

## 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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Compilation of Media Watch 2008-2018 ©

Compiled & Annotated by Barry R. Ashpole

**New directions in hospice and palliative care? Scroll down to [Specialist Publications](#) and ‘What role do death doulas play in end-of-life care? A systematic review’ (p.13), in *Health & Social Care in the Community*.**

## Canada

### The trouble with hospitalized seniors

ONTARIO | CBC (‘White Coat, Black Art’) – 24 September 2018 – Doctors have begun to grapple with a new problem related to the country’s aging demographic. A growing number of older patients are readmitted to hospital shortly after discharge. A recently published study ... uncovers a big gap in health care.<sup>1</sup> Hospital readmissions are a huge and growing problem in Canada. Researchers from Alberta and Ontario looked at more than 700,000 Ontario patients over the age of 65 with an average age of just over 78 years of age. Overall, 88,000 or 12% of the patients had to be readmitted to hospital within 30 days of being discharged. Forty per cent of the patients had five or more chronic medical conditions. The study ... uncovered a new factor associated with hospital readmissions: inadequate home care. Patients who were discharged to their homes with home care provided by the system were the most likely to need readmission. They also had the longest stays in hospital. Patients who were living in a nursing home prior to the first admission were also more likely to be admitted a second time. Patients who were admitted from home and who were dis-

charged to a nursing home were less likely to need readmission. As well, patients who came from home and who were sent home without needing home care were also unlikely to need readmission. The study suggests a significant gap in home care provided to seniors when they’re discharged from hospital. There are limits to the type of care provided at home. And even when the level of home care is adequate, frequently, there is no communication between the agency that provides the care and the patient’s family doctor. <https://goo.gl/mQUUVZ>

### Specialist Publications

‘Frailty trajectories to identify end of life: A longitudinal population-based study’ (p.9), in *BMC Medicine*.

‘Care setting and 30-day hospital readmissions among older adults: A population-based cohort study’ (p.12), in *Canadian Medical Association Journal*.

1. ‘Identification and management of frailty in the primary care setting,’ *Canadian Medical Association Journal*, published online 24 September 2018. Access options at: <https://goo.gl/JMyR78>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *The London Free Press* – 23 September 2018 – **‘Health care super-agency mulls change to assisted death policy.’** The agency that allocates health care dollars for much of Southwestern Ontario wants to revise its policy on medically-assisted death, allowing nurse practitioners to provide the life-ending procedure. The South West Local Health Integration Network (LHIN) ... wants to expand the health care providers allowed to provide medically-assisted death to patients. Allowing nurse practitioners both to assess patients and complete the end-of-life procedures is in line with their legislated scope of practice, a report to the South West LHIN board of directors said. If it’s approved by the board, the Southwestern Ontario regional health authority will become the latest of Ontario’s 14 LHINs to allow nurse practitioners to provide medical assistance in dying. The Toronto Central LHIN, Champlain LHIN near Ottawa and the North East LHIN in northern Ontario all allow nurse practitioners to act as assisted death providers, the report said. <https://goo.gl/47hdmQ>

## U.S.A.

### In the nursing home, empty beds and quiet halls

*THE NEW YORK TIMES* | Online – 28 September 2018 – The most recent quarterly survey from the National Investment Center for Seniors Housing & Care reported that nearly one nursing home bed in five now goes unused. Occupancy has reached 81.7%, the lowest level since the research organization began tracking this data in 2011, when it was nearly 87%. “It’s a significant drop,” said Bill Kauffman, senior principal at the center. “The industry as a whole is under pressure, and some operators are having difficulty.” Such national statistics mask considerable local differences. “The best facilities still have 100% occupancy and waiting lists – that’s how you know they’re good,” said Nicholas Castle, a health policy researcher at the University of Pittsburgh. But in 2015, the National Center for Health Statistics reported that more than a third of beds were empty in some states, including Illinois, Iowa, Nebraska, Oklahoma and Utah. Texas wasn’t far behind. Nationally, “200 to 300 nursing homes close each year,” Dr. Castle said. The number of residents keeps shrinking, too,

from 1.48 million in 2000 to 1.36 million in 2015, according to federal data. Given an aging population, you’d think nursing homes would be coping with the opposite problem – surging demand for their services. But they also face growing financial strains and regulatory requirements intended to control costs, Mr. Kauffman pointed out. <https://goo.gl/S9bt73>

### Specialist Publications

‘Preparation and planning for future care in the Deep South: Adapting a validated tool for cultural sensitivity’ (p.18), in *The Gerontologist*.

‘Predictors of hospice enrollment for patients with advanced heart failure and effects on health care use’ (p.12), in *JACC: Heart Failure*.

‘High burden of palliative care needs of older adults during emergency major abdominal surgery’ (p.13), in *Journal of the American Geriatric Society*.



### 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>

## United Methodist Church and Vatican issue joint declaration supporting palliative care at the end of life

TEXAS | Religion News Service (Houston) – 26 September 2018 – The United Methodist Church and the Vatican have issued a joint declaration on the ‘End of Life and Palliative Care.’ The joint declaration serves as a compassionate response to the global public health crisis related to care for dying patients. Methodists and Roman Catholics are united in advocacy for highly personalized palliative care (PC) as a “new normal” for patients near the end of life. PC, they explain, is scaffolding upon which science, faith and medicine can construct better supports for patients and families. <https://goo.gl/6NhGLY>

### Specialist Publications

‘White paper for global palliative care advocacy: Recommendations from a Pontifical Academy for Life Expert Advisory Group...’ (p.15), in *Journal of Palliative Medicine*.

## Hope, humanity & housing: Terminally ill and living on Sacramento streets

CALIFORNIA | KCRA 3 News (Sacramento) – 21 September 2018 – Pancreatic cancer took Jamie Murphy’s life on 14 August 2018. But not without a leaving behind a legacy of empathy – that the most vulnerable should die with dignity and respect. Murphy was a passionate advocate for Joshua’s House, which is slated to become the first homeless hospice center in the West Coast and one of only a handful in the country. The 46-year-old gave an emotional testimony during a Sacramento City Council meeting taking up Joshua’s House. In May, council members voted unanimously for the homeless hospice center to move forward. “ These kinds of things show who we are as the heart and soul of this country and as a society,” founder Marlene von Friederichs-Fitzwater said. “ And we need to take better care of people.” Murphy’s terminal diagnosis ultimately left him unable to work, rotating from motel to motel. He lived off a little over \$900 a month in supplemental security income. Joshua’s House is scheduled to open in early 2019. The 20-bed facility is partnering with all Sacramento-based hospitals to provide hospice care to those terminally ill on the streets. <https://goo.gl/GoHP9Y>

**N.B.** Selected articles on palliative and end-of-life care for the homeless in the U.S. noted in 2 July 2018 issue of Media Watch (#570, p.5). Joshua’s House website: <https://goo.gl/4T7Y4i>

## International

### Emergency Medical Technicians puzzled by patients who say no to life-saving measures

JAPAN | *The Asahi Shimbun* (Tokyo) – 28 September 2018 – Ambulance attendants are increasingly being forced to make the difficult choice of continuing life-saving efforts for patients with incurable conditions, as more patients receive medical care at home and plan to die in peace there. According to a survey, emergency workers at more than half of local fire defense headquarters across Japan were told by families of terminally ill patients and others to stop cardiac massage or artificial respiration last year due to the patients’ wishes. The findings are from a study of the internal affairs ministry’s Fire & Disaster Management Agency (FDMA). The Fire Service Law stipulates ambulance workers should transport patients in urgent need of treatment to medical centers and provide cardiopulmonary resuscitation (CPR) for them, but it includes no rules on the discontinuation of life-saving measures. A task force set up in May by the FDMA to discuss how to respond to patients who refuse CPR will release its recommendation on whether to suspend resuscitation efforts for those patients by around January next year. <https://goo.gl/rd7kSJ>



### 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.21.

## Enabling someone to die at home is a complex balancing act of needs

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 26 September 2018 – As long as they receive the care and support they need, most people - prefer to be cared for and spend most of the dying process at home, as the memories built into the home often provide a sense of safety and familiarity within the tumult of fast approaching, inexorable changes. However, enabling someone to remain at home can be a complex endeavour... Research has explored the relationship between home environments and palliative care, a term referring to caring for someone who is terminally ill and approaching the end of life. The research entailed conversations with staff at Scottish hospices and housing-related organisations. One of the results revealed that it wasn't necessarily the current physical state of the home that affected a person's wellbeing, but rather how an attachment to that physical state can prevent them from making necessary and useful changes. Many hospices offer home assessments to determine the best options to facilitate someone's needs, and will coordinate the installation of aids and adaptations such as hospital beds to support mobility, comfort, and independence. However, some people living with a terminal illness refuse these practical changes, - possibly because they cannot cope with what a change in their home environment represents. <https://goo.gl/du9ifY>

### Related

- U.K. (Scotland) | *The Sunday Post* (Dundee) – 23 September 2018 – **'A friend at the end: Law firm becomes first in Scotland to offer doula services.'** A law firm is set to be the first in the country to offer doula services to clients facing their final days. Solicitor Hilary Peppiette is the driving force behind the scheme, having spent the past two years training to offer the specialist counselling and support. Hilary, 52, is one of Scotland's first end-of-life doulas, companions for people who are dying. <https://goo.gl/cZukXt>

**N.B.** Scroll down to [Specialist Publications](#) and 'What role do death doulas play in end-of-life care? A systematic review' (p.13). Additional articles on death doulas in 30 July 2018 issue of Media Watch (#574, p.3).

## Life expectancy progress in U.K. "stops for first time"

U.K. | BBC News (London) – 25 September 2018 – Life expectancy (LE) in the U.K. has stopped improving for the first time since 1982... Women's LE from birth remains 82.9 years, and for men it is 79.2, the figures from the Office for National Statistics for 2015-2017 show. In some parts of the U.K. LE has even decreased. For men and women in Scotland and Wales it declined by more than a month, while men in Northern Ireland have seen a similar fall. For women in Northern Ireland, and for men and women in England, LE at birth is unchanged. The data also shows that the U.K. lags other leading countries for LE, including Switzerland, Japan, France, the Netherlands, Spain and Italy. <https://goo.gl/BrwtSN>

### [Specialist Publications](#)

**'An exploration of the lived experience of professional grief among occupational therapists working in palliative care settings'** (p.9), in *Australian Occupational Therapy*.

**'Examining palliative and end of life care research in Ireland within a global context: A systematic mapping review of the evidence'** (p.9), in *BMC Palliative Care*.

**'Oncologic and palliative care in a global setting in the twenty-first century: The patient, family and oncologic health care team'** (p.13), in *Journal of Global Oncology*.

**'Palliative medicine in Pakistan: A developing country's perspective'** (p.16), in *Ochsner Journal*.

**'Physician-related determinants of medical end-of-life decisions: A mortality follow-back study in Switzerland'** (p.17), in *PloS One*.

**'Unexpected death in ill old age: An analysis of disadvantaged dying in the English old population'** (p.19), in *Social Science & Medicine*.

## National Health Service England is not prioritising care for the dying...

U.K. (England) | *The Huffington Post* – 25 September 2018 – National Health Service England is currently consulting on its long-term plan for the National Health Service (NHS). Covering the next ten years, the plan will set out how the NHS will deal with the challenges of providing care to an ageing population under extreme financial pressure. At the time of writing, NHS England will not be prioritising the care that people need when they are dying in its plan for the next decade. Let's put this into perspective. In the next ten years 5.5 million people will die. Most of those people will need palliative care (PC). Most of those people will die at an older age than their parents did and with significantly more complex care needs. Yet the NHS is not considering in any significant way in its 10 year plan how to provide care for these people. NHS England has taken a hands-off approach with clinical commissioning groups (CCGs) on the issue of end-

of-life care (EoLC), which has led to huge variations around the country in the availability of PC. In some parts of the country you will wait less than 48 hours to get out of hospital at the end of life, in others you can be stuck there for nearly two weeks. By not prioritising EoLC in a strategy that looks at improving NHS care for the next ten years, NHS England seems to be signalling that they don't particularly care where people die or how people die. It's as if once illness becomes no longer treatable you are no longer a priority. <https://goo.gl/gDqJsn>

### Specialist Publications

'Guarding against dispassion for doctors in the National Health Service' (p.15), in *Journal of the Royal Society of Medicine*.

Noted in Media Watch 23 July 2018 (#573, p.3):

- U.K. (England) | *The Daily Mail* (London) – 17 July 2018 – '**Dying patients are being neglected by councils, with budgets for end-of-life care as low as £52 per person.**' Dying patients are still being neglected by councils. End-of-life care is being prioritised by only 4% of town halls in England, according to analysis by experts at King's College London.<sup>1</sup> Councils, which have responsibility for social care, face increasing numbers of elderly people needing end-of-life support. Demand is set to increase 42% by 2040. Quality of care and resources varied hugely around the country, with budgets ranging from £52 to £2,329 per patient per year for PC. <https://goo.gl/2Ey6tH>
  - 'Is end-of-life care a priority for policymakers? Qualitative documentary analysis of health care strategies,' *Palliative Medicine*, published online 17 July 2018. **Full text:** <https://goo.gl/dVrfKj>

**N.B.** Selected articles on access to palliative and end-of life care in the U.K. noted in this issue of Media Watch.

Noted in Media Watch 6 March 2017 (#502, p.5):

- U.K. (England) | BT.com News (London) – 1 March 2017 – '**Researchers warn of postcode lottery in care for the dying.**' Dying people are being left with inadequate round-the-clock pain relief and poor access to specialist help, according to new research.<sup>1</sup> They are caught in a postcode lottery which affects whether their families are able to secure proper National Health Service (NHS) end-of-life care on weekends and during the night. In some parts of England, NHS bosses only provide a telephone advice line to cater for people in their last days of life. Meanwhile, others have full palliative care teams with expertise in areas such as controlling cancer pain or lessening distress. <https://goo.gl/0x1Ptz>
  - 'Commissioning of specialist palliative care services in England,' *BMJ Supportive & Palliative Care*, published online 28 February 2017. **Full text:** <https://goo.gl/SnmBW0>

## New guide to commissioning and delivering children's palliative care

U.K. | Together for Short Lives – 25 September 2018 – The charity has launched its new guide to commissioning, planning and delivering children's palliative care (PC) based around the unique needs of the child and family. The guide, now in its 4<sup>th</sup> edition, has played a pivotal role in driving the development of PC for babies, children and young people with life-limiting and life-threatening conditions since it was first published in 1997. It aims to enhance understanding of the specific needs of these children and families and to encourage an integrated approach to delivering sustainable high-quality children's PC services based on evidence and delivered by an appropriately trained, experienced and integrated workforce. The guide is recognised as the cornerstone of good PC for children in the U.K. and internationally. The new edition is endorsed by the National Institute for Health & Care Excel-

lence (NICE), the Royal College of Paediatrics & Child Health, the International Children's Palliative Care Network and the European Association for Palliative Care, and aligns with the NICE guideline on end-of-life care for children.<sup>1</sup> **Download/view 'A Guide to Children's Palliative Care' at:** <https://goo.gl/fRmnMr>

### Specialist Publications

'Challenges in managing parental expectations in paediatric care' (p.10), in *British Journal of Haematology*.

'Pediatric end-of-life simulation: Preparing the future nurse to care for the needs of the child and family' (p.11), in *Journal of Pediatric Nursing*.

1. 'End-of-Life Care for Infants, Children and Young People,' National Institute for Health & Excellence, September 2017. [An early draft of the Institute's guideline, issued as part of the consultation process, noted in 24 April 2017 issue of Media Watch (#509, p.14)] <https://goo.gl/f1dFiv>

Noted in Media Watch 29 January 2018 (#548, p.4):

- U.K. (England) | *The Daily Mail* (London) – 26 January 2018 – '**Charities call to improve end-of-life care for seriously ill children.**' Too many seriously ill children and their families are still unable to access decent end-of-life care, with a "cruel postcode lottery" meaning many cannot decide where they die. Despite a government commitment, good end-of-life support, planning and care based on choice is not available to all families, a coalition of charities said. 5,000 babies, children and young people in the U.K. under the age of 19 die every year, a significant number living with life-limiting or life-threatening conditions who need. <https://goo.gl/YXW2Uz>

**N.B.** See 'Integrating Palliative Care and Symptom Relief into Paediatrics,' World Health Organization, September 2018. **Download/view at:** <https://goo.gl/WR77kx>

## ***Integrating palliative care and symptom relief into responses to humanitarian emergencies and crises***

WORLD HEALTH ORGANIZATION | Online – Accessed 25 September 2018 – Current responses to humanitarian emergencies and crises rightfully focus on saving lives, but for both ethical and medical reasons the prevention and relief of pain, as well as other physical and psychological symptoms, social and spiritual distress, also are imperative. Therefore, palliative care (PC) should be integrated into responses to humanitarian emergencies and crises. Principles of humanitarianism and impartiality require all patients receive care and should never be abandoned for any reason, even if they are dying. There is significant overlap in the principles and mission of PC and humanitarianism: relief of suffering; respect for the dignity of all people; support for basic needs; and, accompaniment during the most difficult of times. This publication is intended to assist anyone involved with planning, implementing or managing responses to humanitarian emergencies and crises. **Download/view at:** <https://goo.gl/tdnWUB>



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Noted in Media Watch 10 September 2018 (#580, p.8):

- *JOURNAL OF INTERNATIONAL HUMANITARIAN ACTION* | Online – 3 September 2018 – ‘**Moral experiences of humanitarian health professionals caring for patients who are dying or likely to die in a humanitarian crisis.**’ The authors undertook an interpretive description study to investigate humanitarian policy-maker and care providers’ experiences and perceptions of palliative care during humanitarian crises. They report on interviews with 23 health professionals, 11 of whom also had experience as policy-makers within a humanitarian organization. Five themes related to participants’ moral experiences were identified, all of which relate to values of compassion in the provision of care and justice in accessing it. **Full text:** <https://goo.gl/i6EiYb>

**N.B.** Additional articles on the provision of palliative care during humanitarian crises or natural disasters noted in 20 August 2018 issue of Media Watch (#577, p.12).

### Royal commission needs to reveal causes of sad stories in aged care

AUSTRALIA (Victoria) | *The Sydney Morning Herald* – 23 September 2018 – These days people requiring aged care are usually frailer and have more complex needs, and who stay for shorter periods [in residential aged care]; this is partly because care at home has markedly improved. Most people go into residential aged care as their final home, meaning that the majority will die there. Yet this fact seems to be ignored in the information given to residents and families and the goals in planning care, including preparing for the dying process. There is little staff professional skill in unique aspects like recognising deterioration and alleviating symptoms, advance care planning for a good death, educating families about what may happen and involving the general practitioner to ensure there are appropriate medicines available. In Victoria, residential aged care services are heavily dependent on external expertise, from either the local community-based palliative care service or a visiting service provided by public hospitals, to provide advice on end-of-life care. <https://goo.gl/vucQ22>



#### Related

- AUSTRALIA | ABC Radio News ('PM') – 28 September 2018 – ‘**Palliative care services busier than ever, but who is missing out?**’ People under 60 with a terminal illness are falling through the cracks, experts say. Australia has a growing and ageing population, with palliative care services around the country busier than ever. It’s provided almost anywhere that health care is available, including neonatal units, acute hospitals and aged care homes. <https://goo.gl/cNmoam>
- AUSTRALIA | ABC Radio News ('PM') – 28 September 2018 – ‘**Palliative care not just about death, but living better with illness.**’ Palliative care (PC) has a very scary reputation. Patients are often frightened to hear the term, thinking it means imminent death, and many doctors are scared to use it. But it could actually mean a longer life, and certainly better quality of life, towards the end. PC doctors say talking about death can also make the inevitable easier. <https://goo.gl/xp6RsH>
- AUSTRALIA | ABC Radio News ('PM') – 27 September 2018 – ‘**How do Australia’s palliative care options measure up?**’ Talking about death ... makes a good one happen. So does receiving palliative care (PC) as early as possible, but this doesn’t always happen. What PC services are on offer in Australia? Who is missing out and what more can be done to ensure everyone that needs it is getting the care and the death they want? <https://goo.gl/DRj4Xv>
- AUSTRALIA | ABC Radio News ('PM') – 26 September 2018 – ‘**Health professionals are calling for a re-branding of palliative care and a national discussion on how to deliver a good death.**’ Palliative care (PC) is a term doctors are reluctant to use and patients are frightened to hear. But in the wake of emotional debates on euthanasia ... those working in PC say it’s time Australia tackled that fear and started talking about how to deliver a “good death.” <https://goo.gl/XNbHgA>



Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

## Specialist Publications

### **Seeing the patient and family through: Nurses and physicians experiences with withdrawal of life-sustaining therapy in the ICU**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 24 September 2018 – Interviews were conducted with critical care nurses and physicians from two medical centers. An inductive approach to data analysis was used to understand similarities between the nurses and the physicians' experiences. Methodological rigor was established, and data saturation was achieved. The main categories that were inductively derived from the data analysis included from novice to expert, ensuring ethical care, uncertainty to certainty, facilitating the process, and preparing and supporting families. The categories aided in understanding the experiences of nurses and physicians, as they worked individually and together to see patients and families through the entire illness experience, withdrawal of life-sustaining therapy decision-making process, and dying process. Understanding the perspectives of health-care providers involved in the withdrawal of life-sustaining therapy process will help other health-care providers who are striving to provide quality care to the dying and to their families. **Abstract:** <https://goo.gl/ZNqi3Z>

Noted in Media Watch 22 January 2018 (#547, p.16):

- *MINERVA ANESTESIOLOGICA* | Online – 17 January 2018 – **'Forgoing life-sustaining treatments in the ICU. To withhold or to withdraw: Is that the question?'** Mortality from severe acute illnesses has considerably declined thanks to the advances in intensive care medicine. Meanwhile, critical care physicians realized that life-sustaining treatments may not be appropriate for every patient, and end-of-life care in the ICU started to receive growing attention. Most deaths occurring in the ICU now follow a decision to forgo, which can be implemented either by withdrawing (WDLST) or withholding (WHLST) life-sustaining treatments. Despite the broad consensus about the equivalence of the two practices from an ethical point of view, the issue of the best option between WDLST and WHLST constantly gives rise to controversies in clinical practice. **Abstract:** <https://goo.gl/8zwRxl>

### **Dying healthy: Public health priorities for fixed population life expectancies**

*ANNALS OF INTERNAL MEDICINE* | Online – 25 September 2018 – A longer life has long been one of the central goals of investments in public health and medicine. Population longevity is frequently used to measure the success of a country's health care system, and life expectancy in many countries increased by more than 30 years in the past century. The 21st century began with new medications and procedures to fight disease, and we are now at the dawn of a genomic revolution that has promised even more remarkable opportunities to cure disease and extend life. However, recent data suggest that the human lifespan probably has an unalterable biological limit of approximately 115 years and that virtually all humans will die before age 90 years. Advances in medical treatment – especially for cancer – are thus increasingly unlikely to provide substantial gains in healthy human longevity, and whatever increase in population lifespan was due to medical advances in the second half of the 20th century is unlikely to be replicated. As such, it is time to stop putting almost all of our resources into the search for life-extending therapies. Instead, we should shift our focus and investments toward identifying strategies that improve quality of life overall and compress illness at the end of life. Three arguments support this conclusion. **Abstract:** <https://goo.gl/T6ksQH>

#### Specialist Publications

**'Predatory open-access publishing in anesthesiology'** (p.19), in *Anesthesia & Analgesia*.

**'Solicitation for article submission by electronic journals'** (p.20), in *Baylor University Medical Center Proceedings*.

## **An exploration of the lived experience of professional grief among occupational therapists working in palliative care settings**

*AUSTRALIAN OCCUPATIONAL THERAPY*, 2018;65(4):329-337. Occupational therapists who work in palliative care (PC) are frequently exposed to the experience of death and dying. Previous occupational therapy research has offered insight into factors that influence feelings relating to death and dying and associated coping strategies. However, existing literature is dated and has not specifically examined the concept of grief. This study addresses this gap in knowledge by exploring the lived experience of professional grief among occupational therapists working in PC settings. Four interrelated themes were identified as core to the lived experience of professional grief among participants: 1) "Knowledge of self"; 2) "Giving permission for connections and feelings"; 3) "Filtering experience"; and, 4) "Being present at work and at home." Considered in combination, these themes offer a guide for therapists to explore their own experience of and responses to professional grief and, in doing so, foster the development of personalised management strategies. **Abstract:** <https://goo.gl/Uo4nJQ>

Noted in Media Watch 28 May 2018 (#565, p.14):

- *PALLIATIVE MEDICINE*, 2018;32(5):960-968. 'Mapping the scope of occupational therapy practice in palliative care: A European Association for Palliative Care cross-sectional survey.' This study is the first to examine the provision of occupational therapy in palliative care in Europe. It shows there is a shared core content of occupational therapy services in direct and indirect patient care and that priority is given to clinical care activities over teaching, service development or research. Occupational therapists understand and value their role in making it possible for people facing dying to participate as fully as they wish and are able in their everyday lives ... but do not feel that this role is used to its full potential. **Full text:** <https://goo.gl/E6HiCd>

**N.B.** Additional articles on the role of occupational therapists in palliative and end-of-life care noted in this issue of Media Watch.

## **Frailty trajectories to identify end of life: A longitudinal population-based study**

*BMC MEDICINE* | Online – 21 September 2018 – This longitudinal population-based study demonstrates that it is possible to use a frailty index calculated within electronic healthcare records to identify people who are at a higher risk of dying within one year. This has potential application in health services to support clinicians in identifying older adults dying with frailty who may have been overlooked by traditional approaches and to help ensure appropriate care is offered. **Full text:** <https://goo.gl/jJvvfU>

**N.B.** Selected articles on recognising older frail patients near the end of life noted in 8 January 2018 issue of Media Watch (#545, p.5).

## **Examining palliative and end of life care research in Ireland within a global context: A systematic mapping review of the evidence**

*BMC PALLIATIVE CARE* | Online – 27 September 2018 – This updated systematic mapping review identified a continued increase in palliative care (PC) research in Ireland with studies demonstrating increased collaborative working both nationally and internationally. Overall the quality and quantity of research increased from the previous review of Irish PC research (2002-2012).<sup>1</sup> This can be attributed to significant investment in terms of research funding and collaborative networks. However, research gaps continue to exist, such as out-of-hours' PC, psychological symptom control, limited use of experimental research design, and over reliance on health care professional's perspective. Key areas for attention include the need to continue to build research capacity across the continuum from doctoral to postdoctoral research opportunities, demonstration of the impact of the research on patient and family carer outcomes, service provision, and cost effectiveness. Whilst this follow up review has outlined progress specifically within the Irish PC context, there are clear lessons and opportunities for the global context. By undertaking such reviews at a country or regional level assists in developing a potential research database that can not only contribute to discussions at a national level but also inform the PC research community globally and by doing so, advance and improve provision of PC for patients and their families. **Full text:** <https://goo.gl/EwKM4b>

Cont.

1. 'Palliative care research on the island of Ireland over the last decade: A systematic review and thematic analysis of peer reviewed publications,' *BMC Palliative Care*, published online 4 September 2013. [Noted in 9 September 2013 issue of *Media Watch* (#322, p.6). **Full text:** <https://goo.gl/LtFfFK>

### **Meaningful connections in dementia end of life care in long term care homes**

*BMC PSYCHIATRY* | Online – 24 September 2018 – The findings of this study suggest opportunities to support end-of-life (EoL) care for persons with dementia in long term care (LTC) homes. It is important to acknowledge and support the value of relationships, the time it takes to establish relationships, and the grief experienced by staff who provide care. Health care aides' intimate knowledge of persons with dementia should be incorporated in interprofessional pain management interventions. Residents with dementia are not immune to grief and loss when other residents die. Further research about their needs is required. Existing rituals within LTC homes may need to be enhanced. Families want and need information about the dementia illness trajectory and EoL. Education and training for staff to be confident in providing this information and answering families' questions is needed. **Full text:** <https://goo.gl/T3UZXe>

**N.B.** Selected articles on palliative for people living with Alzheimer's and other forms of dementia noted in 17 September 2018 issue of *Media Watch* (#581, pp.3-4).

### **The doll is dead: Simulation in palliative care education**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 25 September 2018 – Both simulation and high-fidelity simulation involving manikins, clinical training suites, wards, computer programs and theatres have established themselves in medical undergraduate and postgraduate education. Popular among students, they have been shown to be effective learning tools. Contrasted with this is the potential risk to patients and their proxy associated with learning "at the bedside," which can pose a real challenge in medical and palliative settings. The need for education and training methods that do not expose the patient to preventable communication blunders from less experienced practitioners is a priority. The authors provide a summary review on the current literature and evidence for simulation and high-fidelity simulation in palliative and end-of-life care settings, and discuss potential uses of technologies including virtual and augmented reality in future training. Palliative medicine has been slow to adapt to an educational method and environment that now is widely used across other areas of healthcare. There has been less emphasis on training with manikins and even less on using computer simulation and virtual reality environments to recreate challenging end-of-life care scenarios. The authors provide some examples of where this could benefit the curriculum. **Abstract:** <https://goo.gl/c5UtTF>

### **Challenges in managing parental expectations in paediatric care**

*BRITISH JOURNAL OF HAEMATOLOGY* | Online – 26 September 2018 – Given the recent number of controversial cases featured in the media, it is timely to consider the management of parental expectations in paediatric care. What is sadly overlooked in the controversy is the usual excellent working relationship formed by treating child health professionals, parents (those with parental responsibility) and children themselves in tackling really tough situations. We are able to do more and more to tackle previously deadly diseases, and yet the burden of our treatments is undeniably higher. At the same time, social changes and ready access to information have led to a necessary reduction in medical paternalism, and more empowered and knowledgeable patients. The authors review how things have become very challenging in this arena in the U.K. over the last decades, and consider the issues surrounding disagreements and conflict. On the background of population shifts, religious diversity and populism, parental expectations now vary dramatically given the same situation. The challenge is still met by communicating, listening with empathy but finally by adhering to the basic tenet of Article 3 of the UN Convention of the Rights of the Child – 'The best interests of children must be the primary concern in making decisions that may affect them.' **Abstract:** <https://goo.gl/t5CBDj>

Cont.

## Related

- *JOURNAL OF PEDIATRIC NURSING* | Online – 25 September 2018 – ‘**Pediatric end-of-life simulation: Preparing the future nurse to care for the needs of the child and family.**’ Post simulation, students participating in guided reflection, identified several themes impacting their experience with end-of-life care, including symptom management, emotional care and “what to say.” Nurses’ behaviors and responses when caring for a child can have a significant impact on the family’s experience and memory of their child’s death. Unintended actions may result in the family experiencing negative impressions, causing further distress to the grieving family. **Abstract:** <https://goo.gl/djwRdK>

## **Inter-professional caring for children who are relatives of cancer patients in palliative care: Perspectives of doctors and social workers**

*BRITISH JOURNAL OF SOCIAL WORK* | Online – 24 September 2018 – Interviews with doctors and social workers [i.e., study participants] indicated that professionals had limited contact with patients’ children. Mono- and inter-professional meetings were organising structures for working days of doctors and social workers. Due to hierarchy positions, doctors often set the agenda in inter-professional teamwork. They seldom met patients’ children, only when information about parents’ cancer diseases were needed. Social workers were responsible for psycho-social issues, but mostly only special vulnerable families and their children were prioritised. Meetings between children and professionals were conditional on the parents’ permission and, even if permission was given, meetings seldom took place. Doctors and social workers were subject to the structural frame and a medical logic, which limited their interactions with children of the patients. Children were dependent on both their parents and professionals, who had the power to include or exclude them from parents’ illness situation. **Abstract:** <https://goo.gl/8iqtWA>

## Related

- *QUALITY HEALTH RESEARCH* | Online – 27 September 2018 – “‘**Death lay here on the sofa**’”: **Reflections of young adults on their experience as caregivers of parents who died of cancer at home.**’ Three themes emerged in this study: 1) “I was chosen and was led into that situation” (modes of taking on and performing the role of a caregiver); 2) “My life was on hold” (the experience of performing the caregiving role); and, 3) “I underwent ... the real school of life” (caring for the dying parent as an imprint on self-development). Participants integrated compassionate caring into their identity, reflecting an empowering encounter of young carers with their dying parents as a process of growth in the face of harsh, stressful experiences. **Abstract:** <https://goo.gl/WbpMu5>

## **Chronic heart failure in adults: Summary of updated National Institute for Health & Care Excellence guidance**

*BRITISH MEDICAL JOURNAL* | Online – 24 September 2018 – The prevalence of heart failure (HF) is increasing because of an ageing population and improved survival of chronic diseases that contribute to heart failure. HF includes reduced ejection fraction and preserved ejection fraction disease. The Institute’s guideline on chronic HF was last updated in 2010. Since then, further evidence on novel and existing therapies, for example mineralocorticoid receptor antagonists, has emerged. New research has also been published on diagnosing HF and approaches to HF care, including monitoring,

rehabilitation, and the composition of the multidisciplinary team.<sup>1</sup> **Introductory paragraph:** <https://goo.gl/JDje9w>

### **What’s new in this guidance**

Clearer advice on managing the care of people with heart failure, including a greater emphasis on multidisciplinary working, shared decision making, care planning, lifestyle advice and interventions, comorbidities, and end-of-life care.

1. ‘Chronic Heart Failure in Adults: Diagnosis and management,’ National Institute for Health & Care Excellence, September 2018. **Download/view at:** <https://goo.gl/dJzirP>

Cont.

## Related

- *JACC: HEART FAILURE* (American College of Cardiology), 2018;6(9). ‘**Predictors of hospice enrollment for patients with advanced heart failure and effects on health care use.**’ This study sought to: 1) Identify the predictors of hospice enrollment for patients with heart failure (HF); and, 2) Determine the impact of hospice enrollment on health care use. Beneficiaries’ characteristics, including symptom burden and functional status, do not predict hospice enrollment. Those patients who enrolled in hospice used less health care, survived longer, and were less likely to die in the hospital. A tailored hospice model may be needed to increase enrollment and offer benefits to patients with HF. **Abstract:** <https://goo.gl/FSTX4t>

**N.B.** Selected articles on palliative care in heart failure noted in 10 September 2018 issue of Media Watch (#580, pp.4-5).

## Care setting and 30-day hospital readmissions among older adults: A population-based cohort study

*CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2018;190(38):E1124-E1133. Despite the fact that many older adults receive home or long-term care (LTC) services, the effect of these care settings on hospital readmission is often overlooked. Efforts to reduce hospital readmissions, including capacity planning and targeting of interventions, require clear data on the frequency of and risk factors for readmission among different populations of older adults. In this large cohort of older adults who had been admitted to hospital, the authors found that 40% had been discharged to either home care or LTC and that the discharge setting, coupled with the prior care setting, had important implications for understanding 30-day hospital readmissions. Health system planning and strategies to reduce readmissions among older adults should take into account the care setting both before admission and at discharge. Furthermore, by contextualizing hospitalization within these care set-

tings, the findings of this study suggest an approach to understanding readmissions as a signal of the health system’s preparedness for the aging population. **Full text:** <https://goo.gl/ygxf8Z>

### Extract

Quality end-of-life care (EoLC), in any setting, is also critical to such a strategy. Among those readmitted from home care or long-term care, about 20% died during the readmission. The frequency of death following repeated transitions is concerning. Preferences for death at home, or in a home-like setting, over death in the hospital have been well documented, as has the burden of hospital admissions at the end of life. Quality EoLC reduces symptom burden and hospital transfers that are not desired by patients.

## Is there a role for the funeral service provider in bereavement support within the context of compassionate communities?

*DEATH STUDIES* | Online – 28 September 2018 – This is the first study to explore bereaved individuals’ experiences of funeral service providers using these services’ databases. 839 Australians participated in a postal survey, 6-24 months into their bereavement. Funeral providers were reported to be the third most prevalent form of bereavement support after friends and family. Analysis found six themes related to perceived helpful or unhelpful support: 1) Instrumental support; 2) Professionalism; 3) Informational support; 4) Financial tension; 5) Communication; and, 6) Emotional support. Funeral providers could improve their support by adopting a proactive approach to bereavement needs and offering personalized and ongoing support. The authors develop these suggestions by exploring their potential contributions to building community capacity around death, dying and bereavement. **Abstract:** <https://goo.gl/4Le2AM>



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

## Neuropalliative care aspects in patients with Parkinson's disease

*FORTSCHRITTE DER NEUROLOGIE-PSYCHIATRIE* | Online – 21 September 2018 – Palliative Care (PC) in Parkinson's Disease (PD) is of growing interest. The burden of symptoms of late-stage PD patients is similar or even higher than those of patients suffering from oncological diseases. However, patients suffering from advanced phases of PD have tremendous unmet PC needs. The disease trajectories are often difficult to define, and initiation of PC approach has to be chosen carefully. Swallowing difficulties define the onset of the late and palliative phase and have to be seen as a landmark for PC involvement. The authors provide an approach to PC in PD in the final phase and also care for the relatives. **Abstract:** <https://goo.gl/TRoHyz>

**N.B.** German language article. Selected articles on the palliative and end-of-life care for patients living with Parkinson's disease noted in 17 September 2018 (#581, p.13).

## What role do death doulas play in end-of-life care? A systematic review

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 26 September 2018 – Current health and social care systems do not always meet the needs of the dying in our communities. As a result, patients and families are choosing to place their trust in those who can advocate for them or fill the gaps in care. Birth doulas have been working with women during pregnancy and after birth for many years, and we are now seeing a new role, that of a death doula emerging in the end-of-life (EoL) care space. How death doulas work within health and social care systems is not understood and the authors conducted a systematic review to explore the published literature to explore the role and potential implications for models of care delivery. Their search retrieved 162 unique records of which five papers were included. The authors analysed the papers in relation to relationship to health service, funding source, number and demand for services, training, licensing and ongoing support, and tasks undertaken. Death doulas are working with people at the EoL in varied roles that are still little understood, and can be described as similar to that of "an eldest daughter" or to a role that has similarities to specialist palliative care nurses. Death doulas may represent a new direction for personalised care directly controlled by the dying person, an adjunct to existing services, or an unregulated form of care provision without governing oversight. **Full text:** <https://goo.gl/DbPkPg>

**N.B.** Selected articles on death doulas in 30 July 2018 issue of Media Watch (#574, p.3).

## High burden of palliative care needs of older adults during emergency major abdominal surgery

*JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 24 September 2018 – Of 411 participants (in this retrospective study), 57% had high illness burden. More individuals with high illness burden had complications and in-hospital death than those without. After discharge, individuals with high illness burden experienced more emergency department (ED) visits and were more likely to die. Of those who died after discharge, 75% had high illness burden, median survival was 67 days, 48% enrolled in hospice, 32% died in the hospital, 23% were in the ICU in the last 30 days of life and 37% had an ED visit in the last 30 days of life. Concurrent surgical and palliative care may improve quality of life and end-of-life care in these people. **Abstract:** <https://goo.gl/iSUK12>

## Oncologic and palliative care in a global setting in the twenty-first century: The patient, family and oncologic health care team

*JOURNAL OF GLOBAL ONCOLOGY*, 2018;9(4):1-3. Palliative care (PC) in oncology is a crucial issue and unmet need across the spectrum of cancer care and in countries and communities with varying degrees of resource allocation for cancer care. It is remarkable that the majority of patients newly diagnosed with cancer will ultimately die of their malignancy. Indeed ... 14 million patients were newly diagnosed with malignancy ... in 2012, and approximately 8.2 million individuals died with malignancy in that same

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year...<sup>1</sup> This issue is of particular importance in resource-limited countries in which the mortality rate for all cancers ... is substantially higher at 66%.<sup>1</sup> This is notable because the cancer burden in less-developed countries is greater, with more than 8 million cancer diagnoses. As might be expected, the fact that the mortality of an individual with a cancer diagnosis is significantly greater in lower- and middle-income countries highlights the need for access to PC in these areas and ... this is the most significant value of the Resource-Stratified Practice Guideline on Palliative Care in the Global Setting.<sup>2</sup> Key issues this guideline addresses are the practical issue of how to deliver care in terms of PC models, the timing of PC, spiritual care, and pain management, among other salient and practical concerns when embarking on palliative treatment as it pertains to patients with cancer. However, beyond this obvious need, the guideline highlights another practical issue that can be observed across the globe, regardless of practice location and available resources: that of the oncology team. **Full text:** <https://goo.gl/MiaHZv>

1. 'Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries,' *CA: A Cancer Journal for Clinicians*, published online 12 September 2018. [Noted in 17 September 2018 issue of Media Watch (#581, p.5)] **Full text:** <https://goo.gl/pkz5Cn>
2. 'Palliative care in the global setting: American Society of Clinical Oncology Resource-Stratified Practice guideline,' *Journal of Global Oncology*, published online 8 May 2018. [Noted in 14 May 2018 issue of Media Watch (#563, p.7)] **Full text:** <https://goo.gl/Hydd43>

#### Related

- **HEALTH** | Online – 'What lies beneath? Experiencing emotions and caring in oncology.' Medical encounters – while often viewed as centred on conveying clinical knowledge – are also sites of emotion and for exerting emotional labour by healthcare professionals. The temptation to view these encounters as largely "technical" – an exchange of knowledge or information – can marginalise the complex emotions often experienced by healthcare professionals, and negates the critical work done in these encounters. Drawing on in-depth interviews with 22 Australian medical oncologists, this article explores the experience and meaning of (their) emotions in medical encounters, and the manner in which emotional labour is performed by medical oncologists. **Abstract:** <https://goo.gl/HVV26S>

#### Towards a palliative care approach in psychiatry: Do we need a new definition?

*JOURNAL OF MEDICAL ETHICS* | Online – 28 September 2018 – Psychiatry today is mainly practised within a curative framework. However, many mental disorders are persistent and negatively affect quality of life as well as life expectancy. This tension between treatment goals and the actual illness trajectory has evoked a growing academic interest in "palliative psychiatry," namely the application of a palliative care (PC) approach in patients with severe persistent mental illness. Recently, Trachsel *et al* presented a working definition of palliative psychiatry.<sup>1</sup> This first official attempt to capture the concept is based on WHO's widely accepted definition of PC, but modified and limited to include only severe persistent psychiatric illness. While this is a welcome step in the discussion on PC approaches in psychiatry, it also opens up for new questions. One of the most evident is whether psychiatry actually needs its own definition of PC or, put differently, whether there is something about mental disorders that differs so radically from other medical conditions that it calls for a separate definition. The authors acknowledge the need to discuss the goals of psychiatric care in patients with severe persistent psychiatric illness. However, they question whether a separate definition of PC exclusive to psychiatry is the right way to go. **Abstract:** <https://goo.gl/ZRNjj8>

1. 'Palliative psychiatry for severe persistent mental illness as a new approach to psychiatry? Definition, scope, benefits, and risks,' *BMC Psychiatry*, published online 22 July 2016. [Noted in 1 August 2016 issue of Media Watch (#473, p.11)] **Full text:** <https://goo.gl/Coh8wK>



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## When we document end-of-life care, words still matter

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 21 September 2018 – The study by Wentlandt *et al* focused on specific word choices when documenting about end-of-life care.<sup>1</sup> They accurately note that, in acute care settings, the patient's medical record often becomes the primary mechanism for communication between providers. Imprecise documentation can lead to poor transfer of knowledge and even implicit bias. They describe the "implied state" category as most frequently used by non-palliative care providers, which labels patients by the care they receive... **Abstract:** <https://goo.gl/GCmVx6>

1. 'Language used by health care professionals to describe dying at an acute care hospital,' *Journal of Pain & Symptom Management*, published online 22 May 2018. [Noted in 28 May 2018 issue of *Media Watch* (#565, p.12)] **Abstract (w. link to references):** <https://goo.gl/Ha16WN>

## White Paper for Global Palliative Care Advocacy: Recommendations from a Pontifical Academy for Life Expert Advisory Group...

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 27 September 2018 – Thirteen experts in palliative care (PC) advocacy participated in an online Delphi process. In four iterative rounds, participants were asked to identify the most significant stakeholder groups and then propose for each, strategic recommendations to advance PC. Each round incorporated the feedback from previous rounds until consensus was achieved on the most important recommendations. In a last step, the *ad hoc* group was asked to rank the stakeholders' groups by order of importance on a 13-point scale and to propose suggestions for implementation. A cluster analysis provided a classification of the stakeholders in different levels of importance for PC development. In summary, this White Paper emphasizes the responsibility of healthcare systems and stakeholders to recognize access to pain relief and PC as a basic right of the person and the family and the responsibility of all elements of the healthcare system. For this, it is necessary to recognize health as not only an absence of disease but also as physical, emotional, social, and spiritual well-being, which can be optimized only by making essential PC medicines available, governments integrating PC into their healthcare plans and universal health coverage, and developing public and professional education, as well as clear frameworks for implementing this care to prevent needless suffering. The support of faith-based and philanthropic organizations, non-governmental and governmental actors, and human rights organizations is needed to support PC integration. In short, a civil society response is needed. **Full text:** <https://goo.gl/krMsqj>



**N.B.** See 'Integrating Palliative Care and Symptom Relief into Primary Health Care,' World Health Organization, September 2018. **Download/view at:** <https://goo.gl/WR77kx>

## Guarding against dispassion for doctors in the National Health Service

*JOURNAL OF THE ROYAL SOCIETY OF MEDICINE* | Online – 20 September 2018 – With an ever-growing demand on the National Health Service (NHS) workforce, numerous patient surveys across the U.K. have accused doctors for lacking compassion in their practice, amid the strains of their modern-day commitments. The concept of being caring to our patients is highlighted from the first walks of medical school or indeed any healthcare professional's training programme, meaning that patients will always be our prime audience for compassion. Yet, so often in medical training, it is emphasised how important it is to demonstrate a personal detachment between oneself and the patient and not to get too emotionally involved. So despite numerous challenges, how do we find the correct balance to optimise our day-to-day service and stay sensitive to the needs of our patients? This article reflects upon compassion from multiple perspectives in the NHS pertinent to doctors of all settings and experience levels, exploring the barriers, internal conflicts and facilitators of its delivery. The authors examine the objective evidence of measures that have been put in place to overcome these challenges and summarise key considerations to optimise the enablement of a workforce to deliver compassion at universally higher standards in future practice. **Abstract:** <https://goo.gl/exhNcs>

## Registered nurses' provision of end-of-life care to hospitalised adults: A mixed studies review

*NURSE EDUCATION TODAY*, 2018;71(12):60-74. Nineteen studies met the inclusion criteria. Of them, ten were quantitative, eight qualitative and one mixed-method. All but one quantitative study were conducted in the U.S. and all but one used some form of survey. The qualitative studies were conducted in a variety of countries and all but one used some form of interview for data collection. Five themes were identified including nurse as a protecting provider, nurse as an advocate, nurse as a reflective practitioner, obstacles to providing quality end-of-life care (EoLC) and aids to providing quality EoLC. Registered nurses have aligned their EoLC with practice with the profession's expectations and are enacting a patient centred approach to their practice. They rely on reflective practices and on the support of others to overcome organisational, educational and emotional the challenges they to providing quality EoLC. **Abstract:** <https://goo.gl/koUgAq>

### Related

- *NURSE EDUCATION IN PRACTICE*, 2018;33(11):70-76. '**Assessing nursing assistants' competency in palliative care: An evaluation tool.**' Nursing assistants are the largest aged care workforce providing direct care to older people in residential aged care facilities in Australia and internationally. A palliative approach is a large component of this direct care that necessitates nursing assistants possess requisite knowledge, skills and attitudes. While training needs have been identified to enhance their practices, pre-service education is variable, educational interventions have been *ad hoc* and professional development found to be inadequate to the demands of the workplace. In addition, evaluation of nursing assistants' knowledge, skills and attitudes has lacked an instrument specifically tailored to nursing assistants' level of education and role responsibilities when providing a palliative approach. **Abstract:** <https://goo.gl/Gxa7Vx>

## Palliative medicine in Pakistan: A developing country's perspective

*OCHSNER JOURNAL*, 2018;18(2):114. In Pakistan, palliative medicine (PM) is not recognized as a discipline, so centers have not been established and physicians are not trained in palliative care (PC). According to the survey by the International Observatory on End-of-Life Care, Pakistan has the "least favorable ratio" for PC facilities, with only one service existing for a population of 157,935,000.<sup>1</sup> The medical curriculum taught in Pakistan has neither a dedicated course for PM nor a clinical rotation related to it. PM fellowship programs in Pakistan are lacking as well. The world dreads the future shortage of oncologists, but the situation could be even worse for Pakistan because of the absence of PM facilities and specialists. Physicians in Pakistan have expressed interest in being trained in this discipline, leaving Pakistan in a peculiar place where despite the interest by doctors, no initiative is being taken. **Full text:** <https://goo.gl/maU4et>



1. 'Mapping levels of palliative care development: A global view,' *Journal of Pain & Symptom Management*, 2008;35(5):469-498. **Full text:** <https://goo.gl/TBbnjg>

Noted in Media Watch 12 February 2016 (#550, p.7):

- PAKISTAN | *The News International* (Rawalpindi) – 5 February 2018 – '**World Cancer Day: Pakistan lacks treatment facilities.**' Cancer that has emerged as a major health threat in Pakistan claims not less than 50,000 deaths a year, but still Pakistan lacks badly the facilities for treatment and management of cancers and it is ironical that even palliative care (PC) is not available to cancer patients across the country. PC that is considered as urgent humanitarian need for people with cancer in Pakistan may help people live more comfortably. <https://goo.gl/Y4PDuq>

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Noted in Media Watch 28 November 2016 (#489, p.10):

- *INDIAN JOURNAL OF MEDICAL ETHICS* | Online – 18 November 2016 – ‘**Palliative care in Pakistan.**’ Insufficient public healthcare facilities, poorly regulated private health sector, low budgetary allocation for health, improper priority setting while allocating limited resources, have resulted essentially in an absence of palliative care (PC) from the healthcare scene. This article traces the social and cultural perspectives in Pakistan with regards to accessing PC in the context of healthcare facilities available. **Full text:** <https://goo.gl/kJCECM>

### **Diagnosis-related differences in the quality of end-of-life care: A comparison between cancer and non-cancer patients**

*PLOS ONE* | Online – 25 September 2018 – Cancer, chronic heart failure (CHF) and chronic obstructive pulmonary disease (COPD) in the advanced stages have similar symptom burdens and survival rates. Despite these similarities, the majority of the attention directed to improving the quality of end-of-life care (EoLC) has focused on cancer. Although awareness of the quality and aggressiveness of EoLC in CHF and COPD patients has increased recently, research on these issues is still limited. This study highlights the presence of significant differences in the quality of EoLC received in the last month of life by COPD and CHF compared with cancer patients. These findings suggest the presence of potential diagnosis-sensitive determinants of the quality of EoLC. **Full text:** <https://goo.gl/VEfBFu>

Noted in Media Watch 1 May 2017 (#510, p.14):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 April 2017 – ‘**Comparing the palliative care needs of those with cancer to those with common non-cancer serious illness.**’ The authors conducted a cross-sectional, retrospective analysis of the characteristics and symptoms of patient’s with renal disease (ESRD), heart failure (HF), chronic obstructive pulmonary disease (COPD), and cancer at time of first specialty palliative care (PC) referral. Patients with COPD, ESRD and HF were less functional and more likely to be hospitalized at time of referral to PC than cancer patients. **Full text:** <https://goo.gl/IIXHNw>

### **Physician-related determinants of medical end-of-life decisions: A mortality follow-back study in Switzerland**

*PLOS ONE* | Online – 20 September 2018 – The generally high prevalence of medical end-of-life (EoL) decisions (MELDs) and shared decision-making in Switzerland support the notion that important goals like doctors’ timely anticipation of EoL and departure from paternalistic medicine are largely accomplished. While there were few differences between patient groups in terms of MELDs or shared decision-making, divorced patients may be disadvantaged in the decision-making process and subsequent MELDs. Physicians should be proactive about engaging single and divorced patients in shared decision-making, possibly by identifying a proxy well in advance. The association between several physician’s attributes and MELD practice points to the possibility of inequity in care and a substantial potential for improvement. The findings that older physicians and those graduated from abroad did not only make fewer MELDs, but also if they made an MELD, they discussed it less often with patients, strongly call for additional efforts in residency training programs and physicians’ vocational education in order to improve communication skills, preferably tailored to address local needs and context. Communication has been called “ the cornerstone of good EoL care.” An emphasis should also be given to strengthening physicians’ motivation and increasing awareness among patients and relatives that death is near, both being important elements in the process of improving EoL care. **Full text:** <https://goo.gl/B88sFY>

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## Related

- *THE GERONTOLOGIST* | Online – 19 September 2018 – ‘**Preparation and planning for future care in the Deep South [of the U.S.]: Adapting a validated tool for cultural sensitivity.**’ This study describes the adaptation/validation of Sørensen *et al*’s preparation for future care scale<sup>1</sup> with diverse samples including rural dwelling African Americans and certified nursing assistants. Emergent themes included emotional avoidance of planning, considerations of nursing homes and possible care providers, and coping strategies. **Abstract:** <https://goo.gl/BCZ7jL>
  1. ‘Assessing future care preparation in late life: Two short measures,’ *Psychological Assessment*, 2017;29(12):1480-1495. **Abstract:** <https://goo.gl/8mizN8>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 19 September 2018 – ‘**A three-step letter advance directive procedure to facilitate patient-proxy alignment in advance care planning.**’ The advance care planning process should allow for patient-proxy differences to surface, facilitate a discussion about the granular details with the goal of reaching consensus. The authors’ three-step approach using the letter advance directive is an effective way to identify areas of patient-proxy concordance and discordance about specific treatment preferences. **Abstract:** <https://goo.gl/uXH649>

## Perspectives on using decision-making nudges in physician-patient communications

*PLOS ONE* | Online – 19 September 2018 – Patients engaging in shared decision making must weigh the likelihood of positive and negative outcomes and deal with uncertainty and negative emotions in the situations where desirable options might not be available. The use of “nudges,” or communication techniques that influence patients’ choices in a predictable direction, may assist patients in making complex decisions. However, nudging patients may be perceived as inappropriate influence on patients’ choices. The authors sought to determine whether key stakeholders, physicians, and laypersons without clinical training consider the use of nudges to be ethical and appropriate in medical decision making. Eighty-nine resident-physicians and 336 ... non-clinicians evaluated two hypothetical preference-sensitive situations, in which a patient with advanced cancer chooses between chemotherapy and hospice care. The authors varied the following: 1) Whether or not the patient’s decision was influenced by a mistaken judgment (i.e., decision-making bias); and, 2) Whether or not the physician used a nudge. Each participant reported the extent to which the communication was ethical, appropriate, and desirable. Both physicians and non-clinicians considered using nudges more positively than not using them, regardless of an initial decision-making bias in patients’ considerations. Decomposing this effect ... physicians viewed the nudge that endorsed hospice care more favorably than the nudge that endorsed chemotherapy, while non-clinicians viewed the nudge that endorsed chemotherapy more favorably than the nudge that endorsed hospice care. The authors discuss implications and propose exploring further physicians’ and patients’ differences in the perception of nudges; the differences may suggest limitations for using nudges in medical decisions. **Full text:** <https://goo.gl/qZRM1D>

**N.B.** Additional articles on the ethics of “nudging” noted in 25 June 2018 issue of Media Watch (#569, p.9).

## Professional associations can nurture interdisciplinary partnerships: Serving rural elders, a case study

*QUALITY IN AGEING & OLDER ADULTS* | Online – Accessed 25 September 2018 – The authors present a case study that illustrates how professional associations can provide the context for development of formal and informal interdisciplinary collaboration, and promote advancement and dissemination of useful knowledge among disciplines and across geographic boundaries. This case study reports work of the Rural Aging Special Interest Group of the Gerontological Society of America to develop and disseminate approaches that leverage existing resources for the provision of services to rural elders. The roles of networks in developing and supporting these partnerships and the importance of such partnerships are described. While addressing the unique needs of rural elders can sometimes prove challenging, a number of entities have developed successful interdisciplinary partnerships that have expanded resources and improved effectiveness in addressing these challenges. Professional associations can and have played a key role in supporting creative interdisciplinary and international problem solving. **Abstract:** <https://goo.gl/RiJpxR>

## Home care workers' experiences of client death and disenfranchised grief

*QUALITY HEALTH RESEARCH* | Online – 28 September 2018 – While many types of health care workers experience patient death, home care workers do so under vastly different social and economic circumstances. When a client dies, home care workers often lose both a close relationship and a job. Though research suggests that health care workers' grief may frequently be disenfranchised, there is no in-depth study of the mechanisms that disenfranchise home care workers' grief specifically. To address this gap, this study used focus groups and peer interviews between home care workers in New York City. The authors describe four interrelated grief strategies they employ to navigate social and employer-based "grieving rules." Their findings suggest that home care workers' grief is disenfranchised via employer and societal underestimations of their relationships with clients and their losses when clients die, particularly job loss. Building on the study's findings, the authors suggest alterations to agency practices and home care systems to improve support for workers. **Abstract:** <https://goo.gl/Lo9Uxn>

## Unexpected death in ill old age: An analysis of disadvantaged dying in the English old population

*SOCIAL SCIENCE & MEDICINE* | Online – 25 September 2018 – The literature on death expectation in ill old age is mostly medical. A social science standpoint (especially quantitative) is practically absent. However, whether families, social and healthcare services can anticipate, support and prepare for the deaths of ill old adults is not reducible to the biomedical paradigm. Yet it is critical for end of life care (EoLC) policy. This study's aim is to investigate relatives' perception of death as unexpected in relation to both disease-related and care-related factors. Findings of this study are interpreted considering the containment of sudden death and the trajectories of dying in ill old age. The latter display overall visible decline preceding death. On this basis, EoLC literature and policy evidence death's uncertain timing as much as death's certain emergence in the horizon of expectation. Therefore, unexpected death in ill old age was interpreted as a failure to acknowledge dying, rather than the impossibility of discerning its approach. Very old age, dementia diagnoses and supported care environments were found to shape unexpected death. **Abstract:** <https://goo.gl/SidjF4>

## Journal Watch

### Predatory open-access publishing in anesthesiology

*ANESTHESIA & ANALGESIA* | Online – 18 September 2018 – Predatory publishing is an exploitative fraudulent open-access publishing model that applies charges under the pretense of legitimate publishing operations without actually providing the editorial services associated with legitimate journals. The aim of this study was to analyze this phenomenon in the field of anesthesiology and related specialties (intensive care, critical and respiratory medicine, pain medicine, and emergency care). Two authors independently surveyed a freely accessible, constantly updated version of the original Beall lists of potential, possible, or probable predatory publishers and standalone journals. They identified 212 journals from 83 publishers, and the total number of published articles was 12,871. The reported location of most publishers was in the U.S. Six journals were indexed in PubMed. Although 6 journals were declared to be indexed in the Directory of Open Access Journals, none were actually registered. The median article processing charge was \$634.5 U.S. Several journals reported false indexing/registration in the Committee on Publication Ethics and International Committee of Medical Journal Editors registries and Google Scholar. Only 32% reported the name of the editor-in-chief. Rules for ethics/scientific misconduct were reported in only 24% of cases. In conclusion, potential or probable predatory open-access publishers and journals are widely present in the broad field of anesthesiology and related specialties. Researchers should carefully check journals' reported information, including location, editorial board, indexing, and rules for ethics when submitting their manuscripts to open-access journals. **Abstract:** <https://goo.gl/sut4sY>

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## Solicitation for article submission by electronic journals

*BAYLOR UNIVERSITY MEDICAL CENTER PROCEEDINGS* | Online – 24 September 2018 – The business model, editorial policies, and content quality vary significantly in online medical journals. Some online journals have been labeled as predatory journals because their main effort involves collecting article processing charges with little interest in content, peer review, or manuscript presentation. Some of these journals send frequent email solicitations for submissions. One author affiliated with a department of internal medicine collected all email requests for submissions to online journals over a 6-month period. These emails included 210 unique journal names that covered over 40 medical fields and requested 15 different article types. Most of these journals were not listed in PubMed or the Directory of Open Access Journals. One hundred and eighty two were on Beall's list of predatory journals. The median article processing charge was \$1,035. Faculty and trainees at medical schools receive multiple requests for submissions, but it is difficult to determine the quality of the journal sending these requests. At a minimum, a journal should be listed in the Directory of Open Access Journals and have very clear editorial and publication policies. **Abstract:** <https://goo.gl/cjPRRY>

### Of related interest

- 'How important are journal quality metrics in the era of predatory journals?' *ACCESS: Asia's Newspaper on Electronic Information Products & Services*, 18 September 2018. <https://goo.gl/HiTjS3>
- 'Science, where are we going? From intellectual passion to a market-driven system,' Oxford University Press Blog, 21 September 2018. <https://goo.gl/BL7QyT>

### [Media Watch: Editorial Practice](#)

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### International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/fJczV6>

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

PALLIATIVE CARE NETWORK: <https://goo.gl/YBP2LZ>

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

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at <https://goo.gl/6vdk9v>]

### Asia

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[Scroll down to 'Resource Collection' and 'Media Watch Barry Ashpole']

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CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLgxy2>

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ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>

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

### Europe

HUNGARY | Magyar Hospice Alapítvány: <https://goo.gl/L7D2hw>

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Academia Nacional de Cuidados Paliativos (Brazil): <https://goo.gl/b5CV31>

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