

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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The illness experience: Scroll down to [Specialist Publications](#) and 'Shared decision-making at the end of life: A focus group study exploring the perceptions and experiences of multi-disciplinary healthcare professionals working in the home setting' (p.15), in *Palliative Medicine*.

Canada

End-of-life protocols

Halifax hospital rewrites wait-time rules after man's wretched death

NOVA SCOTIA | *The National Post* (Halifax) – 9 October 2017 – A Nova Scotia hospital has rewritten waiting time rules and end-of-life protocols in response to the disturbing story of how a 68-year-old man dying from pancreatic cancer languished for six hours in an ER hallway. A report on the death of Jack Webb says that as of 1 July the Halifax Infirmity requires internal medicine specialists to meet their patients within two hours when transferred to the hospital after being seen by another facility. Webb's widow, Kim D'Arcy, provided the internal report to The Canadian Press. It outlines changes made by the Nova Scotia Health Authority after the saga of his treatment emerged in late April. The review that followed a public outcry over his case has also brought changes to training of medical students and some procedures for treating dying patients. Under the changes, medical students will be guided in simulated conversations on how to talk to dying patients like Webb about their prognosis. In addition, a written "goals of care" form is being introduced that documents the varying types of care patients with terminal diseases want to receive. <https://goo.gl/5byv4n>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *MACLEAN'S* | Online – 11 October 2017 – '**Who will be the doctors of death in a time of assisted suicide?**' More than 2,000 Canadians have received medically assistance in dying (MAiD), administered by a number of physicians. Few of those doctors are palliative care (PC) specialists, who are purposely keeping their distance from MAiD to avoid further stigmatization as the physicians of death. They do not want to be associated with treatment failure or viewed as only providing care to those who have either given up or been deemed hopeless. This has left MAiD without leadership or co-ordination, leading to unequal access and confusion among the public and health-care providers. To understand why PC does not wish to "own" MAiD requires an understanding of the meaning of PC. PC is an approach that improves the quality of life of patients and their families facing a life-threatening illness by preventing and relieving suffering through treatment of pain and other problems — physical, psychosocial and spiritual. It is often provided alongside disease-focused treatments like chemotherapy, radiation or surgery. <https://goo.gl/SCpMUB>

U.S.A.

New Jersey judge recognizes cause of action for wrongful prolongation of life

NEW JERSEY | *New Jersey Law Journal* – 13 October 2017 – In a case of first impression, a judge has ruled that the family of a woman allegedly resuscitated against her wishes may sue the hospital and its staff for wrongful prolongation of life. Morris County Superior Court Judge W. Hunt Dumont declined to grant summary judgment in favor of the key defendants, Morristown Medical Center, Dr. Andrew Youseff and several nurses for their role in prolonging the life of a patient named Suzanna Stica. Stica was admitted to Morristown Medical Center 29 November 2011, after complaining of breathing problems. She already had signed “do not resuscitate” and “do not intubate” orders ahead of her admission, according to the documents. Despite those orders, the defendants resuscitated her after she went into cardiac arrest. She lived another six months before she finally died, according to Dumont’s ruling. During that time, she experienced pain and suffering, the ruling said. <https://goo.gl/eAUx3n>

Making time to really listen to your patients

HARVARD BUSINESS REVIEW | Online – 9 October 2017 – Actively listening to patients conveys respect for their self-knowledge and builds trust. It allows physicians to assume the role of the trusted intermediary who not only provides relevant medical knowledge but also translates it into options in line with patients’ own stated values and priorities. It is only through shared knowledge, transmitted in both directions, that physicians and patients can co-create an authentic, viable care plan. A doctor’s medical toolbox and supply of best-practice guidelines, ample as they are, do not address a patient’s fears, grief over a diagnosis, practical issues of access to care, or reliability of their social support system. Overlooking these realities is perilous, both for the patient’s well-being and for efficient delivery of care. We believe not only that a clinician should share medical decision making with the patient but also that it must occur in the context of an authentic relationship. <https://goo.gl/Ssh19b>

Research looks at racial differences in end-of-life care

UNITED PRESS INTERNATIONAL | Online – 9 October 2017 – Researchers at the University of Washington analyzed survey data from the National Health & Aging Trends Study for racial disparities in end-of-life care (EoLC), reporting no significant differences in the quality of EoLC among patients.¹ Analysis of the survey, which included more than 1,700 interviews of Medicare enrollees age 65 and older ... showed no significant racial differences in the quality of EoLC among patients. Although some survey respondents reported deficiencies in the quality of EoLC for both black and white patients, including unmet symptom care, communication problems, and less than optimal decision-making. The study ... found that black patients were more likely than white patients to die in the hospital, specifically in the intensive care unit. Results of the analysis also showed fewer black patients used hospice care in the last month of life than

Specialist Publications

‘Examining the role of primary care physicians and challenges faced when their patients transition to home hospice care’ (p.13), in *American Journal of Hospice & Palliative Medicine*.

‘Palliative care in heart failure: Rationale, evidence, and future priorities’ (p.10), in *Journal of the American College of Cardiology*.

‘Nationwide quality of hospice care: Findings from the Centers for Medicare & Medicaid Services Hospice Quality Reporting Program’ (p.12), in *Journal of Pain & Symptom Management*.

Cont.

white patients. Respondents were more likely to report the patient not being treated with respect among white patients. One in five respondents for black and white patients reported that family members were not always kept informed of information. <https://goo.gl/HHqJT7>

1. 'Association of racial differences with end-of-life care quality in the U.S.,' *JAMA Internal Medicine*, published online 9 October 2017. **First page review:** <https://goo.gl/BEWNXH>

N.B. Additional articles on racial disparities in the provision and delivery of hospice and palliative care in the U.S. are noted in the 17 April 2017 issue of Media Watch (#508, p.10).

International

The man who befriends terminally ill Muslims

U.K. (England) | Aljazeera – 14 October 2017 – If the photos to the right of Abu Mumin are anything to go by, he saves his smiles for the people he is helping. Although far from curt or impolite in his demeanour, his voice carries a seriousness that is matched in his expression and body language, rarely fidgeting or breaking eye contact. Several pictures show him with a wide smile posing beside patients at their hospital beds. The social worker from London is part of an organisation called Eden Care, which identifies terminally ill people who have no loved ones to look after them and sets about providing them with companionship towards the end of their lives. As most of the people they work with are estranged from their families, their final weeks of life would otherwise be spent alone. Most of the people Mumin and Eden Care help are Muslims, but the group also befriends people who are not. The organisation works with partners from other faiths to ensure those who are not Muslim have funeral arrangements according to their preferred rites. Converts to Islam, who are often referred to as “reverts” by Muslims, are one of the key demographics that Eden Care works with, and Mumin voiced concern that they were more likely to face difficulties towards the end of their lives than people who were born into the faith. <https://goo.gl/YSJroh>



N.B. Eden Care: <https://goo.gl/BwfbWw>. Additional articles on the Islamic perspective on end-of-life and end-of-life care are noted in the 14 August 2017 issue of Media Watch (#525, p.15).

Mexico improves provisions for end-of-life care

MEXICO | Human Rights Watch – 12 October 2017 – Ensuring good health care at the start of life is a long-standing goal for the global community, and major funding backs efforts to reduce maternal and child deaths. By contrast, healthcare at the end of life – a need almost as universal as care during pregnancy, childbirth and infancy – has long been neglected. A new report¹ ... calls on countries to include such care under the universal insurance provided by governments. Mexico is one of the few low- and middle-income countries that has already taken steps to do so... <https://goo.gl/KjJRbA>



1. 'Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,' *The Lancet*, published online 12 October 2017. **Full text:** <https://goo.gl/i7r9M1>

End-of-life care in Scotland

Staff lack skill to provide care for the dying

U.K. (Scotland) | *The Times* (London) – 12 October 2017 – Care staff in Scotland are not trained well enough to look after people who are dying, according to a survey. Residential and nursing homes admitted that staff were not fully equipped to deliver the care people needed at the end of their lives. In total, 55% of those who took part in the research by Scottish Care, which represents care providers, said the training their organisation provided was insufficient to ensure that staff offered high-quality palliative care. More than a quarter of the respondents said they were unable to offer the care and support they would like to give people at the end of their lives. Scottish Care blamed the findings on the “lack of value placed on independent care services and care workers,” as well as funding shortages. Most of the 45 organisations who took part in the survey were care homes, 69% were owned by private companies, and the rest were voluntary organisations. <https://goo.gl/G6sERL>

Paediatric palliative care in Switzerland

Paediatric palliative care still hard to find

SWITZERLAND | Swissinfo.ch (Geneva) – 11 October 2017 – “Marc, I have had enough. I want to end it all.” Marc is professor Marc Ansari, head of the paediatric oncology and haematology unit at Geneva University Hospitals. He was told this by a teenage patient suffering from an incurable cancer. The message sums up the whole difficulty of the situation: a youngster fighting a disease which, in the end, is not going to let him go; and a doctor trying to give him the treatment and support that makes sense. Ansari says the wish to die is not an unusual one. Mostly, he hears it from patients in their teens. The reasons are many, he says. “You have to try to understand the ‘why’ of such a wish – what triggered it. Sometimes, it is an attempt to deal with problems that have not been talked about yet, to talk about fears. Often, these are youngsters with whom we need to spend more time trying to understand and resolve the issues.”

Specialist Publications

‘Economics of palliative and end-of-life care in India: A concept paper’ (p.9), in *Indian Journal of Palliative Care*.

‘Palliative care for children with cancer in the Middle East: A comparative study’ (p.14), in *Indian Journal of Palliative Care*.

‘Developing macro-indicators of palliative care development in Africa: A process with in-country and international experts’ (p.13), in *Journal of Palliative Medicine*.

The fact that the Geneva team was set up only due to a volunteer effort by a group of pioneering professionals, and the fact that the hospital does not currently have an official paediatric palliative care unit, reflects the situation in Switzerland as a whole. There are only three hospitals (St. Gallen, Zurich and Lausanne) that have such units... Ansari remains hopeful, as more resources slowly become available and more people and institutions become aware of the issue. <https://goo.gl/C3YoRh>

Specialist Publications

‘Health care professionals’ experiences and needs when delivering end-of-life care to children: A qualitative study’ (p.14), in *Palliative Care: Research & Treatment*.

“It saved our marriage and kept our family together”: A national study of the impact on parental relationships of short breaks provided by children’s hospice



U.K. (England & Scotland) | Together for Short Lives – 10 October 2017 – Caring for life-limited and life-threatened children puts pressure on relationships and, unsupported, some parents’ relationships do not survive repeated emotional and physical strain. The unrelenting, exhausting cycle of care means couples can end up leading separate lives. And this division can extend to the whole family. Most parents in this study rated short breaks provided by children’s hospices as having a direct, positive effect on their relationship with a partner, giving them rare time together as a couple. Others used short breaks to spend time with their other children or just enjoyed time to themselves, regaining some balance in their lives, ultimately benefitting the whole family. This research found that 64% of divorced or separated parents cited having a child with complex needs as a reason for the breakdown of their relationship. Of those couples, 75% had no access to short breaks at that time. The study provides evidence to support the need for an immediate review of government policy in order to reduce the emotional burden on families, as this frequently leads to parental break-up – and poten-

tial economic cost. Family disintegration through divorce or separation becomes an expensive burden on the State. Short breaks provided by children’s hospices should form part of a preventative policy solution. <https://goo.gl/UNzB2K>

Quality Care Commission

The state of hospice services in England, 2014-2017

U.K. (England) | Care Quality Commission – 10 October 2017 – The regulator’s latest ratings data shows over 90% (34 out of 37 hospices) inspected so far have been judged to be providing outstanding or good care. These ratings mark one year on since the Commission introduced its more rigorous and expert-led approach that assesses hospices across England on whether they are safe, caring, effective, responsive to people’s needs and well-led. The new approach includes publishing reports that rate hospices, including when this support is provided in people’s homes, as outstanding, good, requires Improvement or inadequate to help members of the public make more informed choices about their care, shine a spotlight on the action being taken to drive up poor care, and to celebrate success. <https://goo.gl/2Zu6og>

N.B. Scroll down to ‘Julia’s House & Bournemouth University Research Impact Report’ to access report.

Related

- U.K. (England, Northern Ireland, Scotland & Wales) | *News & Star* (Carlisle, Cumbria) – 10 October 2017 – ‘**Charity in warning over lack of awareness about hospice services.**’ Only 57% of Britons are aware that services provided by hospices are generally free for those receiving them, a new poll by Hospice UK found.¹ The charity said hospice services can be provided at home and in care homes, but a third of adults believe such care can only be provided in a hospice building. The poll of 2,100 British adults also found one in five of those surveyed believed that hospice care was only available to people in their final days. <https://goo.gl/7EL9GW>

1. ‘Hospice UK Public Perceptions Survey,’ ComRes, October 2017. <https://goo.gl/AknJ7d>



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>

Severe human rights abuses discovered in European nursing homes

CZECH REPUBLIC | *The Prague Post* – 8 October 2017 – A recent report published by the European Network of National Human Rights Institutions found cases of severe human rights abuses in nursing homes.¹ The report highlights a serious issue in Europe's aging population, which is set to increase from 18.5% in 2015 to 30% in 2060. The survey was conducted in six countries: Croatia, Belgium, Hungary, Germany, Romania, and Lithuania. It showed that 0.8%-20% of people over the age of 65 are receiving formal, long-term care. Another 3.3% were receiving care in residential settings. The report found several concerning issues. Many people were admitted to care homes without their consent. <https://goo.gl/2QqJJG>

Extract from European Network of National Human Rights Institutions report

The protection of end-of-life and palliative care (PC) rights are seldom articulated in international or regional binding conventions. The International Covenant on Economic, Social and Cultural rights states that, with regard to the realisation of the right to health of older persons, “attention and care for chronically and terminally ill persons (is important), sparing them avoidable pain and enabling them to die with dignity” and Article 23 of the European Revised Social Charter requires the provision of adequate PC services.

1. ‘Human Rights of Older Persons in Long-term Care in Europe,’ European Network of National Human Rights Institutions, June 2017. <https://goo.gl/YqtS9F>

End-of-life care in Ireland

“People who are mentally ill are less likely to be admitted for cancer treatment”

IRELAND | *The Journal* (Dublin) – 8 October 2017 – Pioneering research on Irish palliative care (PC) has indicated that a high proportion of patients with serious mental health issues aren't being treated for physical conditions. All-island PC research ... examined four main areas relating to PC north and south of the border: those with serious mental illnesses, children and families, those with intellectual disabilities and the effect of giving care had on family carers. The branch of research that focused on serious mental health issues sought to clarify whether people with serious mental health issues such as chronic anxiety and bipolar disorders were being treated for physical illnesses. Their study indicates that a high number of Irish patients with serious mental health conditions aren't often believed when they list symptoms, or the person doesn't recognise that they have a physical illness themselves. <https://goo.gl/fmveJa>

When it comes to death, we need more rights than last rites...

IRELAND | *The Irish Times* (Dublin) – 9 October 2017 – As citizens and as a society we need to break the taboo that surrounds death, Justice Catherine McGuinness has said. In the next 10 years over 300,000 people would die in Ireland, and three million would be bereaved. “Up to €1.3 billion is being spent on end-of-life care, and we don't know whether it is being spent wisely. It matters to those left behind because then we can get on with the business of living.” Justice McGuinness urged people to consider filling in a Think Ahead document which records people's care preferences in the event of emergency serious illness or death when they cannot speak for themselves. <https://goo.gl/LmFtkN>

Noted in Media Watch 2 October 2017 (#532, p.6):

- *AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY* | Online – 25 September 2017 – ‘**End-of-life care preferences in patients with severe and persistent mental illness and chronic medical conditions: A comparative cross-sectional study.**’ Physicians [i.e., study participants] rarely engage severe and persistent mental illness (SPMI) patients in end-of-life care (EoLC) discussion despite an increased risk of debilitating medical illnesses and mortality. SPMI was not correlated to any EoLC intervention, except for medical assistance in dying (MAiD) where SPMI patients were less likely to support its use.. **Abstract:** <https://goo.gl/ubHCoV>

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Noted in Media Watch 17 July 2017 (#521, p.13):

- *INTERNATIONAL JOURNAL OF MENTAL HEALTH NURSING* | Online – 10 July 2017 – ‘**Access to specialist palliative care services by people with severe and persistent mental illness: A retrospective cohort study.**’ Compared to the general population, people with pre-existing serious and persistent mental illness (SPMI) have higher rates of physical illness and die at an earlier age, raising questions about their palliative and end-of-life (EoL) care needs when they are diagnosed with an incurable physical illness. The present study confirms that those diagnosed with an SPMI are less likely to use specialist palliative care services at the EoL. **Abstract:** <https://goo.gl/eiGX7U>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (New South Wales) | *The Sydney Morning Herald* – 12 October 2017 – ‘**Language as a battlefield: How we got from euthanasia to voluntary assisted dying.**’ We have developed a tangled web of words with which to discuss the “euthanasia debate.” If it were a train, this debate would have set off from Euthanasia Central, stopped at Voluntary Euthanasia and Assisted Suicide, moved on to Medically Assisted Death and Assisted Dying, before arriving at Voluntary Assisted Dying, the form of words that our parliamentarians have settled on (and which some would further reduce to the neutral acronym VAD). Support varies significantly depending on how the question is framed, and what language is used. Use the word “suicide,” for instance, and support plummets. <https://goo.gl/2aoH1V>
- INDIA | *The Asian Age* (New Delhi) – 12 October 2017 – ‘**Supreme Court reserves verdict on ‘living will’ issue.**’ The Supreme Court ... reserved its verdict on whether “living will” authorising stoppage of medical treatment to the person suffering from an ailment with no chance of survival can be allowed in India. The court will also decide on allowing passive euthanasia (to withdraw or withhold treatment) to a terminally ill patient with point of no return with sufficient safeguards. The Bench said it would lay down guidelines for drafting living wills and how it can be authenticated. <https://goo.gl/3LPhNN>
- AUSTRALIA (New South Wales) | *The Sydney Morning Herald* – 7 October 2017 – ‘**The hidden implications of assisted suicide and euthanasia.**’ A feature of the current debate on assisted dying, particularly among its proponents, has been the personal stories of distress involving the death of loved ones. It is not surprising that euthanasia’s supporters conceive it as a means of eliminating that distress, not just for the dying person, but also their families. The responsibilities of being a family carer to a person with a terminal illness can be extraordinarily demanding. Rates of psychological distress among family carers have been reported as high as 40%. Indeed, family carers are often referred to as “hidden patients” with emotional and support needs that often exceed those of their terminally ill family member. Without suitable professional support many family carers feel isolated and overwhelmed by the many tasks and emotional implications of caring for a loved one with a life-threatening condition. In such circumstances, the promise of a painless and uncomplicated death via assisted suicide, must sometimes seem attractive. If only it were true. <https://goo.gl/qoywM1>

Noted in Media Watch 15 May 2017 (#512, p.14):

- *BEREAVEMENT CARE*, 2017;36(1):8-10. ‘**The experience of bereavement following a physician assisted suicide. What do we know about the needs of these bereaved?**’ The author explored the experience of bereaved people who had experienced multiple or single deaths of a family member or friend ... occurring by physician assisted suicide (PAS) taking place in a country that has a legal framework to allow a PAS. It is hoped that the findings will inform professionals working to support those bereaved to access support and services they need. **Abstract:** <https://goo.gl/a71Lq4>



Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.17.

Specialist Publications

“My future is now”: A qualitative study of persons living with advanced cancer

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 9 October 2017 – Advance care planning enables individuals to deliberate about future preferences for care based upon their values and beliefs about what is important in life. For many patients with advanced cancer, however, these critical conversations do not occur. A growing body of literature has examined the end-of-life wishes of seriously ill patients. Few studies have explored what is important to persons as they live with advanced cancer. The aim of the current study was to address this gap and to understand how clinicians can support patients' efforts to live in the present and plan for the future. Four overarching themes were identified: 1) Living in the face of death; 2) Who I am; 3) My experience of cancer; and, 4) Impact of my illness on others. Twelve sub-themes are also reported. These findings have significant implications for clinicians as they partner with patients to plan for the future. The authors' data suggest that clinicians consider the following prompts: 1) “What is important to you now, knowing that you will die sooner than you want or expected?” 2) “Tell me about yourself.” 3) “Tell me in your own words about your experience with cancer care and treatment.” 4) “What impact has your illness had on others?” In honoring patients' lived experiences, we may establish the mutual understanding necessary to providing high-quality care that supports patients' priorities for life. **Abstract:** <https://goo.gl/L8mbJH>

Recognising older frail patients near the end of life: What next?

EUROPEAN JOURNAL OF INTERNAL MEDICINE | Online – 6 October 2017 – Frailty is a state of vulnerability resulting from cumulative decline in many physiological systems during a lifetime. It is progressive and considered largely irreversible, but its progression may be controlled and can be slowed down and its precursor – pre-frailty – can be treated with multidisciplinary intervention. 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. They acknowledge the barriers to systematically assess frailty and the absence of consensus on best instruments for different settings. Nevertheless, given its potential consequences including prolonged suffering, disability and death, the authors recommend identification of frailty levels should be universally attempted in older people at any health service, to facilitate care coordination, and honest discussions on preferences for advance care with patients and their caregivers. **Abstract:** <https://goo.gl/azdMq7>

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

End-of-life care in Sweden

End of life after stroke: A nationwide study of 42,502 deaths occurring within a year after stroke

EUROPEAN STROKE JOURNAL | Online – 6 October 2017 – In most countries, advances in acute stroke care, rehabilitation and secondary prevention have resulted in reduced stroke mortality over recent decades. However, stroke remains one of the leading causes of death and is the underlying cause in approximately 1 in 10 deaths worldwide. Because stroke is one of the most common causes of death, it may seem paradoxical that so little empirical information related to end-of-life (EoL) issues after stroke is available in the scientific literature. Respiratory distress and pain have been identified as the most disturbing symptoms at the EoL, and symptom control at the EoL has been reported as insufficient. It is a common perception that people prefer to die at home with their family members present. The authors

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hypothesised that there is considerable discordance between this presumed “good death” and the actual circumstances at the EoL late after stroke. They have related the place of death to key issues at the EoL during the first year after stroke with special emphasis on unaccompanied death, i.e., dying without any next of kin or member of the care team present at the time of death. This study used datasets from three nationwide Swedish registers. Basic information was available in 42,502 unselected cases of death after stroke, and more detailed information was available for more than 16,408 deaths. **Full text** (click on pdf icon): <https://goo.gl/JQxqje>

Noted in Media Watch 15 February 2016 (#449, p.15):

- *PLOS ONE* | Online – 4 February 2016 – ‘**End-of-life care for patients dying of stroke: A comparative registry study of stroke and cancer.**’ There is limited data on end-of-life care (EoLC) for patients dying from stroke. Compared to patients dying of cancer, the patients dying of stroke [i.e., study participants] had a significantly higher prevalence of having death rattles registered, but a significantly lower prevalence of, nausea, confusion, dyspnea, anxiety, and pain. Patients dying of stroke had significantly lower odds ratio of having informative communication from a physician about the transition to EoLC and of their family members being offered bereavement follow-up. **Full text:** <http://goo.gl/XALKff>

How can timing and efficacy of palliative care referrals be improved?

EXPERT REVIEW OF QUALITY OF LIFE IN CANCER CARE | Online – 3 October 2017 – The authors present a role for palliative care (PC) in the care of any cancer patient. Patients undergoing treatment for malignancy have many questions regarding life expectancy, tolerance of treatment, functional status, and social support deserving of personalized medicine. There have been many barriers from providers including poor training in communication and prognostication that limit advance care planning. Early integration of PC into cancer treatment is evidence based and has been shown to significantly improve morbidity and mortality, while allowing patients to maintain a greater quality of life. This review explores the challenges in cancer care, current trends in end-of-life care, and strategies to improve early integration of PC into cancer care. The challenge of providing PC should be recognized as a national priority. Despite high quality evidence, there has been limited adoption in both the outpatient and inpatient setting. Integration is both a research and clinical priority. **Abstract:** <https://goo.gl/HTJK9c>

Economics of palliative and end-of-life care in India: A concept paper

INDIAN JOURNAL OF PALLIATIVE CARE, 2017;23(4):456-461. Only a few studies have assessed the economic outcomes of palliative care (PC) in India. The major areas of interest include hospice care, the process and structure of care, symptom management, and palliative chemotherapy compared to best supportive care. At present, there is no definite healthcare system followed in India. In situations where patients bear most of the costs, medical decision-making might have significant implications on economics of healthcare. Game theory might help in deciphering the underlying complexities of decision-making when considered as a two person nonzero sum game. Overall, interdisciplinary communication and co-operation between health economists and PC team seem necessary. This will lead to enhanced understanding of the challenges faced by each other and hopefully help develop ways to create meaningful, accurate, and reliable health economic data. These results can then be used as powerful advocacy tools to convince governments to allocate more funds for the cause of PC. Eventually, this will save overall costs and avoid unnecessary health-care spending. **Full text:** <https://goo.gl/Eyrpr2>

Caregiver experiences across three neurodegenerative diseases: Alzheimer's, Parkinson's, and Parkinson's with dementia

JOURNAL OF AGING & HEALTH | Online – 7 October 2017 – This article asks whether distinct caregiver experiences of Alzheimer's disease (AD), Parkinson's disease (PD), and Parkinson's disease with dementia (PDD) spouses are accounted for by disease diagnosis or by a unique combination of symptoms, demands, support, and quality of life (QoL) cross disease groups. This study identified four clusters that cut across disease diagnosis. "Succeeding" cared for mild symptoms and had emotional support. "Coping" managed moderate stressors and utilized formal supports. "Getting by with support" and "Struggling" had the greatest stressors; available emotional support influenced whether burden/depression was moderate or severe. This study supports going beyond disease diagnosis when examining caregiver experiences. **Abstract:** <https://goo.gl/Un8Z48>

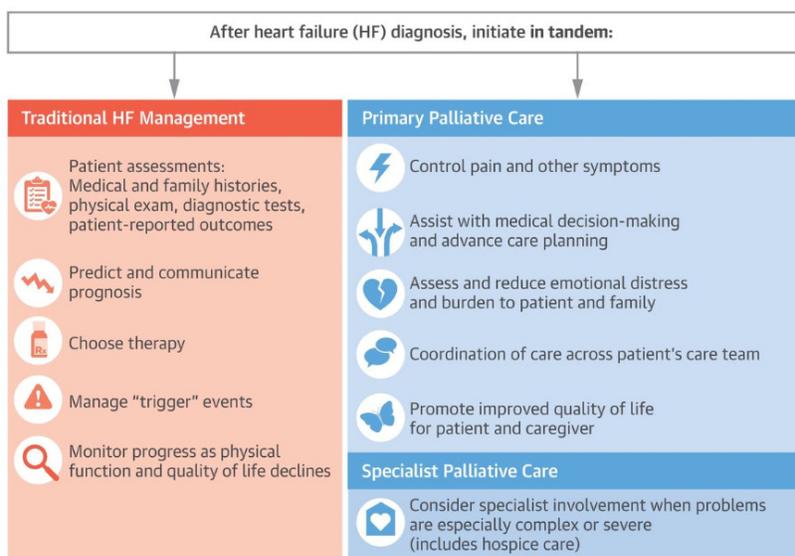
N.B. Articles on palliative care for people – both patients and family caregivers – living with neurodegenerative diseases are noted in the 9 October 2017 and 24 July 2017 issues of *Media Watch* (#533, p.14, #522, p.14, respectively).

Related

- *PALLIATIVE MEDICINE* | Online – 12 October 2017 – 'End-of-life care: A qualitative study comparing the views of people with dementia and family carers.' People with dementia and carers expressed the need for receiving care in place, ensuring comfort and a skilled care team. However, they disagreed about the importance of planning for the future and the role of families in organising care and future decision-making. Further comparison of the authors' findings with expert consensus views highlighted key areas of divergence and agreement. Discordant views concerning perceptions of dementia as a palliative condition, responsibility for future decision-making, and the practical coordination of end-of-life care may undermine the provision of optimal palliative care. **Abstract:** <https://goo.gl/GvjHna>

Palliative care in heart failure: Rationale, evidence, and future priorities

JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY, 2017;70(15):1919-1930. Patients with heart failure (HF) and their families experience stress and suffering from a variety of sources over the course of the HF experience. Palliative care is (PC) an interdisciplinary service and an overall approach to care that improves quality of life and alleviates suffering for those living with serious illness, regardless of prognosis. The authors synthesize the evidence from randomized clinical trials of PC interventions in HF. While the evidence base for PC in HF is promising, it is still in its infancy



and requires additional high-quality, methodologically sound studies to clearly elucidate the role of PC for patients and families living with the burdens of HF. Yet, an increase in attention to primary PC (e.g., basic physical and emotional symptom management, advance care planning), provided by primary care and cardiology clinicians, may be a vehicle to address unmet palliative needs earlier and throughout the illness course. **Abstract:** <https://goo.gl/rqfdL4>

Cont.

Noted in Media Watch 11 September 2017 (#529, p.7):

- **CURRENT HEART FAILURE REPORTS** | Online – 6 September 2017 – ‘**Cardiac palliative medicine.**’ The American Heart Association has released a policy statement recommending continuous, high-quality access to palliative care (PC) for all patients with heart failure,¹ and the Center for Medicare Services requires PC involvement in mechanical circulatory support teams. The National Quality Forum developed eight domains of PC that are required for high-quality delivery of comprehensive PC. This article assesses each domain and how it pertains to evolving care of patients with advanced heart failure. **Abstract:** <https://goo.gl/BeWC5W>
 1. ‘Palliative care and cardiovascular disease and stroke: A policy statement from the American Heart Association and the American Stroke Association,’ *Circulation*, 2016;134(11):e198-e225. [Noted in Media Watch 18 September 2017 (#530, p.2)] **Abstract:** <https://goo.gl/2u9mE2>

N.B. Additional articles on end-of-life care for people living with heart failure are noted in the 28 August 2017 issue of Media Watch (#526, pp.11-12).

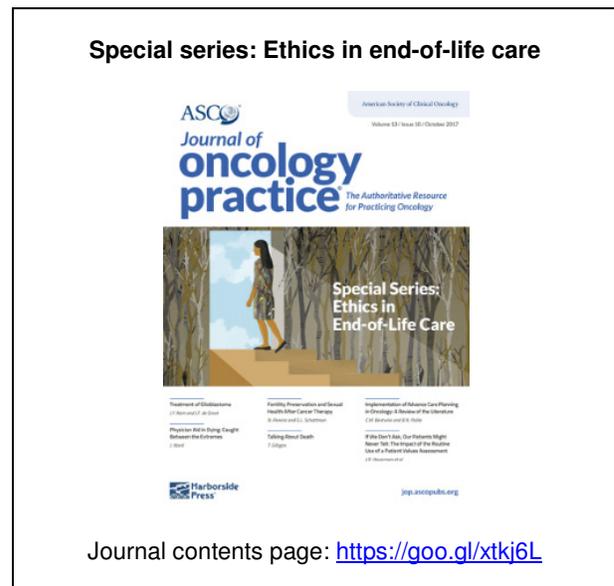
Hope, Phase I trials, and palliative care: So you’re telling me there’s a chance?

JOURNAL OF ONCOLOGY PRACTICE, 2017; 13(10):675-677. In its modern form, palliative care (PC) is no longer reserved for situations where treatment options are exhausted; rather, high-quality specialty PC can and should be provided along with a clinical trial or any other active cancer treatment in patients with advanced disease (per ASCO guidelines¹). In this context, PC is another vehicle through which to maintain and facilitate realistic hope and to help patients to plan for all possible outcomes, including those that receive comparatively less attention in our discussions about clinical trial participation: symptoms, quality of life, distress, and suffering. These outcomes matter a great deal to patients and families, but they are less often the focus of our discussions about clinical trial participation. The evidence, however, is clear: concurrent PC can improve these important outcomes among patients with advanced cancer... **Full text:** <https://goo.gl/4w6h7H>

1. ‘Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline update,’ *Journal of Clinical Oncology*, 2017;35(1):96-112. [Noted in the 31 October 2016 issue of Media Watch (#486, p.7)] **Full text:** <https://goo.gl/RGjFMP>

Enhancing care of aged and dying prisoners: Is e-learning a feasible approach?.

JOURNAL OF FORENSIC NURSING | Online – 4 October 2017 – Prisons and jails are facing sharply increased demands in caring for aged and dying inmates. The authors’ Toolkit for Enhancing End-of-life Care in Prisons effectively addressed end-of-life care (EoLC) care; however, geriatric content was limited, and the product was not formatted for broad dissemination. Prior research adapted best practices in EoLC and aging; but, delivery methods lacked emerging technology-focused learning and interactivity. An environmental scan was conducted with 11 participants from U.S. prisons and jails to ensure proper fit, in



Journal contents page: <https://goo.gl/xtkj6L>

Cont.

terms of content and technology capacity, between an envisioned computer-based training product and correctional settings. Findings focused on content of training, desirable qualities of training, prominence of “home-grown” products, and feasibility of commercial e-learning. **Abstract:** <https://goo.gl/bQJSJ6p>

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report can be downloaded/viewed at: <http://goo.gl/ZpEJyQ>

Addressing a patient’s hope for a miracle

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 10 October 2017 – Ill patients may make decisions to continue aggressive life-prolonging care based on hope for a miraculous recovery, and clinicians can find goals of care discussions with these patients extremely challenging. Thus, palliative care (PC) providers may be asked to help in these discussions. The concept of “miracle” can express a multitude of hopes, fears, and religious commitments. Effective, sensitive engagement requires the PC provider to attend to these variegated hopes, fears, and commitments. This case presents a typology of ways patients express hope for a miracle along with analysis of the motivations and beliefs underlying such hopes and suggestions for tailored responses by PC providers. **Abstract:** <https://goo.gl/P3Hnb1>

Noted in Media Watch 13 March 2017 (#503, p.12):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(2):115-119. ‘**Hope for a miracle: Treatment requests at the end of life.**’ It is not uncommon for patients and caregivers facing medical uncertainties to utilize religious coping as a tool to foster adjustment to changes along an illness trajectory. Religious coping can promote a sense of meaning, emotional well-being, and hope. This article explores requests for aggressive treatment stemming from strongly held religious beliefs and overarching hope for a miracle. **Abstract:** <https://goo.gl/JUJiDg>

Noted in Media Watch 13 June 2011 (#205, p.8):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 6 June 2011 – ‘**Approaching patients and family members who hope for a miracle.**’ Belief in miracles is found to be common in the U.S. and is an important determinant of how decisions are made for those with advanced illness. There is a growing amount of evidence that suggests end-of-life outcomes improve with the provision of spiritual support from medical teams, as well as with a proactive approach to medical decision making that values statements given by patients and family members. **Abstract:** <http://goo.gl/D4mAAa>

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

Nationwide quality of hospice care: Findings from the Centers for Medicare & Medicaid Services Hospice Quality Reporting Program

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 9 October 2017 – With increasing use of the Medicare hospice benefit, policymakers recognize the need for quality measurement to assure that terminally ill patients receive high quality care and have the information they need when selecting a hospice. Towards these goals, the Centers for Medicare & Medicaid Services has been collecting standardized patient-level quality data via the Hospice Item Set (HIS) since 1 July 2014. This article presents a first look at the national hospice HIS quality data. The authors’ sample included 1,218,786 hospice patients discharged from 3,922 hospices from 1 October 2014 to 30 September 2015. Over 90% of patients received screenings and assessments captured by six of the seven quality measures. The only exception was pain assessment, for which the national mean score was 78.2%. A small number of hospices (156, 4.0%) had perfect scores for all seven quality measures. Most hospices conduct critical assessments and discuss treatment preferences with patients at admission, although few hospices have perfect scores. **Abstract:** <https://goo.gl/AazYeH>

Cont.

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 October 2017 – ‘**Examining the role of primary care physicians and challenges faced when their patients transition to home hospice care.**’ The transition into home hospice care is often a critical time in a patient’s medical care. Studies have shown patients and caregivers desire continuity with their physicians at the end of life. However, it is unclear what roles primary care physicians (PCPs) play and what challenges they face caring for patients transitioning into home hospice care. Most PCPs [from 3 academic group practices in New York City] noted that there was a discrepancy between their actual role and ideal role when their patients transitioned to home hospice care. **Abstract:** <https://goo.gl/Z8FhyR>

Developing macro-indicators of palliative care development in Africa: A process with in-country and international experts

JOURNAL OF PALLIATIVE MEDICINE | Online – 13 October 2017 – Indicators specific to the African context are important to measure palliative care (PC) development accurately. One hundred three indicators were rated by [participating] country experts, and 58 proceeded to the Delphi. Thirty-eight indicators were rated as important by the international committee, and the project team ranked 19 of these as most important. Service indicators included the number of types of services most important in Africa (e.g., hospices, home based) and coverage. Policy indicators included the existence of PC in national policies, guidelines, and budget and a responsible person. Education indicators consisted of inclusion of PC in medical and nursing curricula and recognition as a specialty. Medicine indicators focused on morphine availability, consumption, and prescribing barriers. Vitality indicators reflected the existence of a national association and its activity. The process to develop African-specific PC indicators resulted in 19 indicators that were used to measure PC development as a comparative baseline for development in African countries. **Abstract:** <https://goo.gl/NistqD>

Noted in Media Watch 4 September 2017 (#528, p.13):

- *LANCET ONCOLOGY*, 2017;18(9):e522-e531. ‘**Palliative care in Africa: A scoping review from 2005-2016.**’ Information on 26 (48%) of 54 African countries was found. Most services were concentrated in Kenya, South Africa, and Uganda, and 14 (26%) countries showed an increase in services during this timeframe. Stand-alone palliative care (PC) policies exist in Malawi, Mozambique, Rwanda, Swaziland, Tanzania, and Zimbabwe. Restricted access to opioids, prescriber restriction laws, and a low prevalence of morphine use remain common barriers to adequate PC provision. Although information on PC is unevenly distributed, the available information showed an increased development of PC services in a subset of African countries. Despite this growth, however, there is still minimal to no identified PC development in most African countries. **Summary:** <https://goo.gl/fFh7Ht>

Noted in Media Watch 10 July 2017 (#520, p.12):

- *JOURNAL OF GLOBAL ONCOLOGY* | Online – 30 June 2017 – ‘**Palliative care development in Africa: Lessons from Uganda and Kenya.**’ The authors examined the impact of approaches to promoting the development of palliative care (PC) in Uganda and Kenya, and considered how these and other strategies could be applied more broadly. Both countries have implemented strategies across all five domains [i.e., education and training, access to opioids, public and professional attitudes, integration into national health systems, and research] to develop PC. In both countries, successes in these endeavors seem to be related to efforts to integrate PC into the national health system and educational curricula, the training of health care providers in opioid treatment, and the inclusion of community providers in PC planning and implementation. **Abstract:** <https://goo.gl/RP8FWv>

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

The Lancet Commission

Alleviating the access abyss in palliative care and pain relief : An imperative of universal health coverage

THE LANCET | Online – 12 October 2017 – The lack of global access to pain relief and PC throughout the life cycle constitutes a global crisis, and action to close this divide between rich and poor is a moral, health, and ethical imperative. The need for PC and pain relief has been largely ignored. Yet, PC and pain relief are essential elements of universal health coverage (UHC). This *Lancet* Commission aims to: 1) Quantify the heavy burden of serious health-related suffering associated with a need for PC and pain relief; 2) Identify and cost an essential package of PC and pain relief health services that would alleviate this burden; 3) Measure the unmet need of an indispensable component of the package – off patent, oral, and injectable morphine; and, 4) Outline national and global health-systems strategies to expand access to PC and pain relief as an integral component of UHC while minimising the risk of diversion and non-medical use. **Full text:** <https://goo.gl/i7r9M1>

N.B. For commentaries on *The Lancet* Commission report and related content: <https://goo.gl/Q49X96>

Pediatric palliative care in Switzerland

Health care professionals' experiences and needs when delivering end-of-life care to children: A qualitative study

PALLIATIVE CARE: RESEARCH & TREATMENT | Online – Accessed 11 October 2017 – This study aimed to describe the experiences and needs of healthcare professionals (HCPs) in pediatric end-of-life care (EoLC) and to develop recommendations for the health ministry. The key aspect in EoLC provision was identified as the capacity to establish a relationship with the dying child and the family. Barriers to this interaction were ethical dilemmas, problems in collaboration with the interprofessional team, and structural problems on the level of organizations. A major need was the expansion of vocational training and support by specialized palliative care (PC) teams. The authors recommend the development of a national concept for the provision of EoLC in children, accompanied by training programs and supported by specialized pediatric PC teams located in tertiary children's hospitals. **Full text:** <https://goo.gl/qfSTLi>

Related

- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2017;23(4):379-386. '**Palliative care for children with cancer in the Middle East: A comparative study.**' The aim of this study is to compare the status of pediatric palliative care (PC) in Egypt, Lebanon, Jordan, Turkey, and Iran. PC in children in the Middle East is still in its early stages and there are many obstacles to its development, namely, lack of professional knowledge, inadequate support of policy makers, and lack of access to opioids and financial resources. Despite these challenges, providing services at the community level, support of non-governmental organizations, using trained specialists and multi-disciplinary approach is an opportunity in some countries. **Abstract:** <https://goo.gl/EzVwpw>

N.B. The Indian Academy of Pediatrics recently published, in *Indian Pediatrics*, a consensus statement on end-of-life care. **Abstract:** <https://goo.gl/EWK8mY>. The full statement can be viewed/downloaded at the journal's website (scroll down to 'Consensus Statement'): <https://goo.gl/Gi91hY>

- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 11 October 2017 – '**Parents' and physicians' perceptions of children's participation in decision-making in paediatric oncology: A quantitative study.**' Results indicate that for six aspects of information provision examined, parents' and physicians' perceptions differed. Moreover, parents felt that the children were more competent to understand diagnosis and prognosis, assessed the disease of the children as worse, and reported higher satisfaction with decision-making on the part of the children. A patient's age and gender predicted involvement. In the decision-making process, parents held a less active role than they actually wanted. **Abstract:** <https://goo.gl/kioKZu>

N.B. Additional articles on children's participation in decision making are noted in the 9 October 2017 issue of *Media Watch* (#533, pp.6-7).

Shared decision-making at the end of life: A focus group study exploring the perceptions and experiences of multi-disciplinary healthcare professionals working in the home setting

PALLIATIVE MEDICINE | Online – 12 October 2017 – Globally recommended in healthcare policy, shared decision-making (SDM) is also central to international policy promoting community palliative care. Yet realities of implementation by multi-disciplinary healthcare professionals who provide end-of-life care in the home are unclear. While the rhetoric of SDM was recognised [among study participants], its implementation was impacted by several interconnecting factors, including: 1) Conceptual confusion regarding SDM; 2) Uncertainty in the process; and, 3) Organisational factors which impeded SDM. Multiple interacting factors influence implementation of SDM by professionals working in complex community settings at the end of life. Moving from rhetoric to reality requires future work exploring the realities of SDM practice at individual, process and systems levels. **Abstract:** <https://goo.gl/w8g24g>

Related

- *PATIENT EDUCATION & COUNSELING* | Online – 11 October 2017 – ‘**Is patient behavior during consultation associated with shared decision-making? A study of patients’ questions, cues and concerns in relation to observed shared decision-making in a cancer outpatient clinic.**’ Patients asked an average of 17 questions and expressed 1.9 emotional cues/concerns. Questions mainly pertained to treatment/practical issues. The number of questions was associated with patients’ level of anxiety. Physician shared decision-making behavior was not associated with patient behavior. **Abstract:** <https://goo.gl/Nb6ozo>

Patients’ and caregivers’ needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries¹

PALLIATIVE MEDICINE | Online – 12 October 2017 – Five themes are described [by study participants] : 1) Patients’ and caregivers’ spiritual concerns; 2) Understanding of spirituality and its role in illness; 3) Views and experiences of spiritual care; 4) Preferences regarding spiritual care; and, 5) Research priorities. Participants reported wide-ranging spiritual concerns spanning existential, psychological, religious and social domains. Spirituality supported coping, but could also result in framing illness as punishment. Participants emphasised the need for staff competence in spiritual care. Spiritual care was reportedly lacking, primarily due to staff members’ de-prioritisation and lack of time. Patients’ research priorities included understanding the qualities of human connectedness and fostering these skills in staff. Caregivers’ priorities included staff training, assessment, studying impact, and caregiver’s spiritual care needs. To meet patient and caregiver preferences, healthcare providers should be able to address their spiritual concerns. The study’s findings should inform patient- and caregiver-centred spiritual care provision, education and research. **Full text:** <https://goo.gl/ok27qg>

1. Belgium, Canada, Finland, Kenya, Poland, South Africa, South Korea, the U.K., and the U.S.

Noted in Media Watch 25 September 2017 (#531, p.11):

- *HAREFUAH*, 2017;156(8):502-506. ‘**Do we have medical measures that attest to the effect of spiritual care in time of illness.**’ Spiritual care (SC) is provided in thousands of hospitals worldwide, and in limited fashion in over ten hospitals in Israel. By the nature of SC, it is difficult to clinically measure its full impact on and contribution to patients and family members. Nonetheless, studies have found a correlation between a hospital’s providing SC, lowered mortality rates in the hospital and increased use of hospice care. Receipt of SC correlated with higher quality of life at the end of life (EoL). When the staff, including the SC provider, attends to patients’ spirituality, studies find a substantial reduction in aggressive medical interventions at the EoL. **Abstract:** <https://goo.gl/Kjw4x5>

N.B. Additional articles on spirituality in the context of end-of-life care are noted in the 16 January 2017 issue of Media Watch (#495, p.3).

What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death

PALLIATIVE MEDICINE | Online – 10 October 2017 – Projections show that there will be substantial increases in deaths at home and in care homes over the next 25 years, if current trends continue, putting significant pressure on community services. If the reduction of deaths in hospital is to be sustained, there is an urgent need to expand the number of care home places and invest in community services and social care. If care home capacity does not increase or alternative approaches developed, the projected reduction of deaths in hospital will reverse, and demands on hospitals to provide end-of-life care will escalate. An urgent policy decision and strategic response to these imminent challenges is required to ensure that there is adequate infrastructure across settings to provide high quality care to people reaching the end of their life in future years. **Full text:** <https://goo.gl/nhXAVS>

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>

Palliative care content on cancer center websites

SUPPORTIVE CARE IN CANCER | Online – 9 October 2017 – The authors conducted a systematic content analysis of 62 National Cancer Institute (NCI) designated cancer center websites. They assessed the content of center homepages and analyzed search results using the terms palliative care (PC), supportive care, and hospice. For palliative and supportive care web pages, the authors assessed services offered and language used to describe care. NCI designated cancer center homepages presented information about cancer directed therapy more frequently than PC. Ten percent of cancer centers had no webpage with PC information for patients. Among centers with information for patients, the majority (96%) defined palliative or supportive care, but 30% did not discuss delivery of PC alongside curative treatment, and 14% did not mention provision of care early in the disease process. Improving accessibility of PC information and increasing emphasis on early provision of services may improve integration of palliative and cancer care. **Abstract:** <https://goo.gl/6vEYhL>

Noted in Media Watch 2 January 2017 (#493, p.8):

- *CANCERS* | Online – 13 December 2016 – ‘**Ensuring quality in online palliative care resources.**’ The internet is changing how health information is being distributed and accessed. Clinicians, patients, community members, and decision makers have an unprecedented capacity to find online information about palliative and end-of-life care. However, it is clear not all individuals have the skills to be able to find and assess the quality of the resources they need. **Full text:** <https://goo.gl/c1RC98>

End-of-life caregiver social support activation: The roles of hospice clinicians and professionals

QUALITATIVE HEALTH RESEARCH | Online – 11 October 2017 – Caregivers of those with life-limiting illness face many complicated tasks, including providing direct patient care, communicating with professionals, and managing the logistical demands of daily activities. To assist with caregiving responsibilities, caregivers require social support from social network members at all points in the illness process. This study analyzes themes from interviews with 61 caregivers of patients enrolled in hospice services to identify the types of support caregivers mobilize from new social network members for social support during the end-of-life care process. Themes indicate that caregivers receive accessible, immediate, caregiver-centered emotional support from hospice health care professionals, and situationally tailored, understandable informational support from other types of professionals. In addition, caregivers received overlapping emotional and informational support from hospice health care professionals. Findings enhance the understanding of how caregivers receive tailored emotional and informational support. **Abstract:** <https://goo.gl/oA7DpS>

N.B. Additional articles on family caregivers' social support are noted in the 9 October 2017 issue of Media Watch (#533, p.12).

[Media Watch: Online](#)

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/3oecYD>

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

PALLIATIVE CARE NETWORK COMMUNITY: <http://goo.gl/8JyLmE>

PALLIMED: <http://goo.gl/7mrgMQ>

[Scroll down to 'Aggregators' and 'Media Watch by Barry Ashpole']

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/lXO4mD>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <https://goo.gl/JL3j3C>

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 ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W>
[Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Magyar Hospice Alapítvány: <http://goo.gl/5d119K>

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

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Something Missed or Overlooked?

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

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