de Cuidados Paliativos de Latinoamérica,’ Asociación Latinoamericana de Cuidados Paliativos, 2012. [Noted in Media Watch 7 January 2013 (#287, p.8)] **Download at:** <https://bit.ly/3ldpJmu>

**N.B.** Click on pdf icons to access either Portuguese, Spanish or English language editions of the Atlas.

2. ‘Atlas de Cuidados Paliativos de Latinoamérica,’ Asociación Latinoamericana de Cuidados Paliativos, 2020. **Download Spanish edition of the atlas at:** <https://bit.ly/3c5PQtr>

## Good quality care for patients with cancer dying in hospitals, but information needs not met: Bereaved relatives' survey within seven countries

*THE ONCOLOGIST* | Online – 1 June 2021 – Recognized disparities in quality of end-of-life care exist. The authors assess the quality of care for patients dying from cancer, as perceived by bereaved relatives, within hospitals in seven European and South American countries (i.e., Argentina, Brazil, Uruguay, Germany, Norway, Poland and the U.K.). The authors' findings suggest many elements of good care were practiced, but improvement in communication with relatives of imminently dying patients is needed. Previous studies have shown that bereaved relatives' views represent a valid way to assess care for dying patients in the last days of their life. The Care Of the Dying Evaluation questionnaire is a suitable tool for quality improvement work to help determine areas where care is perceived well and areas where care is perceived as lacking. Healthcare professionals need to sustain high quality communication into the last phase of the cancer trajectory. In particular, discussions about what to expect when someone is dying and the provision of hydration in the last days of life represent key areas for improvement. **Abstract:** <https://bit.ly/2Ra03hg>

### Using the nurse coaching process to support bereaved staff during the COVID-19 crisis

*JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 2 June 2021 – Nurses are confronting a number of negative mental health consequences owing to high burdens of grief during COVID-19. Despite increased vaccination efforts and lower hospitalization and mortality rates, the long-term effects of mass bereavement are certain to impact nurses for years to come. The nurse coaching process is an evidence-based strategy that nurse leaders can use to assist staff in mitigating negative mental health outcomes associated with bereavement. The End-of-Life Nursing Education Consortium brought together a team of palliative nursing experts early in the pandemic to create resources to support nurses across settings and promote nurse well-being. This article shares a timely resource for health systems and nursing administration that leverages the nurse coaching process to support bereaved staff in a safe and therapeutic environment. **Abstract:** <https://bit.ly/3uT2qeV>

## Are public health measures and individualised care compatible in the face of a pandemic? A national observational study of bereaved relatives' experiences during the COVID-19 pandemic

*PALLIATIVE MEDICINE* | Online – 31 May 2021 – This research represents the first U.K. study of bereaved relatives' views about quality of care and family support provided during the last days of life and highlights the challenges and emotions experienced during the COVID-19 pandemic. COVID-19 studies from The Netherlands, U.S. and China, have explored acute grief and the psychological impact during the bereavement period. This study, however, closely examines the quality of the dying experience which can have subsequent impact on grief. Though challenging, public health measures in response to a pandemic can be actioned in ways that maintain high quality of end-of-life care for patients and their families. Care services must acknowledge the significance of individual deaths and ensure active approaches to support those who are bereaved. This may achieve headway in healing the barriers between what was required to limit the spread of the virus and the subsequent compromise on individualized care. Recognising dying, communicating holistic aspects of care, and enabling visits whenever is possible, should continue to be priorities, during the ongoing pandemic. These approaches should be allied with risk stratification measures to help identify those in most need of bereavement support, including the identification of those unable to visit. **Full text:** <https://bit.ly/2Twab4X>

### Related:

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 31 May 2021 – **'COVID-19 family support team: Providing person and family-centered care during the COVID-19 pandemic.'** COVID-19 brought about many disruptions to our world and communities. The hospital visitation restrictions were one of the more, if not most, challenging aspects of psychosocial care for patients and families. It was difficult to anticipate the emotional toll visitation restrictions would take on patients, families, and staff. The Palliative Care team at a large, urban, Midwestern academic medical center [in the U.S.] created an interprofessional Family Support Team in the spring of 2020 to address the psychosocial needs of the families of critically ill COVID-19 patients. **Abstract:** <https://bit.ly/3ily75x>

## Identification of palliative care needs among people with dementia and its association with acute hospital care and community service use at the end-of-life: A retrospective cohort study using linked primary, community and secondary care data

*PALLIATIVE MEDICINE* | Online – 31 May 2021 – This is one of the first studies to use linked data across primary, community and hospital services in England to explore end-of-life care. In this cohort of people dying with dementia, identification of palliative care (PC) needs in the last year of life was associated with more contacts with primary and community care professionals, and a lower risk of multiple non-elective admissions to hospital in their last 90 days of life. Only 19.7% of people with dementia [i.e., the patient population studied] had their PC needs formally identified before their last 90 days of life. Further research is needed to understand strategies to help primary care physicians to improve recognition of PC needs in their patients with dementia and to understand the mechanisms that lead to a lower risk of multiple hospital admissions in this population. **Full text:** <https://bit.ly/2SIB05o>

**N.B.** Search back issues of Media Watch for additional articles on PC in “dementia” care at: <http://bit.ly/2ThijkC>

## The terms supportive and palliative care: Analysis of their prevalence and use quasi-systematic review

*PALLIATIVE MEDICINE IN PRACTICE* | Online – 26 May 2021 – It seems that the term supportive care (SC) is better perceived by medical personnel, patients and their families. The analysis of publications from recent years reveal that the term palliative care (PC) is used 18.5 times more often in scientific literature than the term SC. Similarly, population-wise, the term PC is searched more often in Google, which suggests that it is much more ingrained in social consciousness. In addition, the trend associated with the use of the term PC has been increasing in the last 10 years, while the use of the term SC oscillates around the same level. The algorithm of Google designates a number that determines the popularity of a term in relation to the most frequently searched term and per number of searches in a given country. Despite the fact that the tool is not perfect, its extensive database makes it one of the most objective criteria for the assessment of the interests of a society and the popularity of a given term, and in the case of the terms PC and SC – in total as well as in individual countries. A 2011 survey by the Centre to Advance Palliative Care [in the U.S.] revealed that the term PC is only slightly or not at all correctly understood by respondents, many of whom identify it with end-of-life care which is intrinsically associated with death; therefore, the authors’ believe that it is very important to promote the term SC as an alternative. SC indicates a more holistic aspect of PC, namely supporting patients and providing them with comfort during their illness and death. Importantly, patients’ approach to the term is better and more optimistic. It turns out that the term PC has negative connotations. It’s uncertain, however, whether its perception would not change with the popularization of the term SC in the context of PC, with SC taking on the negative connotations associated with PC. **Full text (click on pdf icon):** <https://bit.ly/2Tp9oCF>



**N.B.** The Center to Advance Palliative Care conducted a more recent survey on public awareness and understanding of PC. See ‘Palliative care still relatively unknown among the general public: Shows education for consumers and physicians necessary to make a difference.’ [Noted in Media Watch 12 August 2019 (#626, p.1)] <http://bit.ly/2ZXaHXX>

## Advance care planning in pediatric serious illness: Centering in the family experience

*PEDIATRICS* | Online – 1 June 2021 – As advancements enable us to manage increasingly complex pediatric illness, we must be purposeful in ensuring that we meet patient and family goals. Thompson *et al* examine the impact of an advanced care planning intervention, the Family-Centered Advance Care Planning for Teens with Cancer (FACE-TC), on families’ assessment of their experiences in caregiving and on familial distress.<sup>1</sup> The FACE-TC is a National Cancer Institute-recognized evidence-based intervention developed to foster goals of care discussions and completion of advanced directives between adolescent

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patients and their families. The authors conducted a multicentered randomized control trial with adolescents and young adults with cancer, along with their families, over three years. Patient-family dyads received either three weekly structured sessions through the FACE-TC intervention or treatment as usual. Participants in the FACE-TC intervention had a statistically significant increase in positive estimations of their caregiving, with no notable difference in distress. **Introductory:** <https://bit.ly/3uF5oLn>

**N.B.** 'Pediatric advance care planning and families' positive caregiving appraisals: A randomized clinical trial,' *Pediatrics*, published online 1 June 2021. **Abstract:** <https://bit.ly/3fEPUmQ>

**Related:**

- *PEDIATRICS* | Online – 1 June 2021 – '**Prognostic communication between oncologists and parents of children with advanced cancer.**' How oncologists disclose information about disease progression and incurability and how prognostic communication impacts parental understanding of prognosis are poorly understood. The authors characterize communication strategies used by pediatric oncologists to share prognostic information across a child's advancing illness course, and explore relationships between different communication approaches and concordance of oncologist-parent prognostic understanding. When oncologists provided direct statements about incurability, prognostic understanding appeared to improve. **Abstract:** <https://bit.ly/34CJw8Y>

**Dying in the margins: A literature review on end of life in English prisons**

*RELIGIONS* | Online – 4 June 2021 – This article can be read as a starting point for future research on dying in English prisons. While dying in prison has wider implications for various groups within prison, the majority of dying in prison is not witnessed by people in the general population and thus not clearly understood. There is little evidence that helps understand the experience of dying from the perspective of those dying in prison. While deaths in custody are investigated, more attention could be given to what happens prior to death. This article has looked at four types of dying related to prison: suicides in prison, deaths in older age, deaths post-release, and COVID-19 deaths. These four "types" only begin to scratch the surface of how loss, death, and dying are inherent within custodial environments. In England, there is a paucity of research that tries to understand dying from the perspective of people in prison, yet there is increased awareness that deaths in custody require emotional labour from prison healthcare staff and prison officers... Involving dying prisoners in research will help

illuminate the complexity and diversity of dying that occurs in prison. Putting dying in prison on the research agenda can help to take dying in prison out of the margins and into the collective consciousness of society. Furthermore, open and honest conversations about dying in prison, and acknowledging that prison is in fact a place where people die, will help those dying in prison to achieve a "good death" and can help making the Dying Well in Custody ambitions a reality. **Full text:** <https://bit.ly/3uT6i71>

**Extract from *Religions* article**

For prison healthcare staff, palliative and end-of-life care is often something for which they have not received training. Prison officers working with older prisoners similarly describe not anticipating having to work with this group when they started working in the prison service.

**N.B.** End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report, last updated 1 May 2021, can be downloaded at the Palliative Care Network website at: <http://bit.ly/2RdegnL>

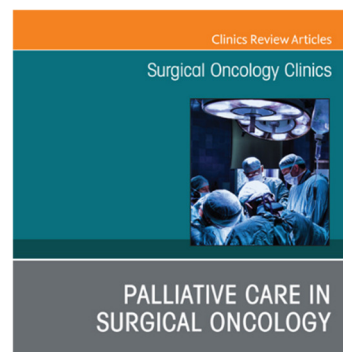


**Media Watch: Access Online**

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.17.

## Palliative care in surgical oncology

*SURGICAL ONCOLOGY CLINICS OF NORTH AMERICA*, 2021;30(3). In a discipline such as oncology, PC has particular relevance. Many patients with cancer are in need relief of symptoms, pain, and the existential stress of a cancer diagnosis that may be life-limiting. As such, the integration of palliative care (PC) needs to be “best practice” in oncology – not only at the end of life but also throughout the entire patient care journey. Concurrent with the increased recognition of the importance of PC in oncologic care, there has been a growing body of academic scholarship focused on the impact of PC in the care of patients with cancer. This issue of the journal covers a number of important topics, including selecting patients for palliative procedures, as well as approaches to malignant bowel obstruction, peritoneal carcinomatosis, and strategies for optimizing perioperative pain management for the patient with cancer. In addition, other important topics, such as how to navigate difficult discussions, breaking bad news, and a detailed overview of the ethical considerations in caring for patients with advanced malignancy, are provided. The wide range of topics, as well as the depth covered in each article, presents the readers with an unparalleled opportunity to learn about the role of PC in surgical oncology. **Journal contents page:** <https://bit.ly/2S3SvNM>



Noted in Media Watch 29 March 2021 (#710, p.12):

- *SURGERY* | Online – 18 March 2021 – ‘**Palliative medicine and end-of-life care in surgery.**’ Surgeons are privileged to offer treatments that often cure disease. Optimizing comfort for those who cannot be cured is also a core part of every clinician’s duty: surveys repeatedly tell us that when death is approaching, people value quality of life above length of survival. Recognizing when someone is dying can be difficult. Tools exist to help; it is worth noting that emergency presentation with life-threatening symptoms can be a marker of poor prognosis. Clear, effective communication is crucial: understanding the patient’s perspective and expectations is vital before attempting to offer information that allows future care planning. **Abstract:** <http://bit.ly/319k3ID>

Noted in Media Watch 30 November 2020 #694, p.5):

- *THE AMERICAN SURGEON* | Online – 24 November 2020 – ‘**Surgical palliative care: Where are we in 2020?**’ Dr. Balfour Mount, a retired urologic surgeon is considered the father of North American palliative care (PC). Dr. Geoffrey P. Dunn, a retired general surgeon and hospice and palliative medicine specialist along with other like-minded surgical colleagues were instrumental in developing the field of surgical PC in the U.S. Dr. Olga Jonasson, championed the American Board of Surgery becoming one of the sponsoring boards of the hospice and palliative medicine certifying exam. Dr. Anne Mosenthal advocated for PC to be integrated as parallel clinical aims so espoused in the ‘Trauma Quality & Improvement Program Palliative Care Best Practice Guidelines.’ **Abstract (w. references):** <https://bit.ly/2V0IGyZ>

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

## Research Matters

### What is realist research, when should we consider it, how and why?

*ARCHIVES OF DISEASE IN CHILDHOOD* (Education & Practice Edition) | Online – 3 June 2021 – Clinicians with medical training work in an environment where randomised controlled trials (RCTs) overshadow other forms of medical evidence in informing clinical practice, policy and guidance. It is no surprise that clinical researchers tend towards RCTs, since they are considered the “gold standard” of research, placed firmly at the top of traditional hierarchies of evidence. RCTs are grounded in a positivist paradigm, seeking to answer the question “does this intervention work?” by generating and testing a hypothesis in order to

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propose or dispute a particular truth. This approach may work well for research about specific medical treatments or technologies, including drug treatments such as a new pain medication. However, it is limited when it comes to research that examines less well-circumscribed, complex interventions, such as pain management through a new clinic or play therapy. Furthermore, in the “real world” of clinical practice, it is rarely possible to control the environment in which a healthcare intervention is delivered. In paediatrics, the nature of a child’s illness or ability to comply with medical treatments is multifactorial, depending on their medical condition and on other factors including their family dynamics, access to education, housing and mental health. **Abstract:** <https://bit.ly/3uMtsfr>

### **Views of patients with advanced disease and their relatives on participation in palliative care research**

*BMC PALLIATIVE CARE* | Online – 5 June 2021 – Patients with advanced disease may not be invited to participate in research based on the assumption that participation would be too burdensome for them. This study highlights some important aspect in research with patients with advanced illness and their relatives. Most of the study participants identified their participation as an interesting experience giving them an opportunity to express their opinion and to do some good such as support research or improve care. Participation in a longitudinal study with repetitive measurements was not experienced as unpleasant, and respondents were able to withdraw from the study if it became too burdensome. The need to respect patient’s autonomy should be acknowledged in research. This article supports evidence that patients with advanced illness should be given the option to participate in research as they are able to decide for themselves. **Full text:** <https://bit.ly/3fRVEck>

### **Emotional disclosure in palliative care: A scoping review of intervention characteristics and implementation factors**

*PALLIATIVE MEDICINE* | Online – 29 May 2021 – Emotional disclosure is the therapeutic expression of emotion. It holds potential as a means of providing psychological support. However, evidence of its efficacy in palliative settings is mixed. This may be due to variation in intervention characteristics. This review maps the range of emotional disclosure-based interventions tested in people with advanced disease and proposes a multi-level taxonomy classifying their core characteristics. This is important as these low-cost interventions have therapeutic potential in palliative care settings. The review could help researchers adopt a common language to describe emotional disclosure-based interventions for people with advanced disease (and perhaps beyond) and inform design of future research, including systematic reviews and meta-analyses. The authors describe paths for researchers to move forward with the development of interventions that can be practically implemented, drawing on key facilitators and barriers. It also provides recommendations into promising avenues for future intervention evaluation to help guide selection of appropriate outcome measures. Additionally, the paper acts as an exemplar of a review approach that may be used to inform development and evaluation of complex, multi-component interventions where pre-existing evidence is mixed. **Full text:** <https://bit.ly/2RYhxxB>

## **Publishing Matters**

### **Is rapid scientific publication also high quality? Bibliometric analysis of highly disseminated COVID-19 research papers**

*LEARNED PUBLISHING* | Online – 1 June 2021 – This review of the most widely disseminated COVID-19 research papers at the early stage of the pandemic shows a preponderance of low-quality case series with few studies adhering to good standards of reporting. Poor quality research is not new and emphasizes, with greater information availability, the need for adherence to established good practice in transparency of reporting, that is, funding, competing interests, protocol registration. As subsequent waves of the pandemic occur, these findings highlight the need for cautious interpretation of research and emphasize the increasingly vital role and responsibility that journals have in ensuring rigorous high-quality publications particularly during a pandemic. **Full text:** <https://bit.ly/2SOxhDs>

## Scientific production about palliative care and communication in online journals: A scoping review

*REVISTA BRASILEIRA DE ENFERMAGEM*, 2021;74(2). The findings revealed a significant number of articles related to communication in palliative care (PC), which mainly address topics such as the importance of communication, communication strategies, breaking the bad news, and training professionals/staff for communication in PC. The profile traced through the results and discussed in this study, as well as the low level of evidence, conjecture the practice of PC, still largely performed in an empirical way and without theoretical-scientific basis. Associated with the limited knowledge on this subject, the inability to carry out actions through communication is characterized as a barrier to good quality care, involving the varied needs of human beings. This review showed that communication strategies are seldom used and that little training is done to use them. It is possible to affirm that professionals need to be better informed about “palliative care and communication,” based on the increase in chronic diseases, and that knowing communication strategies is mandatory when seeking a humanized and good quality healthcare. Therefore, given the results, it is expected that the mapping on communication in PC will motivate new studies, in order to configure a scenario of qualified scientific production and with more strength of evidence in the area, to present contributions beyond the thematic awareness and serve as support to reformulate and restructure related communication practices. It is hoped that, in this way, it will be possible to improve, in addition to scientific production, assistance in PC and communication. **Full text:** <https://bit.ly/3fKdi1B>

**N.B.** English language article.

### 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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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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Barry R. Ashpole, Ontario CANADA

e-mail: [BarryRAshpole@bell.net](mailto:BarryRAshpole@bell.net)