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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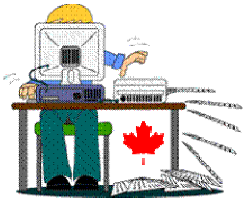

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Psycho-social aspects of end-of-life care: Scroll down to Specialist Publications and 'Between a rock and a hard place: When affirming life reduces depression, but increases anxiety' (p.16), in *Journal of Social & Clinical Psychology*.

Canada

Assisted (or facilitated) death

Organ donation changes dying for those getting medically assisted death

CBC NEWS | Online – 4 January 2018 – Medical assistance in dying (MAiD) has been legal in Canada since 1 July 2016. Since then, some of those opting for assisted dying have also donated organs and tissues for transplant, but the numbers are small. In Ontario, there have been fewer than five organ donations and 56 tissue donors as a result of MAiD. In British Columbia, the numbers are so low they're not provided, to protect the identity of patients. So far, MAiD donor numbers in Canada haven't affected organ transplant wait times – but that could soon change. People who have chosen to die with medical assistance are often the best candidates for donation. Doctors know which organs are healthy ahead of time and can plan for both the removal procedure and the transplant. "In donation after cardiac death, regardless of if it's from MAiD or from conventional withdrawal of life-sustaining therapy, the more quickly the patient dies, the less stress the organ goes through, and patients with medical assistance in dying tend to die fairly quickly," says Dr. Adrian Robertson, of Transplant Manitoba's Gift of Life program. Which is why the medical system is working through logistical issues and ethical concerns that don't come up for non-MAiD donors. For one thing, the dying process becomes more medicalized. Patients need to undergo sometimes uncomfortable and inconvenient medical tests to see if their tissues and organs are viable for transplant. If someone is getting medical assistance in dying and wants to donate their organs, they have to be in a transplant-capable hospital, close to an operating room. https://goo.gl/aHbTsp

Assisted dying in religious facilities means tough choices for families

THE GLOBE & MAIL | Online – 5 January 2018 – It is not clear if these institutions enjoy the same Charter-protected religious freedoms as individuals when it comes to refusing assisted deaths because the issue has not yet been tested in court. In the vast majority of cases, such patients are transferred to another facility to die. But it isn't always easy to find a place to send them. Sometimes overcrowded secular hospitals say no. Sometimes the only hospital or nursing home in town is faith-based. https://goo.gl/P7FXnu

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Noted In Media Watch 27 March 2017 (#505, p.2):

- *THE NATIONAL POST* | Online – 20 March 2017 – **'Doctors harvesting organs from Canadian patients who underwent medically assisted death.'** Doctors have already harvested organs from dozens of Canadians who underwent medically assisted death, a practice supporters say expands the pool of desperately needed organs, but ethicists worry could make it harder for euthanasia patients to voice a last-minute change of heart. https://goo.gl/9By6xt

N.B. Articles on organ transplantation in the context of palliative and end-of-life care are noted in the 18 December and 9 October 2017 issues of Media Watch (#543, p.11 and #533, p.9, respectively).

U.S.A.

Researchers studying dreams, visions of dying

STATE OF NEW YORK | WNDU-TV (South Bend, Indiana) – 5 January 2018 – Dreams and visions of the dying have been well-documented throughout history and across cultures. They often give patients comfort as they approach death, but they have never been studied scientifically – until now. Hospice Buffalo is working on a groundbreaking research study on dreams and visions of the dying. "I was taking care of patients all of a sudden who were all dying, and I was witnessing something that I neither been trained to understand or knew how to interpret," says Christopher Kerr, chief medical officer at Hospice Buffalo. Dr. Kerr began a study in 2011 with 66 patients. They now have 1,300 reported incidents in several follow-up studies.[1] https://goo.gl/TeCVbW

Specialist Publications

'National Comprehensive Cancer Network issues updated guidelines for palliative care' (p.11), in *Journal of Clinical Pathways*.

1. 'End-of-life dreams and visions: A longitudinal study of hospice patients' experiences,' *Journal of Palliative Medicine*, 2014;17(3):296-303. [Noted in the 20 January 2014 issue of Media Watch (#341, p.13)] **Abstract:** https://goo.gl/xh1VWK

Diabetics may often fare poorly in hospice care

UNITED PRESS INTERNATIONAL | Online – 4 January 2018 – Decisions about diabetes care can become harder as people age, and that may be especially true for those needing hospice care. A new study has found that, among people getting hospice care in a nursing home, diabetes care may lead to higher rates of dangerous low blood sugar episodes, known as hypoglycemia.[1] That finding came from the researchers' analysis of data on nearly 20,000 people with type 2 diabetes, all in nursing homes and receiving hospice care. https://goo.gl/C8N9ip

1. 'Hypoglycemia in hospice patients with type 2 diabetes in a national sample of nursing homes,' *JAMA Internal Medicine*, published online 26 December 2018. **Research letter:** https://goo.gl/ByBdEr

"Put the fire under us": Church spurs parishioners to plan for illness and death

KAISER HEALTH NEWS | Online – 3 January 2018 – Nationwide, only a third of Americans have documented their end-of-life (EoL) wishes, according to a recent poll.[1] For black adults 65 or older, rates are much lower: Only 19% have documented their EoL wishes, compared with 65% of whites. Older black adults are half as likely as whites to have named someone to make medical decisions on their behalf if they became incapacitated. Another Foundation poll found that blacks are more likely than whites to say that living as long as possible is "extremely important," and that the U.S. medical system places too little emphasis on extending life.[2] As part of the discussion at Bethel American Methodist Episcopal Church,

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Reverend Gloria White-Hammond asked attendees to look through the 'Five Wishes' EoL planning document.[3] At monthly workshops, White-Hammond has introduced over 100 parishioners to the document over the past two years. She said people often get stuck when filling out the second wish, which asks whether they want life support in certain grim scenarios that they may not be familiar with, such as permanent brain damage. Mistrust of the medical establishment is one major reason black Americans are less likely to write down their EoL wishes, and more reluctant to end life support... https://goo.gl/tXcxuW

1. 'Serious illness in late life: The public's views and experiences' (Differences by race/ethnicity), Kaiser Family Foundation, November 2017. [Noted in the 6 November 2017 issue of Media Watch (#537, p.2)] **Download/view at:** https://goo.gl/BYKWrK

2. 'Views and experiences with end-of-life medical care in the U.S.,' Kaiser Family Foundation (in partnership with *The Economist*), April 2017. [Noted in the 1 May 2017 issue of Media Watch (#510, p.3)] **Download/view at:** https://goo.gl/5exxYd

3. 'Five wishes,' Aging with Dignity **website:** https://goo.gl/Ved87Z

Noted in Media Watch 8 February 2016 (#448, p.15):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2016;19(2):143-148. **'The impact of faith beliefs on perceptions of end-of-life care and decision making among African American church members.'** African Americans underuse palliative care (PC) and hospice services because of a combination of factors including faith beliefs. As the spiritual family for many African Americans, the church presents an opportunity to improve communication about PC and hospice services and end-of-life decision making. **Abstract:** http://goo.gl/hO0qUe

This cat sensed death. What if computers could, too?

THE NEW YORK TIMES MAGAZINE | Online – 3 January 2018 – Of the many small humiliations heaped on a young oncologist in his final year of fellowship, perhaps this one carried the oddest bite: a 2-year-old black-and-white cat named Oscar was apparently better than most doctors at predicting when a terminally ill patient was about to die. The story appeared, astonishingly, in the *New England Journal of Medicine* in the summer of 2007.[1] Adopted as a kitten by the medical staff, Oscar reigned over one floor of the Steere House nursing home in Rhode Island. When the cat would sniff the air, crane his neck and curl up next to a man or woman, it was a sure sign of impending demise. The doctors would call the families to come in for their last visit. Over the course of several years, the cat had curled up next to 50 patients. Every one of them died shortly thereafter. No one knows how the cat acquired his formidable death-sniffing skills. Perhaps Oscar's nose learned to detect some unique whiff of death – chemicals released by dying cells, say. Perhaps there were other inscrutable signs. I didn't quite believe it at first, but Oscar's acumen was corroborated by other physicians who witnessed the prophetic cat in action. As the author of the article wrote: "No one dies on the third floor unless Oscar pays a visit and stays awhile." https://goo.gl/jx75cB

1. 'A day in the life of Oscar the cat,' *New England Journal of Medicine*, 2007;357(4):328-329. **Full text:** https://goo.gl/eNc8v9

Just hold on: Do people postpone death for the holidays?

THE WASHINGTON TIMES | Online – 1 January 2018 – In a 1990 paper,[1] University of California sociologist David Phillips found that for Chinese, deaths dipped by 35.1% in the week before the Harvest Moon Festival, one of their most significant holidays, and then peaked by 34.6% the week after. This methodology was further explored with Jewish subjects and Passover – as both groups celebrate holidays based on lunar calendars and are therefore independent of any influence of specific months or weather. In looking at 1,919 death certificates between 1966 and 1984 for people with Jewish surnames, the total number of deaths were lower than expected in the week before Passover and higher than expected in the week after the holiday. In 2004, researchers analyzed more than 300,000 cancer deaths in

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Ohio that occurred between 1989 and 2000. They found no evidence to suggest people postpone their deaths because of significant "religious, social or personal events." Ten years later, German researchers embarked on a similar study, looking at more than 3 million cancer deaths in that country, and found little data to support that people put off death until after birthdays or major Christian holidays like Christmas or Easter. https://goo.gl/kqyA2o

1. 'Postponement of death until symbolically meaningful occasions,' *Journal of the America Medical Association*, 1990;263(14):1947-1951. **Abstract:** https://goo.gl/Kftay9

International

African Palliative Care Association

Africa needs investment in palliative care

AFRICA | Devex – 3 January 2018 – Palliative care (PC) services are seriously lacking in Africa. Nineteen percent of African countries do not have identified palliative services and 71% of the services that do exist are concentrated in Uganda, South Africa, and Kenya. The HIV epidemic played a driving role in developing PC services and resources in many countries in Africa, with initial funding in HIV helping to boost hospices and PC services on the continent. However, a decrease in funding as well as a move away from vertical, disease-specific funding to horizontal, health systems funding is negatively affecting PC service delivery and development in many countries across the continent. New research shows that while PC developed rapidly in South Africa through funding available for HIV, the proliferation of earmarked funds for hospices mean programs are often only allowed to care for patients with HIV that had palliative needs.[1] This is the same in other countries, such as Côte d'Ivoire, where the majority of hospice services are only available for HIV patients. Currently, hospices are seeing non-HIV patients through funds provided by private donors in addition to public funds and grants. This interplay between HIV and PC reflects the short- and long-term benefits, as well as harm, that earmarked global aid can play in the health care systems of recipient countries. https://goo.gl/rQ69Hw

1. 'Atlas of Palliative Care in Africa,' African Palliative Care Association, Kampala, Uganda, January 2018. **Download/view at:** https://goo.gl/94wUHP

N.B. Selected articles on palliative and end-of-life care in Africa are noted in the 30 October and 16 October 2017 issues of Media Watch (#536, p.13 and #534, p.13, respectively).

Specialist Publications

'The status of palliative care in the Asia-Pacific Region' (p.6), in *Asia-Pacific Journal of Oncology Nursing.*

'Translating a U.S. early palliative care model for Turkey and Singapore' (p.6), in *Asia-Pacific Journal of Oncology Nursing.*

'National quality indicators and policies from 15 countries 'leading in adult end-of-life care: A systematic environmental scan' (p.9), in *BMJ Supportive & Palliative Care.*

'Towards evidence-based palliative care in nursing homes in Sweden: A qualitative study informed by the organizational readiness to change theory' (p.10), in *Implementation Science.*

'End-of-life decision making in palliative care and recommendations of the Council of Europe: Qualitative secondary analysis of interviews and observation field notes' (p.15), in *Journal of Palliative Medicine.*

'Refugees in conflict: Creating a bridge between traditional and conventional health belief models' (p.16), in *The Oncologist.*

Specialist Publications

Frailty: Mind the gap

AGE & AGEING | Online – 29 December 2017 – The conceptualisation of frailty in very different ways – as a syndrome or a risk state – has created semantic dissonance: the frailest patients by one definition may have early sarcopenia, by another be bedbound and in institutional care. Caution is required in transferring findings between studies enrolling these different populations. Furthermore, a yawning gap has emerged between the number of studies reporting the associations of frailty and those investigating interventions such that the empirical benefits of identifying and treating frailty currently remain unclear. Perhaps most importantly, frailty research has evolved with little account of the perspectives and preferences of patients themselves. The label of "frail," being linked to mental or moral weakness, has pejorative implications and care should be taken to avoid the adverse functional effects of negative priming. The authors suggest pathways for future studies to provide a stronger evidence base to apply this important concept. **Abstract:** https://goo.gl/Javsvq

Noted in Media Watch 16 October 2017 (#534, p.8):

- *EUROPEAN JOURNAL OF INTERNAL MEDICINE* | Online – 6 October 2017 – **'Recognising older frail patients near the end of life: What next?'** The authors provide an overview of the different ways of measuring frailty in community settings, hospital, emergency, general practice and residential aged care; suggest occupational groups who can assess frailty in various services; discuss the feasibility of comprehensive geriatric assessments; and, summarise current evidence of its management guidelines. The authors also suggest practical recommendations to recognise frail patients near the end of life, so discussions on goals of care, advance care directives, and shared decision-making including early referrals to palliative and supportive care can take place before an emergency arises. **Abstract:** https://goo.gl/azdMq7

N.B. Additional articles on palliative and end-of-life care for the frail and elderly are noted in the 31 July 2017 issue of Media Watch (#523, pp.15-16).

Media Watch: Editorial Practice

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

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Links to Sources

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5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
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Something Missed or Overlooked?

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

The status of palliative care in the Asia-Pacific Region

ASIA-PACIFIC JOURNAL OF ONCOLOGY NURSING, 2018;5(1):12-14. The need of the hour is for education and training in palliative care (PC) on a scale not previously achieved. There are diverse and complementary approaches to the more traditional or comprehensive institutional-, university-, or college-based education which are often too expensive for professionals living and working in low- and middle-income countries. Free online courses such as e-cancer's PC e-learning course for health professionals in Africa, Stanford's Palliative Care Always program, and the relatively low-cost Education in Palliative & End-of-Life Care distance learning course are accessible to the global community of practitioners. Mentorship projects such as Project Hamrahi, a collaboration between Pallium India and Australasian Palliative Link International, reduce isolation and facilitate sharing of experience and expertise. The Palliative Care-Promoting Access and International Cancer Experience is a new quality improvement collaboration sponsored and coordinated by Stanford's PC program, drawing on Stanford's Clinical Excellence Leadership Training program, and aims to develop quality improvement skills and increase access to PC in India. Intensive in-country training of trainers programs, such as that developed by the Lien Collaborative for Palliative Care in Myanmar, Bangladesh and Sri Lanka, encourage multidisciplinary education and integration of PC into oncology and other aspects of health care. Project Echo, originally developed in New Mexico, the U.S., has now been introduced to India for PC education and development of care management expertise. The International Palliative Medicine Fellowship program is another innovation which successfully influenced PC development globally. International peak bodies such as International Association of Hospice & Palliative Care, the Asia Pacific Hospice Palliative Care Network, and the European Association of Palliative Care also play a major role in fostering PC through provision of free resources, scholarships, fellowship and providing collaborative and interactive platforms for members. **Full text:** https://goo.gl/nCthhe

Asia-Pacific Journal of Oncology Nursing

ONS Asian Oncology Nursing Society

The current issue includes several articles on different aspects of palliative and end-of-life care. **Journal contents page:** https://goo.gl/qtnsKN

Related

- *ASIA-PACIFIC JOURNAL OF ONCOLOGY NURSING*, 2018;5(1):33-39. **'Translating a U.S. early palliative care model for Turkey and Singapore.'** Despite professional guidelines supporting early palliative care (PC), there are few models that have been created that can be translated into practice cross-culturally. In the U.S., the Educate, Nurture, Advise, Before, Life Ends (ENABLE) early PC telehealth model has demonstrated effectiveness in improving quality of life, mood, symptom relief, and survival for patients with cancer and is now being tested in patients with heart failure. Family caregivers of patients who have received ENABLE concurrent with their care recipients have also demonstrated positive outcomes in quality of life and caregiver burden. Internationally, a number of investigators are culturally adapting ENABLE for patients and family caregivers. **Full text:** https://goo.gl/HkcGnW

Manipulation, salience, and nudges

BIOETHICS | Online – 28 December 2017 – Not surprisingly, healthcare practitioners and public policy professionals have become interested in whether nudges might be a promising method of improving health-related behaviors without resorting to heavy-handed methods such as coercion, deception, or government regulation. Many nudges seem unobjectionable as they merely improve the quality and quantity available for the decision-maker. However, other nudges influence decision-making in ways that do not involve providing more and better information. Nudges of this sort raise concerns about manipulation. This paper focuses on non-informational nudges that operate by changing the salience of various options. It surveys two approaches to understanding manipulation, one which sees manipulation as a kind of

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pressure, and one that sees it as a kind of trickery. On the pressure view, salience nudges do not appear to be manipulative. However, on the trickery view (which the author favors), salience nudges will be manipulative if they increase the salience so that it is disproportionate to that fact's true relevance and importance for the decision at hand. By contrast, salience nudges will not be manipulative if they merely highlight some fact that is true and important for the decision at hand. The paper provides examples of both manipulative and non-manipulative salience nudges. **Abstract:** https://goo.gl/TR7cYa

Noted in Media Watch 27 November 2017 (#540, p.13):

- *JOURNAL OF MEDICAL ETHICS* | Online – 16 November 2017 – '**Nudging, informed consent and bullshit.**' Some philosophers have argued that during the process of obtaining informed consent, physicians should try to nudge their patients towards consenting to the option the physician believes best, where a nudge is any influence that is expected to predictably alter a person's behaviour without (substantively) restricting her options. **Abstract:** https://goo.gl/bX8yfD

Noted in Media Watch 20 March 2017 (#504, p.7):

- *THE HASTINGS REPORT*, 2017;47(2):32-38. '**Justifying clinical nudges.**' The most straightforward justification for nudge interventions is that they help people bypass their cognitive limitations – for example, the tendency to choose the first option presented even when that option is not the best for them – thereby allowing people to make choices that best align with their rational preferences or deeply held values. **Abstract:** https://goo.gl/mDEMxg

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 January 2018 – '**"I'd recommend ..." How to incorporate your recommendation into shared decision making for patients with serious illness.**' Patients and families facing serious illness often want and need their clinicians to help guide medical decision making by offering a recommendation. The authors describe an expert approach to formulating a recommendation using a shared decision-making framework. They offer three steps: 1) Valuate the prognosis and treatment options; (2) Understand the range of priorities that are important to your patient given the prognosis; and, 3) Base your recommendation on the patient's priorities most compatible with the likely prognosis and available treatment options. **Abstract:** https://goo.gl/TVKP4p

Continuous palliative sedation for patients with advanced cancer at a tertiary care cancer center

BMC PALLIATIVE CARE | Online – 4 January 2018 – This study provides relevant information on palliative sedation (PS) practice patterns and characteristics in an advanced cancer population of a tertiary cancer center and represents one of the largest cohorts to date. The use of PS to manage refractory symptoms in the end-of-life of cancer patients was a relatively common intervention in our setting as we found a PS frequency of 54.2%. This is somewhat comparable to that found by others. For example, Mercadante *et al* found a 54.5% frequency of PS in a prospective cohort of 77 terminally ill cancer patients admitted to an acute pain relief and palliative care unit. Similarly, Kohara *et al* reported that half of the cancer patients admitted to a Japanese palliative care unit had their refractory symptoms managed with PS. On the other hand, others had described percentages that were as high as 64% or as low as 12%. We believe that this great variability could be explained by considerable differences in many factors involving PS administration: patient population, clinical settings, PS definition and methods, the degree of experience with PS and adherence with current guidelines, cultural aspects and PS institutional policies. All of these may be responsible for the wide range of PS prevalence found in the literature. In this study, sedated patients were more likely to be younger and have a diagnosis of lung cancer. Particularly, age differences in PS prevalence and a more frequent use of the procedure in younger patients seem to be common findings in several studies. This possibly reflects the aggressive behavior of some types of tumors in these individuals, the intense treatment received by them and the complexity of clinical situations presented by a younger population. **Full text:** https://goo.gl/FE8gbj

N.B. Additional articles on continuous/palliative sedation, including international variations in clinical practice guidelines, are noted in the 27 November and 17 July 2017 issues of Media Watch (#540, p.17 and #521, p.16, respectively).

What does “complex” mean in palliative care? Triangulating qualitative findings from three settings

BMC PALLIATIVE CARE | Online – 4 January 2018 – Palliative care (PC) services need to recognize that while complexity may be defined by inherent patient needs, in one of more dimension of care, which are difficult to manage, it is also perceived by clinicians considering referral. Perceived complexity is highly dependent on individual factors such as time constraints, training, alternative treatments and referrals, resources and relationships with specialists. Inherent patient complexity is theoretically a relatively predictable source of need for access to PC services, although it is important to acknowledge many complex patients, such as those with dementia and multi-morbidity are not referred to specialist PC. By comparison, perceived complexity is “in the eye of the beholder” and may be amenable to training and support. Professionals in all settings require confidence to start PC through identification, early in the illness trajectory and care planning. However, education is essential to ensure health professionals in all settings feel competent and confident to provide person-centered end-of-life care for all. PC models of the future need to be flexible and sensitive to the changing nature of complex need, yet simultaneously devise a strategy to integrate PC with disease management in non-specialist areas. **Full text:** https://goo.gl/qPfoSt

End-of-life care in Singapore

Paediatric palliative care improves patient outcomes and reduces healthcare costs: Evaluation of a home-based program

BMC PALLIATIVE CARE | Online – 3 January 2018 – Around the world, different models of paediatric palliative care (PC) have responded to the unique needs of children with life shortening conditions. However, research confirming their utility and impact is still lacking. This study compared patient-related outcomes and healthcare expenditures between those who received home-based paediatric PC and standard care. The quality of life (QoL) and caregiver burden for patients receiving home-based paediatric PC were also tracked over the first year of enrolment to evaluate the service’s longitudinal impact. Compared to the control group, patients receiving home-based paediatric PC spent more time at home than in hospital in the last year of life by 52 days with at least two fewer hospital admissions; and, were five times more likely to have an advance care plan formulated. Medical costs incurred by this group were also considerably lower (by up to 87%). Moreover, both patients’ QoL ... and caregiver burden showed improvement within the first year of enrolment into the programme. These findings suggest that home-based paediatric PC brings improved resource utilization and cost-savings for both patients and healthcare providers. More importantly, the lives of patients and their caregivers have improved, with terminally ill children and their caregivers being able to spend more quality time at home at the final stretch of the disease. **Full text:** https://goo.gl/QhTD3x

Retrospective review of resuscitation planning at a children’s hospital

CHILDREN | Online – 4 January 2018 – Resuscitation plans (RP) are an important clinical indicator relating to care at the end of life in paediatrics. This study demonstrated that both the underlying condition (life-limiting or life-threatening) and the setting of care (paediatric intensive care unit or home) influenced the development of resuscitation plans. Patients referred to the paediatric palliative care (PPC) service had a significantly longer time interval from documentation of a resuscitation plan to death and were more likely to die at home. All of the patients who died in the paediatric intensive care unit (PICU) had a RP that was documented within the last 48 hours of life. Most RPs were not easy to locate. With varied diagnoses and settings of care, it is important that there is interprofessional collaboration, particularly involving PICU and PPC services, in developing protocols of how to manage this difficult but inevitable clinical scenario. **Full text:** https://goo.gl/aAnWDB

PALLIMED
A Hospice & Palliative Medicine Blog

Media Watch: Behind the Scenes
http://goo.gl/XDjHxz

Advance directives from haematology departments: The patient's freedom of choice and communication with families. A qualitative analysis of 35 written documents

BMC PALLIATIVE CARE | Online – 2 January 2018 – In France, few patients with malignant haemopathies write advance directives (ADs), as this can be perceived as a complex and anxiogenic process. As members of care teams involved in accompanying patients at the end of their lives, the authors believe that more can be done to support patients in writing their ADs. Their study results highlight that ADs are not limited to end-of-life patients, and that patients use them to pass on personal messages to their loved ones, in addition to expressing their wishes concerning treatment choices. This emerging role of ADs encourages intra-familial communication and should be valued, even if it is not their primary purpose. People in the general population should be made more aware of the concept of ADs so that they can already think about it before the onset of disease and discuss these issues with their loved ones outside of an emotional context. Each patient should be given the possibility of writing their own ADs, an exercise that requires personal reflection. Nevertheless, the writing and legal formalization of ADs should consider the dialogue between the patient and his/her doctor, relatives, and caregivers, and respect the patient's choices. **Full text:** https://goo.gl/5KBvQ4

Noted in Media Watch 5 June 2017 (#515, p.15):

- *MÉDECINE PALLIATIVE* | Online – 31 May 2017 – **'Haematologists' perceptions about end-of-life discussion: A qualitative study.'** Haematological patients have half as much access to palliative care (PC) than their counterparts with solid malignancies. The main objective of the study was to understand what makes an end-of-life discussion easy or difficult at the time of relapse of an aggressive haematologic malignancy. A side issue was to explore the consequences of such discussions on integration of PC in haematology. **Abstract:** https://goo.gl/7eAWso

N.B. French language article.

National quality indicators and policies from 15 countries leading in adult end-of-life care: A systematic environmental scan

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 4 January 2018 – The importance of measuring the quality of end-of-life care (EoLC) provision is undisputed, but determining how best to achieve this is yet to be confirmed. This study sought to identify and describe national EoLC quality indicators and supporting policies used by countries leading in their EoLC provision. Ten countries (66%) have national policy support for EoLC measurement, five have national indicator sets, with two indicator sets suitable for all service providers. No countries mandate indicator use, and there is limited evidence of consumer engagement in development of indicators. Two thirds of the 128 identified indicators are outcomes measures (62%), and 38% are process measures. Most indicators pertain to symptom management (38%), social care (32%) or care delivery (27%). Measurement of EoLC quality varies globally and rarely covers all care domains or service providers. There is a need to reduce duplication of indicator development, involve consumers, consider all care providers and ensure measurable and relevant indicators to improve EoLC experiences for patients and families. **Abstract:** https://goo.gl/G8qiVh

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 4 January 2018 – **'End-of-life care in the Western world: Where are we now and how did we get here?'** Recent movements in end-of-life care (EoLC) emphasise community care for the dying; however, integrating community with medical care continues to be a work in progress. While contemporary EoLC emphasises community care for the dying, implementation of these new approaches must be considered in its historical context. We must question whether it is possible to hand death responsibilities back to the community when medical services have largely assumed this responsibility in countries supporting individualism, secularism and materialism. **Abstract:** https://goo.gl/EjsKe1

Towards evidence-based palliative care in nursing homes in Sweden: A qualitative study informed by the organizational readiness to change theory

IMPLEMENTATION SCIENCE | Online – 4 January 2018 – Sweden has a policy of supporting older people to live a normal life at home for as long as possible. Therefore, it is often the oldest, most frail people who move into nursing homes. Nursing home staff are expected to meet the existential needs of the residents, yet conversations about death and dying tend to cause emotional strain. This study explores organizational readiness to implement palliative care (PC) based on evidence-based guidelines in nursing homes in Sweden. The aim was to identify barriers and facilitators to implementing evidence-based PC in nursing homes. Analysis of the data yielded ten factors acting as facilitators and/or barriers. Four factors constituted barriers: the staff's beliefs in their capabilities to face dying residents, their attitudes to changes at work as well as the resources and time required. Five factors functioned as either facilitators or barriers because there was considerable variation with regard to the staff's competence and confidence, motivation, and attitudes to work in general, as well as the managers' plans and decisional latitude concerning efforts to develop evidence-based PC. Leadership was a facilitator to implementing evidence-based PC. There is a limited organizational readiness to develop evidence-based PC as a result of variation in the nursing home staff's change efficacy and change commitment as well as restrictions in many contextual conditions. There are considerable individual- and organizational-level challenges to achieving evidence-based PC in this setting. The educational intervention represents one of many steps towards developing a culture conducive to evidence-based nursing home PC. **Full text:** https://goo.gl/rLBoJN

Noted in Media Watch 5 June 2017 (#515, p.13):

- *JOURNAL OF POST ACUTE & LONG-TERM CARE MEDICINE*, 2017;18(6):465-469. **'International survey of end-of-life care in nursing homes.'** This article reports the findings of a survey on end-of-life (EoL) care in nursing homes of 18 long-term care (LTC) experts across 15 countries. Overall experts strongly agreed that hospice and palliative care should be available in LTC facilities and that both are defined by holistic, interdisciplinary approaches using measures of comfort across domains. However, it appears the experts felt that in most countries the reality fell short of what they believed would be ideal care. As a result, experts call for increased training, communication, and access to specialized EoL services within the nursing home. **Abstract:** https://goo.gl/U3c3Xy

Noted in Media Watch 24 April 2017 (#509, p.12):

- *JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 13 April 2017 – **'Palliative care development in European care homes and nursing homes: Application of a typology of implementation.'** The authors identified three levels of palliative care (PC) implementation: 1) Macro (national/regional policy, legislation, financial and regulatory drivers); 2) Meso (implementation activities, such as education, tools/frameworks, service models, and research); and, 3) Micro (PC service delivery). This typology was applied to data collected from 29 European countries and demonstrates the diversity of PC implementation activity across Europe with respect to the scope, type of development, and means of provision. **Full text:** https://goo.gl/hphppR

Acceptance in the end of life

JAMA ONCOLOGY | Online – 4 January 2018 – Why are terminally ill patients so often over-treated? One major reason is that cancer diagnosis and treatment decisions have been made more difficult by the field's complexities. While it is acceptable for an aggressive patient to pursue treatment against our recommendation, people tend to simplify situations and settle for suboptimal solutions. I trust experts to tell me what to do when I am lost in a maze that they can get out of. Likewise, we are called to help patients see through the misinformation, denial, over-confidence, distrust, and confusion that clouds their reasoning. When patients have metastatic cancer, they frequently do not know their prognosis, nor do they always understand the palliative intent of our treatment. This misconception holds for oncologists as well, who tend to over-estimate survival time. Another major cause of over-treatment is that both physicians and patients tend to over-value the end of life (EoL) and make irrational decisions. A life's ending is

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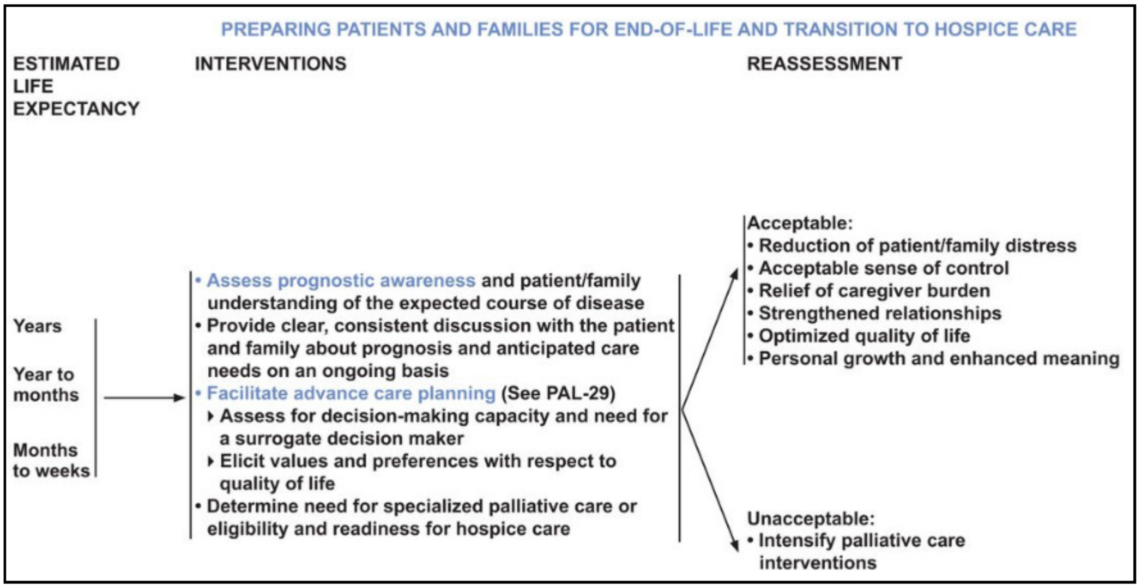
weighted especially heavily when quality of life (QoL) is judged. If you ask people to judge how desirable their life was, they over-weight their life's quality at the end and ignore the duration. Physicians grasp this fact, preferring to avoid high-intensity EoL care more than non-physicians. However, we do not effectively communicate this skepticism to patients. Supportive care often yields a better QoL than active treatment, but it is underused and undervalued. Extending a poor QoL is considered a success due to biased thinking shaped by having extended lives of good quality. This misconception holds for oncologists, who tend to over-estimate survival time... **First page view:** https://goo.gl/wphGhQ

End-of-life care in the U.S.

National Comprehensive Cancer Network updated guidelines for palliative care

JOURNAL OF CLINICAL PATHWAYS | Online – 4 January 2018 – In the palliative care (PC) general overview section, a few new indications were added, including 'Complex psychosocial needs' and 'Poor prognostic awareness.' Additionally, a few more reassessment bullet points were added, including 'Re-evaluate intervention options and intensify as possible' (which is modified throughout the guidelines) and 'Consult with other providers and refer to specialist if available.' As for the criteria for consultation with a PC specialist, the second bullet under assessment 'High-risk for persistent complex bereavement disorder' is new to the page, with the corresponding footnote: "Persistent complex bereavement disorder is a chronic heightened state of mourning that significantly impairs functioning." In the section for benefits and burdens of anticancer therapy, a new intervention listed in the Year to months sub-section is 'Encouraging advance care planning (ACP).' In the Months to weeks subsection, the new bullet 'Encouraging ACP, if not already accomplished' is also listed. Another new bullet listed – in the Weeks to days sub-section – is 'Consider short course palliative radiation therapy for painful bone metastases.' 'Child life services if available' and 'Art and music therapy if available' are new additions to the page for social support/resource management/interventions. The section for ACP and interventions now lists 'Assess decision-making capacity and need for surrogate decision-maker' as the first bullet on the page. If any of the listed interventions are deemed unacceptable, 'Consider ethics consult' is a new option. **Full text:** https://goo.gl/9mEy4s



- Assess prognostic awareness and patient/family understanding of the expected course of disease
- Provide clear, consistent discussion with the patient and family about prognosis and anticipated care needs on an ongoing basis
- Facilitate advance care planning (See PAL-29)
  - Assess for decision-making capacity and need for a surrogate decision maker
  - Elicit values and preferences with respect to quality of life
- Determine need for specialized palliative care or eligibility and readiness for hospice care

Acceptable:
- Reduction of patient/family distress
- Acceptable sense of control
- Relief of caregiver burden
- Strengthened relationships
- Optimized quality of life
- Personal growth and enhanced meaning

Unacceptable:
- Intensify palliative care interventions

1. 'National Comprehensive Cancer Network guidelines insights: Palliative care, Version 2.2017,' *Journal of the National Comprehensive Cancer Network*, 2017;15(8):989-997. **Full text:** https://goo.gl/HXng9d

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Related

- *JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK*, 2018;16(1):35-41. **'The right place at the right time: Medical oncology outpatients' perceptions of location of end-of-life care.'** Using a sample of Australian medical oncology outpatients, this study examined 1) Their preferred location of end-of-life care; 2) Their perceived benefits and worries of receiving care in that location; 3) The percentage who had discussed preferences with their doctor and/or support person; and, 4) Whether they wanted their doctor to ask them where they wanted to die. Less than half [of the survey respondents] preferred to be cared for at home (47%), 34% preferred a hospice/palliative care unit, and 19% preferred the hospital. Common benefits and worries associated with locations included perceived burden on others, familiarity of environment, availability of expert medical care, symptom management, and likelihood of having wishes respected. More patients had discussed preferences with their support persons (41%) than doctors (7%). Most wanted a doctor to ask them about preferred location of care (87%) and thought it was important to die in the location of their choice (93%). Although home was the most preferred location for many patients, the overall variation suggests that clinicians should adopt a systematic approach to eliciting patient preferences. **Abstract:** https://goo.gl/QfFrPB

End-of-life care in the U.S.

We're the eyes and the ears, but we don't have a voice: Perspectives of hospice aides

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2018;20(1):47-54. Hospice aides (HA) are integral to the delivery of home hospice care and play an essential role in the effective communication and collaboration of the hospice interdisciplinary team. Despite their critical role, little is known about their perceptions of their role in providing hospice services. This qualitative study explores HA's perspectives of their work; their relationships with patients, families, and interdisciplinary team members; and, their contributions to end-of-life care. Two focus groups of HAs and 16 hours of observation of in-home caregiving were conducted. Three themes were identified: 1) "We're the eyes and ears"; 2) "We're kept out of the loop"; and, 3) "We have no voice." HAs described themselves as frontline providers based on the close relationships they formed with patients and family members yet felt under recognized by members of the hospice team. Better understanding of their role could enhance the integration of HA into patient- and family-centered team interactions, leading to both improved patient and family outcomes and retention and support of this critical component of the hospice workforce. **Abstract:** https://goo.gl/iQmRxC

A systematic review of palliative care intervention outcomes and outcome measures in low-resource countries

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 2 January 2018 – To meet the growing need for palliative care (PC) in low-resource countries, PC programs should be evidence-based and contextually appropriate. Eighteen papers were reviewed, reporting on interventions conducted across nine low-resource countries. These interventions evaluated home-based PC models, a community managed model, PC integrated with hospitals, hospices, or HIV clinics, and models focused on patient self-management. Three studies were randomized controlled trials. Other studies used non-randomized trials, cohort studies, mixed methods, pre-post test evaluation, cost-accounting evaluation, and cross-sectional

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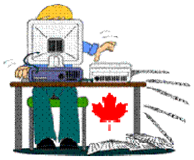

Barry R. Ashpole

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://goo.gl/5CHoAG surveys. Thirteen studies measured physical outcomes, ten using multi-dimensional instruments. Nine studies measured psychological outcomes, eight using multi-dimensional instruments. Nine studies measured social outcomes, seven using multi-dimensional instruments. Nine studies measured outcomes across multiple domains. Across outcomes evaluated, results were reported in the direction of benefit associated with PC interventions. Many PC intervention models exist to serve patients in low-resource countries. Yet, limited high quality evidence from low-resource countries is available to document intervention outcomes. Rigorous experimental studies and greater measurement of multidimensional aspects of PC are needed to advance the science of PC in low-resource settings. **Abstract:** https://goo.gl/NWyxmR

Noted in Media Watch 1 January 2018 (#544, p.18):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 December 2017 – **'Distributive justice: An ethical priority in global palliative care.'** As appetites for expanding global palliative care services increase so do questions of fair and culturally appropriate distribution. The ethical principle of distributive justice underpins questions of resource allocation at a fundamental level. Notions of distributive justice vary across cultural, societal and even individual norms, with some definitions allowing for discrimination based on merit or need. Resource allocation in the absence of cultural humility or a genuine willingness to understand decision making priorities in a given culture can contribute to inequity and may have harmful consequences. **Abstract:** https://goo.gl/3ws9CQ

Noted in Media Watch 20 February 2017 (#500, p.8):

- *BMJ GLOBAL HEALTH* | Online – 14 February 2017 – **'What is the value of palliative care provision in low-resource settings?'** Of the 40 million people globally in need of palliative care (PC), just 14% receive it, largely in high-income countries. While proven to be "cost-effective" in high-income settings based on principles of cost avoidance, the costs of illness for incurable disease in low-resource settings is largely unknown. The critical absence of PC services in low-resource settings results in significant costs being absorbed by the individual, family and local community. In considering the direct, indirect and broader societal costs of incurable disease in low-resource countries, PC should be considered as a poverty-reduction strategy. **Full text:** https://goo.gl/nMsqQu

End-of-life care in Taiwan

Accurate prognostic awareness facilitates, whereas better quality of life and more anxiety symptoms hinder end-of-life care discussions: A longitudinal survey study in terminally ill cancer patients' last six months of life

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 29 December 2017 – Terminally ill cancer patients do not engage in end-of-life care (EoLC) discussions or do so only when death is imminent, despite guidelines for EoLC discussions early in their disease trajectory. Most studies on patient-reported EoLC discussions are cross-sectional without exploring the evolution of EoLC discussions as death approaches. Cross-sectional studies cannot determine the direction of association between EoLC discussions and patients' prognostic awareness, psychological well-being and quality of life (QoL). The authors examined the evolution and associations of accurate prognostic awareness, functional dependence, physical and psychological symptom distress, and QoL with patient-physician EoLC discussions among 256 terminally ill cancer patients in their last 6 months... The prevalence of physician-patient EoLC discussions increased as death approached ... but, only reached significance in the last month. Accurate prognostic awareness facilitated subsequent physician-patient EoLC discussions, whereas better patient-reported QoL and more anxiety symptoms hindered such discussions. Physicians should facilitate EoLC discussions by cultivating patients' accurate prognostic awareness early in their cancer trajectory when they are physically and psychologically competent, with better QoL, thus promoting informed and value-based EoLC decision-making. **Abstract:** https://goo.gl/wgSWQH

N.B. Additional articles on palliative and end-of-life care in Taiwan are noted in the 11 December 2017 issue of Media Watch (#542, p.16).

Exploring opportunities for primary outpatient palliative care for adults with cystic fibrosis: A mixed-methods study of patients' needs

JOURNAL OF PALLIATIVE MEDICINE | Online – 3 January 2018 – Persons with cystic fibrosis (CF) experience high morbidity and mortality, yet little is known about their palliative care (PC) needs. Forty-nine patients participated [in this study]. Three main domains of PC needs were identified: 1) To be listened to, feel heard, and be "seen"; 2) Understanding the context around CF and its trajectory, with the goal of preparing for the future; and, 3) Information about, and potential solutions to, practical and current circumstances that cause stress. In questionnaires, few patients (4.3%) reported talking with their clinician about their wishes for care if they were to become sicker, but mixed-methods data demonstrated that more than half of participants were willing to receive PC services provided those services were adapted to CF. Patients expressed a need for and openness to PC services, as well as some reluctance. **Abstract:** https://goo.gl/AtLrRD

Noted in Media Watch 6 November 2017 (#537, p.9):

- *JOURNAL OF CYSTIC FIBROSIS* | Online – 30 October 2017 – **'Defining palliative care in cystic fibrosis: A Delphi study.'** A working group of 36 cystic fibrosis (CF) care providers, researchers, palliative care (PC) providers, quality improvement experts, individuals with CF, and CF caregivers completed a series of questionnaires to rate the value of each of 22 attributes of PC, rank top attributes to construct definitions of PC, and then rate proposed definitions. Many identified overlaps in routine CF care and PC and highlighted the importance of a definition that feels relevant across the lifespan. Modified Delphi methodology was used to define PC in CF. **Abstract:** https://goo.gl/z4bZmn

N.B. Additional articles on palliative and end-of-life care for people living with cystic fibrosis are noted in this issue of Media Watch.

The progression of end-of-life wishes and concordance with end-of-life care

JOURNAL OF PALLIATIVE MEDICINE | Online – 3 January 2018 – Since 2013, Kaiser Permanente Northern California has engaged in a systematic effort to elicit, document, and honor the care preferences of patients as they near the end of life (EoL). This is done through its Advanced Steps program, in which selected patients discuss their preferences for future medical care with their healthcare agent during a structured conversation with a trained advance care planning (ACP) facilitator. The facilitator then translates the patient's wishes into an actionable medical order set using a Physician's Order for Life-Sustaining Treatment (POLST) form. The authors wanted to know whether these patients' recorded wishes were concordant with care received at the EoL. To evaluate, they conducted an in-depth chart review of 300 patients who died in 2015 and had participated in the program. The authors determined that 290 patients received concordant care, whereas three patients received care discordant with their wishes before death. Seven patients did not have sufficient information in their record to determine concordance. Interestingly, care preferences often changed over time. Most changes to preferences were made verbally in the final setting of care. While ACP and the POLST form provide invaluable tools for recording patients' wishes, this study highlights a need to track patients' wishes as they evolve over time and a need for ongoing, real-time conversations about goals of care, even after a POLST is completed. **Abstract:** https://goo.gl/FHWnpe

Noted in Media Watch 1 January 2018 (#539, p.12):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 December 2017 – **'Respecting Choices and related models of advance care planning: A systematic review of published evidence.'** The authors found that there is a low level of evidence that Respecting Choices (RC) and derivative models increase the incidence and prevalence of advance directive and Physician Orders for Life-Sustaining Treatment completion. Evidence is mixed, inconclusive, and too poor in quality to determine whether RC and derivative models change the consistency of treatment with wishes and overall health-care utilization in the end of life. **Abstract:** https://goo.gl/pnq22k

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Noted in Media Watch 20 November 2017 (#539, p.12):

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 16 November 2017 –'**Are Physician Orders for Life-Sustaining Treatments the answer to the end-of-life care quality conundrums in cancer care?'** Pedraza *et al* identify patients with advanced cancer for whom Physician Orders for Life-Sustaining Treatments completion – by an affirmative response to the question, "Would I be surprised if this patient died in the next year?" – is appropriate.[1] Moss *et al* have demonstrated that this question has some prognostic validity in identifying patients for whom palliative care services are appropriate.[2] **Full text:** https://goo.gl/GT5WPv

    1. 'Association of Physician Orders for Life-Sustaining Treatment form use with end-of-life care quality metrics in patients with cancer,' *Journal of Oncology Practice*, 2017;13(10):e881-e888. **Abstract:** https://goo.gl/gQmPNu

    2. 'Prognostic significance of the "surprise" question in cancer patients, *Journal of Palliative Medicine*, 2010;13(7):837-840. **Abstract:** https://goo.gl/y8z1cQ

End-of-life care in Portugal

End-of-life decision making in palliative care and recommendations of the Council of Europe: Qualitative secondary analysis of interviews and observation field notes

JOURNAL OF PALLIATIVE MEDICINE | Online – 3 January 2018 – End-of-life (EoL) decisions are embedded in clinical, socio-cultural, political, economic, and ethical concerns. In 2014, the Council of Europe through its Committee on Bioethics launched the "Guide on the decision-making process regarding medical treatment in end-of-life situations," aiming at improving decision-making processes and empowering professionals in making EoL decisions.[1] The majority of professionals [interviewed] considered the ethical principle of autonomy paramount in EoL decision making. Justice and beneficence/nonmaleficence were also valued. Although not mentioned in the guide, the professionals also considered other ethical principles when making EoL decisions, namely, responsibility, integrity, and dignity. Most of the interviewees and field notes [studied] referred to the collective interprofessional dimension of the decision-making process. Palliative sedation and the wish to hasten death were the most mentioned disputed/controversial issues. The nature, limitations, and benefits of qualitative secondary analysis are discussed. **Abstract:** https://goo.gl/kzbJjV

1. 'Guide on the decision-making process regarding medical treatment in end-of-life situations,' Council of Europe, 2014. **Download/view at:** https://goo.gl/a3oWW7

A contemporary paradigm: Integrating spirituality in advance care planning

JOURNAL OF RELIGION & HEALTH | Online – 29 December 2017 – In the 25 years since advance care planning (ACP) first drew the attention of the national healthcare and legal systems, gains in the rate of advance care directive completion have been negligible despite the effort of researchers, ethicists, and lawmakers. With the benefit of sophisticated healthcare technology, patients are living longer. Despite the benefits of increased longevity, it is widely acknowledged that enough has not been done to adequately address end-of-life (EoL) care decisions at the crossroads between medical futility and quality of life. To arrive at a solution, researchers have focused on patient self-reflection, provider attitudes, health literacy, communication and the logistics of surrogacy, setting, payment, and documentation. However, a survey of the literature reveals one conspicuously absent theme. It is a phenomenon one would expect in the context of EoL discussion and decision making, that of spiritual inquiry. This article explores the history leading up and past approaches to ACP and then suggests the use of a theoretical model and a body of work concerning spiritual care as a new tack in the ongoing development of ACP. **Abstract (inc. list of references):** https://goo.gl/BJVUmV

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From the journal's archives:

- *JOURNAL OF RELIGION & HEALTH*, 2015;54(2):759-764. **'Embracing a broad spirituality in end-of-life discussions and advance care planning.'** A broad view of spirituality is needed, one that may involve traditional religious beliefs, but also includes personal understandings of what is holy or sacred. Embracing this broad practice of spirituality will help both familial and professional caregivers honor an essential aspect of end-of-life discussions and promote greater discernment of the deep meaning in advance care documents. **Abstract (inc. list of references):** https://goo.gl/NSoM25

Noted in Media Watch 1 January 2018 (#544, p.9):

- *BMC PALLIATIVE CARE* | Online – 28 December 2017 – **'Religious leaders' perceptions of advance care planning: A secondary analysis of interviews with Buddhist, Christian, Hindu, Islamic, Jewish, Sikh and Bahá'í leaders.'** Religious beliefs and values around death and dying could be useful in preparing health professionals for advance care planning with patients of different religions. Equally important is the need for health professionals to provide culturally sensitive care without assumptions based on religion or culture. **Full text:** https://goo.gl/jM8zuA

Between a rock and a hard place: When affirming life reduces depression, but increases anxiety

JOURNAL OF SOCIAL & CLINICAL PSYCHOLOGY, 2017;36(10):860-882. Research suggests that depression may stem from the conflicted relationship between the goal to continue living and the knowledge of death... From this perspective, awareness of inevitable death can trigger withdrawal from the goal to continue living, which precipitates a general collapse in the goal-approach system and causes depression. Withdrawal from life functions to resolve motivational conflict regarding life and death, however, and thereby reduces feelings of anxiety. The current research extends this theorizing by testing the hypothesis that reactivating the goal to continue living among people who are life-withdrawn reduces feelings of depression but increases anxiety. Based on the evidence, we propose a model of depression and anxiety stemming from death-awareness that sheds light on depression-anxiety co-morbidity, and discuss implications of the model for understanding depressive symptomatology. **Abstract:** https://goo.gl/zXNmeF

Noted in Media Watch 18 December 2017 (#543, p.13):

- *BMC PALLIATIVE CARE* | Online – 11 December 2017 – **'"Worried to death": The assessment and management of anxiety in patients with advanced life-limiting disease, a national survey of palliative medicine physicians.'** This study highlights the infrequent use of screening tools, substantial variation in prescribing practice, potentially inappropriate use of benzodiazepines in patients with a prognosis of months, training gaps, and poor access to psychological and psychiatric services. **Full text:** https://goo.gl/GMNxDq

Refugees in conflict: Creating a bridge between traditional and conventional health belief models

THE ONCOLOGIST | Online – 28 December 2017 – The recent wave of migration from Middle Eastern countries to Europe presents significant challenges to the European health profession. These include the inevitable communication gap created by differences in health care beliefs between European oncologists, health care practitioners, and refugee patients. This article presents the conclusions of a workshop attended by a group of clinicians and researchers affiliated with the Middle East Cancer Consortium, as well as four European-based health-related organizations. Workshop participants included leading clinicians and medical educators from the field of integrative medicine and supportive cancer care from Italy, Germany, Turkey, Israel, Palestine, Iran, Lebanon, Jordan, Egypt, and Sudan. The workshop illustrated the need for creating a dialogue between European health care professionals and the refugee population in order to overcome the communication barriers to create healing process. The affinity for complementary and traditional medicine (CTM) among many refugee populations was also addressed, directing participants to the mediating role

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that integrative medicine serves between CTM and conventional medicine health belief models. This is especially relevant to the use of herbal medicine among oncology patients, for whom an open and non-judgmental (yet evidence-based) dialogue is of utmost importance. The workshop concluded with a recommendation for the creation of a comprehensive health care model, to include bio-psycho-social and cultural-spiritual elements, addressing both acute and chronic medical conditions. These models need to be co-designed by European and Middle Eastern clinicians and researchers, internalizing a culturally sensitive approach and ethical commitment to the refugee population, as well as indigenous groups originating from Middle Eastern and north African countries. **Abstract:** https://goo.gl/ozAfiD

> **N.B.** Selected articles: 1) on palliative and end-of-life care in Middle Eastern countries are noted in the 19 January 2015 issue of Media Watch (#393, p.5); and, 2) on the provision of palliative and end-of-life care during humanitarian emergencies are noted in the 4 December 2017 issue of Media Watch (#541, p.13).

Acquire, apply, and activate knowledge: A pyramid model for teaching and integrating cultural competence in medical *curricula*

PATIENT EDUCATION & COUNSELING | Online – 30 December 2017 – The importance of cultural competence in health care has been more acknowledged since modern societies are becoming increasingly multi-cultural. Research evidence shows that cultural competence is associated with improved skills and patient satisfaction, and it also seems to have a positive impact on adherence to therapy. Based on this evidence, the acknowledged importance of cultural competence and its poor integration into medical *curricula*, we present a pyramid model for building cultural competence into medical *curricula* whereby medical students can enhance their skills through acquiring, applying and activating knowledge. **Abstract:** https://goo.gl/pkzxhd

Noted in Media Watch 17 July 2017 (#521, p.8):

- *THE ASCO POST* | Online – 10 July 2017 – **'Understanding the cultural differences among ethnic minorities in palliative and end-of-life care.'** To ensure oncologists provide high-quality and effective palliative and end-of-life care to minority patients, it is important to understand and practice cultural humility, which acknowledges limited knowledge about another culture, rather than cultural competency, which implies a thorough knowledge about the mores of another culture, and use culturally congruent approaches in their minority patients' care. **Full text:** https://goo.gl/iMuX4g

Noted in Media Watch 19 June 2017 (#517, p.13):

- *PALLIATIVE MEDICINE & HOSPICE CARE* | Online – 17 April 2017 – **'Product or process: Cultural competence or cultural humility?'** Perhaps nowhere in the health-care delivery system is the emphasis on patient-centered, culturally sensitive care more important than for those addressing life-limiting illness or for frail elders who are coping with the advanced stages of multiple chronic conditions. This editorial examines two leading methods for acquiring some degree of cultural sensitivity: cultural competence and cultural humility. **Full text:** https://goo.gl/jaF3xJ

Talking about unspeakable: Insights from patient-centered medicine to palliative paternalism

RECENTI PROGRESSI MEDICINA, 2017;108(12):508-510. The literature highlights the importance of involving the patient as a partner of care, using a patient-centered approach aimed at improving a process of share decision-making. However, there are clinical situations in which a shared decision-making process is difficult and its actual achievement is even more complex, as in the case of end-of-life (EoL) decisions, in which a decision about death is a tremendous weight for both patients and their caregivers. In such situations, we wonder what kind of position physicians should assume in order to be patient-centered, but also to reduce the patient suffering. The authors' proposal is to assume the perspective of palliative paternalism: doctors should provide a communication approach that determines the appropriate level of patient/parent autonomy in the process of decision making. In other words, doctors are required

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to share the information with patients, according to their desires, possibilities and resources, and to facilitate a share-decision making process. However, when the time of the decision comes, physicians should take full responsibility for giving voice to the patient's choices, putting them in action in his/her EoL and raising patients and their caregivers from the burden linked to the actual implementation of the decision. **Abstract:** https://goo.gl/L4ho3r

N.B. Italian language article.

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *AMERICAN JOURNAL OF BIOETHICS* | Online – Accessed 1 January 2018 – '**"God is the giver and taker of life." Muslim beliefs and attitudes regarding assisted suicide and euthanasia.'** In the context of the Belgian debates on end-of-life care, the views of Muslims remain understudied. The aim of this article is two-fold. First, the authors seek to document the relation between contemporary normative Muslim ideas on assisted suicide and voluntary euthanasia on the one hand and real-world views and attitudes of Muslims living in Belgium on the other hand. Second, they aim to identify whether a shift is observable in the views and attitudes regarding active termination of life between first and second generation Muslims. The authors have observed that when dealing with these bioethical issues, both first and second generation Muslims adopt a theological line of reasoning similar to the one that can be found in normative Islamic views. They have found an absolute rejection of every act that deliberately terminates life based upon the unconditional belief in an afterlife and in God's sovereign power over life and death. **Abstract:** https://goo.gl/LAj3bW

  Noted in Media Watch 7 December 2015 (#439, p.14):

  - *JOURNAL OF PASTORAL CARE & COUNSELING*, 2015;69(4):215-221. '**Physician-assisted suicide and other forms of euthanasia in Islamic spiritual care.'** The muteness in the Qur'an about suicide due to intolerable pain and a firm opposition to suicide in the Hadith literature formed a strong opinion among Muslims that neither repentance nor the suffering of the person can remove the sin of suicide or mercy "killing" (al-qatl al-rahim), even if these acts are committed with the purpose of relieving suffering and pain. **Abstract (inc. list of references):** https://goo.gl/bHeQ8h

  N.B. Additional articles on the Islamic perspective on death, end of life and end-of-life care are noted in the 16 October 2017 issue of Media Watch (#534, p.3).

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 4 January 2018 – '**Euthanasia and palliative sedation in Belgium.'** The aim of this article is to use data from Belgium to analyse distinctions between palliative sedation and euthanasia. There is a need to reduce confusion and improve communication related to patient management at the end of life (EoL) specifically regarding the rapidly expanding area of patient care that incorporates a spectrum of nuanced yet overlapping terms such as palliative care, sedation, palliative sedation, continued sedation, continued sedation until death, terminal sedation, voluntary euthanasia and involuntary euthanasia. Some physicians and nurses mistakenly think that relieving suffering at the EoL by heavily sedating patients is a form of euthanasia, when indeed it is merely responding to the ordinary and proportionate needs of the patient. Concerns are raised about abuse in the form of deliberate involuntary euthanasia, obfuscation and disregard for the processes sustaining the management of refractory suffering at the EoL. Some suggestions designed to improve patient management and prevent potential abuse are offered. **Abstract:** https://goo.gl/THof6q

Journal Watch

"Easier ways to get a publication": The problem of low quality scientific publications

ANDROLOGY | Online – 26 December 2017 – The "get a publication" mentality has accelerated due to changes in technology and the marketplace, such as the advancement of online publication, in itself a boom to the advancement of knowledge, but in the hands of those without scientific integrity a valuable tool to facilitate easy publication, usually for a nice fee. **Full text:** https://goo.gl/PFZuc2

Predatory publishing: Top 10 things you need to know

AUTHOR RESOURCE REVIEW | Online – December 2017 – Many open access journals are legitimate and reputable, and offer authors the means for maintaining copyright (i.e., right to distribute, etc.) over their own work. Those considered to be "predatory" are merely pay-to-publish websites that exploit researchers and ultimately reduce the credibility of published research. **Full text:** https://goo.gl/c7xxvQ

Predatory publishing and Beall's list: Lessons for the countries adapting novel research evaluation criteria

SCIENCE & EDUCATION, 2017;Issue 8;39-43. The term "predatory" journals was invented by Jeffrey Beall, a librarian from the University of Colorado Denver. Although Jeffrey Beall is considered to be an academic expert in questionable publishing practices by many scientists, one has to remember that he always acknowledged himself quite openly that his list included just "potential, possible, or probable predatory scholarly open-access journals." The choice of words "potential, possible and probable" speaks for itself – Beall's List never meant to be a definitive list of journals and only served as a reference point, a personal opinion of an individual expressed on his personal blog – and it was and is meant to be treated as such. Moreover, Beall's List has never been officially recognized or made official, by any means, in most of the countries in the world, for instance in the Czech Republic where the researchers are recently preoccupied by the debates and mutual accusations of "predatory" publishing and invent new publishing rules for themselves and among themselves that differ from the official publishing guidelines set up by the Czech authorities and by the Czech universities themselves. Beall's List featured "potential, possible, or probable predatory scholarly open access journals" without directly accusing any of them. The list existed for several years and gained a notable number of supporters. However, it did not survive for long. On 17 January 2017, Jeffrey Beall mysteriously shut down his blog, removed it from the Internet and stopped all his online activities altogether (even though he is still invited as a speaker to various conferences on "predatory" publishing, most often to the countries that he used to blame for recognizing the papers published in the "predatory" journals). **Full text:** https://goo.gl/5iRtzk

Worth Repeating

Bad words: Clinical case study about the desires of a patient to prolong her life and the doctors to communicate with her only using "positive" language

THE HASTINGS REPORT, 2014;44(2):13-14. The clinical ethicist met with Ms. H to clarify what information she wants and does not want to know. First, she wants to receive any treatment that could prolong her life, regardless of how the treatment affects her ability to engage in activities of daily living. Second, she wants to be included in the decision-making process as much as possible, as long as clinicians use only "positive" language. Ms. H considers the words "dying," "chemotherapy," "radiation," and "cancer" to be "bad words." For conversations in which these words cannot be avoided, she wants her clinicians to talk to her son. Her desired engagement includes hearing about risks, benefits, and alternatives to treatments if clinicians use only "positive" language. Finally, she says that she rarely sees doctors and that she is "very scared" of hospitals, despite exhibiting a comfortable demeanor. Should clinicians honor Ms. H's waiver of specified information and, if so, to what degree? [Noted in the 24 March 2014 issue of Media Watch (#350, p.12)] **Abstract:** https://goo.gl/zxzNi3

A commentary on 'Bad words'

- The case study is about words concerning illness and its management. They are common words but important and needed to educate patients about their condition and treatment. Nevertheless, they pose an emotional hazard and pain to some patients hearing them. In the case presented, the patient refused to hear those words from her doctors. The dilemma is how medical professionals should respond: how can they be attentive to fully informed and autonomous decision-making by the patient, an ethical and legal requirement in our culture, yet preserve the patient's autonomous right to limit the information he or she is told or to decide even not to be told about health and treatment options? [Published in *The Hastings Report*, 2014;44(4):3-4)] **Full text:** https://goo.gl/MVoUb9

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/m9u1bB

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://goo.gl/frPgZ5

PALLIATIVE CARE NETWORK-e: http://goo.gl/8JyLmE

PALLIMED: http://goo.gl/7mrgMQ
[Scroll down to 'Aggregators' and 'Media Watch by Barry Ashpole'; see also 'Media Watch: Behind the Scenes' at https://goo.gl/6vdk9v]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: https://goo.gl/ZRngsv
[Scroll down to 'Resource Collection' and 'Media Watch Barry Ashpole]

Canada

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: https://goo.gl/BLgxy2
[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): https://goo.gl/wGi7BD
[Scroll down to 'Additional Resources']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): https://goo.gl/IOSNC7

ONTARIO | Mississauga Halton Palliative Care Network: https://goo.gl/ds5wYC
[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

Europe

EUROPEAN JOURNAL OF PALLIATIVE CARE: https://goo.gl/sBTcJS
[November/December 2017 issue (Scroll down to 'Vulnerable populations: From the homeless to the unbefriended)]

HUNGARY | Magyar Hospice Alapítvány: http://goo.gl/5d1l9K

U.K. | Omega, the National Association for End-of-Life Care: http://goo.gl/UfSZtu

Palliative Care Network

Closing the Gap Between Knowledge & Technology

http://goo.gl/OTpc8I

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