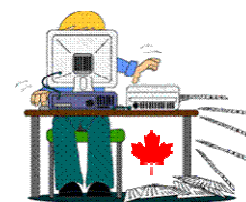


## Media Watch...

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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Compiled & Annotated by Barry R. Ashpole

**As the population ages and health and social care services are under greater pressure to provide care for people ageing or at end of life, new models of care which involve more input from families and volunteers may need to be developed.**

'Public responses to volunteer community care: Propositions for old age and end of life' (p.12), in *Plos One*.

## Canada

### Medical researchers developing tool to make end-of-life care more effective

ALBERTA | *Folio* (University of Alberta) – 2 July 2019 – A University of Alberta project is hoping to provide patients and healthcare providers with a roadmap for treating the final stages of chronic illnesses that will boost standards of care and help more patients stay out of the ER and hospital. The 'Supportive Care Pathway for Patients with Advanced-Stage Chronic Disease' project will develop a standardized process of care, or a clinical pathway, for treating some of the most common chronic diseases seen in emergency rooms and hospitals, like heart failure or late-stage cancers. The goal is to help primary care physicians and specialists work together to provide better patient care, improve quality of life and reduce the burden on acute care resources like emergency rooms. Clinical pathways are a fundamental tool in managing the quality of healthcare provided to patients. Similar to standard operating procedures in business environ-

ments, a clinical pathway is meant to address a patient's journey throughout their illness and each of the healthcare encounters they will have along the way. The pathway will indicate to any health-care provider what care a patient has already received, as well as the care they are likely to receive in the future. Not only can it help patients understand what they can expect as their disease progresses, it also makes it easier to approach patient care in a more comprehensive way, and improve the use of resources. <http://bit.ly/2xmUY7Y>

### Specialist Publications

'Medical assistance in dying (MAiD): A descriptive study from a Canadian tertiary care hospital' (p.13), in *American Journal of Hospice & Palliative Medicine*.



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## International

### Doctors urge people to tackle taboo topic

AUSTRALIA (Queensland) | *Central Queensland News* (Emerald) – 4 July 2019 – The Royal Commission into Aged Care has confirmed doctors' concerns Queenslanders are being denied their dying wish because they leave it too late to put end-of-life plans in place. The Commission's report<sup>1</sup> ... revealed most older Australians did not prepare for the sort of care they wanted in the event they became unable to communicate because of an accident, dementia or illness. Australian Medical Association Queensland president Dr. Dilip Dhupelia said the report found only 3% of Australians aged over 65 years had an advance care directive. Dr. Dhupelia called on the State Government to launch a public education campaign to encourage Queensland-

ers to tackle the taboo topic of death with their loved ones and GP. <http://bit.ly/2XpXzbJ>

#### Specialist Publications

**'Advance care planning in rural New South Wales from the perspective of general practice registrars and recently fellowed general practitioners'** (p.4), in *Australian Journal of Rural Health*.

**'Geriatricians' attitudes towards voluntary assisted dying: A survey of Australian and New Zealand Society for Geriatric Medicine members'** (p.13), in *Australasian Journal on Ageing*.

1. **Download/view at:** <http://bit.ly/2Jf4TDf>

### Terminally ill “denied lifeline” as they are forced to go through “burdensome” benefits process, finds report

U.K. (England, Northern Ireland & Wales) | *The Independent* (London) – 3 July 2019 – Terminally ill people are being denied the “lifeline they need” because they are forced them to go through a “burdensome” process to access benefits, MP's have warned. The government's definition of terminal illness states that a person's death can be reasonably expected within six months. But this was described as “outdated, arbitrary and not based on clinical reality” by the All-Party Parliamentary Group for Terminal Illness.<sup>1</sup> The six-month rule, introduced into law 30 years ago, means terminally ill people expected to live longer than half a year are missing out on being able to have their benefits claims fast-tracked and simplified under special rules for those given a short time to live, a report from the MPs said. <http://bit.ly/2XHjkrL>

1. 'Six Months To Live? Report of the All-Party Parliamentary Group for Terminal Illness inquiry into the legal definition of terminal illness,' July 2019. **Download/view at:** <http://bit.ly/2XJTXp8>

Noted in Media Watch 28 January 2019 (#599, p.4):

- U.K. (England, Northern Ireland & Wales) | *The Daily Express* (London) – 23 January 2019 – **'Change cruel law to help the dying: Scandal of terminally ill denied benefits.'** Charity Marie Curie said according to government figures, thousands of terminally ill patients were among the 17,000 who died awaiting decisions from 2013-2018. People can get fast-track access to tax-free Personal Independence Payments (PIP) at the highest rate if a doctor or nurse says they have less than six months to live. But Marie Curie says those with unpredictable illnesses like lung and motor neurone disease cannot always meet this criteria and face being left without support. <https://goo.gl/Qrgmbv>

### Charity succeeds in battle to ring-fence National Health Service funding for children's hospices

U.K. (England) | Third Sector (Twickenham) – 2 July 2019 – Together for Short Lives has won its battle to ring-fence National Health Service (NHS) funding for children's hospices, which is due to more than double to £25 million a year. England promised last year that funding for children's hospices would more than double from £12 million to £25 million by 2023/24, dependent on clinical commissioning groups pro-

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viding additional match funding to the NHS's £7 million investment. But Together for Short Lives last month accused NHS England of renegeing on its promise to properly fund children's hospices by making the money available to non-palliative care services too. The charity had also warned that the average amount received by each children's hospice had fallen by £7,000 on average to £364,076 a year, with 74% expecting a real-terms cut in the money they received in 2018-2019. Following Together for Short Lives' intervention, NHS England said that it would provide the full £25 million itself without input from Clinical Commissioning Groups (CCGs). NHS England will also carry out an assessment to understand whether additional funding, either nationally or from CCGs, is needed to provide children's palliative care in non-hospice settings. <http://bit.ly/2NtiZoM>

Noted in Media Watch 24 June 2019 (#619, p.3):

- U.K (England) | BBC News – 19 June 2019 – ‘**Children’s hospices “to shut if National Health Service does not increase funding.”**’ Children’s hospices in England will be forced to cut services or shut unless the National Health Service increases its funding, a charity has warned. Together for Short Lives, which helps terminally ill children, highlights a “dangerous cocktail” of higher costs and a drop in state funding. Its recent report examined funding for 27 of the 34 children’s hospices in England.<sup>1</sup> <https://bbc.in/2WVlu6s>

1. ‘Statutory Funding for Children’s Hospice and Palliative Care Charities in England, 2018-2019,’ Together for Short Lives, June 2019. **Download/view at:** <http://bit.ly/2FIGoSu>

#### Related

- U.K. (England) | *The Bury Times* (Bolton, Greater Manchester) – 2 July 2019 – ‘**Children’s hospice set to close only months after opening.**’ A children’s hospice may have to close due to a lack of funding, only six months after opening. Bosses at Grace’s Place hospice in Radcliffe say they have been left with “no choice” but to launch a consultation proposing to cease services at the facility. Rising costs have left the charity in an “unsustainable position” as it chases a £56,000 shortfall, which it has blamed on insufficient funding from the National Health Service. <http://bit.ly/306Cdlg>

**N.B.** Recent news media coverage on funding issues impacting hospices in general in England noted in 17 June 2019 issue of Media Watch (#618, p.5).

#### Bereaved families to get up to £2,000 for children’s funeral costs

U.K. (England) | *The Daily Telegraph* (London) – 30 June 2019 – Thousands of bereaved families who lose children through death or stillbirth are to get up to £2,000 funeral costs paid by the Government irrespective of their wealth. A new funeral fund for England will cover the costs of cremation or burial, which can range from £500 to more than £1,500, as well as £300 for a coffin. The Government will fully fund the estimated £14 million annually to cover the 3,800 children who die under the age of 18 each year and the 2,700 stillbirths. The fund will be available regardless of the family’s income. <http://bit.ly/2FMRxvN>

#### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Western Australia) | *Mandurah Mail* – 1 July 2019 – ‘**Western Australia death debate to intensify as voluntary assisted dying report handed down.**’ Western Australia (WA) is one step closer to adopting euthanasia laws, with a final report from an expert panel presented in state parliament last week.<sup>1</sup> Voluntary assisted dying has been a hot topic in WA and across Australia in recent years, with Victoria last month passing legislation allowing certain residents more freedom over how they die. A ministerial expert panel ... was formed last year to consider the views and opinions of the community. Over the last 12 months the panel has held public consultations across WA, with 867 people attending the sessions and a further 541 providing written submissions. <http://bit.ly/2xpzhE2>

1. ‘Voluntary Assisted Dying,’ Ministerial Expert Panel, Government of Western Australia, July 2019. **Download/view at:** <http://bit.ly/2YvNDyW>

Cont.

- BELGIUM | *The Tablet* – 1 July 2019 – ‘**Belgium’s bishops issue guidelines on pastoral care before euthanasia.**’ Belgium’s bishops have issued guidelines for pastoral care of the dying, stressing the need to accompany patients at the end of life but drawing a line at being present if they opt to induce their own death. Requesting euthanasia, which has been legal in Belgium since 2002, “has become more and more normal in our society” and creates for pastoral workers “tensions that are not easy to bear,” they said in a new brochure entitled “I’ll take you by the hand.” The brochure starts from the Biblical principle that nobody should be abandoned and praises all those – family, medical staff, chaplains and other pastoral workers – who accompany the dying. <http://bit.ly/2xrkiW>

## Specialist Publications

### Who makes decisions for incapacitated patients who have no surrogate or advance directive?

*AMA JOURNAL OF ETHICS*, 2019;21(7):E587-593. Unrepresented patients are those who have no surrogate or advance directive to guide medical decision making for them when they become incapacitated. While there is no perfect solution to the problem of making medical decisions for such vulnerable patients, three different approaches are noted in the literature: 1) A physician approach; 2) An ethics committee approach; and; 3) A guardianship approach. Recent policies and laws [in the U.S.] have required an approach that is “tiered” with respect to both who is involved and the gravity of the medical treatment questions at issue. In a general sense, some variant of a tiered approach is likely the best possible solution for jurisdictions and health institutions – both those already with and those without a tiered approach – to the challenging puzzle of treating unrepresented patients. **Full text:** <http://bit.ly/2J3CEaG>



#### Ethics of representing unrepresented patients

How should we respond to needs of patients who have neither decision making capacity nor identifiable surrogates? Unrepresented patients – whether homeless, disabled, elderly, or incarcerated, for example – are among our most vulnerable. This issue of the journal addresses ethical complexities of making decisions for these patients and of determining just criteria according to which such decisions are made. **Journal contents page:** <http://bit.ly/2RNrtWe>

#### Related

- *AUSTRALIAN JOURNAL OF RURAL HEALTH* | Online – 28 June 2019 – ‘**Advance care planning in rural New South Wales from the perspective of general practice registrars and recently followed general practitioners.**’ This study demonstrates the significant benefits that advance care planning (ACP) could bring in patients living in rural communities if delivered effectively. Given that rural GPs face a number of barriers to providing routine healthcare, these results highlight an important need to provide GPs and rural communities with support, education, incentive, better administrative tools, options and greater awareness of ACP. **Abstract:** <http://bit.ly/2Ls49Mt>
- *JOURNAL OF INTELLECTUAL DISABILITY RESEARCH* | Online – 24 June 2019 – ‘**Advance care planning in the palliative phase of people with intellectual disabilities...**’ Advance care planning (ACP) in the palliative phase of people with intellectual disabilities (ID) focuses mainly on medical issues. Challenges concern a proactive identification of changing needs, fear to initiate ACP discussions, documentation of ACP in medical files and involvement of people with ID in ACP. Relatives and professionals should be informed about the content of ACP and professionals should be trained in communicating in advance about wishes for future care. **Abstract:** <http://bit.ly/324oX2n>

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

- *REAL PROPERTY, TRUST & ESTATE LAW JOURNAL*, 2019;53(2):401-446. ‘**The enigma of end-of-life decisions in advance directives.**’ The article first examines legal issues created by the various available types, and then moves into religious and philosophical views affecting a person’s end-of-life (EoL) choices. Issues involving a person’s health, age, and financial and emotional situation are also discussed. The article also discusses quality-of-life issues arising from a minimally conscious state, a vegetative state, a locked-in state, and coma. There is then a discussion of the default position courts and medical providers take when no advance directive (AD) has been filled out, and the risks of leaving a person’s EoL decisions to an agent. This article concludes that an AD tends for most to be an enigma because so few have ever thought out the many complex issues raised by this type of document. **Synopsis:** <http://bit.ly/2NyaWa5>

**A systematic literature review of the current state of knowledge related to interventions for bereaved parents**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 3 July 2019 – This review highlights the need for individualized, well-tested, and effective bereavement care interventions to support bereaved parents. In summary, the state of the science on interventions for bereaved parents is poor and much work needs to be done to effectively address the needs of bereaved parents, including both their physical and emotional health needs. **Abstract:** <http://bit.ly/2L2S2q2>

**Defining “specialist palliative care”: Findings from a Delphi study of clinicians**

*AUSTRALIAN HEALTH REVIEW* | Online – 28 June 2019 – This study aimed to achieve consensus regarding what distinguishes specialist from non-specialist palliative care (SPC) to inform service organisation and delivery to patients with life-limiting conditions. Thirty-one clinicians (nurses, doctors and social workers) working with a wide range of patients participated... Consensus was gained on 75 items that define SPC and distinguish it from non-SPC. Consensus was gained that SPC clinicians have advanced knowledge of identifying dying, skills to assess and manage complex symptoms to improve quality of life, have advanced communication skills, and perform distinct clinical practices (e.g., working with the whole family as the unit of care and providing support in complex bereavement). Non-SPC involves discussions around futile or burdensome treatments, and care for people who are dying. Areas of connection were identified: clinicians from disease-

specific specialties should be more involved in leading discussions on futile or burdensome treatment and providing care to people in their last months and days of life, in collaboration with specialists in palliative care (PC) when required. At present there is no evidence-based definition or agreement about what constitutes SPC (as opposed to PC delivered by non-specialists) in the Australian Capital Territory. **Abstract (w. list of references):** <http://bit.ly/2NnLGn2>

**Extract from *Australian Health Review* article**

This study offers, for the first time, an evidence-based definition that distinguishes SPC from non-SPC. End-of-life care and bereavement support are not just the remit of SPC clinicians. Clinicians from beyond SPC should lead discussions about futile or burdensome treatment.

Noted in Media Watch 1 July 2019 (#620, p.8):

- *BRITISH MEDICAL JOURNAL* | Online – 28 June 2019 – ‘**Hierarchy disruptors: Bringing specialist knowledge from hospital to community care.**’ Imagine comprehensive community based health-care, 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. 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>

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Noted in Media Watch 29 April 2019 (#612, p.11):

- *PALLIATIVE MEDICINE* | Online – 24 April 2019 – ‘**Non-specialist palliative care: A principle-based concept analysis.**’ Building palliative care (PC) capacity among all healthcare practitioners caring for patients with chronic illnesses, who do not work in specialist PC services (i.e., non-specialist PC), is fundamental in providing more responsive and sustainable PC. Varying terminology such as “generalist,” “basic” and “a palliative approach” are used to describe this care but do not necessarily mean the same thing. Internationally, there are also variations between levels of PC which means that non-specialist PC may be applied inconsistently in practice because of this. Thus, a systematic exploration of the concept of non-specialist PC is warranted. **Abstract:** <http://bit.ly/2vnc8Ba>

### **End-of-life decision-making and advance care directives in Italy. A report and moral appraisal of recent legal provisions**

*BIOETHICS* | Online – 2 July 2019 – The author reviews the state of public debate and legal provisions concerning end-of-life decision-making in Italy and offers an evaluation of the moral and legal issues involved. She examines the content of a recent law concerning informed consent and advance treatment directives, the main court pronouncements that formed the basis for the law, and developments in the public debate and important jurisprudential acts subsequent to its approval. The moral and legal grounds for a positive evaluation of this law, which attests that the patient may withhold or withdraw from life-prolonging treatment, are offered with reference to liberal approaches and particularly to the frameworks of care and virtue ethics; but reasons are also be offered in order to consider not only the latter but also broader range of EoL treatment decisions as morally apt options. In this light, the author argues in favour of a further development of the Italian legislation to encompass forms of assisted suicide and active euthanasia. **Abstract:** <http://bit.ly/2J3v7Zk>

### **Interpretation and timing of death: The development and initial validation of the interpretation of death scale and the attitudes toward medical interventions in the timing of death scale**

*DEATH STUDIES* | Online – 2 July 2019 – Decreasing religious authority and increasing medical interventions at the end-of-life emphasize the importance of the interpretation and timing of death. Therefore, the three-dimensional interpretation of death scale (evaluating religious, rational, and personal interpretation of death) and the three-dimensional attitudes toward medical interventions in the timing of death scale (evaluating euthanasia, life prolongation and non-intervention) were constructed and assessed in a survey among 356 older Dutch adults. Religious interpretation of death was found to be associated with disapproval of euthanasia and approval of non-intervention, rational interpretation of death with approval of euthanasia, and personal interpretation of death with approval of nonintervention. **Full text (w. link to references):** <http://bit.ly/2Xi4js9>

**N.B.** Additional articles on religious and spiritual beliefs in the context of end-of-life care noted in 11 March 2019 issue of Media Watch (#605, p.8).



### **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>

## Hospice in the U.S.

### **Closing the gap in hospice utilization for the minority Medicare population**

*GERONTOLOGY & GERIATRIC MEDICINE* | Online – 27 June 2019 – With average *per capita* end-of-life medical spending in the last year of life at \$80,000 in the U.S. – comprising a larger fraction of its gross domestic product than that for all eight other countries examined in a 2017 study.<sup>1</sup> Implementing strategies to increase the inclusiveness of all racial/ethnic groups to hospice may be one way Medicare can simultaneously lessen its financial burden and improve the quality of life for its beneficiaries. This research finds a positive association between the prevalence of for-profit hospices and racial/ethnic minority Medicare hospice utilization, highlighting a potential business ownership model to further examine when developing strategies for racial/ethnic minority Medicare enrollees' inclusion in hospice care. With the potential to provide nearly \$270 million in annual cost savings while also improving health outcomes, further research on specific programs that successfully reduce the racial/ethnic minority hospice enrollment gap is paramount. In addition, collaboration between hospices, health systems, and community organizations is needed to reduce the disparities between racial/ethnic minority and White Medicare beneficiary hospice utilization. **Abstract:** <http://bit.ly/307JLVf>

1. 'End-of-life medical spending in last twelve months of life is lower than previously reported,' *Health Affairs*, 2017;36(7):1211-1217. [Noted in 10 July 2017 issue of Media Watch (#520, p.10)] **Full text:** <http://bit.ly/2XhOpOy>

#### **Related**

- *JOURNAL OF RACIAL & ETHNIC HEALTH DISPARITIES* | Online – 27 June 2019 – '**Integrating palliative care into the chronic illness continuum: A conceptual model for minority populations.**' The goal of the conceptual model is to provide a roadmap for healthcare professionals to use when designing, implementing, managing, and/or evaluating palliative care (PC) services for chronically ill minority Americans. A literature review demonstrated that minority patients benefitted the most from culturally tailored, systematic interventions (such as advanced care planning education) in all phases of PC, which led to increases in advance directive completion, better symptom control, and hospice utilization. **Abstract (w. list of references):** <http://bit.ly/2YknMtn>

**N.B.** Additional articles on ethnic and racial disparities in the provision and delivery of PC in the U.S. noted in 1 July 2019 issue of Media Watch (#620, p.2).

### **End-of-life care: Redesigning access through leveraging the Institute of Medicine future of nursing recommendations**

*HOME HEALTHCARE NOW*, 2019;37(4):208-212. In 2010, the [U.S.] Institute of Medicine published the vision for how to transform healthcare to achieve a more seamless patient-centered, high-quality system of care.<sup>1</sup> Among the recommendations were four specifically focused on leveraging nursing which is the largest group of healthcare workers: 1) Ensure that nurses can practice to the full extent of their education and training; 2) Improve nursing education; 3) Provide opportunities for nurses to assume leadership positions and to serve as full partners in healthcare redesign and improvement efforts; and, 4) Improve data collection for workforce planning and policy making. The authors redesigned access to end-of-life care by leveraging these recommendations. An experienced palliative care (PC) nurse practitioner (NP) leads the program development to improve care delivered by home healthcare nurses and NP specialists. This program was designed to allow patients to remain in their preferred setting of care – their home – until the end of their life. In the 5 years of this program's existence, it has achieved a yearly impact on community-based PC and hospice services. The number of documented advance directives increased by 75%, referrals to PC and hospice increased by 300% and the length of time on hospice doubled. **Abstract (via PubMed):** <http://bit.ly/2Jv58c8>

1. 'The Future of Nursing: Leading Change, Advancing Health,' Institute of Medicine, October 2010. **Download/view at:** <http://bit.ly/2L7mVcz>

Cont.

## Related

- *WESTERN JOURNAL OF NURSING RESEARCH* | Online – 4 July 2019 – ‘End of the beginning.’ A major issue in moving the field of palliative/supportive care forward is development of a specialized workforce. This is no easy task, especially considering that most nurses will care for persons with serious illness, regardless of the care setting. Glover, Åkerlund, Horgas & Bluck faced this issue head on by integrating an innovative immersion experience into nursing students’ coursework to increase confidence in providing primary palliative care (PC).<sup>1</sup> Despite a growing focus on professional training needs in PC, many practicing clinicians did not have the benefit of having exposure to palliative/supportive care principles and content in their student experiences. In fact, until the past few years, most medical and nursing textbooks had little if any content on PC. Cunningham, Ducar & Keim-Malpass described barriers and benefits in the use of “The Pause,” a contemplative practice to foster meaning for clinicians when caring for patients at the end of life.<sup>2</sup> **Full text:** <http://bit.ly/2xwdlam>

1. ‘Experiential palliative care immersion: Student nurse’s narratives reflect care competencies,’ *Western Journal of Nursing Research*, published online 19 February 2019. [Noted in 4 March 2019 issue of *Media Watch* (#604, p.15)] **Abstract:** <http://bit.ly/2SrhgNY>
2. “The Pause”: A Delphi methodology examining an end-of-life practice,’ *Western Journal of Nursing Research*, published online 30 January 2019. **Abstract:** <http://bit.ly/2RZ8asZ>

## **Balancing between maintaining and overriding the self: Staff experiences of residents’ self-determination in the palliative phases**

*INTERNATIONAL JOURNAL OF OLDER PEOPLE NURSING* | Online – 5 July 2019 – There are serious threats to residents’ self-determination but also strategies to cope with these threats. Physical and cognitive frailty and other people setting the terms hinder both making and executing decisions. However, staff can strengthen residents’ self-determination and assist in the presentation of residents’ self by adopting a relational view of autonomy and by taking personal preconditions into account. There is a need to come to terms with the lack of end-of-life care (EoLC) planning and to give residents a voice in these matters. Implementing a palliative approach early in the illness trajectory could facilitate communication about EoLC both within the group of staff and among the residents, relatives and staff. To maintain residents’ self-determination and protect their self, staff need knowledge about residents’ life stories and personal preconditions. This in turn requires continuity of care and spending time with residents to build relationships. Implementing an early palliative approach with a focus on factors that promote quality of life for each resident might facilitate communication and enhance decision making both in everyday life and in planning for EoLC. **Abstract:** <http://bit.ly/2L69MAL>

## **“It could have been me”: An interpretive phenomenological analysis of healthcare providers’ experiences caring for adolescents and young adults with terminal cancer**

*JOURNAL OF ADOLESCENT & YOUNG ADULT ONCOLOGY* | Online – 28 June 2019 – Adolescents and young adults (AYAs) with terminal cancer are a marginalized population with unique medical and psychosocial needs. AYAs commonly report challenges with their healthcare experiences, however, little is known about the experiences of the healthcare providers (HCPs) who deliver this specialized care. The purpose of the current study was to understand HCPs’ experiences caring for AYAs with terminal cancer. In-depth semi-structured interviews with participants in this study revealed four superordinate themes present in the data: 1) Many unknowns and uncertainties associated with providing care for AYAs compounded by minimal or no training specifically concerning this population; 2) An intense emotional experience compared with caring for patients with terminal cancer of other ages; 3) Personal identification with patients and their families; and, 4) Attempts to make sense of the circumstance thwarted by feelings of injustice and unfairness. HCPs’ experiences highlight the need for training to support clinicians in caring for AYAs with terminal cancer to optimize their own well-being and delivery of healthcare services to this population. **Abstract:** <http://bit.ly/324p6CZ>

Cont.



Noted in Media Watch 24 June 2019 (#619, p.11):

- *PEDIATRIC BLOOD & CANCER* | Online – 17 June 2019 – ‘**Things that matter: Adolescent and young adult patients’ priorities during cancer care.**’ Study participants’ frequent priorities were cure (97%), being good to the people they care about (95%), and having supportive people around them (94%). Most prioritized being with family (90%), returning to school/work (89%), maintaining relationships with friends (88%), and feeling normal (85%). Fewer prioritized minimizing long-term (78%) and acute side effects (68%) and fertility (59%). Many participants (88%) said that cure influenced their decisions “a great deal,” while fewer were influenced by side effects (32%), fertility (36%), or relationships (16%). Most patients (85%) thought their oncologist understood what was most important to them when treatment started. **Abstract:** <http://bit.ly/2KWqstz>

### **Clustering of 27,525,663 death records from the U.S. based on health conditions associated with death: An example of big health data exploration**

*JOURNAL OF CLINICAL MEDICINE* | Online – 27 June 2019 – Insight into health conditions associated with death can inform healthcare policy. Clustering of more than 27 million death records based on the health conditions at the time of death resulted in 16 distinct clusters, with significant differences in socio-demographics, place of death, the cause of death, and, obviously, the health condition(s) at the time of death. Healthcare organizations and professionals need to be prepared to offer interdisciplinary palliative care (PC) to a growing number of people dying with multiple health conditions. Indeed, the high prevalence of multiple health conditions requires a shift from primarily disease-oriented care towards person-centred PC at the end of life (EoL), including timely advance care planning. Understanding differences in population-based patterns and clusters of EoL experiences for patients and their families is an

important step toward portend developing a strategy for implementing population-based PC. **Full text:** <http://bit.ly/2RJXUO>

#### **Extract from *Journal of Clinical Medicine* article**

Indeed, the need for PC services will increase because of the ageing population and the increase in non-communicable diseases. In 2015, life expectancy at birth was 78.7 years in the U.S. Recent analyses of the Global Burden of Disease Study highlighted how improvements in early mortality for several conditions have resulted in older populations living with complex diseases. This poses challenges for healthcare systems and requires integration of PC into existing healthcare services and within the continuum of care for persons with chronic, progressive life-limiting illnesses.

### **Improving end-of-life care for hospitalized older adults: What can nurses and healthcare systems do?**

*JOURNAL OF GERONTOLOGICAL NURSING* | Online – 25 June 2019 – The hospital remains an important place for patients to receive end-of-life (EoL) care. For a variety of reasons, such as patient and family preference as well as unforeseen circumstances, it will remain a significant setting for dying patients for many years to come. Patients and families are extremely vulnerable during this difficult time and finding ways to ensure they are well supported throughout the dying process must be a priority for health systems. Because nurses play such an important part in caring for hospitalized patients, additional efforts should be focused on the nurse’s role to improve care of the dying patient and his/her family. By focusing these additional efforts, systems can support and help empower nurses to better address EoL issues. Care systems can better prepare professional nurses to conduct goals of care conversations and work to provide formal and informal opportunities for them to share the information that they gather about patient goals and values. This support and collaboration can also improve the nurse practice environment and decrease moral distress, both of which play an active role in the quality of care provided to patients. Attention to these factors and implementing ways to improve EoL care will prove to be a significant benefit to not only patients and their families but also to nurses, providers, and healthcare systems as a whole. **Full text:** <http://bit.ly/2Lwa5nD>

## **Integration of a mandatory palliative care education into hematology-oncology training in a comprehensive cancer center: A survey of hematology oncology fellows**

*JOURNAL OF ONCOLOGY PRACTICE* | Online – 3 July 2019 – Hematology and medical oncology (HMO) fellows (i.e., survey respondents) reported that palliative care (PC) rotation improved assessment and management of symptoms (98%); opioid prescription (89%), opioid rotation (78%), and identification of opioid adverse effects (87%); communication with patients and families (91%), including advance care planning discussion (88%) and do-not-resuscitate discussion (88%); and, they reported comfort with discussing ethical issues (74%). Participants reported improvement in knowledge of symptom assessment and management as compared with efficacy in ethics and for coping with stress of terminal illness. **Abstract:** <http://bit.ly/2JanKiP>

## **Longer duration of palliative care in patients with chronic obstructive pulmonary disease is associated with death outside the hospital**

*JOURNAL OF PALLIATIVE CARE* | Online – 2 July 2019 – Few patients with chronic obstructive pulmonary disease (COPD) [i.e., patient population studied] received palliative care (PC), similar to national trends. Initial outpatient palliative contact had the longest duration of care and death in the preferred home environment. The extent of emphysema ... and more frequent disease exacerbations identified in patients were more likely to receive PC. This study begins to define the benefits of PC in advanced COPD and confirms underutilization in the years before death, where a prolonged impact on the quality of life may be realized. **Abstract:** <http://bit.ly/2JkIPWx>

**N.B.** Additional articles on PC for people living with COPD noted in 6 May 2019 issue of Media Watch (#615, p.13).

## **YouTube videos as a source of palliative care education: A review**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 July 2019 – Online videos may not provide accurate and appropriate information on palliative care (PC). A total of 833 videos were screened; 84 met criteria for analysis. The most prominent video styles were providing PC information (85%) and personal testimony (50%). One-third were uploaded by hospice/PC services or medical organizations, while another one-third by advocacy organizations. More than two-thirds mentioned “end of life” and 35% mentioned “hospice.” Physicians most frequently appeared and served as protagonists. Protagonists were primarily female (71.0%), aged 18-64 years (81.7%), and white (90.3%). Compared with videos uploaded by healthcare agencies, those uploaded by advocacy organizations had 6.41 times higher odds of having more than one view per day. There is minimal ethnic diversity in terms of physician and family representation. More research is needed to determine the effectiveness of these videos in improving consumer knowledge of PC. **Abstract:** <http://bit.ly/2YA0BvC>

## **Vlogging at the end of life**

*THE LANCET ONCOLOGY*, 2019;20(7):911-912. Despite advances in treatment options, many patients diagnosed with cancer ultimately face the premature ending of their life. Under these circumstances, patients are confronted with the challenge of re-articulating their personal experiences and identities in ways that accommodate a changed reality and help them create meaning at the end of life (EoL). Their storytelling constitutes a particular type of illness story, distinct from other related categories. For example, although restitution narratives are driven by recovery, EoL stories come forth in relation to unattainable health and the contemplation of death. Healthcare professionals may support the storytelling process. Techniques include diary keeping, reading stories written by other patients, and the co-creation of stories between patients and spiritual guides. Beyond having a therapeutic function, these personal stories are valuable pedagogical materials that help healthcare professionals understand the EoL experience and they create more efficient care for patients. **Abstract:** <http://bit.ly/2JiWfsG>

## **Palliative care provision in long-term care facilities differs across Europe: Results of a cross-sectional study in six European countries**

*PALLIATIVE MEDICINE* | Online – 1 July 2019 – While the need for palliative care (PC) in long-term care facilities is growing, it is unknown whether PC in this setting is sufficiently developed. The authors included 1,298 residents in 300 facilities, of whom a majority received PC in most countries (England: 72.6%; Belgium: 77.9%), except in Poland (14.0%) and Italy (32.1%). PC typically started within 2 weeks before death and was often provided by the treating physician (England: 75%; the Netherlands: 98.8%). A PC specialist was frequently involved in Belgium and Poland (57.1% and 86.7%). Residents with cancer, dementia or a contact person in their record more often received PC, and it started earlier for residents with whom the nurse had spoken about treatments or the preferred course of care at the end of life. The late initiation of PC (especially when advance care planning is lacking) and PC for residents without cancer, dementia or closely involved relatives deserve attention in all countries. Diversity in PC organization might be related to different levels of its development. **Abstract:** <http://bit.ly/2J1oeYg>



Noted in Media Watch 5 November 2018 (#588, p.10):

- *JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 23 October 2018 – ‘Physician visits and recognition of residents’ terminal phase in long-term care facilities: Findings from the PACE cross-sectional study in 6 European Union countries.’ Physicians from Poland and Italy were least inclined to recognize that the resident was in the terminal phase, and residents in these countries had palliation as main treatment goal the least. Overall, however, there were positive associations between the number of physician visits and the recognition of the resident’s terminal phase and between the number of physician visits and the resident having palliation as main treatment goal in the last week of life. **Abstract (w. link to references):** <http://bit.ly/2LvKEHJ>

Noted in Media Watch 9 July 2018 (#571, p.14):

- *PALLIATIVE MEDICINE* | Online – 4 July 2018 – ‘The palliative care knowledge of nursing home staff: The European Union FP7 PACE cross-sectional survey in 322 nursing homes in six European countries.’ Although the authors found that many problematic issues are the same across countries, huge heterogeneity persists even after adjusting for confounders. Knowledge about basic palliative care (PC) issues is generally poor among nurses and care assistants in all countries, but particularly so in Poland and in Italy. A White Paper of the European Association for Palliative Care on PC education identifies nursing homes as a setting in which the staff, irrespective of their discipline, need to know the basic principles of PC.<sup>1</sup> **Full text:** <http://bit.ly/2NjCKif>

1. ‘Core Competencies in Palliative Care: White Paper on Palliative Care Education...’ *European Journal of Palliative Care*, 2013;20(2):86-91. [Noted in 4 March 2013 issue of Media Watch (#295, p.7)]  
**Download/view at:** <http://bit.ly/2Ns7RIA>

**N.B.** PACE website: <http://bit.ly/2KOOCH9>

## **Barriers to communication in a pediatric intensive care unit: A qualitative investigation of family and provider perceptions**

*PEDIATRIC CRITICAL CARE MEDICINE* | Online – 1 July 2019 – The families interviewed represented 16 previously healthy children, and 26 children with a chronic health condition. Staff interviewed included three residents, three fellows, three attending intensivists, and three nurses. Participants’ perceptions and experiences of barriers to communication included the following: 1) Communication breakdowns related to coordination of care among several services; 2) Family-centered rounds are insufficient for effective communication; 3) Undervaluing the knowledge of families of children with chronic health conditions or special needs; and, 4) Communication breakdowns occur across provider hand-offs. Theme 3 was identified by families, but not by providers. **Abstract:** <http://bit.ly/2LvXH7m>

Cont.

## Related

- *THE HASTINGS REPORT*, 2019;49(3):18-25. 'The relational potential standard: Rethinking the ethical justification for life-sustaining treatment for children with profound cognitive disabilities.' In this era of rapidly advancing biomedical technologies, it is not unusual for parents of children with profound cognitive disabilities to ask clinicians to provide invasive life-sustaining treatments. Parental requests for such interventions pose a moral dilemma to the treating medical team, as there may be a discrepancy between the team's perception of the child's best interest and the apparent rationale underlying a parent's request. **Abstract:** <http://bit.ly/2LCxm7B>

**N.B.** See 'Relational potential versus the parent-child relationship,' *The Hastings Report*, 2019;49(3):26-27. **Abstract:** <http://bit.ly/2YG0AX3>.

## Improving home hospice and palliative care policies [in the U.S.]

*PEDIATRICS* | Online – 3 July 2019 – Children with serious illness make up 10% of the U.S. population yet account for at least 50% of hospital resources for all children. While most of these children and their families would rather not be hospitalized or at the doctor's office, addressing the children's physical, emotional, and practical needs within the home can be challenging. Parents report struggling to ensure their children are comfortable and receiving needed treatments while addressing the emotional and practical needs of the entire family. Professional home-based care (HBC) services can be helpful, yet until recently, few options for this support existed. Home nursing care has been restricted to technology-dependent children and provides a limited range of services. Traditionally, home hospice, focusing on symptom management and psychosocial support, is only available at advanced disease stages if parents agree to forgo disease-directed treatment of their children. With these constraints, only a fraction of children with serious illness received HBC and typically do so only late in the disease course. Fortunately, recent federal and state policies have expanded options for HBC for children with serious illness. **Introductory paragraphs:** <http://bit.ly/2YtB72P>

## Public responses to volunteer community care: Propositions for old age and end of life

*PLOS ONE* | Online – 1 July 2019 – Policy makers and politicians internationally face difficult choices in addressing the issue of caring for older populations at the end of life. Institution-based care is expensive and seen by many as unsatisfactory, with evidence of poor quality of care in hospitals not geared up to provide palliative care. In addition, given that most of the public express a preference to end their lives at home but relatively few actually do so, there remains an urgency to solve this problem. In seeking solutions, public opinion generally, and public support for new ideas in particular, is key. The authors examined public opinions on possible community care models in England. The results offer initial indications that future co-operation may be possible, but suggest there is a long way to go before the English public is ready to fully embrace such ideas. In setting these results in an international context, the authors suggest the use of collectivist-individualist measures as a possible initial benchmark indicator of a country's cultural willingness to co-operate. For those countries such as England with very high measures of individualism, there are likely to be significantly higher resources and time required to create the conditions necessary for community care to succeed. **Full text:** <http://bit.ly/2xsjOmI>



University of the West of England

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## Related

- *BMC PALLIATIVE CARE* | Online – 6 July 2019 – ‘**Unregulated care providers’ engagement in palliative care to older clients and their families in the home setting: A mixed methods study.**’ Unregulated care providers (UCPs) ... are required to meet the demand for home-based palliative care (PC) from a growing older population, yet understanding of UCPs involvement in care is limited. This study aimed to identify the types and frequencies of tasks performed by UCPs in home-based PC to older clients and their families and to describe UCPs’ engagement in care, and barriers and facilitators to their work. Challenges and facilitators to UCPs’ work in this context are discussed with recommendations to support UCPs in their roles. **Full text:** <http://bit.ly/30irDYQ>

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 30 June 2019 – ‘**Medical assistance in dying (MAiD): A descriptive study from a Canadian tertiary care hospital.**’ In June 2016, the Government of Canada passed Bill C-14 decriminalizing medically assisted death. Increasing numbers of Canadians are accessing medical assistance in dying (MAiD) each year, but there is limited information about this population. The authors describe the characteristic outcomes of MAiD requests in a cohort of patients at an academic tertiary care center in Toronto, Ontario, Canada. 107 formal requests for MAiD assessment were received. Ninety-seven patients were found eligible, of whom 80 received MAiD. Cancer was the primary diagnosis for 78% and median age was 74 years. The majority of patients (64%) cited “functional decline or inability to participate in meaningful activities” as the main factor motivating their request for MAiD. Half of patients who received MAiD (46%) described their request as consistent with a long-standing, philosophical view predating their illness. The 10-day reflection period was reduced for 39% of provisions due to impending loss of capacity. The patients seeking MAiD were similar to those described in other jurisdictions where assisted dying is legal and represent a group for whom autonomy and independence is critical. The authors noted a very high rate of risk of loss of capacity, suggesting a need for both earlier assessments and regular monitoring. **Abstract:** <http://bit.ly/2KN7w1f>
- *AUSTRALASIAN JOURNAL ON AGEING* | Online – 28 June 2019 – ‘**Geriatricians’ attitudes towards voluntary assisted dying: A survey of Australian and New Zealand Society for Geriatric Medicine members.**’ 226 members completed the survey equating to a 20% response rate. About 24% of respondents supported legalisation of voluntary assisted dying, whilst 53% opposed. If voluntary assisted dying was legalised, 12% would be willing to prescribe to an appropriate patient, and 61% would be willing to refer them onto a third party. Risk to vulnerable patients was the most important concern identified. Key areas of concern highlighted were risk to vulnerable patients, estimating prognosis, and capacity assessments. **Abstract:** <http://bit.ly/2Nqt0D3>
- *THE HASTINGS REPORT*, 2019;49(3):6-7. ‘**Dying with dignity: Living with laws (and ethics).**’ An increasing number of jurisdictions allow individuals to obtain medication prescribed by their physicians for medical assistance in dying (MAiD). But discussion of whether (and to what extent) individuals have the right to use the healthcare system to control the time and manner of their death is not limited to MAiD. The right also exists in other contexts, such as directing the withdrawal of life-sustaining treatments. Palliative (or terminal) sedation involves medications to render a patient unconscious, coupled with either the withdrawal of artificial nutrition and hydration or their not being administered at all. In high-enough doses, these medications may further suppress already-weakened cardiopulmonary function even if there is no intent to hasten death. When teaching about these topics, I challenge students to consider whether there are meaningful differences between practices like euthanasia, MAiD, aggressive use of morphine, terminal sedation, or the withdrawal of ventilator support. Whether their differences are morally, ethically, or legally meaningful can be difficult to tease out. After recently watching a loved one, whom I call “Stephan,” direct the time and manner of his death within hospice care in a state that does not allow MAID, I am less inclined than ever to believe that the differences are meaningful in a way the law should recognize. **Abstract:** <http://bit.ly/2XJ2tot>

## Publishing Matters

### **European Journal of Palliative Care: Free access to the complete archive**

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Online – 3 July 2019 – The publishers of the Association's former official journal, Hayward Medical Publishing, are enabling free access to around 2,000 journal articles. The journal ceased publication a year ago. In the 24 years of its existence (1994-2018), the journal built up an impeccable reputation for diverse and high-quality articles on palliative and end-of-life care. Equally, it was the source of several seminal Association white papers as well as being the official "book of abstracts" for many Association congresses. **Download/view at:** <http://bit.ly/2XI1kBL>



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**Barry R. Ashpole, Ontario CANADA**

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