

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 ‘Reframing medical appropriateness: A case study concerning the use of life-sustaining technologies for a patient with profoundly diminished quality of life’ (p.13), in *Narrative Inquiry in Bioethics*.

Canada

Surprise court ruling halts family’s efforts to remove man from life support

ONTARIO | *The National Post* (Toronto) – 17 July 2017 – Fernando Ferreira had been in hospital for three days when his family made the heart-wrenching decision. The 53-year-old had suffered a cardiac arrest, causing what doctors believed was irreparable brain damage and leaving him unconscious. Now his common-law wife had agreed to having Ferreira taken off life support and his organs donated for transplant when he died. But just before that was to happen, an apparently unprecedented court ruling put a sudden halt to the process. Georgiana Masgras, a lawyer who had represented Ferreira in an unrelated car-accident case and who worried the family was acting rashly, had convinced a judge to order a stop to the plan. The surprise ruling ... sparked a flurry of legal activity as doctors at St.

Mary’s General Hospital in Kitchener, Ontario, warned that the delay could render their patient’s organs unusable. Finally ... another judge agreed to overturn the original injunction. <https://goo.gl/KhWtvD>

Extract from *The National Post* report

Canadian courts have seen a series of bitter disputes over end-of-life care in the last decade or so, but most involved clashes between family members and medical staff – or among family members – about when to stop treatment. Lawyer Mark Handelman, one of the country’s leading experts in the area, said he has never heard of an unrelated third-party intervening in that way.

Specialist Publications

‘An analysis of journey mapping to create a palliative care pathway in a Canadian First Nations community: Implications for service integration and policy development’ (p.15), in *Palliative Care: Research & Treatment*.

‘Medical Assistance in Dying: Our lessons learned’ (p.16), in *JAMA Internal Medicine*.

U.S.A.

The right things to say – and not say – to the bereaved

STATE OF NEW YORK | *The New York Daily News* – 21 July 2017 – “I can’t believe you just said that to me!” Yes, so many times the bereaved walk away with that very thought flashing across their mind. That is because well-meaning people who have every intention of offering words of sympathy to those who are grieving, manage to do just the opposite. They do so because they simply do not know the right thing to say so the wrong words fly out of their mouths. These same people will slide on by those grieving because they feel uncomfortable in their presence for the same reason. Oh, but there are plenty of appropriate ways to express support that can be so helpful to the bereaved. Because people are creatures of habit, they continue to say and do the same old things they have heard time and again. There is a need to move past

these sayings and even forget the majority of them. If you never utter another grieving *cliché* again, you would be doing us (the bereaved) a great service. <https://goo.gl/fjGEjp>

Specialist Publications

‘A community-developed, culturally-based palliative care program for African American and White rural elders with a life-limiting illness: A program by the community for the community’ (p.13), in *Narrative Inquiry in Bioethics*.

‘Dying for leave: How societal views on end-of-life care pushed Ballard to expand the meaning of care under the Family & Medical Leave Act’ (p.15), in *Washington University Law Review*.

Noted in Media Watch 15 December 2014, #388 (p.14):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 December 2014 – **‘Providers’ beliefs about expressing condolences to the family of a deceased patient: A qualitative and quantitative analysis.** Most providers [i.e., study participants] do not receive training in expressing condolences to bereaved families, and most health care institutions do not have policies in place encouraging expression of condolences. <https://goo.gl/LWqzDY>

Age and emotional well-being: The varied emotional experience of family caregivers

OHIO | Stanford Center on Longevity and the Stanford University – 18 July 2017 – A study has found family caregivers run the risk of social isolation and depression when they take on the job of caring for a severely ill loved one without help. The study found the emotional well-being of older adults managing the care of severely ill loved ones is markedly lower than average for their age due to the caregiver’s inability to engage in social pursuits. Among older adults managing a loved one’s health care, the study discovered that emotional well-being negatively correlates with the severity of the loved one’s illness. Older adults who care for a relative with a mild illness report greater well-being than do younger adults, much like the general population. However, older adults caring for a relative with a severe illness do not experience the typical high levels of emotional well-being compared to other older adults. <https://goo.gl/f1NSv3>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- WASHINGTON DC | *The Washington Post* – 17 July 2017 – **‘Assisted suicide is legal and available in D.C. – for now.’** District officials say doctors in the city may now begin the process of prescribing life-ending drugs to terminally ill patients, setting up a showdown with Republicans in Congress who are trying to void the city’s assisted-suicide law. City officials say the rules and regulations to implement the law took effect Monday, adding the District to six states that authorize the practice. The move comes a week after a U.S. House panel voted largely on party lines to advance a measure that would repeal the city’s Death With Dignity Act. <https://goo.gl/ntYqv4>

Cont.

- HAWAII | *Maui Now* – 16 July 2017 – ‘**Circuit court dismisses medical aid-in-dying case.**’ O’ahu circuit judge dismissed a lawsuit asking the court to prevent existing Hawaii criminal laws from being applied to medical aid in dying practices. The State Attorney Generals office says that in its decision, the court relied upon state legal precedent that prohibited it from issuing such relief. Legislation was introduced this year to legalize medical aid in dying in Hawaii and establish a regulatory process under which an adult resident of the state with a medically confirmed terminal disease may obtain a prescription for medication to be self-administered to end the patient’s life. The bill was deferred in March 2017. Noting that the legislation generated 2,613 pages of testimony and comments, the court said “this underscores that the relief sought by the plaintiffs is political, not judicial, in nature and should be addressed by the political branches of government.” <https://goo.gl/tjnfod>

International

“Old people’s homes with walls” required for elderly prisoners, says watchdog

U.K. (England & Wales) | *The Daily Telegraph* – 18 July 2017 – The Government should build “care homes with walls” to house a growing number of elderly prisoners, the chief prisons inspector has said. Speaking at the launch of his annual report,¹ Peter Clarke said that he had raised the idea with ministers in response to a rise in the number of older prisoners who struggle to cope with standard prison facilities. The number of over-70s in prison is predicted to increase from 1,400 in June of last year to 1,900 over the next three years. <https://goo.gl/hTRqai>

Extract from Chief Inspector of Prisons’ annual report

Support for prisoners with palliative and end-of-life needs was good in most prisons inspected, and exemplary in Norwich, Whatton and Stafford.

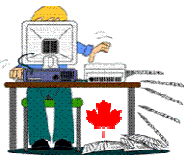
1. ‘HM Chief Inspector of Prisons,’ Annual Report for 2016-17,’ July 2017. <https://goo.gl/BgarSA>

Noted in Media Watch 26 June 2017, #518 (p.4):

- U.K. (England & Wales) | *The Guardian* – 20 June 2017 – ‘**Prisons taking role of care homes and hospices as older population soars.**’ Prisons are the largest providers of residential care for frail and elderly men in England & Wales and are increasingly turning into hospices, providing end-of-life-care for older prisoners and even managing their deaths. <https://goo.gl/8x4V93>

1. ‘Thematic Review: Older Prisoners,’ Prisons & Probation Ombudsman, 2017. <https://goo.gl/hshbkH>

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 is posted on the Palliative Care Community Network website at: <http://goo.gl/ZpEJyQ>



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>

Elder care in England & Wales

Advancing Care: Research with Care Homes

U.K. (England & Wales) | National Institute for Health Research – Accessed 18 July 2017 – There are more than twice as many people living in care homes in England & Wales than there are people staying in hospital. Yet we know far more about effective treatments in hospital and less about what works most effectively to improve care for older people in care homes. Research in care homes is a relatively new and emerging field. This report provides an overview of recent Institute research on improving the health and care of care home residents. It highlights current research taking place now and explores new approaches being developed relating to the care of older people in care homes focused on: 1) Living well – maintaining good health and quality of life; 2) Ageing well – managing long term conditions associated with ageing; and, 3) Dying well – ensuring a good quality end of life. <https://goo.gl/UN1gbT>

N.B. See ‘Dying Well,’ beginning on page 25 of the Institute’s report. Additional articles on palliative and end-of-life care in care homes and nursing homes are noted in the 12 June 2017 issue of Media Watch (#516, p.9).

End-of-life care in England

Right to die off the street

U.K. (England) | *Big Issue North* (Manchester) – 17 July 2017 – The U.K.’s end-of-life strategy includes the concept of advanced care planning – where people write down their wishes for the end of their life. The guidelines state everyone has the right to palliative care, but the reality is different. Even people in stable housing may struggle to get a hospice place if they have an illness other than cancer, so those on the margins of society are almost completely excluded. In just two London boroughs there are around 20 clinical nurse specialists who carry out outreach work with homeless residents, helping them access medical appointments – something that does not exist in York. A number of hostels in the capital also have medical beds, with access to doctors, nurses and psychologists. Homeless people die in surroundings in which they feel comfortable. To mark its 30-year anniversary, St Leonard’s [Hospice] recently ran sessions at a homeless shelter, Arlight. Twenty staff were trained in how to hold delicate conversations with people who are unwell – finding out how they would like to die. <https://goo.gl/FrzPnS>

N.B. Additional articles on end-of-life care for the homeless are noted in the 10 July 2017 issue of Media Watch (#520, pp. 5,9).

Extract from National Institute for Health Research report

An non-Institute study of the views of residents, relatives and staff identified six priorities for end-of-life care:

Personalised care – maintaining relationships and having personal items to hand.

Dignity and respect – paying attention to cleanliness, explaining while carrying out personal tasks, thoughtfulness on the part of staff, culturally relevant care.

Making time – sitting with residents, listening, touch, patience, reorganising the workload to enable this.

Talking about end-of-life issues (and death) – staff can feel they are protecting residents by not talking about it, while most residents want to talk about it (especially the practical aspects).

Relatives’ roles and collaboration – relatives are often willing to work with staff and residents are reassured if staff and relatives collaborate. relatives help by staying overnight and providing care, and there are benefits to staff of having a “bond” with relatives.

Staff support and training – staff readily admit the need for emotional support for themselves, which is more likely to be informal. They like to attend the funerals of the people they cared for. They also recognise the importance of ongoing education and training.

Why dying in Hong Kong is getting more complicated ... and expensive

CHINA (Hong Kong) | *The South China Morning Post* (Hong Kong) – 15 July 2017 – In the city, where land is scarce, there is a growing shortage of public spaces for placing urns holding cremated people's ashes, let alone burial plots. More than 90% of the city's deceased were cremated in 2013, but the city is still struggling to find spots for them in public columbariums [i.e., "a respectful place for the storage of urns holding a deceased's cremated remains]. In Chinese culture, it is important for a deceased family member to be buried close to his or her native place, so he or she can watch over descendants and they in turn can visit the grave or permanent resting place regularly to pay their respects. Families can either bury a relative in a public cemetery or columbarium, or pay a bigger fee for a private one. The average waiting time for a space at a public columbarium, which costs about HK\$3,000 (US\$385), is now four years, making it about the same as getting a public

housing rental flat. A space in a private columbarium can put you back about HK\$1million (US\$128,550). The city could face a shortage of 400,000 urn spaces by 2023... The crisis is being exacerbated by Hong Kong's ageing population. The number of annual deaths in Hong Kong increased from 24,832 in 1981 to 46,108 in 2015... <https://goo.gl/YyX7ag>

Specialist Publications

'The philosophical and cultural situatedness of spirituality at the end of life in India' (p.9), in *Indian Journal of Palliative Care*.

'Policy measures to support palliative care at home: A cross-country case comparison in three European countries' (p.11), in *Journal of Pain & Symptom Management*.

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

Sick patients dying "unnecessarily" in National Health Service because of poor care

U.K. (England, Northern Ireland, Scotland & Wales) | *The Guardian* (London) – 15 July 2017 – Some of the sickest patients that hospitals treat are dying unnecessarily because they receive poor care, blighted by shortages of staff and equipment, a new National Health Service (NHS) inquiry has revealed.¹ A death rate of one in three among patients who need emergency help with breathing is already high by international standards, and is getting worse. The analysis by the National Confidentiality Enquiry into Patient Outcome & Death of the NHS services for the 50,000 patients a year who receive emergency oxygen treatment uncovered a series of major flaws in the care they received. The growing numbers of patients who receive non-invasive intervention oxygen through a face mask usually have chronic obstructive pulmonary disease, pneumonia or other conditions which mean they cannot breathe unaided. Despite their lives being at risk, the vast majority receive sub-standard care, according to an in-

depth examination of 353 patients during February and March 2017. <https://goo.gl/VHq5ti>

National Confidentially Enquiry into Patient Outcome & Death

Advance care planning, end-of-life and palliative care (pp. 78-79): Case study

A frail elderly patient was admitted with chronic obstructive pulmonary disease and acute ventilatory failure. A plan for ward-based NIV as the ceiling of treatment was made. The patient's family were involved in decision making and the palliative care (PC) team was involved from the outset. This facilitated good end-of-life care when it became clear that treatment was failing and was withdrawn 48 hours later.

The reviewers considered this case study was an example of good practice in particular commenting on the standard of documentation, involvement of the family and good use of (PC).

1. 'Inspiring Change: A review of the quality of care provided to patients receiving acute non-invasive ventilation,' National Confidentiality Enquiry into Patient Outcome & Death, Healthcare Quality Improvement Partnership, June 2017. <https://goo.gl/hZRBqW>

End-of-life care in Australia

Palliative care in Parkes

AUSTRALIA (New South Wales) | *The Parkes Phoenix* (Canowindra) – 14 July 2017 – Palliative care (PC) is often overlooked when discussing health management and delivery, but it is an essential service that can have a tremendous and far-reaching effect on well-being, not just for the patient, but for their families and carers as well. Quality PC isn't just dependent on nursing staff – many volunteers work alongside health professionals to provide crucial and compassionate end-of-life care. The not-for-profit organization Neighbourhood Central has been involved with PC volunteers since about 2012, and works in conjunction with the Parkes Palliative Care team. The volunteers visit people at home or in the community, offering support and companionship for people in PC, as well as their family and carers. Palliative Care New South Wales recently completed a survey of nurses' experiences of PC volunteers.¹ The survey emphasised the importance of volunteers in providing care. Of the respondents, 89% agreed that volunteers display empathy and emotional awareness and contributed to better PC, and 70% said they would like more volunteers in their service. [Scroll across to p.11] <https://goo.gl/65pwXB>



1. 'A Space of Caring: New South Wales nurses experience of palliative care volunteers in in-patient settings,' Palliative Care New South Wales, June 2017. [Noted in Media Watch 17 July 2017, #521 (p.7)] <https://goo.gl/ErcFuK>

Canadian perspective

- *BMC PALLIATIVE CARE* | Online – 3 July 2017 – '**Piloting a compassionate community approach to early palliative care.**' A compassionate community approach provides important rationale for building community-based hospice volunteer capacity. The authors piloted a capacity-building model in which volunteers and a nurse partnered to provide support beginning in the early palliative phase for adults living in community. [Noted in Media Watch 10 July 2017, #520 (p.7)] <https://goo.gl/2vvZe6>

Norwegian perspective

- *BMC PALLIATIVE CARE* | Online – 14 March 2017 – '**To be a trained and supported volunteer in palliative care: A phenomenological study.**' The findings highlight that volunteering is experienced as meaningful and satisfying, and that the volunteers have an independent and important role to play among seriously ill or dying people in the palliative care team by providing practical help and emotional support. [Noted in Media Watch 20 March 2017, #504 (p.6)] <https://goo.gl/AJVbNh>

N.B. Additional articles on hospice and palliative care volunteers are noted in this issue of Media Watch.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Victoria) | ABC News – 21 July 2017 – '**Euthanasia deaths to be permitted in Victoria by 2019 under committee proposal.**' Victorians suffering with an advanced and incurable illness, disease or medical condition would be able to seek a medically assisted death from 2019, under a model to be considered by the Victorian Parliament. Only people over the age of 18, who live in Victoria and are an Australian citizen or permanent resident would be eligible. Politicians will be granted a conscience vote on the matter later this year. If the law is passed it would not become operational for 18 months. <https://goo.gl/vEUixK>



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.18.

Specialist Publications

Palliative care covers more than end-of-life issues: Why is this not common practice in dementia care and what are the implications?

ANNALS OF PALLIATIVE MEDICINE, 2017;6(4):390-392. There is a body of literature which suggests that a palliative care (PC) approach from the diagnosis onwards could help prevent unnecessary suffering and pain, enhance symptom management, enable informed decision making and help address spiritual and social aspects of care, thus contributing towards improving the quality of life of people with dementia and their families. The White Paper on PC in dementia proposes a two-tier model consisting of: 1) a PC approach which refers to all treatment and care, and should be offered to every person with dementia; and, 2) Specialist PC for people with dementia with complex problems.¹ However, the initial association between PC and the end of life is still prevalent. Whilst numerous governments in Europe have shown commitment to providing a balanced portrayal of living with dementia and tackling the stigma surrounding dementia, several studies suggest that stereotypes of dementia, focusing predominantly on the advanced stages, persist, even though ironically, many lay people and healthcare professionals do not recognise dementia as a terminal condition. Moreover, there may also be differences between and amongst different healthcare professionals regarding the way they perceive and portray PC for people with dementia and their families. <https://goo.gl/h8X26m>

1. 'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,' *Palliative Medicine*, 2014;28(3):197-209. [Noted in Media Watch 8 July 2013, #313 (p.10)] <https://goo.gl/LoFDWE>

N.B. Several articles in this issue of *Annals of Palliative Medicine* focus on end-of-life care for people living with dementia. Journal contents page: <https://goo.gl/ZRn8uY>. Additional articles on the issue are noted in the 10 July 2017 and 19 June 2017 issues of Media Watch (#520, p.6 & #517, p.15, respectively).

Hospices and care homes: Similarities and differences in relation to palliative care

ANNALS OF PALLIATIVE MEDICINE, 2017;6(4):396-398. As early as 1989, Balfour Mount highlighted the similarities between palliative care (PC) and geriatric practice: "Both make the whole person and his or her family the focus of care, while seeking to enhance quality of life and maintain the dignity and autonomy of the individual. Judicious use of investigations is advocated and both eschew unwarranted treatment while providing symptom control and relief of suffering." Both are necessarily multi-disciplinary and both are areas which prompt phobic reactions from society-at-large. Both geriatrics and PC are new medical technologies which challenge the restorative, often aggressive and increasingly technological practices in technological areas of medicine." The author believes there are more subtle differences between PC and geriatrics that we need to be alert to if we are not going to impose a model of PC developed for cancer onto the care of frail older people at the end-of-life [see table]. <https://goo.gl/M1CDdo>

Cancer palliative care	End-of-life care in the elderly dying
Focus in one disease process	Multiple disease processes
Emphasis on dying in mid-age or younger when life is generally seen as being 'cut short'	Natural ending of life often understood by both the resident and those caring within the context of care homes
Clearer concept of "prognosis" so terminal care can be planned	Often quicker dying trajectory following a more dependent, lengthier disease process
Professional holistic relationship between patient and staff	Often a much closer/emotional relationship between resident and care home staff as resident becomes "part of the family" and may have lived in the care home over a year
More support from family/friends	Less support from family/friends—often care home staff and other residents seen as family
Both patient and family often want life extended	Elderly, frail people in nursing homes frequently speak about dying and that it would be nice "to go to bed one night and not wake up"
Morphine and other medication frequently used to control symptoms	Pain requiring strong opioids less common
Multidisciplinary model of care	Nurses and care workers having the greatest input of care
Patients more often cognitively intact	Greater percentage of residents in nursing homes are cognitively impaired

Cont.

Noted in Media Watch 17 April 2017, #508 (p.7):

- *CLINICS IN GERIATRIC MEDICINE* | Online – 6 April 2017 – ‘**Integrating quality palliative and end-of-life care into the geriatric assessment.**’ Although the quality of palliative and end-of-life care (P&EoLC) for older adults has improved greatly, there are still many opportunities to improve the quality of life and function for older adult patients in the last few years of their life. More clinical expertise in comprehensive P&EoLC must be developed and maintained. <https://goo.gl/5vhdzr>

Noted in Media Watch 6 February 2017, #498 (p.6):

- *GERONTOLOGY & GERIATRICS EDUCATION* | Online – 27 January 2017 – ‘**Geriatric education utilizing a palliative care framework.**’ The dramatic growth of persons over 65 and the increased incidence of multiple, chronic illness has resulted in the need for more comprehensive healthcare. Geriatrics and palliative care are medical specialties pertinent to the elderly, yet neither completely addresses the needs of older adults with chronic illness. <https://goo.gl/KZn9Cw>

N.B. Noted in this issue of Media Watch are selected articles on the common ground shared by geriatric and palliative medicines.

Should heart failure be regarded as a terminal illness requiring palliative care? A study of heart failure patients’, carers’ and clinicians’ understanding of heart failure prognosis and its management

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 21 July 2017 – This is the first study exploring the experiences of prognostic communication at all stages of heart failure (HF). Overall, the majority of participants rejected notions of HF as a terminal illness in favour of a focus on day-to-day management and maintenance, despite obvious deterioration in disease stage and needs over time. Clinicians revealed frustration about the uncertain nature of HF prognosis, leading to difficulties in planning. Others highlighted the need to deliver problem-based, individualised care, but felt constrained sometimes by the lack of multidisciplinary advance care planning.. Patients reported an absence of prognostic discussions with clinicians. <https://goo.gl/Jzfyoc>

Selected articles on palliative care in heart failure

- *JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY*, 2017;70(3). ‘**Palliative care in heart failure.**’ The authors investigated whether an interdisciplinary palliative care intervention in addition to evidence-based heart failure care improves certain outcomes. The former showed consistently greater benefits in quality of life, anxiety, depression, and spiritual well-being compared with usual care alone. [Noted in Media Watch 17 July 2017, #521 (p.14)] <https://goo.gl/r5XdeJ>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 30 May 2017 – ‘**A review of prognostic tools in heart failure.**’ Educating stakeholders, including primary care, cardiology, and critical care of the benefits of hospice and palliative medicine for patients with poor prognosis, may increase appropriately timed referrals and improve quality of life for these patients. [Noted in Media Watch 5 June 2017, #515 (p.7)] <https://goo.gl/bEIG4V>
- *PROGRESS IN CARDIOVASCULAR DISEASES* | Online – 5 May 2017 – ‘**Palliative care in heart failure: What triggers specialist consultation?**’ The use of general palliative care strategies, as well as expert consultation, is limited by a dearth of evidence-based interventions in the heart failure patient population and the knowledge as to when to initiate these interventions, uncertainty regarding patient desires, prognosis and the respective roles of each member of the care team, and a general shortage of specialist providers. [Noted in Media Watch 15 May 2017, #512 (p.11)] <https://goo.gl/l0d2Jn>

Palliative Care Network Community

<http://goo.gl/OTpc8I>

Troubling meanings of family and competing moral imperatives in the family lives of young people with a parent who is at the end of life

CHILDREN'S GEOGRAPHIES | Online – 12 July 2017 – This article draws on a narrative study of young people with a parent who is at the end of life (EoL) to examine how family lives are troubled by life-limiting parental illness. Young people struggled to reconcile the physical and emotional absence of family members with meanings of “family”; the extent to which young people could rely on family to “be there” in these troubling circumstances was of practical, emotional and moral significance. The authors’ discussion is situated in the context of an English EoL care policy predicated on the ideal of a good death as one that takes place at home accompanied by family members. They explore how the shift away from family as a site for nurturing children towards family as a space to care for the dying is experienced by young people, and consider how these competing moral imperatives are negotiated through relational practices of care. <https://goo.gl/8MRM6G>

Related

- *JOURNAL OF CHILD & FAMILY STUDIES* | Online – 18 July 2017 – ‘**Caregivers’ positive emotional expression and children’s psychological functioning after parental loss.**’ The authors investigated whether the frequency of caregivers’ use of positive emotion words (e.g., “love”, “happy”, “hope”) during a reminiscing task about the deceased was associated with children’s psychological functioning and coping. When caregivers used more positive emotion words, children were less likely to experience depression, anxiety, and avoidant coping. <https://goo.gl/L1Sd16>

Noted in Media Watch 17 October 2016, #483 (p.8):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 3 October 2016 – ‘**How to support teenagers who are losing a parent to cancer: Bereaved young adults’ advice to healthcare professionals – a nationwide survey.**’ Four themes emerged: 1) To be seen and acknowledged; 2) To understand and prepare for illness, treatment, and the impending death; 3) To spend time with the ill parent; and, 4) To receive support tailored to the individual teenager’s needs. <https://goo.gl/ZqeiCB>

The philosophical and cultural situatedness of spirituality at the end of life in India

INDIAN JOURNAL OF PALLIATIVE CARE, 2017;23(3):338-340. The sustained interest in exploring the spiritual domain at end of life (EoL) in the Indian context reflects the recognition of its significance as an integral part of palliative care (PC). A key aspect of findings from studies so far is the identification of challenges, inadequacies, limitations and ethical dilemmas in relation to spirituality at the EoL. India is known for its rich spiritual heritage and has unique ways of understanding, experiencing and expressing spirituality. The philosophical and cultural frames of reference, with which communities in India make sense of life, death and dying, determine the characteristics of Indian spirituality at the EoL. Exploring the concepts of the human person, the purpose of human life, the meaning of death and caring for the dying using Indian philosophical and cultural resources can help address some of the identified limitations and challenges in the Indian context. A cross-disciplinary approach, drawing together expertise from clinical PC, philosophy, theology and sociology, will enrich the understanding of spirituality at the EoL and can contribute to effective spiritual care in PC in specific contexts around the world. <https://goo.gl/Kvh83o>

Related

- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2017;23(3):306-311. ‘**Signs of spiritual distress and its implications for practice in Indian palliative care.**’ The authors have formulated recommendations to assess spiritual distress in a socio-culturally appropriate manner in Indian palliative care (PC). By applying these recommendations, some of the barriers to the provision of spiritual care to PC patients in India may be overcome, as the recommendations empower clinicians to take a spiritual history of these patients with more competence. <https://goo.gl/bwFA3X>

N.B. Additional articles on taking a spiritual history are noted in Media Watch 3 July 2017, #519 (p.11).

Cont.

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 18 July 2017 – ‘**State of the science of spirituality and palliative care research... (Part 1)**’ Spirituality frequently plays a central and complex role in patients’ and families’ experiences of incurable illness, including influencing quality of life and medical decision-making. Advances in this field that expand the understanding of the relationships between spirituality and health outcomes and lead to the rigorous development of interventions to address patient and family spiritual needs hold tremendous potential for improving a comprehensive approach to care in serious illness. <https://goo.gl/uNe8G3>

N.B. Part 2: <https://goo.gl/EiWqdd>

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).

Prevalence of burnout in health professionals working in palliative care: A systematic review

JBIR DATABASE OF SYSTEMATIC REVIEWS & IMPLEMENTATION REPORTS, 2017;15(7):1905-1933. More than ever, the current increasing need for palliative care (PC) leads to health professionals providing this type of care which further leads to multiple challenges, and stressful and demanding situations. The multiple challenges of working in PC put health professionals working in this context at the risk of burnout. Eight cross-sectional studies met the inclusion criteria, with a total of 1,406 health professionals. The sample was limited to nurses, physicians and social workers. None of the included articles presented data about other health professionals. Seven of the included studies assessed the prevalence of burnout using the same instrument – the Maslach Burnout Inventory. Data revealed a prevalence of burnout of 17.3% among health professionals. Personal accomplishment was the sub-scale from the Maslach Burnout Inventory that had the highest prevalence (19.5%). Nurses had higher levels of emotional exhaustion (19.5%) and depersonalization (8.2%), and physicians had lower levels of personal accomplishment (41.2%). The prevalence of burnout was, however, higher in social workers (27%). The PC context with the highest prevalence of burnout was home care (19.6%). <https://goo.gl/2yFzFc>

Noted in Media Watch 3 April 2017, #506 (p.8):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 28 March 2017 – ‘**Compassion fatigue among palliative care clinicians: Findings on personality factors and years of service.**’ Palliative medicine is a rewarding field, but providers encounter patient trauma on a routine basis. Compassion fatigue, marked by burnout, secondary traumatic stress and low satisfaction may result. Professionals differ markedly in how they respond to patient trauma. <https://goo.gl/n62JxS>

Noted in Media Watch 13 February 2017, #499 (p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 11 February 2017 – ‘**Addressing palliative care clinician burnout in organizations: A workforce necessity, an ethical imperative.**’ Efforts to mitigate and prevent burnout currently focus on individual clinicians. However, analysis of the problem of burnout should be expanded to include both individual- and systems-level factors as well as solutions; comprehensive interventions must address both. <https://goo.gl/q2l0Te>

N.B. Additional articles on clinician burnout in the context of hospice and palliative care are noted in Media Watch 23 January 2017, #496 (p.11).

Use of non-pharmacological interventions for comforting patients in palliative care: A scoping review

JBIR DATABASE OF SYSTEMATIC REVIEWS & IMPLEMENTATION REPORTS, 2017;15(7):1867-1904. The use of non-pharmacological interventions to promote comfort in palliative care (PC) settings has been increasing. However, information on implemented and evaluated interventions, their characteristics, contexts of application, and population is scattered in the literature, hampering the formulation of accurate

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questions on the effectiveness of those interventions and, consequently, the development of a systematic review. Ten non-pharmacological interventions were identified, of which the most common were music therapy and massage therapy. Their characteristics differed significantly across interventions and even in the same intervention. They were mostly implemented in PC units and hospices, and in patients with a cancer diagnosis. <https://goo.gl/3Ujf16>

Noted in Media Watch 20 February 2012, #241 (p.12):

- *PLoS MEDICINE*, 2012;9(2):1-10. '**Complexity in non-pharmacological caregiving activities at the end of life: An international qualitative study.**' Palliative care staff at 16 units in nine countries listed in detail non-pharmacological caregiving activities they performed... Several forms for communication were described; information and advice was at one end of a continuum, and communicating through non-verbal presence and bodily contact at the other. Rituals surrounding death and dying included not only spiritual/religious issues, but also more subtle existential, legal, and professional rituals. An unexpected and hitherto under-researched area of focus was on creating an aesthetic, safe, and pleasing environment, both at home and in institutional care settings. <https://goo.gl/J5SG5i>

How do clinicians prepare family members for the role of surrogate decision-maker?

JOURNAL OF MEDICAL ETHICS | Online – 17 July 2017 – Although surrogate decision-making (SDM) is prevalent in intensive care units (ICUs) and concerns with decision quality are well documented, little is known about how clinicians help family members understand the surrogate role. The authors investigated whether and how clinicians provide normative guidance to families regarding how to function as a surrogate. They audio-recorded and transcribed 73 ICU family conferences in which clinicians anticipated discussing goals of care for incapacitated patients at high risk of death. The authors developed and applied a coding framework to identify normative statements by clinicians regarding what considerations should guide surrogates' decisions, including whether clinicians explained one or more of Buchanan and Brock's (1989) three standard principles of SDM to family members. Clinicians did not provide normative guidance about the surrogate role in two-thirds of family conferences for incapacitated patients at high risk for death. When they did, clinicians' guidance was often incomplete and sometimes conflicted with standard principles of SDM. <https://goo.gl/6GzYv7>

Noted in Media Watch 11 July 2016, #470 (p.15):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2016;316(1):35-37. '**Strategies to support surrogate decision makers of patients with chronic critical illness: The search continues.**' Surrogate decision makers for patients with chronic critical illness face challenging decisions about whether to continue life-prolonging treatments given uncertain outcomes. A growing body of research indicates that surrogates often experience symptoms of depression, anxiety, and post-traumatic stress in the months following the intensive care unit admission of a family member. <http://goo.gl/NuAyQh>

Noted in Media Watch 19 January 2015, #393 (p.9):

- *CRITICAL CARE MEDICINE* | Online – 6 January 2015 – '**How clinicians discuss critically ill patients' preferences and values with surrogates: An empirical analysis.**' In a third of 71 intensive care unit (ICU) family conferences recorded for patients at high risk of death, neither clinicians nor surrogates discussed patients' preferences or values about end-of-life (EoL) decision making. In less than 12% of family conferences did participants address the values of high importance to most patients.. <https://goo.gl/32a8a6>

Policy measures to support palliative care at home: A cross-country case comparison in three European countries

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 20 July 2017 – All three countries [i.e., Belgium, Germany and France] have policy measures that allow informal caregivers to adapt their working patterns or take leave of absence to provide care without losing employee rights; however, only Belgium

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offers specific paid palliative care leave. All three countries offer various allowances to people who are dying at home and their caregivers. Cost-reductions for out-of-pocket expenses are available, based on the level of care dependency in Germany and on prognosis in Belgium, but are not provided in France. Mobile home support teams exist in all three countries and are free of charge for patients and caregivers, but only in Belgium and Germany are they specialist multidisciplinary palliative home care teams. Belgium and Germany provide respite care for palliative patients. <https://goo.gl/oVxRiY>

Related

- *INTERNATIONAL JOURNAL OF ENVIRONMENTAL & PUBLIC HEALTH RESEARCH* | Online – 18 July 2017 – ‘**Socioeconomic differences in and predictors of home-based palliative care health service use in Ontario, Canada.**’ The results of this study demonstrated that both the propensity and intensity of home-based nurse and personal support worker visits fell with socioeconomic status. These findings may assist health service planners in the appropriate allocation of resources and service packages to meet the complex needs of palliative care populations. <https://goo.gl/Uv6gFH>

End-of-life care in Switzerland

Relationship between spirituality, meaning in life, psychological distress, wish for hastened death, and their influence on quality of life in palliative care patients

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 14 July 2017 – Spiritual, existential, and psychological issues represent central components of quality of life (QoL) in palliative care. A better understanding of the dynamic underlying these components is essential for the development of interventions tailored to the palliative context. A cross-sectional study involving face-to-face interviews with Swiss palliative patients was performed, including the Schedule for Meaning in Life Evaluation, the Spiritual Subscale of the Functional Assessment of Chronic Illness Therapy, the Idler Index of Religiosity, the Hospital Anxiety & Depression Scale, and the Schedule of Attitudes Toward Hastened Death. QoL was measured with a single item visual analogue scale. Both spiritual well-being and meaning in life appear to be potential protective factors against psychological distress at the end of life (EoL). Since non-physical determinants play a major role in shaping QoL at the EoL, there is a need for the development of meaning-oriented and spiritual care interventions tailored to the fragility of palliative patients. <https://goo.gl/sg76Td>

Noted in Media Watch 10 July 2017 #520 (p.13):

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 1 July 2017 – ‘**Assumptions and moral understanding of the wish to hasten death: A philosophical review of qualitative studies.**’ Qualitative studies of the wish to hasten death have found that such a wish may have different meanings, none of which can be understood outside of the patient’s personal and socio-cultural background, or which necessarily imply taking concrete steps to ending one’s life. <https://goo.gl/cpiKba>

N.B. Additional articles on the desire to hasten death are noted in this issue of Media Watch.

A battle of words: “Dignity” and “peace” in the writings of Elisabeth Kübler-Ross

JOURNAL OF PALLIATIVE CARE | Online – 14 July 2017 – This article analyzes the writings of Elisabeth Kübler-Ross through the discursive lens of the phrase “dying with dignity.” For her, the phrase meant allowing someone to die comfortably his/her own death. This phrase has to be understood in relationship with the final “stage of acceptance” of her model. Describing this key part of her well-known scientific output, she often used, in the early 1970s, the phrase “dying in peace and dignity.” An evaluation of the evidence suggests that because the concept of dignity was co-opted by the pro-euthanasia movement during this decade, the language of dignity was little by little abandoned by her. In later years, only “peace” survived from her favorite expression. Although this concept of peace remains present to the end in all Kübler-Ross writings, the pro-euthanasia movement has also started to speak the language of peace. <https://goo.gl/QwsFu1>

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Noted in Media Watch 25 May 2015, #411 (p.10):

- **ILLNESS, CRISIS & LOSS** | Online – 21 May 2015 – ‘**Let’s stop “staging” persons who are coping with loss.**’ This article offers a critical analysis of Elisabeth Kübler-Ross and David Kessler’s *On Grief & Grieving: Finding the Meaning of Grief Through the Five Stages of Loss*. Although the five stages of grief are described in Chapter 1, they play little role thereafter. Further, readers are told these stages are neither universal nor linear. Consequently, it would be desirable to stop staging persons who are coping with loss or at least be extremely cautious in using this stage-based model in appreciating their unique journeys. <https://goo.gl/rIBjCG>

A community-developed, culturally-based palliative care program for African American and White rural elders with a life-limiting illness: A program by the community for the community

NARRATIVE INQUIRY IN BIOETHICS, 2017;7(1):36-40. African American and White caregivers in rural South Carolina who had been involved in the care of a loved one who had recently died, were asked what they found helpful or beneficial about the professional care (i.e., care provided by physicians, nurses, other hospital and hospice and nursing home staff) and what they considered ineffective or inadequate. Gaining an understanding of their perspective, through focus groups, was the first phase of this study. While this insight is important in and of itself, the more substantial purpose was to use this information to develop a culturally-based palliative care (PC) consult program for African American and White rural southern patients with a life-limiting diagnosis. Development of the program, in full collaboration with PC researchers and a team of African American and White community members, occurred in the next phase. Patient and family acceptance of this community-developed and culturally-based PC consult program was tested in the last phase. PC consults, in which a PC expert consults with the treating physician and makes recommendations for care, have been proven equally effective. Culture shapes how people make meaning out of illness, suffering and dying. Therefore, in PC, consideration of the culture of the patient and family is essential. Yet end-of-life care in the U.S. is rooted in values that represent the cultural and religious values of the white middle class. This was the first study to design a culturally based PC program for rural southern elders with life-limiting illness, and the first to do so with full community participation. <https://goo.gl/H1yBvx>

Noted in Media Watch 25 April 2016, #459 (p.3):

- **POLITICAL NEWS** | Online – 18 April 2016 – ‘**Legislation to expand rural hospice care.**’ Bipartisan legislation to improve access to hospice care in rural America has been tabled in the Senate. Only 32% of those eligible in rural areas utilize hospice compared to 48% in urban areas, according to a report from the Medicare Payment Advisory Commission. The Rural Access to Hospice Act of 2016 aims to level the playing field. <http://goo.gl/paarBo>

Reframing medical appropriateness: A case study concerning the use of life-sustaining technologies for a patient with profoundly diminished quality of life

NARRATIVE INQUIRY IN BIOETHICS, 2017;7(1):87-95. This case study considers the clinical ethics issues of medical appropriateness and quality of life (QoL) for patients who are critically ill. The case involves a terminally ill cancer patient with a profoundly diminished QoL and an extremely poor prognosis; his spouse desires to bring him home, where she will arrange to keep him alive for as long as possible via life-sustaining interventions. The analysis engages with the complicated notion of medical appropriateness, both in general and as it pertains to life-sustaining interventions in a critical care setting, and considers the ethical implications of the various ways in which one might understand this concept. It also addresses the significance of QoL determinations, emphasizing the role of individualized values in determining the importance of QoL for clinical decision-making. The discussion concludes with a description of the two strategies employed by the ethics team in helping to alleviate the medical team’s concerns about this case. <https://goo.gl/Jn9rBR>

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Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 22 July 2017 – ‘**Patient-family agreement on values and preferences for life-sustaining treatment: Results of a multicentre observational study.**’ Crude agreement between patients and family members [i.e., study participants] about values related to life-sustaining treatment was 42% across all eight items about values related to life-sustaining treatment, but varied widely: 20% when asking how important it was for the patient to respect the wishes of family members regarding their care; 72% when asking how important it was for the patient to be kept comfortable and suffer as little as possible. Crude agreement on preferences for life-sustaining treatment was 91% ... when looking at preferences for cardiopulmonary resuscitation (CPR) versus no CPR, but fell to 56% when including all five response options with varying degrees of resuscitative, medical or comfort options... <https://goo.gl/Q22jkU>

End-of-life care in Germany

New structures in neurology: Palliative care for neurological patients

NEUROLOGY INTERNATIONAL OPEN, 2017;1(03):e117-e126. Although patients with incurable neurological diseases suffer from a variety of distressing symptoms and may die from their neurological condition and associated complications, palliative and hospice care (P&HC) for these patients to date remains rare. Initial estimates indicate on average 10% of all patients suffering from a neurological disease need P&HC. However, within German neurology departments, only few physicians and nurses are specialized in P&HC and only about 3% of patients cared for in P&HC structures suffer from neurological diseases (in contrast to the approximately 80% of patients suffering from oncological diseases). This rather low number is due to the gradual increase in the awareness of P&HC needs for neurological patients and a currently predominant supply of oncological patients in P&HC structures that are primarily aimed at these patients. Correspondingly, the special aspects of neurological patients are currently not adequately addressed in the palliative training curricula of healthcare professionals. Rather, patients with advanced neurological conditions are medically cared for by general practitioners and by the existing inpatient and outpatient neurology structures, which may also offer sub-specialty services. Consequently, adequate care for severely affected neurological patients becomes difficult as soon as these patients are hardly able to visit these structures because home-based specialist treatment is currently rendered and financed only to a limited degree. Novel yet to date rare approaches, mostly of international origin, suggest these patients may benefit from specialized home-based services, combining neurological and palliative care expertise. <https://goo.gl/i6q6wP>

Selected articles on palliative care for patients living with a neurological disease

- *THE LANCET NEUROLOGY*, 2017;16(7):489. ‘**Integrating palliative care into neurological practice.**’ When initiating end-of-life care (EoLC) discussions, both clinicians and patients often fail to distinguish palliative care (PC) from hospice care – palliative treatment which is delivered at the end of life. However, in recent years, PC specialists have begun to provide support more frequently in the early stages of disease, alongside disease-directed therapy. [Noted in Media Watch 3 July 2017, #519 (p.12)] <https://goo.gl/TPXKh5>
- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(5):232-235. ‘**Palliative care in chronic and progressive neurological disease: Summary of a consensus review.**’ A taskforce of the European Association for Palliative Care makes recommendations on the early integration of palliative care, multidisciplinary team care, communication, symptom management, carer support, end-of-life care and training and education of professionals. [Noted in Media Watch 3 October 2016 #482 (p.9)]

N.B. Access to this article requires a subscription to the journal. Contents page: <https://goo.gl/IUscng>

- *NEUROLOGICAL SCIENCES* | Online – 14 June 2016 – ‘**Need for palliative care for neurological diseases.**’ The realization of an effective palliative approach to neurological diseases requires specific skills and expertise to adapt the concept of palliation to the peculiarities of these diseases; this approach should be realized through the cooperation of different services and the action of a multidisciplinary team in which the neurologist should play a central role to identify and face the patient’s needs. [Noted in Media Watch 20 June 2016, #467 (p.14)] <http://goo.gl/kOQ9z7>

An analysis of journey mapping to create a palliative care pathway in a Canadian First Nations community: Implications for service integration and policy development

PALLIATIVE CARE: RESEARCH & TREATMENT | Online – 21 July 2017 – The goal of this participatory action research was to improve quality and access to palliative care (PC) at home by better integrating First Nations' health services and urban non-Indigenous health services. Four journey mapping workshops were conducted to create a care pathway which was implemented with six clients. Workshop data were analyzed for learnings and promising practices. A follow-up focus group, workshop, and health care provider surveys identified the perceived benefits as improved service integration, improved PC, relationship building, communication, and partnerships. It is concluded that journey mapping improves service integration and is a promising practice for other First Nations communities. The implications for creating new policy to support developing culturally appropriate PC programs and cross-jurisdictional integration between the federal and provincial health services are discussed. Future research is required using an Indigenous paradigm. <https://goo.gl/Z7Dxxm>

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

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 12 July 2017 – ‘**Priorities and challenges for a palliative approach to care for rural indigenous populations: A scoping review.**’ Key challenges include: 1) Environmental and contextual issues; 2) Institutional barriers; and, (3) Interpersonal dynamics challenging client/clinician interactions. Priorities include: 1) Family connections throughout the dying process; 2) Building local capacity for palliative care to provide more relevant and culturally appropriate care; and, 3) Flexibility and multi-sectoral partnerships to address the complexity of day-to-day needs for patients/families. <https://goo.gl/YKjD6p>

N.B. Additional articles on end-of-life care for Canada's indigenous peoples are noted in the 6 February 2017 issue of Media Watch (#498, p.1).

New guidelines on Parkinson's disease released by National Institute for Health & Care Excellence

THE PHARMACEUTICAL JOURNAL | Online – 19 JUL 2017 – The National Institute for Health & Care Excellence, England's health technology assessment body, has released new clinical guidelines on the diagnosis and management of Parkinson's disease in adults aged 18 years and over.¹ The updated guidelines ... aim to improve care from the time of diagnosis, including monitoring and managing symptoms, providing information and support, and palliative care. Dudley Group National Health Service Foundation Trust neurology specialist pharmacist Janine Barnes was a member of the guideline development group for the Parkinson's disease update, the first time there has been pharmacist involvement in this area. <https://goo.gl/FqGSuH>

1. 'Parkinson's disease in adults,' National Institute for Health & Care Excellence, July 2017. (Scroll down to '1.9 Palliative care.')

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

Dying for leave: How societal views on end-of-life care pushed Ballard to expand the meaning of care under the Family & Medical Leave Act

WASHINGTON UNIVERSITY LAW REVIEW, 2017;94(3):707-737. The Seventh Circuit's recent decision in *Ballard v. Chicago Park District* shook employers and employment law attorneys to their core, forcing re-evaluation of what it means to care for a family member with a serious medical condition under the Family & Medical Leave Act (FMLA). Ballard, a former employee of the Chicago Park District, requested FMLA leave to take her terminally-ill mother on vacation to Las Vegas as part of her mother's end-of-life plan, constructed by her mother and her mother's hospice team. The Seventh Circuit agreed with Ballard that her employer should have granted FMLA leave for the trip. In fact, Ballard created a circuit split on the issue, placing the Seventh Circuit at odds with the First and Ninth [Amendments] on the meaning of

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care in the context of traveling. By holding that an employer improperly denied FMLA leave to an employee accompanying her dying mother on a Las Vegas vacation, the Seventh Circuit stretched the FMLA's meaning of care when applied to a seriously ill family member. Ballard expanded the meaning of care by finding aspects of end-of-life care (EoLC) acceptable as caregiving activities. The unique facts of this case and the court's emphasis on the nature of the mother's terminal illness introduce the subtle notion that the meaning of care loosens when applied to a dying family member. This case creates a lower threshold that was likely not intended by Congress and will frustrate employers, but is very much in line with American values and societal norms regarding EoLC. <https://goo.gl/1timGh>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *JAMA INTERNAL MEDICINE* | Online – 17 July 2017 – **'Medical Assistance in Dying: Our lessons learned.'** On 6 February 2015, the Supreme Court of Canada struck down the prohibition of physician-assisted dying and ordered the federal parliament to enact legislation to allow it within 12 months. On 7 June 2016, Bill C-14 received royal assent, the final step by which a bill becomes both an Act of Parliament and Canadian law. This act made it legal for physicians to provide assistance in dying to individuals in an advanced state of irreversible decline whose natural death was "reasonably foreseeable." Canada's health care system rapidly developed protocols for Medical Assistance in Dying, which became known by its acronym, MAiD. Like many physicians, the authors felt that changing the law and delivering this service was the right thing to do for the right kind of patient (and there was vigorous debate about who that was). At the same time, they both felt that for at least the near future, they would likely be reluctant to directly or indirectly participate in MAiD. <https://goo.gl/5Rfahy>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 14 July 2017 – **'Healthcare professionals' attitudes about physician-assisted death: An analysis of their justifications and the roles of terminology and patient competency.'** The authors' questionnaire presented three cases: 1) Physician-assisted suicide; 2) Euthanasia for a competent patient; and, 3) Euthanasia for an incompetent patient with an advance directive for euthanasia. The 220 participants included physician clinicians, researchers, non-physician clinicians, and other non-clinical staff at a major [U.S.] academic medical center. The majority thought each case was ethical and should be legal. In order of declining favorability, justifications supporting physician-assisted death legalization were relief of suffering, right to die, mercy, acceptance of death, non-abandonment, and saving money for the healthcare system; opposing justifications were the slippery slope argument, unnecessary due to palliative care, killing patients is wrong, religious views, and suicide is wrong. <https://goo.gl/WHGHBf>
- *SCIENCE & ENGINEERING ETHICS* | Online – 19 July 2017 – **'Euthanasia: Global scenario and its status in India.'** The legal and moral validity of euthanasia has been questioned in different situations. In India, the status of euthanasia is no different. It was the Aruna Ramachandra Shanbaug case that got significant public attention and led the Supreme Court of India to initiate detailed deliberations on the long ignored issue of euthanasia. Realising the importance of this issue and considering the ongoing and pending litigation before the different courts in this regard, the Ministry of Health & Family Welfare ... issued a public notice on May 2016 that invited opinions from the citizens and the concerned stakeholders on the proposed draft bill entitled The Medical Treatment of Terminally Ill Patients (Protection of Patients & Medical Practitioners) Bill. Globally, only a few countries have legislation with discreet and unambiguous guidelines on euthanasia. The ongoing developments have raised a hope of India getting a discreet law on euthanasia in the future. <https://goo.gl/bezYVj>

Noted in Media Watch 18 April 2016, #458 (p.11):

- *NEUROLOGY TODAY*, 2016;16(7):8. **'A campaign to change end-of-life care in India.'** Although the Supreme Court of India ruled for passive euthanasia in 2011, which meant that life support could be withdrawn from patients in a persistent vegetative state, it did not change the situation for Aruna Ramachandra Shanbaug. The court did not grant permission to remove her feeding tube since both her doctors and caregivers were in agreement about continuing care. She died naturally of pneumonia in May 2015. <http://goo.gl/RXKAfX>

N.B. Additional articles on ethics and the law in the context of end-of-life care in India are noted in this issue of Media Watch.

Worth Repeating

Standards for the psychosocial care of children with cancer and their families: An introduction to the special issue

PEDIATRIC BLOOD & CANCER, 2015;62(S5):S419-S424. Pediatric oncology psychosocial professionals collaborated with an interdisciplinary group of experts and stakeholders and developed evidence-based standards for pediatric psychosocial care. Given the breadth of research evidence and traditions of clinical care, 15 standards were derived. Each is based on a systematic review of relevant literature and used the Appraisal of Guidelines for Research & Evaluation II process [developed by the Canadian Institutes of Health Research] to evaluate the quality of the evidence.¹ This article describes the methods used to develop the standards and introduces the 15 articles included in this special issue. Established standards help ensure that all children with cancer and their families receive essential psychosocial care. [Noted in Media Watch 4 January 2016, #443 (p.15)] <https://goo.gl/5f5Pcy>

1. 'Appraisal of Guidelines for Research & Evaluation II,' Agree Research Trust. <https://goo.gl/VbbeH2>

N.B. Special issue of *Pediatric Blood & Cancer* contents page: <https://goo.gl/Z5jt3z>

Noted in Media Watch 4 May 2015, #408 (p.14):

- *PALLIATIVE MEDICINE* | Online – 28 April 2015 – ‘**Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review.**’ Integration of patient, parent and clinician perspectives on end-of-life needs reveal mutual themes: 1) Holding to hope; 2) Communicating honestly; 3) Striving for relief from symptom burden; and, 4) Caring for one another. Shared priorities included: 1) Care access; 2) Cost analysis; 3) Social support to include primary caregiver support; 4) Sibling care; 5) Bereavement outreach; 6) Symptom assessment and interventions to include physical and psychological symptoms; 7) Communication approaches to include decision-making; and, 8) Overall care quality. <https://goo.gl/ZwLmME>

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

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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.

Media Watch: Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/nZMuK7>

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

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

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

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

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/XO4mD>

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

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLqxy2>
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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/5d1I9K>

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

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