

## 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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For doctors, the question “Would you be surprised if this patient died in the next 12 months?” is meant to help us think about when the discussion [about care planning] might be relevant. But our surprise (or otherwise) has been shown to be a very poor indicator of the likelihood of death.

‘Talking about death’ (p.9), in the *British Medical Journal*.

## U.S.A.

### Cannabis in hospice: Growing demand and acceptance for end-of-life care

*FORBES* | Online – 25 June 2019 – In hospices across North America, medical cannabis is increasingly replacing mind-muddling medications to enable patients to experience their final days relaxed and without pain, able to interact with loved ones consciously and coherently. The utility of cannabis in elder-care and palliative settings is supported in an important new study...<sup>1</sup> A total of 310 palliative care professionals, including nurses, administrators and physicians from 40 different states responded to a survey on practice, experience and opinions regarding medical cannabis, as part of the largest national survey on this topic to date. <http://bit.ly/2FyJZN7>

1. ‘A survey of hospice professionals regarding medical cannabis practices,’ *Journal of Palliative Medicine*, published online 16 May 2019. **Abstract:** <http://bit.ly/2JMncAg>

**N.B.** Additional articles on cannabinoids in hospice and palliative medicine noted in 29 April 2019 issue of Media Watch (#612, p.9).

### Specialist Publications

‘Shackled at the end of life: We can do better’ (p.5), in *American Journal of Bioethics*.

‘Systematic review of the hospice performance literature’ (p.7), in *Health Care Management Review*.

‘New guidelines aim to expand palliative care beyond specialists’ (p.8), in *Journal of the American Medical Association*.

‘Home-based palliative care: Toward a balanced care design’ (p.10), in *Journal of Palliative Medicine*.



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## Not all Americans have a fair path to a good death – racial disparities are real

*THE CONVERSATION* | Online – 24 June 2019 – What does it mean to “die well”? The world got an idea recently from the 92-year-old Buddhist monk and peace activist Thich Nhat Hanh, who popularized mindfulness and meditation in the U.S. The monk returned to his home in Vietnam to pass his remaining years. Many admired his desire to live his remaining time in peace and dignity. Researchers from the University of California, San Diego recently did a literature search to understand what Americans might consider to be a “good death” or “successful dying.”<sup>1</sup> As can be expected, their findings varied. People’s views were determined by their religious, social and cultural norms and influences. The researchers urged healthcare providers, caregivers and the lay community to have open dialogues about preferences for the dying process. As scholars who study social health and human services psychology, we found something missing in these conversations – how race impacts life span. It’s important to recognize that not everyone has an equal chance at “dying well.” <http://bit.ly/2X5UD8Q>

1. ‘Defining a good death (successful dying): Literature review and a call for research and public dialogue,’ *American Journal of Geriatric Psychiatry*, 2016;24(4):261-271. [Noted in 1 February 2016 issue of Media Watch (#447, p.6)] **Abstract (w. list of references):** <http://bit.ly/2YeeQ92>

**N.B.** Link to the full text of the *American Journal of Geriatric Psychiatry* article is embedded in the text of *The Conversation* article. Additional articles on ethnic and racial disparities in the provision and delivery of palliative and end-of-life care in the U.S. noted in 4 February 2019 issue of Media Watch (#600, p.3).

## Many doctors are terrible at breaking bad news. These Northwest doctors want to change that

OREGON | *The Seattle Times* (State of Washington) – 24 June 2019 – The botched delivery of his grim diagnosis left [Dr. Ron] Naito determined to share one final lesson with future physicians: Be careful how you tell patients they’re dying. Since August, when he calculated he had six months to live, Naito has mentored medical students at Oregon Health & Science University and spoken publicly about the need for doctors to improve the way they break bad news. “Historically, it’s something we’ve never been taught,” said Naito, thin and bald from the effects of repeated rounds of chemotherapy. “Everyone feels uncomfortable doing it. It’s a very difficult thing.” Robust research shows that doctors are notoriously bad at delivering life-altering news, said Dr. Anthony Back, a professor of medicine at the University of Washington, who wasn’t surprised that Naito’s diagnosis was poorly handled. “Dr. Naito was given the news in the way that many people receive it,” said Back... “If the system doesn’t work for him, who’s it going to work for?” Up to three-quarters of all patients with serious illness receive news in what researchers call a “suboptimal way,” Back estimated. <http://bit.ly/2xdrppo>

### Related

- *THE NEW YORK TIMES* | Online – 23 June 2019 – “**Don’t tell me when I’m going to die.**” We are living through a Cambrian explosion of personalized information – every time we hit return, our preferences seem to reproduce themselves parthenogenetically. Our phones are geysers, frothing update after update that we can’t possibly absorb but somehow feel compelled to try. That applies to our health, too. We have the ability to scan our entire bodies for the tiniest irregularities. We can spit into a mail-order test tube and find out what secrets are encoded in our genomes. Now that the technology is here, it’s hard to ignore it. And given the option of knowing as much as we can all of the time, it seems a bit old-fashioned, and possibly foolhardy, to decide to know less about the thing that might kill us. <https://nyti.ms/2xaiQvd>



### Media Watch Online

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

## International

### How Jews, Christians and Muslims disagree on medical ethics

ISRAEL | *Breaking Israel News* (Bet Shemesh) – 24 June 2019 – Eight Orthodox rabbis, two Catholic priests, one Sunni Muslim *imam* (religious leader) and a Sunni Muslim *kadi* (religious judge) were asked to comment on four hypothetical questions on medical ethics. Two pediatrician neonatologists, one pediatric neurologist and Israel Prize-winning expert on Jewish medical ethics and a professor at the Hebrew University's Faculty of Medicine presented the clergymen with a questionnaire related to four simulated cases – Case 1, a non-viable, extremely premature infant; Case 2, a severely asphyxiated full-term infant with extensive brain damage; Case 3, a small pre-term infant with severe brain hemorrhage and likely extensive brain damage; and Case 4, a full-term infant with Down syndrome and a severe heart malfunction. All were asked to present the approach of their religious/ethical approach. Their answers ... showed major differences among the three religious opinions in the definition of viability and in their approaches to quality of life.<sup>1</sup> The aim of the study was to describe the attitudes of the three major monotheistic religions when encountering four complex neonatal situations. Israel's population consists of 75.6% Jews, 20.6% Mus-

lim Arabs, 4.2% Christian Arabs or others. It is “diverse, with people of different religions, many of whom seek spiritual guidance during ethical dilemmas,” wrote the authors. “It is paramount for healthcare providers to be familiar with different religious approaches. Neonatologists must be sensitive to culture and religious when dealing with major ethical issues in the neonatal intensive care unit.” <http://bit.ly/2N9pTzi>

#### Specialist Publications

**'Evaluating a human rights approach to health in the Indian context: Emerging needs and challenges'** (p.9), in *Journal of Human Rights & Social Work*.

**'British Medical Association votes to poll members on its assisted dying stance'** (p.13), in *British Medical Journal*.

**'Royal Australian College of General Practitioners releases position statement on voluntary assisted dying'** (p.14), in *NewsGP*.

1. 'Four theoretical cases and three monotheistic approaches: A pilot study,' *Israel Medical Association Journal*, 2019;21(5):314-317. **Download/view full text at:** <http://bit.ly/2RyHkbe>

### Government to increase access to hospice care by 2023

KOREA | *The Korea Times* (Seoul) – 24 June 2019 – The government ... will make hospice care more accessible for terminally ill patients by offering more end-of-life (EoL) care, easing eligibility and increasing counseling. The plan is part of the Ministry of Health & Welfare's comprehensive program to increase access to palliative care (PC), respect EoL decisions made by patients, and improve their families' quality of life. The move came as the number of patients who end life-sustaining treatment has been rising – from 5,046 in 2008 to 17,333 in 2017. However, support from the government and local communities is barely meeting the growing demand. Current EoL care is centered on providing inpatient services in hospice facilities, which that account for nearly half of all care service providers. The government plans to provide additional services focused on nearly doubling the number of home care specialists and consultants from 33 to 60 and 25 to 50, respectively, by 2023. According to a survey by the National Cancer Center, 60.2% of Koreans want to die at home with family members by their side, but only 14.4% did so in 2017. In the case of cancer patients this was only 6.2%. Currently, those who suffer from cancer, acquired immune deficiency syndrome (AIDS), chronic obstructive pulmonary disease and chronic liver cirrhosis receive state-run PC, but the government will expand eligibility to 13 diseases for adults and eight for children to meet global standards. <http://bit.ly/2NiGsIW>



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Noted in Media Watch 25 March 2019 (#607, p.4):

- KOREA | *The Hankyoreh* (Seoul) – 20 March 2019 – ‘**Health Ministry expands scope of “life-sustaining” treatments that can be discontinued.**’ Discontinuation of life-sustaining treatment will also be allowed with the consent of the patient’s family members rather than by the patient’s doctor only, with relaxed conditions for family members who cannot be contacted to provide their consent. The term “life-sustaining treatment” refers to medical procedures without healing effects that are performed on terminal-stage patients whose conditions are no longer treatable by modern medicine; their sole aim is to prolong the patient’s life. The new measures expand the scope of procedures, which currently include cardiopulmonary resuscitation, respirator use, hemodialysis, and the administration of anti-cancer agents. <http://bit.ly/2ulfuo2>

Noted in Media Watch 4 February 2019 (#600, p.4):

- KOREA | *The Korea Herald* (Seoul) – 30 January 2019 – ‘**Over 35,000 patients refused life-sustaining treatment since last year.**’ Under the law, any individual over the age of 19 can submit a written form in advance indicating his or her intention of refusing treatment, even before receiving a diagnosis of terminal illness. Patients can also exercise the right to die naturally if two doctors certify that they they are expected to die within a few months. If the patient is incapable of expressing his or her wishes and has not submitted the form in advance, the doctor in charge can terminate life-sustaining treatment with the confirmation of another doctor and a statement from the family that the patient would not want the treatment. A total of 35,431 patients – 21,291 male patients and 14,140 female patients – had forgone life-prolonging medical treatment in keeping with the law. <http://bit.ly/2CYSmzk>

**N.B.** Additional articles on EoL care in South Korea noted in 7 January 2019 issue of Media Watch (#596, p.8).

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- FRANCE | BBC News (London) – 28 June 2019 – ‘**Vincent Lambert: French court ends life support tug-of-war.**’ France’s highest court has given a final ruling that doctors can stop feeding a man who has been in a persistent vegetative state since a road accident nearly 11 years ago. The Court of Cassation overturned an appeal court ruling issued on 20 May. The case of quadriplegic Vincent Lambert, 42, has been at the centre of the right-to-die debate in France. The European Court of Human Rights ruled against the parents in 2015 but doctors did not immediately fulfil the plan to turn off his life support until last month, because of security concerns. <https://bbc.in/2Xqqa8i>
- U.K. | *The Sunday Times* (London) – 23 June 2019 – ‘**GPs consider dropping opposition to assisted dying.**’ The Royal College of General Practitioners is to consult its more than 53,000 members on whether to drop opposition to assisted dying. The move by the college that represents family doctors comes just three months after the Royal College of Physicians dropped its opposition to assisted dying and adopted a neutral stance. The governing council of the GPs’ college decided to seek family doctors’ views on assisted dying. The move comes six years after its previous consultation on the subject. <http://bit.ly/31OcqQF>

Noted in Media Watch 25 March 2019 (#607, p.6):

- U.K. | *The Daily Telegraph* (London) – 21 March 2019 – ‘**Royal College of Physicians drops their opposition to assisted dying, following controversial poll.**’ The Royal College of Physicians has dropped its opposition to assisted dying, following a controversial poll. The college will adopt a “neutral” stance after a survey of its 36,000 members about whether the law should be changed to permit doctor-assisted dying. <http://bit.ly/2UMXkaj>

## Specialist Publications

### **Shackled at the end of life: We can do better**

*AMERICAN JOURNAL OF BIOETHICS*, 2019;19(7):61-63. The obligation to provide care at the end of life that preserves human dignity in the correctional setting is not only an ethical one but has legal underpinnings as well. In *Estelle v. Gamble* the U.S. Supreme Court established that deliberate indifference to serious medical needs of prisoners is a violation of the Eighth Amendment, which prohibits “cruel and unusual punishment.” Subsequent case law has established that the incarcerated have a *de facto* right to a “community standard” of healthcare (*Estelle v. Gamble*, 1976). Similarly, the United Nations ‘Standard Minimal Rules for the Treatment of Prisoners’ (Mandela Rules) dictate that “all prisoners shall be treated with the respect due to their inherent dignity and value as human beings” and “enjoy the same standards of healthcare that are available in the community” (McCall-Smith, 2016). **First page view (w. link to references):** <http://bit.ly/2YdU8pJ>

**N.B.** Also in this issue of the *American Journal of Bioethics*: ‘What does ethical treatment of a dying inmate entail?’ (access at: <http://bit.ly/2RyYRzY>). End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report, can be downloaded/viewed on the Palliative Care Network website at: <http://bit.ly/2RdegnL>

### **End-of-life care in rural general practice: How best to support commitment and meet challenges?**

*BMC PALLIATIVE CARE* | Online – 25 June 2019 – Few studies have specifically assessed the scope, nature and challenges of palliative and end-of-life care (P&EoLC) in rural general practice. These knowledge gaps limit the development of evidence-based policies and services for patients in the last months of life. This study aimed to explore the perspectives of general practitioners (GPs) and other stakeholders on rural GPs’ involvement and challenges in providing P&EoLC in regional Australia. The rural GPs’ central role in EoLC was recognized by the majority of participants but multiple challenges were also identified. Some challenges were comparable to those found in urban settings but others were more pronounced, including resource limitations and lack of training. Inappropriate payment models discouraged GPs’ involvement in some aspects of EoLC, such as case conferences and home visits. Compared to GPs in urban settings, those in rural/regional communities often reported closer doctor-patient relationships and better care integration and collaboration. These positive aspects of care could be further developed to enhance service provision. This study highlights the importance of regular interactions with other professionals and patients in providing EoLC, but many GPs and other stakeholders found such interactions more challenging than the more “technical” aspects of care. **Full text:** <http://bit.ly/2X2ViDd>



#### **Related**

- *AUSTRALIAN JOURNAL OF RURAL HEALTH* | Online – 26 June 2019 – ‘**Living, loving, dying: Insights into rural compassion.**’ Participants in this study discussed the challenges they experienced during end-of-life (EoL) caring, including transport into the city for treatment, and access to basic and specialised services. However, they also reported positive aspects of formal and informal palliative care, and described experiences of personable, expert, flexible and innovative caregiving. The rural location enabled personalised and innovative expressions of care. This research adds new insight into rural EoL palliation, as a complex intersection of supererogation, innovation and place-driven care. **Abstract:** <http://bit.ly/31VFHZE>

**N.B.** Additional articles on the provision and delivery of P&EoLC in rural and remote regions of Australia noted in 4 March 2019 issue of Media Watch (#604, p.11).



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

## The nature of suffering and its relief: A proposal for a redefinition

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 25 June 2019 – Recent advances in our understanding of the nature of suffering and its different dimensions have exposed certain deficits in the current definition of suffering. These shortcomings have impacted negatively on the appropriate formulation of precise treatment objectives for each dimension of suffering within the overall framework of the goals of medicine. Existential suffering offers a clear example where the lack of a universally accepted definition has led to confusion regarding what should constitute appropriate relief for this particular dimension of suffering. The authors propose a redefinition of suffering based on three elements: first, suffering refers to a specific state of a person (the essence of suffering); second, this state is characterised by a specific psychosomatic anguish reaction (the manifestation of suffering); and third, this reaction is in response to a perceived threat to the integrity of the person (the cause of suffering). The proposed definition allows for an important and clear distinction to be made between the primary and symptomatic relief of suffering and the role of medicine in each form of relief. The terms of the proposed definition and the distinction between primary and symptomatic relief provide useful tools for further research regarding the different dimensions of suffering and its relief. **Abstract:** <http://bit.ly/2J6JTV>

Noted in Media Watch 15 April 2019 (#610, p.5):

- *JOURNAL OF PALLIATIVE CARE* | Online – 10 April 2019 – ‘**The physician’s role in responding to existential suffering: What does it mean to comfort always?**’ Existential suffering (ES) is commonly experienced by patients with serious medical illnesses despite the advances in the treatment of physical and psychological symptoms that often accompany incurable diseases. Palliative care clinicians wishing to help these patients are faced with many barriers including the inability to identify ES, lack of training in how to address it, and time constraints. They are uniquely positioned to coordinate the necessary resources for addressing ES in their patients. **Abstract:** <http://bit.ly/2lhw6Wr>

## Addressing sexuality and intimacy in people living with Parkinson’s during palliative care and at the end of life

*BRITISH JOURNAL OF NURSING* | Online – 26 June 2019 – Sexuality and intimacy are poorly researched in both people living with Parkinson’s and in older people. Triggers for discussion usually centre on sexual dysfunction and hypersexuality in relation to Parkinson’s. However, there are many more factors that impact on physical and emotional connectedness. Despite highlighting this unmet need there are limited tools or comprehensive assessments available to help improve quality of life. Further research is required within this field, with emphasis on health professionals’ education and on highlighting to patients that they have permission for this topic to be discussed and actioned. **Abstract:** <http://bit.ly/320uFCL>

Noted in Media Watch 2 April 2019 (#557, p.13):

- *JOURNAL OF ADVANCED NURSING* | Online – 25 March 2018 – ‘**Addressing sexual issues in palliative care: A qualitative study on nurses’ attitudes, roles and experiences.**’ Patients and their partners in palliative care (PC) might experience dramatic changes in their sexuality and want nurses to provide the opportunity to address them. Moreover, it is argued that the holistic philosophy of PC encourages nurses working in this area to include sexual issues in their daily care. The way PC nurses addressed sexual issues was clearly influenced by their own interpretation of the philosophical principles underlying PC. **Abstract:** <http://bit.ly/2YgawGn>

Noted in Media Watch 11 September 2017 (#529, p.5):

- *AUSTRALIAN HOSPITAL & HEALTHCARE BULLETIN* | Online – 1 September 2017 – ‘**Sexuality, intimacy and palliative care.**’ “Sexuality and dying are considered taboo subjects, and most people feel that people in this stage of their lives are too ill to think about sex,” says Brigitte Karle, clinical nurse educator with HammondCare. “But our palliative care staff – and our patients – recognise that sexuality is part of the holistic care of patients, and this has resulted in the ‘Let’s Talk About It’ program. We need to make it easier for patients, their partners and staff to feel that they can have the conversation without being uncomfortable,” she said. **Full text:** <http://bit.ly/31Z8xsq>

## Hospice care in the U.S.

### **Systematic review of the hospice performance literature**

*HEALTH CARE MANAGEMENT REVIEW* | Online – 20 June 2019 – Hospice is the key provider of end-of-life care to patients. As the number of U.S. hospice agencies has rapidly increased, the performance has been scrutinized more deeply. To foster understanding of how hospice performance is measured and what factors are associated with performance, the authors conducted a systematic review of empirical research on hospice performance in the U.S. Hospice agencies adopted different strategies (e.g., service provision strategy and staffing strategy) to improve performance. Two strategic approaches (innovation and volunteer usage) were associated with better outcomes. Hospice organizational factors, market environment, and patient characteristics were related to hospice strategic conduct and performance. The majority of hospice performance studies have examined the relationship between hospice structure and strategic conduct/process, with fewer studies focusing on structure performance and even fewer concentrating on strategy performance. The majority of the literature considered the impact of hospice organizational characteristics, whereas only a few studies included patient and market factors. The summarization of factors that may influence hospice performance provides insight to different stakeholders. **Abstract:** <http://bit.ly/2J64KRc>

### **The implicit soul: Factors between the representation of death and dehumanization of patients**

*HEALTH PSYCHOLOGY OPEN* | Online – 16 June 2019 – Spiritual approaches in healthcare settings proved effective in reducing the negative outcomes of dehumanization processes impacting health professionals and patients. Although previous literature focused on explicit measures of spirituality, the present research explored the role of implicit components of spirituality and their effects on the humanization of patients in two healthcare contexts. Professionals from hospices and nursing homes completed an implicit task to assess whether the diverse representation of death as physical or spiritual led to perceive patients with more uniquely human traits. Results showed that only for hospice participants, implicit and explicit spirituality predicts more humanness attribution to patients. This article discusses palliative care models and death education as a resource for reducing dehumanization. **Full text:** <http://bit.ly/2L6Fk8C>

Noted in Media Watch 24 June 2019 (#619, p.10):

- *PATIENT EDUCATION & COUNSELING* | Online – 19 June 2019 – ‘**How and how much is spirituality discussed in palliative care consultations for advanced cancer patients with and without a question prompt list?**’ Palliative care (PC) patients were randomised to either receive a question prompt list (QPL) prior to a consultation or not, to see whether its provision influenced patients’/caregivers’ questions and discussion of topics relevant to end-of-life care during consultations with a PC physician. Spirituality was discussed in half the consultations. Patients receiving a QPL discussed spirituality 1.38 times more than controls. **Abstract:** <http://bit.ly/2Ku6JSr>

**N.B.** Additional articles on spirituality in the context of PC noted in this issue of Media Watch.

### **End-of-life care for people who use alcohol and other drugs: Findings from a rapid evidence assessment**

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | In Press – 24 June 2019 – People who use alcohol and other drugs ... and who are over the age of 40 are now more likely to die of a non-drug related cause than people who use substances under the age of 40. This population will therefore potentially need greater access to palliative and end-of-life (EoL) care services. Initially, the purpose of this rapid evidence assessment ... was to explore the peer-reviewed evidence base in relation to EoLC for people with problematic substance use. Given the dearth of evidence emerging on interventions and practice responses to problematic substance use, the inclusion criteria were broadened to include any peer-reviewed literature focusing on substance use specifically and EoL care. There were 60 papers that met the inclusion crite-

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ria. They fell into three broad groups: 1) Pain and symptom management; 2) Homeless and marginalised groups; and, 3) Alcohol-related papers. In general, this small and diverse literature lacked depth and quality. The papers suggest there are clear challenges for health and social care professionals in meeting the EoL needs of people who use substances. Addressing issues like safe prescribing for pain management becomes more challenging in the presence of substance use and requires flexible service provision from both alcohol/drug services and EoL care providers. Work is needed to develop models of good practice in working with co-existing substance use and EoL conditions as well as prevalence studies to provide a wider context for policy and practice development. **Abstract:** <http://bit.ly/2Xv9Aki>

Noted in Media Watch 20 May 2019 (#614, p.4):

- U.K. (England) | *About Manchester* – 16 May 2019 – ‘**Adopt new policy standards for terminally ill patients with substance use problems, says report.**’ Researchers have outlined six policy standards urging policy-makers, National Health Service commissioners and service providers to introduce measures that would improve provision and tackle stigma towards terminally ill patients who are, or have been, problematic users of alcohol or other drugs.<sup>1</sup> The recommendations – the first of their kind in the U.K. – are based on consultation with professionals in leadership and policy roles across health and social care services in Liverpool, particularly specialist palliative, end-of-life and substance use services. <http://bit.ly/2W65Hle>

1. ‘Policy Standards: A Working Document. Palliative and End-of-Life Care for People with Alcohol and Drug Problems,’ (1<sup>st</sup> edition), Manchester Metropolitan University, May 2019. **Download/view at:** <http://bit.ly/2w0StY3>

**N.B.** Additional articles on terminal ill patients with drug and alcohol addictions noted in 19 November 2018 issue of Media Watch (#590, pp.13-14).

## New guidelines aim to expand palliative care beyond specialists

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 26 June 2019 – Too few patients get the day-to-day support they need to live as well as possible through serious or terminal illness, especially outside of



hospitals and hospice care, Martha Twaddle [medical director for palliative medicine and supportive care at Northwestern Medicine Lake Forest Hospital in Illinois] said in a recent interview. For that to change, more healthcare organizations and clinicians must embrace PC principles and practices, according to the newest guidelines developed by the National Consensus Project for Quality Palliative Care, which is comprised of 16 national organizations.<sup>1</sup> Published by the National Coalition for Hospice & Palliative Care and endorsed by more than 80 groups, the practice guidelines have been around since 2004, but the newest iteration – which Twaddle co-chaired – broadens the focus from PC specialists to all clinicians who see seriously ill patients. **Full text:** <http://bit.ly/2FwhNKM>

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

### Related

- *BRITISH MEDICAL JOURNAL* | Online – 28 June 2019 – ‘**Hierarchy disruptors: Bringing specialist knowledge from hospital to community care.**’ Imagine comprehensive community based healthcare, where more patients can receive specialist advice locally, without having to go to a hospital. Where ongoing training enables generalists to develop specialist skills. And which routinely enables hospital consultants to share their knowledge with, as well as learn from, clinicians on the ground. Such an approach is being piloted around the world. If it works, its proponents claim it could provide a new model of care for the whole National Health Service. There are already 60 examples of its use in U.K. care, particularly in community palliative care. Introductory paragraphs: <http://bit.ly/2xiAddF>



Would this article be of interest to a colleague?

## Building a better death, one conversation at a time

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 26 June 2019 – The Departure Lounge is a U.K. campaign spearheaded by the Academy of Medical Sciences to get people talking about death. Forget euphemisms like passing away, pushing up daisies, kicking the bucket, or in the British vernacular, popping your clogs. This is immersion in a conversation about death, complete with a sound-track. Designed to appear as a travel agency, the Departure Lounge and its companion website gave visitors a lot to think and talk about. Posters suggested ways to start a conversation with family and friends about life's finale: ask whether they would change how they live if they knew when they were going to die, or whether they'd prefer more time vs better time at the end. Importantly, ask when they would want medical treatment to end. Visitors could also write their thoughts about death on story panels on the walls or open a box containing quotes or personal stories about death. The ultimate intent is to "encourage people to think about the journey of their life and also the final part of the journey," said Irene Higginson MD, a fellow of the Academy and director of the Cicely Saunders Institute, a palliative care research center at King's College London. **Full text:** <http://bit.ly/2KHGXgs>

### Talking about death

*BRITISH MEDICAL JOURNAL* | Online – 25 June 2019 – Any emergency hospital admission of frail, elderly patients means a decision about what to do if their heart stops beating. Should we attempt cardiopulmonary resuscitation (CPR)? The medical answer isn't always clear, and the decision should involve the patient and sometimes relatives. For the admitting team, it would be useful if that discussion had already taken place with a doctor who knows the patient, with a decision recorded somewhere accessible. This sounds like common sense, so why aren't GPs routinely discussing end-of-life care with patients who may need it soon? National Health Service England encourages doctors to engage in care planning conversations, but these don't always happen. One of the main challenges is choosing the right time. Some patients are proactive and inform me that they don't want CPR in any event, often making formal advance directives to this effect even when they have many healthy years in prospect. Although some illnesses have a well known trajectory, for most patients the future is unpredictable. For doctors, the question "Would you be surprised if this patient died in the next 12 months?" is meant to help us think about when the discussion might be relevant. But our surprise (or otherwise) has been shown to be a very poor indicator of the likelihood of death. **Full text:** <http://bit.ly/2IJNn9W>

Noted in Media Watch 20 May 2019 (#614, p.5):

- U.K. (England) | *The Guardian* (London) – 5 May 2019 – '**Welcome to the Departure Lounge. Destination: death.**' Death is one of the most under-researched areas in healthcare, accounting for less than half of 1% of money spent. The idea of the Departure Lounge is to enable visitors to ask any questions they might have about the dying process, and also to collect ideas and experiences that could inform future research. The best time to have conversations about death probably isn't when you're confronting it, but well before... The hope is that the Departure Lounge will attract people who might not be regular visitors to science museums. <http://bit.ly/2Y6TObR>

## Evaluating a human rights approach to health in the Indian context: Emerging needs and challenges

*JOURNAL OF HUMAN RIGHTS & SOCIAL WORK* | Online – 21 June 2019 – Health has been one of the most important human rights concerns around the world since the inception of the United Nations. Health in this essay is viewed from a joint perspective of medicine and public health. This paper aims to examine the health and human rights concerns from an Indian perspective with regard to four main themes: 1) Availability of basic necessities; 2) Affordability and accessibility of healthcare services; 3) Specialized care for patients; and, 4) Availability of palliative care for a dignified life and death. The issues raised around these four themes are analyzed in sociological, psychological and cultural theoretical perspectives highlighting the actions needed to bring about appropriate change in the Indian context. This paper delineates the scope of the government's actions and people's participation in considering health as a basic human right for all people in India. **Abstract (w. list of references):** <http://bit.ly/31Upi80>

Cont.

Noted in Media Watch 20 May 2019 (#614, p.6):

- INDIA (Karnataka) | The News Minute (Bangalore) – 7 May 2019 – ‘**Why palliative care is not getting the attention it deserves in Hyderabad.**’ Although there has been some progress in the last five years, Hyderabad and India, in general, are poorly equipped to provide palliative care (PC). It is estimated that less than 3% of patients in India have access to adequate PC. India ranks last in the list of 40 countries when it comes to the availability of painkillers for end-of-life care. Awareness of PC is essential for patients with terminal or life-threatening illnesses so that they can forgo a lot of the pain associated with their treatment. This cause has been widely acknowledged by several other countries and even the World Health Organisation ... urging countries to invest in primary healthcare, which includes PC, as the first step to universal healthcare. <http://bit.ly/2DXbfnT>

Noted in Media Watch 11 February 2019 (#601, p.6):

- *BMC PALLIATIVE CARE* | Online – 4 February 2019 – ‘‘**Small small interventions, big big roles.**’’ **A qualitative study of patient, caregiver and healthcare worker experiences of a palliative care programme in Kerala, India.** Home-based palliative care (PC) is an essential resource for many communities. Doctors, nurses and volunteers have interdependent roles in providing PC to patients, including mentorship, training, patient care and advocating for patient needs. Volunteers also considered themselves to be mediators between families and the programme. Caregivers were mainly female and were caring for relatives. They have physically demanding, psychologically stressful and socially restrictive experiences of caregiving. They felt that the programme facilitated their role as caregivers by giving them training and support. **Full text:** <http://bit.ly/2RFEK0X>

### **Behavioral economics: Applying defaults, social norms and nudges to supercharge advance care planning interventions**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 24 June 2019 – Care that people receive at the end of their lives is not always consistent with their goals and values. Incongruent care can have emotional and financial consequences for individuals, families, and the overarching healthcare system. Advance care planning is a lifelong process that elucidates a person’s goals and values in the event of serious illness. Despite policy changes, system overhauls, and educational interventions only one-third of people in the U.S. have completed some form of an advance care plan. **Abstract:** <http://bit.ly/2IHWHuN>

### **Home-based palliative care [in the U.S.]: Toward a balanced care design**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 27 June 2019 – Palliative care (PC) for seriously ill adults is spreading rapidly, giving rise to a fast-growing business sector: the home-based palliative care (HBPC) industry. These programs offer services common to most PC programs; what distinguishes them is that services are delivered to patients in their homes. Research shows these programs hold promise for improving patient outcomes at lower cost than usual care. Given this, growth in the HBPC business is likely fueled partly by the sector’s money-making potential. As in many emerging industries, there are concerns that HBPC benefit may not be enjoyed equitably by patients and other stakeholders. To safeguard HBPC quality, the authors took stock of where quality problems may manifest and discuss strategies to forestall these problems. They examined HBPC trends with significant implications for care quality and cost, including HBPC payment, patient enrollment, staff management, and patient visits. **Abstract:** <http://bit.ly/2LIQMG>

### **Top ten tips palliative care clinicians should know about telepalliative care**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 25 June 2019 – The field of telehealth is rapidly growing and evolving across medical specialties and healthcare settings. While additional data are needed, telepalliative care – the application of telehealth technologies to palliative care (PC) – may help address important challenges inherent to our specialty, such as geography and clinician staffing; the burden of traveling to brick-and-mortar clinics for patients who are symptomatic and/or functionally limited; and, the

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timely assessment and management of symptoms. Telepalliative care can take many forms, including, but not limited to, video visits between clinicians and patients, smartphone applications to promote caregiver well-being, and remote patient symptom-monitoring programs. This article, created by experts in telehealth and PC, provides a review of the current evidence for telepalliative care and potential applications and practical tips for using the technology. **Abstract:** <http://bit.ly/2ILi0M6>

#### Related

- *PALLIATIVE MEDICINE* | Online – 28 June 2019 – ‘**Robotic technology for palliative and supportive care: Strengths, weaknesses, opportunities and threats.**’ The opportunities of robotics in palliative, supportive and end-of-life care include a number of assistive, therapeutic, social and educational uses. However, there are a number of technical, societal, economic and ethical factors which need to be considered to ensure meaningful use of this technology in palliative care. There is a need for collaborative research to establish use-cases and inform policy, to ensure the appropriate use (or non-use) of robots for people with serious illness. **Abstract:** <http://bit.ly/2YhoYhe>

#### **The arc of generational care: A case series considering grandparent roles and care needs in pediatric palliative care**

*JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 22 June 2019 – Children receiving palliative care (PC) services are held within the context of a family and often within multiple-generational arms. The purpose of this case series paper is to recognize grandparents’ roles in their family system from a personal, cultural, and anthropological perspective; to explore emotions and experiences as applies to grandparents of children receiving PC; and to provide tangible insight into caring well for families across the generational arc. **Abstract:** <http://bit.ly/2IJ3d4s>

Noted in Media Watch 31 December 2018 (#595, p.15):

- *JOURNAL OF FAMILY NURSING* | Online – 17 December 2018 – ‘**How grandparents experience the death of a grandchild with a life-limiting condition.**’ Traditionally, family-focused care extends to parents and siblings of children with life-limiting conditions. Only a few studies have focused on the needs of grandparents, who play an important role in the families of children with illness and with life-limiting conditions, in particular. The findings of this study about the unique footprint of grandparent grief suggest development of family nursing practice to better understand and support grandparents during the illness of a grandchild, in addition to bereavement support. **Abstract:** <http://bit.ly/2NbLBCP>

#### **Why is it just so hard? Making sense of end-of-life communication between adult children and their terminally ill parental figures**

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 26 June 2019 – The aging population in the U.S. is predicted to become one fifth of the population by 2050. With that increase, more individuals in the country will be experiencing chronic health conditions and the need for care, with end of life (EoL) becoming more of a topic that needs to be discussed. This study aims to explore the ways adult children talk to their parents about EoL, death, and dying. Six themes emerged: 1) Protection; 2) Meeting needs; 3) Guilt and regret; 4) Control; 5) Family dynamics; and, 6) Communication type. Each was prevalent in responses to how adult children cope, how they cared for their parent, and how hope played into the interactions. **Abstract:** <http://bit.ly/31YGCc0>

#### **Healthcare professionals perceived barriers to effective cancer pain management in the home hospice setting: Is dying at home really best?**

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 25 June 2019 – Twenty experienced hospice healthcare professionals (HPs), recruited from a regional hospice agency, were interviewed. An unexpected finding revealed patient’s religious and cultural beliefs about suffering and family caregiver’s beliefs that patients deserve to suffer due to past actions are barriers to pain management in home hospice. Hospice HPs can identify patients at risk for suffering at the end of life. Interventions targeting spiritual suffering and needs are needed. **Abstract:** <http://bit.ly/2KGwEGV>

## **Establishing key criteria to define and compare models of specialist palliative care: A mixed-methods study using qualitative interviews and Delphi survey**

*PALLIATIVE MEDICINE* | Online – 28 June 2019 – Specialist palliative care (SPC) services have various configurations of staff, processes and interventions, which determine how care is delivered. Until now, there has not been a clear set of criteria to define models of U.K. SPC, making it challenging to compare different models of care provided by services. The authors identify 20 criteria to characterise and differentiate models of SPC – a major paradigm shift to enable accurate reporting and comparison in practice and research. **Full text:** <http://bit.ly/2Lny1cZ>

## **Challenges and support needs of parents and children when a parent is at end of life: A systematic review**

*PALLIATIVE MEDICINE* | Online – 27 June 2019 – Preparing children for the death of a parent is challenging. Parents are often uncertain if and how to communicate and support their children. Many parents feel it is protecting their children by not telling them about the prognosis. Children less prepared for parental death from a terminal illness are more susceptible to later adversities. This review synthesised evidence on the experiences of parents and children when a parent is at end of life to discern their challenges, support needs and factors that facilitated good practice. Eight descriptive themes were identified, further categorised into two broad themes: 1) Barriers and facilitators in sharing the news that a parent is dying; and, 2) Strategies to manage the changing situation. Lack of understanding in relation to the parent's prognosis, denial and feeling ill-equipped were suggested as barriers for parents to share the news with their children. Engagement with social networks, including extended family relatives and peers, and maintaining routines such as attending school were suggested supportive by parents and children. Findings are limited primarily to White, middle-class two-parent families. A number of areas for future research are identified. **Abstract:** <http://bit.ly/2ZPFTrz>

**N.B.** The Children & Youth Grief Network of Peel Region (Ontario, Canada) recently published a review of the literature focused on the many different aspects of grief and bereavement among children and young people. See 'Parental illness. Dying and Death' (p.13) and 'Death of a Parent' (p.30). **Download/view at:** <http://bit.ly/2QZBaAs>

## **Impact of specialized pediatric palliative care programs on communication and decision-making**

*PATIENT EDUCATION & COUNSELING*, 2019;102(8):1404-1412. The authors reviewed 13 studies analyzing the impact of specialized pediatric palliative care (SPPC) programs on communication and decision-making using a wide range of outcome indicators. Study quality was poor in 58% of included papers. SPPC programs generally support and improve communication and decision-making for children with life-threatening conditions, their families and associated healthcare professionals. Families referred to an SPPC program had more discussions with HCPs on a broad variety of topics. However, data on communication with children, siblings, and other family members was scarce and of poor quality. More research on SPPC program efficacy is needed from the perspective of the ill child, as well as about barriers to end-of-life discussions and the specific aspects of SPPC programs responsible for improving outcomes. **Abstract:** <http://bit.ly/2FuWGZq>

### **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>



## **Making it relevant: Qualitative inquiry in the public sphere focusing end-of-life care and migration**

*QUALITATIVE INQUIRY* | Online – 21 June 2019 – Qualitative inquiry in the public sphere is discussed with a study concerning intercultural palliative care. For the case of Russian-speaking immigrants in Germany, language problems in care are analyzed as an issue of organizational ethics. Interviews with this target group originally addressing barriers of access to professional care are reanalyzed for the roles of language, limited language skills, and the lack of professional translation in care. The focus is on ethical implications for organizing services and the healthcare system planned for organizational justice for all groups in a diversifying society. **Abstract:** <http://bit.ly/31PgC2N>

**N.B.** Additional articles on palliative and end-of-life care for immigrants in Germany noted in 28 January 2019 issue of Media Watch (#599, p.7).

## **Physician's knowledge about patient's religious beliefs in pediatric care**

*REVISTA PAULISTA DE PEDIATRIA* | Online – 19 June 2019 – Scholars have noted that parents and children who have received comprehensive palliative care had faith as an important aid during the dying process, helping them understand situations and accept procedures that would not prolong the child's life unnecessarily. In this study, most of the doctors (93%) said they knew about the meaning of death according to Catholicism, but this number is reduced to 84% when questioned if they feel prepared to cope with this information when dealing with patients in the dying process and their families. The same findings were repeated with the other less prevalent religions, with higher rates of knowledge about the meaning of death compared to their readiness to approach it, suggesting doctors' insecurities and lack of knowledge about religious views. One of the most relevant data of this study is that among the 116 interviewees, 91% reported not knowing the religion of the patients they treated, showing how ... little interest is given to this aspect in clinical practice and medical education. In addition, 91% of the respondents are of the opinion that pediatricians and pediatric residents are generally unable to cope with the religious aspects of their patients. **Full text:** <http://bit.ly/2KJiq80>

**N.B.** English language article. Click on pdf icon to access Portuguese language version.

## **Assisted (or facilitated) death**

Representative sample of recent journal articles:

- *BRITISH MEDICAL JOURNAL* | Online – 25 June 2019 – **'British Medical Association votes to poll members on its assisted dying stance.'** The Association has voted to poll its members to ascertain their views on whether the association should adopt a neutral position on assisted dying rather than one against. After a lively debate, representatives passed this part of the motion by 149 votes to 115, at their [recent] annual meeting... The association's current policy, reaffirmed at the 2016 annual meeting, is to oppose legalised physician assisted suicide for terminally ill people. Jacky Davis, a consultant radiologist, proposing the 2019 motion on behalf of the Islington division, said that even if everyone had access to the best hospice care at least 5000 people a year would die suffering in unrelieved pain. **Introductory paragraphs:** <http://bit.ly/2YbL4lm>
- *DEMENTIA & GERIATRIC COGNITIVE DISORDERS*, 2019;9(2):217-226. **'Clinical considerations in physician-assisted death for probable Alzheimer's disease: Decision-making capacity, anosognosia, and suffering.'** Requests for physician-assisted death (PAD) in patients with dementia are complex and require careful consideration. Of particular difficulty is the determination of whether the request is voluntary and well considered. Capacity to consent to medical treatment has a clinical, an ethical, and a legal domain. A physician evaluating a PAD request must know the legal framework of his or her jurisdiction and should consider the ethical implications, as well as the clinical circumstances, that surround an end-of-life (EoL) request. The determination of decisional competence and awareness of his memory deficits is of considerable importance when assessing if the patient's request meets the due care criteria of a voluntary and well-considered EoL request. **Full text:** <http://bit.ly/2XccwmG>

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- *EUROPEAN JOURNAL OF HEALTH LAW*, 2019;26(3):221-239. ‘**The Marco Cappato and Fabiano Antoniani (dj Fabo) case paves the way for new assisted suicide legislation in Italy: An overview of statutes from several European countries.**’ This article looks into the case involving Fabiano Antoniani, who, following a major road accident, was left tetraplegic. Marco Cappato drove him to a Swiss clinic where Mr. Antoniani took his own life by self-administration of lethal pentobarbital sodium. Cappato was put on trial, but the Italian Constitutional Court urged the Parliament to decriminalise assisted suicide in extremely serious cases. From a comparison with other European countries, approaches range from restrictive (banning both active euthanasia and assisted suicide), to entirely permissive. An intermediate approach only entails a ban on active euthanasia. It would be desirable to uniformise the diverse national statutes on a European level, which would make it possible for everyone to receive assistance towards ending their suffering, with limitations to incurable cases to be medically verified, and at the end of a path designed to ensure that patient freedom of choice is upheld at all time. **Download/view at:** <http://bit.ly/2J8WrEn>
  
- *NEWSGP* | Online – 26 June 2019 – ‘**Royal Australian College of General Practitioners releases position statement on voluntary assisted dying.**’ The statement acknowledges that states across Australia are either considering or have passed voluntary assisted dying legislation, and goes on to assert that any legislation must protect both doctors and patients from coercion.<sup>1</sup> It aims to provide frameworks and commentary to ensure patients and GPs are supported when or if legislation for voluntary assisted dying comes into the clinical setting. The College believes any legislation must: protect both patients and doctors from coercion; ensure doctors are not compelled in any way to participate; have clear eligibility criteria; and, support the optimisation of end-of-life and palliative care services. **Full text:** <http://bit.ly/2X0TGKb>
  1. ‘Voluntary assisted dying legislation,’ Royal Australian College of General Practitioners, June 2019. **Download/view at:** <http://bit.ly/2YbfQLd>
  
- *PALLIATIVE MEDICINE* | Online – 27 June 2019 – ‘**Family members’ experiences of assisted dying: A systematic literature review with thematic synthesis.**’ Nineteen articles met the inclusion criteria. Publications were derived from four countries: The Netherlands, U.S. (Oregon, Washington and Vermont), Canada and Switzerland. Dutch studies predominately investigated family involvement in euthanasia, while Swiss and American studies only reported on assisted suicide. Eleven studies had a qualitative design, using predominately in-depth interviews; seven were retrospective surveys. Five analytical themes represented families’ experiences in assisted dying: 1) Context of the decision; 2) Grounding the decision; 3) Cognitive and emotional work; 4) Experiencing the final farewell; and; 5) Grief and bereavement. The results showed that families can be very involved in supporting patients seeking assisted dying, where open communication is maintained. Family involvement appeared to be influenced by the type of legislation in their country and the families’ perception of the social acceptability of assisted dying. Family needs are under-researched, and clinical guidelines should incorporate recommendations about how to consider family needs and how to provide them with evidence-based tailored interventions. **Abstract:** <http://bit.ly/2NhuJdJ>

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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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