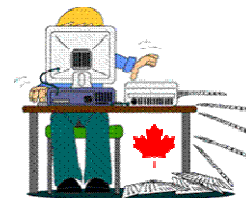


Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

Nuances of medication management in end-of-life care: Scroll down to [Specialist Publications](#) and 'Ten tips palliative care pharmacists want the palliative care team to know when caring for patients' (p.13), in *Journal of Palliative Medicine*.

Canada

Why we need a clear definition of when death occurs

THE GLOBE & MAIL | Online (Toronto) – 6 July 2018 – Ontario Superior Court Justice Lucille Shaw released her long overdue decision ... in the case of a young Brampton woman pronounced dead in September 2017, six months after closing arguments ended. Shaw concluded that Taquisha McKitty, 27, is in fact dead, rejecting arguments presented by her family that she was alive and had the right to continuing mechanical life support. Justice Shaw determined that this woman died last September when doctors determined her brain had irreversibly ceased to function. While the wait was painful for everyone, the decision was clear: People need and deserve to know with simplicity, clarity and consistency when their family member is dead. At the heart of this ruling is the principle that identifying death has to be carried out in the same manner for all people in society, even if people choose to understand life in different ways. Why do we need a common definition of

death, if we might have different ideas about the nature of life? Some cultures believe that the essence of life is in the air moving in and out of our lungs; others believe that our soul resides in our heart; and still others believe that we exist by virtue of our brain's ability to interact with the world. If individuals can choose their own understanding of life, then why must they accept a common understanding of death? Justice Shaw answered this question clearly: With modern critical care, a line must be drawn where death is objectively determined. <https://goo.gl/B9kK2E>

Specialist Publications

'Medical assistance in dying (MAiD): Canadian nurses' experiences' (p.17), in *Nursing Forum*.

N.B. Additional articles on the Taquisha McKitty case and also on defining death noted in the 2 July 2018 issue of Media Watch (#570, p.2).

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Back Issues of Media Watch
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Ontario judge refuses family's plea to keep brain dead woman on life-support

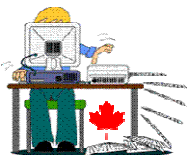
ONTARIO | CBC News (Toronto) – 26 June 2018 – An Ontario court has rejected a Toronto-area family's plea to keep their 27-year-old daughter, who has been declared brain dead, on life-support. Taquisha McKitty's parents were seeking an order to keep her on a mechanical ventilator, arguing she continues to show signs of life and that her Christian fundamentalist beliefs say she's alive as long as her heart's still beating. However, the Ontario Superior Court of Justice ruled, in a complex and potentially precedent-setting decision, that McKitty can be considered dead and can be removed from life-support. However, judge Lucille Shaw's decision notes doctors have found "uncontroverted medical evidence" that there's no blood flow to McKitty's brain and that it will not be able to recover. The movements, the decision notes, originate in the spinal cord and "do not involve any brain activity." That has been proven by a series of medical tests, Shaw wrote. Unlike four other Canadian provinces, including Manitoba and Nova Scotia, Ontario does not have a statutory definition of death, the court decision notes. Instead, death in Canada is determined by physicians in accordance with accepted medical practice. "There is no legislation that requires physicians to consider an individual's views, wishes or religious beliefs as factors to be considered in the determination of death," the judge wrote in her decision. <https://goo.gl/xvVmjk>

Noted in Media Watch 20 November 2017 (#539, p.1):

- ONTARIO | CBC News (Toronto) – 16 November 2017 – '**Science must be the guiding factor when diagnosing brain death.**' Ontario courts have ordered artificial breathing machines remain attached to Taquisha McKitty and Shalom Ouanounou after their families launched legal challenges in order to prolong treatment. Both families have claimed that their loved ones are not dead by their respective religions' definitions of death. Teams of doctors in each case, however, have established irreversible death of the brain, which means that medically speaking, McKitty and Ouanounou are gone. The courts are nevertheless being asked to reaffirm decades of science, medicine and ethics, while also weighing the value of religious belief. <https://goo.gl/9TACZ9>

Quebec's forgotten dead: "Something isn't right"

QUEBEC | *The Montreal Gazette* – 3 July 2018 – When someone dies in Quebec, if no one comes forward police are charged with finding next of kin. If the police can't find family, or family members don't want to claim the body, the government takes charge of it. Quebec's ministry of health and social services oversaw 308 unclaimed bodies last year, a number that has steadily grown for the last decade. The Quebec coroner's office, which becomes involved when the death is considered obscure, violent or the result of negligence, handled an additional 104 cases. By law, the coroner's office will store a body at a morgue for at least 30 days before burying it. It keeps a burial certificate for each person, indicating the lot where they're buried, in the eventuality that someone remembers them in the future. The office lists the deaths online – birth date, last known address, date the coroner took over the case – in hopes that someone might find a long-lost family member that way. There are currently 340 people on the list, with entries dating back more than a decade. Beneath the title, "Do you know these people?" are the names and information of 285 men and 55 women. <https://goo.gl/QbZocz>



[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>

U.S.A.

Recommendations to the Food & Drug Administration about how to improve chronic pain

NATIONAL PAIN REPORT | Online – 4 July 2018 – As states implement regulations forcing people into pain clinics and away from their primary care and specialty care providers (who may have provided long term care), this forces individuals with multiple chronic morbidities into a care model that for many is inappropriate and which may result in harms. Few board-certified anesthesiologists have experience with rare and complex disease progression and few have interacted effectively with palliative care (PC). These are also unfamiliar with patient histories and are often consumed with fitting them into an interventional pain or surgical model whether or not it is appropriate. Physicians should have the ability to reconfigure their care provision to meet individuals where they are. Serving persons who need PC within the acute care model or forcing them into higher expense models for care delivery is absurd. It is well understood that PC is a model that leads to better quality of life at lesser cost for affected individuals. Supporting PC with adjunctive supports that widen the insurance payer system reduces reliance on higher cost prescriptions and health care utilization while improving community function for many. Insurers

should be required to contract with physicians who can serve persons with chronic care needs through a continuum of integrated medical home models – community located, in home, PC, assisted living, nursing home, hospice, hospital. <https://goo.gl/CcW7kr>

Specialist Publications

'Influences of religion and spirituality in medicine' (p.7), in *AMA Journal of Ethics*.

'Relationships among palliative care, ethical climate, empowerment, and moral distress in intensive care unit nurses' (p.7), in *American Journal of Critical Care*.

'History and perspectives on nutrition and hydration at the end of life' (p.16), in *Yale Journal of Biology & Medicine*.

'Twelve myths concerning medical aid in dying, or physician-assisted suicide' (p.17), in *MD Magazine*.

'Til death (or lack of profits) do us part healthcare: Humana's debut in hospice

NONPROFIT QUARTERLY | Online – 3 July 2018 – As nonprofits ceased to dominate the hospice field in recent years and for-profits became the majority players ... quality of care has arguably decreased while fraud and overbilling has increased. With profit margins as high as 16%, it comes as no surprise that for-profit companies want a piece of the pie and have eagerly joined the industry. Since the year 2000, the number of for-profit hospice providers has “more than quadrupled.” In this time, dozens of lawsuits have found for-profit outfits guilty of a wide variety of infractions ranging from inappropriately accepting patients into hospice, to substandard care, overbilling, and even causing untimely death. Throughout it all, hospice providers have received “slap on the wrist” penalties with no real changes to the industry occurring. Part of the reason there are few changes being made to the industry is that the field itself is rather subjective. In the face of terminal illness, some physicians and patients opt for aggressive treatment, whereas others do not. While the National Hospice & Palliative Care Organization has put out a tip sheet on compliance,¹ even this indicates that “each patient and his or her symptoms will differ.” The subjective nature of the field does not lend itself to strict standards and ... may be another reason that hospice should stay within the nonprofit sector. Without a profit motive, nonprofit organizations are better able to focus on quality care and keep the patients' best interest front and center. <https://goo.gl/vNsz5n>

1. 'Managing General Inpatient Care for Symptom Management Tips for Providers,' Compliance Tip sheet (3rd Edition, 2012), National Hospice & Palliative Care Organization. **Download/view at:** <https://goo.gl/49Xrh5>

Cont.

Noted in Media Watch 25 June 2018 (#569, p.3):

- **THE NEW YORK TIMES** | Online – 22 June 2018 – ‘**When a health insurer also wants to be a hospice company.**’ Hospice ... has become a booming multibillion-dollar industry that is attracting more and more for-profit companies, including one of the nation’s major insurers. That insurer, Humana, is making an unusual bet beyond the current strategy of health insurers to merge with pharmacies or buy up doctors’ practices. In teaming up with two investment firms, Humana plans to buy two hospice chains that together would create the industry’s biggest operator with hundreds of locations in dozens of states. But a spate of government lawsuits charging negligence and malfeasance against some hospice providers underscores the risks of profiting from the dying... <https://goo.gl/1iboK3>

N.B. Additional articles on the hospice “market” in the U.S. noted in this issue of Media Watch.

Does palliative sedation ease suffering during end-of-life care?

PBS NEWS HOUR | Online – 2 July 2018 – While aid-in-dying, or “death with dignity,” is now legal in seven states and Washington DC, medically assisted suicide retains tough opposition. Palliative sedation (PS), though, has been administered since the hospice care movement began in the 1960s and is legal everywhere. Doctors in Catholic hospitals practice PS even though the Catholic Church opposes aid-in-dying. According to the U.S. Conference of Catholic Bishops, the church believes that “patients should be kept as free of pain as possible so that they may die comfortably and with dignity.” Since there are no laws barring PS, the dilemma facing doctors who use it is moral rather than legal, said Timothy Quill, who teaches psychiatry, bioethics and palliative care

(PC) medicine at the University of Rochester Medical Center in New York. Some doctors are hesitant about using it “because it brings them right up to the edge of euthanasia,” Quill said. But Quill believes that any doctor who treats terminally ill patients has an obligation to consider PS. “If you are going to practice PC, you have to practice some sedation because of the overwhelming physical suffering of some patients under your charge.” <https://goo.gl/BgmrLZ>

Specialist Publications

‘Sedation and care at the end of life’ (p.16), in *Theoretical Medicine & Bioethics*.

N.B. Additional articles on palliative sedation noted in the 23 April 2018 issued of Media Watch (#560, p.15).

International

Terminally ill homeless people are dying on our streets. They deserve dignity like the rest of us

U.K. | *The Independent* – 6 July 2018 – We do know the average age at death of a homeless person is about 47 years; that homeless people attend A&E six times as often as people with a home; and, that homeless people are admitted to hospital four times as often, and stay three times as long. And yet in Britain in 2018, terminally ill homeless people have no legal rights to appropriate housing and most don’t access the care and support they need in their last few days, weeks and months. Developed with the advice of organisations like Pathway, St. Mungo’s, Hospice UK and Shelter, a proposed new law aims to provide the clearest possible legal framework for terminally ill homeless people. Without such clarity, they will continue to fall between the cracks of local housing and social service departments and the National Health Service (NHS). Yet legislation alone never delivers. To achieve good end-of-life care for society’s most marginalised people, we also need to reform services, with better integration and new types of accommodation, including specialist hospice hostels. We will need to train staff in the NHS, in homeless hostels and in hospices. <https://goo.gl/87q1oS>

1. Homelessness (End-of-Life Care) Bill 2017-19. **Download/view at:** <https://goo.gl/vBMSBu>

N.B. Additional articles on end-of-life care (EoLC) for the homeless in the U.K. noted in the 30 April 2018 issue of Media Watch (#561, p.10). Also, see ‘A second class ending: Exploring the barriers and championing outstanding EoLC for people who are homeless,’ Care Quality Commission, November 2017, noted in the 6 November 2017 issue of Media Watch (#537, p.5). <https://goo.gl/5aygwT>.

Putting death on the school timetable

AUSTRALIA | BBC News (London, England) – 4 July 2018 – Maths, science, history and death? This could be a school timetable in a state in Australia, if a proposal by the Australian Medical Association Queensland is accepted. They want young people to be made more familiar with talking about the end of life. Doctors say that improvements in medicine and an ageing population mean that there are rising numbers of families facing difficult questions about their elderly relatives and how they will face their last days. But too often young people in the West are not prepared for talking about such difficult decisions. There is a taboo around the subject and most deaths happen out of sight in hospitals. Pupils might have reservations about lessons in death education. But the Australian doctors argue that if the law and ethics around palliative care and euthanasia were taught in classrooms, it would make such issues less “traumatic” and help people to make better informed decisions. <https://goo.gl/sLkPh1>

Noted in Media Watch 4 June 2018 (#566, p.7):

- AUSTRALIA (Queensland) | *Education HQ* (Melbourne, Victoria) – 25 May 2018 – ‘**Australian Medical Association of Queensland calls for death classes in schools.**’ Schools should be teaching children about ageing and death so they can better cope with the loss of loved ones and their own mortality, the Australian Medical Association of Queensland says. Adolescents should also be writing advanced care plans so that if they suffer a debilitating or life-threatening accident or illness, families and doctors can understand their wishes. Australia’s ageing population meant younger people also needed a better understanding of their older relatives’ end-of-life care options. <https://goo.gl/TpZ1GH>

N.B. Additional articles on initiatives to educate young people about palliative and end-of-life care noted in this issue of Media Watch.

English bishop cautions Catholics on palliative care in state-funded hospitals

U.K. (England) | Catholic News Service – 4 July 2018 – Bishop Philip Egan of Portsmouth issued a “pastoral message” to clergy and laity after the publication of a report, which concluded that 650 people died in a hospital within his diocese after they were given large doses of painkillers without medical justification. Bishop Egan said he was “shocked and saddened” by the report, published in late June by the Gosport Independent Panel,¹ and he described the deaths at the Gosport War Memorial Hospital from 1989 to 2000 as “a terrible tragedy.” The panel began in 1998 to investigate the medical care and deaths of patients at the hospital. The bishop warned the faithful that gravely ill patients continued to face threats within Britain’s National Health Service. He suggested that over-sedation and dehydration were so commonplace that people were safer receiving care at home than being hospitalized. <https://goo.gl/45ffgC>

1. ‘Gosport War Memorial Hospital: The Report of The Gosport Independent Panel,’ June 2018. **Download/view at:** <https://goo.gl/XZeJkH>

N.B. See 1. ‘Gosport deaths: Lethal failures in care will happen again,’ and 2) ‘Lessons from Gosport,’ *British Medical Journal*, published online 4 July 2018. 1. **Full text:** <https://goo.gl/iBKf51>; 2. **Abstract:** <https://goo.gl/dsH9Gm>

Specialist Publications

“‘A tool doesn’t add anything.’ Use of observational pain tools with patients with advanced dementia approaching the end of life: A qualitative study of physician and nurse experiences and perspectives’ (p.10), in *International Journal Geriatric Psychiatry*.

‘How might organisational institutionalism support the challenges of the modern hospice?’ (p.10), in *International Journal of Health Planning & Management*.

‘Evaluating a model of delivering specialist palliative care services in rural New Zealand’ (p.13), in *Journal of Primary Healthcare*.

‘The palliative care knowledge of nursing home staff: The European Union’s Seventh Framework Programme Palliative Care for Older People cross-sectional survey in 322 nursing homes in six European countries’ (p.14), in *Palliative Medicine*.

Soaring demand at Ballarat Hospice shows how palliative care is changing for the better

AUSTRALIA (Victoria) | ABC News (Melbourne) – 2 July 2018 – Ballarat Hospice [is] a community organisation that has seen a 431% increase in the number of patients being referred to its service over the past 10 years. The hospice's 15 part-time nurses and counsellors service an almost 3,500 square kilometre area around the regional Victorian city, and handled 372 cases in 2017 alone. Its growth is symbolic of the palliative care (PC) sector itself... Ballarat Hospice does not charge for its services, instead it receives funding from government grants, community donations and sales at its op shops, to help patients stay at home for as long as possible. Palliative Care Victoria chief executive Odette Waanders said demand for in-home PC services had grown on the back of an ageing population. There were just two nurses working at Ballarat Hospice in 1987, but 30 years later it has more than 100 active volunteers and has received \$6.2 million in state funding to build a new facility. The funding was announced by the Minister for Regional Development, Jaala Pulford, whose daughter was in the care of Ballarat Hospice before passing away in 2014. When Robert Knowles, a patron of Ballarat Hospice, became Victoria's Minister for Aged Care in 1992, PC was in an 'embryonic' state. Mr. Knowles said throughout the 1990s he helped to implement a designated funding stream for PC and establish community and hospice-based care in regional centres. <https://goo.gl/AdJKrS>

Noted in Media Watch 28 May 2018 (#565, p.5):

- AUSTRALIA (New South Wales) | SBS News (Crows Nest) – 23 May 2018 – **'Palliative care need in hospitals soars.'** The use of palliative care (PC) in Australian hospitals is rising at a faster rate than any other hospital service. New data shows the number of Australians admitted to hospital for PC has soared by 28%, rising from about 57,600 in 2011-2012 to almost 74,000 in 2015-2016.¹ In 2015-2016, cancer was responsible for about half of all PC hospital admissions and deaths among PC patients. <https://goo.gl/L9misv>

1. 'Palliative care services in Australia,' Australian Institute of Health & Welfare, May 2018. **Download/view at:** <https://goo.gl/aQffoh>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND | Newsroom (Auckland) – 4 July 2018 – **'Is assisted dying a Pākehā issue?'** That is one of the questions being raised in submissions on [ACT New Zealand MP] David Seymour's End of Life Choice Bill which, if passed, would make it legal to apply for medically assisted dying. So far, the issue of euthanasia and race is raised in three different ways. First there is the question of whether the Bill takes into account worldviews of Māori, Asian or Pacific people. That leads to the second question, a philosophical one: Is there a disconnect between people who say there should be an individual human right to choose to end one's life (an idea seen as a Western one by some submitters) and others who see life in collective terms, by saying we belong to families, whānau, groups or society and those relationships trump the individual (an idea seen by some submitters as being more in accord with Māori, Asian and Pacific peoples). Thirdly, are ethnic minority groups submitting their views on the Bill? This, too, is being asked in submissions. There are submitters who identify themselves as Māori, Asian and Pacific people among the thousands of submissions released so far, but the numbers are small. <https://goo.gl/gJuKBP>

N.B. Pākehā is a Māori-language term for New Zealanders of European descent.

Specialist Publications

Influences of religion and spirituality in medicine

AMA JOURNAL OF ETHICS, 2018;20(7):609-612. Today, clinical chaplaincy remains an underutilized resource in health care, as patient spirituality continues to be an area that clinicians do not discuss as often as they should. This finding is disappointing, given the potential benefits of integrating patient religion and spirituality into clinical practice by improving empathy, building trust, and understanding behaviors. In looking at the state of religiosity of America, a Pew Research Center report found that 70.6% of U.S. adults identified as Christian in 2014; the report also revealed trends toward religious diversity, with small increases from 2007 to 2014 in the percentage of the population identifying as Muslim and Hindu and a 6.7% increase in the unaffiliated or “nones,” some of whom may identify as “spiritual but not religious.” Acknowledging the moral underpinnings (spiritual or religious) that drive certain care-seeking behaviors – from end-of-life care to contraception – is critical in achieving a more holistic medical practice. Moreover, awareness of our patients’ spiritual or religious beliefs helps us to be more aware of our own motivations, as spirituality and religion are important components that shape behaviors of many clinicians. **Full text:** <https://goo.gl/Hw5a9Y>



N.B. Selected articles on spirituality in the context of palliative and end-of-life care noted in the 30 April and 18 June 2018 issues of *Media Watch* (#561, p.14 and #568, pp.7-8, respectively). The focus of the current issue of the *American Medical Association Journal of Medical Ethics* is on religion and spirituality in health care practice. **Journal contents page:** <https://goo.gl/8BwomN>

Relationships among palliative care, ethical climate, empowerment, and moral distress in intensive care unit nurses

AMERICAN JOURNAL OF CRITICAL CARE, 2018;27(4):295-302. Discussions about moral distress continue to underscore the need for well-integrated teams to respectfully collaborate and communicate goals and strategies for individualized patient care. There remains a knowledge gap for nurses regarding the role and potential benefit of palliative care (PC) for patients in the ICU. Individual empowerment is a meaningful concept for ICU nurses, but it is not more important than the nurse’s relationship to the team and unit. The findings of this study support the incorporation of organizational support and team collaboration, including leadership, staff, and clinicians, for any attempted changes in a care delivery process when planning interventions to improve ICU end-of-life care or the ethical climate in the workplace. Education about PC and ethics may contribute to each individual’s ability to work within upgraded expectations, but all organizational change must be actively supported by administrative and clinical teams. **Full text:** <https://goo.gl/xPkz8d>

Paediatric palliative care in low-resource countries

Outcome measurement in paediatric palliative care: Lessons from the past and future developments

ANNALS OF PALLIATIVE MEDICINE | Online – Accessed 1 July 2018 – The lack of an outcome measure for paediatric palliative care (PPC) has been consistently cited as one reason for the lack of robust evidence in the field. Outcomes can be measured in a variety of ways, and due to the multi-dimensional nature of PPC, outcomes can be complex and hard to measure. Whilst there are a variety of outcome measures for use in adult palliative care (PC), a similar range of tools does not exist in PPC. Literature reviews have confirmed the absence of a multi-dimensional PPC outcome measurement tool. Following on from their success in developing an outcome scale for adults in Africa, the African Palliative Care Association (APCA) have developed a multi-dimensional outcome tool for PPC – the African Children’s Palliative Outcome Scale (C-POS). The draft C-POS consists of 12 questions, 8 in Section A for the child,

Cont.

and 4 in Section B for the parents/carers. The tool has been developed across eight African countries and is the first specifically designed, multi-dimensional outcome measure for PPC. Lessons have been learnt in the development of outcome scales in PC, including those specifically for PPC, such as: undertaking research in PPC; the definition of PPC; if you ask a child what their concerns are they will tell you; do you use child and or proxy report?; do you have different tools for different ages?; what methods of scoring should be used?; is it an outcome tool, an assessment tool or both?; the length of the outcome measure; the length of time it takes to develop; and, it won't be perfect. Whilst progress has occurred through the development of the C-POS there is still a long way to go in the development of outcome measures for PPC. Future developments include: finalization and publication of the African C-POS; utilization of the C-POS in clinical practice, research and audit; collation and review of data sets; and, the development of C-POS in different settings. **Abstract:** <https://goo.gl/C6bvbj>

N.B. To access full text click on pdf icon. Additional articles on paediatric palliative care in poor-resource countries noted in the 14 May 2018 issue of Media Watch (#563, pp.5-6).

Related

- *ANNALS OF PALLIATIVE MEDICINE* | Online – Accessed 1 July 2018 – ‘**Pediatric palliative care nursing.**’ This article aims to increase nurses’ and other healthcare providers’ awareness of selected recent research initiatives aimed at enhancing life and decreasing suffering for these children and their families. Topics were selected based on identified gaps in the pediatric palliative care (PC) literature. Published articles and authors’ ongoing research were used to describe selected components of pediatric palliative nursing care including: 1) Examples of interventions (legacy and animal-assisted interventions); 2) International studies (parent-sibling bereavement, continuing bonds in Ecuador, and circumstances surrounding deaths in Honduras); 3) Recruitment methods; 4) Communication among pediatric patients, their parents, and the healthcare team; 5) Training in pediatric PC; (6) nursing education; and, 7) Nurses’ role in supporting the community. Nurses are in ideal roles to provide pediatric PC at the bedside, serve as leaders to advance the science of pediatric PC, and support the community. **Abstract:** <https://goo.gl/VRki3R>

N.B. To access full text click on pdf icon.

The “lived experience” of palliative care patients in one acute hospital setting: A qualitative study

BMC PALLIATIVE CARE | Online – 6 July 2018 – There is limited understanding of the “lived experience” of palliative care patient within the acute care setting. Failing to engage with and understand the views of patients and those close to them, has fundamental consequences for future health delivery. Understanding “patient experience” can enable care providers to ensure services are responsive and adaptive to individual patient need. Despite the acknowledged organisational pressures, the interviews with the patients in this study highlight the importance of concepts such as kindness, compassion and dignity; taking the time to “care for patients” rather than time to “do to patients,” taking the time to listen to what is most important and taking the time to respond to the patient as an individual. When the patients’ voice is heard and healthcare professionals “see the person behind the name” rather than the illness, this provides opportunities for relationships to be built based on trust, confidence and mutual respect. This ultimately impacts on the patients’ experience of care, and their perception of self-worth and identity and sense of dignity. The palliative nature of illness reinforced the “preciousness” of time, underlining there is “one chance to get it right.” Having listened to our patients it is time to learn and change; this study has provided an opportunity for the “patient voice” to be heard and the individual patient experience to be explored. **Full text:** <https://goo.gl/iKyH31>



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 beginning on p.18.

“It doesn’t exist...”

Negotiating palliative care from a culturally and linguistically diverse patient and caregiver perspective

BMC PALLIATIVE CARE – 2 July 2018 – The end of life represents a therapeutic context that acutely raises cultural and linguistic specificities, yet there is very little evidence illustrating the importance of such dynamics in shaping choices, trajectories and care practices. Culture and language interplay to offer considerable potential challenges to both patient and provider, with further work needed to explore patient and caregiver perspectives across cultures and linguistic groups, and provider perspectives. The objective of this study was to develop a critical, evidence-based understanding of the experiences of people from culturally and linguistically diverse (CALD) backgrounds, and their caregivers, in a palliative care (PC) setting. The authors’ research identified four prevalent themes among participants: 1) Terminology in the transition to PC; 2) Communication, culture and pain management; 3) (Not) Talking about death and dying; and, 4) Religious faith as a coping strategy: challenging the terminal diagnosis. CALD patients and caregivers’ experiences are multifaceted, particularly in negotiating linguistic difficulties, beliefs about treatment, and issues related to death and dying. Greater attention is needed to develop effective communication skills, recognise CALD patients’ particular cultural, linguistic and spiritual values and needs, and acknowledge the unique nature of each doctor-patient interaction. **Full text:** <https://goo.gl/zrfe7A>

Noted in Media Watch 21 May 2018 (#564, p.13):

- *PALLIATIVE MEDICINE* | Online – 16 May 2018 – “**Death is difficult in any language**”: **A qualitative study of palliative care professionals’ experiences when providing end-of-life care to patients from culturally and linguistically diverse backgrounds.**’ The following themes emerged: 1) Determining the rules of engagement around discussion of diagnosis and prognosis; 2) Navigating the challenge of language to patient understanding; 3) Understanding migration experiences to establish trust; 4) Maintaining the balance between patient safety and comfort care; 5) Providing a good death experience through accommodation of beliefs; and, 6) Navigating the important role of family members while privileging patient preferences. **Abstract:** <https://goo.gl/ezBDFx>

End-of-life care in high-grade glioma patients. The palliative and supportive perspective

BRAIN SCIENCES | Online – 30 June 2018 – Patients affected by a primary brain tumor have complex needs. High-grade gliomas (HGG) patients experience a variety of neurological symptoms together with a progressive physical and cognitive deterioration that require a proper multimodal management. The end-of-life (EoL) phase of HGG patients represents a time when no therapy has further effects on disease progression, and only symptomatic and supportive treatment can be adopted. Palliative care (PC) in HGG patients during their EoL requires multidisciplinary interventions consisting of medical therapy, rehabilitation, psychological and social support, addressed both to patients and to their caregivers, who experience a high rate of distress and overburdening. Proper and prompt adopted PC enhances the quality of life of patients and relatives, reduces the health costs, improves patient satisfaction, ensures the fulfilment of patient’s wills, and promotes, in most cases, a dignified death. However, the literature lacks large studies on the EoL phase of HGG patients. Furthermore, clinical, psychological, and social investigations should be performed on PC in order to develop new strategies to provide a better EoL care, which seems to be an unheeded part of HGG patients’ management. **Full text:** <https://goo.gl/twtzui>

Noted in Media Watch 1 January 2018 (#544, p.4):

- U.S. | United Press International – 28 December 2017 – ‘**Many with deadly brain cancer don’t opt for hospice care.**’ Many patients with a deadly type of brain tumor don’t receive adequate hospice care, a new study finds.¹ Even though timely hospice enrollment is an important measure of quality oncology care, the authors found that 37% of malignant glioma patients received no hospice at all prior to death. Sixty percent of patients did enroll in hospice care, and the average length of stay was 21 days. However, 23% of patients enrolled within a week before their death, and 11% less than three days before their death, which was likely too late to do much good. <https://goo.gl/G2ZH65>

1. ‘Hospice utilization in patients with malignant gliomas,’ *Neuro-Oncology*, published online 10 October 2017. **Abstract:** <https://goo.gl/ZHP8FM>

Are transfusions a barrier to high-quality end-of-life care in hematology?

THE HEMATOLOGIST | Online – 6 July 2018 – Unfortunately, evidence suggests that patients with hematologic malignancies are significantly less likely to use hospice care services than patients with solid tumors, instead receiving aggressive care at the end of life (EoL), including chemotherapy in the last 14 days, or spending time in a hospital, intensive care unit, or emergency department in their last month, sometimes even dying in the hospital. Furthermore, when hematologic malignancy patients do use hospice, they are more likely to do so for a very short period of time, thus missing out on many of its benefits. While the origins of this problem are likely multifactorial, it is often said that hematologic malignancies themselves pose unique barriers, such as the frequent need for transfusion support. This is because transfusions are often not able to be provided to patients receiving hospice care, since they may be homebound, making the logistics of transfusion more difficult. Additionally, the cost of regular transfusions generally exceeds the “per diem” payment that hospice agencies [in the U.S.] receive to pay for the costs of caring for a patient, thus precluding transfusion support entirely at many smaller agencies. While there is no legal provision preventing the use of transfusions in hospice, the practical implications of doing so have made this service unavailable at most hospice agencies. A national survey study of 349 practicing hematologic oncologists confirms this observation with 62% stating that lack of transfusion support from hospices is a barrier to hospice referral, and that they would refer more patients if red cell or platelet transfusions were allowed. Clearly, many of us believe that transfusion support provides real benefits to our patients. This raises important questions: What do data show about the role of transfusions near the EoL? Do transfusions truly have palliative benefits? **Full text:** <https://goo.gl/k1dpoj>

1. ‘Why are patients with blood cancers more likely to die without hospice?’ *Cancer*, 2017;123(17):3377-3384. [Noted in the 29 May 2017 issue of Media Watch (#514, p.4)] **Abstract:** <https://goo.gl/4F7NX1>

“A tool doesn’t add anything.”

Use of observational pain tools with patients with advanced dementia approaching the end of life: A qualitative study of physician and nurse experiences and perspectives

INTERNATIONAL JOURNAL GERIATRIC PSYCHIATRY | Online – 1 July 2018 – This study reveals several key issues regarding integration and implementation of observational pain tools (OPTs) as part of pain assessment protocols in primary, secondary, hospice, and nursing home settings. Difficulties in applying the tools in practice, lack of guidance regarding the rationale for changing practice, and how to integrate tools with existing protocols, along with uncertainty regarding clinical validity and reliability of these tools with dying patients with advanced dementia, were significant barriers to their use. Policy makers should exercise caution in placing emphasis on ease and simplicity of OPT use alone, particularly in clinically challenging and complex areas as this could prove counterintuitive, leading to lack of engagement with OPT use. Health care professionals continue to report pain assessment as challenging and emphasise a need for ongoing investment in training and education, which must take into consideration educational needs, and balance theory with practical application of knowledge and skills. **Full text:** <https://goo.gl/cXHJ88>

N.B. Additional articles on palliative and end-of-life care for people living with Alzheimer’s and other forms of dementia noted in the 18 June 2018 issue of Media Watch (#568, p.4).

How might organisational institutionalism support the challenges of the modern hospice?

INTERNATIONAL JOURNAL OF HEALTH PLANNING & MANAGEMENT | Online – 28 June 2018 – The external environment within which U.K. charitable hospice care operates is changing. More people are dying with conditions other than cancer; however, this disease still dominates modern hospice care. Organisational institutionalism offers a theoretical lens through which to consider the challenges facing the hospice movement. Concepts such as legitimacy, decoupling, deinstitutionalisation, and reinstitutionalisation can help hospice leaders understand the challenges of change and some of the strategies that can

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be employed at local and national levels. The authors outline a number of environmental and influencing factors driving and impacting change. A model of institutional change is introduced, explored, and considered from the context of hospice. When it comes to understanding change, legitimacy is a major concept introduced to challenge and pose questions for hospices to address. The authors propose a model demonstrating a perspective regarding the current structure of services within hospice organisations. The model argues that only hospice care for people with cancer is truly institutionalised and that other areas of care lack comparable legitimacy. It provides three directions for hospice in addressing the challenges faced: 1) Decoupling; 2) Deinstitutionalisation then reinstitutionalisation; and, 3) A new social movement. The article concludes with recommendations for future consideration. **Summary:** <https://goo.gl/MZeXVv>

End-of-life care in Australia

Who benefits from aggressive rapid response system treatments near the end of life? A retrospective cohort study

JOINT COMMISSION JOURNAL ON QUALITY & PATIENT SAFETY | Online – 27 June 2018 – Many patients near the end of life (EoL) are subject to rapid response system (RRS) calls. A study was conducted in a large teaching hospital to identify a cut-off point that defines non-beneficial treatment for older hospital patients receiving an RRS call, describe interventions administered, and measure the cost of hospitalization. Overall, 8.9% of the 733 patients studied had a pre-existing not-for-resuscitation (NFR) or not-for-RRS order; none of those patients survived to three months. By contrast, patients without an NFR or not-for-RRS order had three-month survival probability of 71%. Compared with survivors, RRS recipients who died were more likely to be older, to be admitted to a medical ward, and to have a larger mean number of admissions before the RRS. The average cost of hospitalization for the very old transferred to the ICU was higher than for those not requiring treatment in the ICU. Identifiable risk factors clearly associated with poor clinical outcomes and death can be used as a guide to administer less aggressive treatments, including reconsideration of ICU transfers, adherence to NFR orders, and transition to EoL management instead of calls to the RRS team. **Abstract:** <https://goo.gl/18otCA>

Development and applicability of a tool for identification of people with intellectual disabilities in need of palliative care (PALLI)

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Online – 1 July 2018 – The authors developed a screening tool for deteriorating health, indicative of a limited life expectancy. They describe development of PALLI and explore its applicability. They used a five-stage mixed-methods procedure to develop PALLI based on knowledge from practice. For exploring applicability, professionals caring for people with intellectual disabilities completed PALLI for 185 people with intellectual disabilities and provided information on applicability after 5-6 months. The final version of PALLI included 39 questions relevant for people with intellectual disabilities. Applicability was adequate: Most professionals found PALLI relevant and reported no ambiguous questions. Added value of PALLI was reflecting on and becoming aware of the process of decline in health. **Abstract:** <https://goo.gl/Qev4Mj>

N.B. Selected articles on palliative and end-of-life care for people living with intellectual and developmental disabilities noted in the 23 April 2018 issue of Media Watch (#560, p.12).

Development of death education training content for adult cancer patients: A mixed methods study

JOURNAL OF CLINICAL NURSING | Online – 3 July 2018 – Death education is often combined with hospice care, which is based on a clear six-month survival period. However, the survival of adult cancer patients has improved with improved cancer diagnoses and treatments, and death education should be initiated before the dying stage. At the same time, patients' needs for medical information become increasingly important in daily clinical practice. Therefore, a death education program based on adult can-

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cer patients' needs was developed to help these patients reflect on the meanings of life and death. The aim of this mixed methods study was to develop science-based content for a systematic death education training system based on the needs of adult cancer patients. The study contained two parts: survey development and Delphi survey. First, a small sample test was conducted to check the reliability and validity of the questionnaire. Next, this questionnaire was applied to investigate adult cancer patients' needs for death education. Then, the authors invited experts in the fields of nursing management, clinical medicine, clinical nursing, and psychological care to carry out two rounds of Delphi consultations to revise the training content. **Abstract:** <https://goo.gl/NtGrFB>

Enabling advance directive completion: Feasibility of a new nurse-supported advance care planning intervention

JOURNAL OF GERONTOLOGICAL NURSING, 2018;44(7):31-42. Adults who complete an advance directive (AD) are not consistently offered information about the risks, benefits, or alternatives (RBA) of the life-sustaining medical procedures addressed on standardized forms. This article describes a new patient-centered nurse-supported advance care planning (NSACP) intervention focused on providing information about RBA of life-sustaining procedures. Of participants in the NSACP group, 94% completed an AD. Participants who received NSACP made more decisions to decline life-sustaining treatment than those who were randomized to the comparison group. Promising feasibility data include brevity, high patient satisfaction, participant retention, and treatment fidelity. **Abstract:** <https://goo.gl/D96Pjh>

Embedding palliative care into healthy aging: A narrative case study from Thailand

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2018;20(4):416-420. This article provides a conceptual framework for understanding the relationship between palliative care (PC) and healthy aging using a narrative case study from Thailand. The Thai context is used to clarify two concepts: healthy aging and good death. This case study describes a Thai female older adult's perspective and her drive to stay physically, cognitively, and socially active for as long as possible – strong indicators of healthy aging until the end of life. Family support is a vital part of helping older adults stay active and achieve a good death. The Thai healthy aging model explains a lifelong process of how to be a healthy ager in the Thai context. The model is closely related to a PC philosophy, which focuses on dying without unnecessary suffering and promotes closeness to family. This model supports the inclusion of PC in healthy aging strategies to maximize quality of life and well-being, particularly in older adults experiencing multi-morbidity and health inequalities. Improved healthy aging is integrally related to the provision of high-quality PC. **Abstract:** <https://goo.gl/FB65Jm>

Responding better to desperate parents: Warnings from the Alfie Evans saga

JOURNAL OF LAW & MEDICINE, 2018;25(4):899-918. The end-of-life litigation involving Alfie Evans (9 May 2016 - 28 April 2018) ... who suffered from an incurable and degenerative neurological condition was extraordinary. It emerged in the shadow of comparable but not as extensive litigation enabled by crowd-funding in relation to Ashya King and Charlie Gard. Although Alfie's parents lost repeatedly in the High Court, the Court of Appeal and the Supreme Court of England, as well as before the European Court of Human Rights, they persisted in bringing more legal challenges. The public relations campaign on their behalf at times was threatening and accusatory of the clinicians and of Alder Hey Hospital. Both persons employed at the Christian Legal Centre, which represented the parents at times, and medical practitioners from Europe who participated in forensic assessments behaved unethically. There are many lessons to be learned from the Alfie Evans saga. If we are to maintain morale and commitment among those who provide paediatric clinical services to the very ill and the dying, they must be protected from the public relations and litigation campaigns deployed by those purporting to represent the Alfie Evans family, and better non-adversarial methods need to be constructed as a matter of urgency to resolve matters involving disagreements about the treatment of terminally ill children. **Abstract:** <https://goo.gl/p2gavB>

N.B. Selected articles on the Alfie Evans and the Charlie Gard cases noted in the 28 May 2018 issue of *Media Watch* (#565, p.3) and the 11 June 2018 issue of the weekly report (#567, p.10), respectively.

Ten tips palliative care pharmacists want the palliative care team to know when caring for patients

JOURNAL OF PALLIATIVE MEDICINE, 2018;21(7):1017-1023. As palliative care (PC) moves upstream in the course of serious illness and the development of drugs and their indications rapidly expand, PC providers must understand common drug indications and adverse effects to ensure safe and effective prescribing. Pharmacists, experts in the nuances of medication management, are valuable resources and colleagues for PC providers. This article offers PC providers 10 useful clinical pharmacy tips that PC pharmacists think all PC providers should know for safe and effective symptom management. **Abstract:** <https://goo.gl/uZsva4>

Noted in Media Watch 29 August 2016 (#477, p.5):

- *AMERICAN JOURNAL OF HEALTH-SYSTEM PHARMACY*, 2016;73(17):1351-1367. ‘**American Society of Health-System Pharmacists Guidelines on the Pharmacist’s Role in Palliative & Hospice Care.**’ Despite representation within the first hospice demonstration project in the U.S., participation of the pharmacist as an essential member of the interdisciplinary team has been traditionally overlooked. Evidence of the pharmacist’s contribution to the delivery of PC and supportive care services beyond the original role of medication dispensing and compounding has garnered growing recognition across numerous practice settings. **First page view:** <http://goo.gl/gV9VcJ>

N.B. Access the American Society of Health-System Pharmacists guidelines at: <https://goo.gl/X5xboF>

Evaluating a model of delivering specialist palliative care services in rural New Zealand

JOURNAL OF PRIMARY HEALTHCARE, 2018;10(2):125-131. Various methods of delivering specialist palliative care (SPC) to rural areas have been discussed in the literature, but published evaluations of these models are sparse. This study surveyed the stakeholders of a rural SPC service to help identify potential gaps and inform planning regarding the future vision. A survey was sent to all relevant stakeholders across the West Coast of New Zealand, including staff in primary care, aged residential care and the hospital. It focused on understanding the local model of palliative care, the quality of the current service and perceived gaps. The medical respondents rated the quality of the service higher than nursing and allied health participants. All of the groups reported feeling the SPC team was under-resourced. Additional educational opportunities were considered essential. Stakeholders found the service easy to access, but improvements in communication, educational opportunities and forward planning were identified as being needed. **Full text:** <https://goo.gl/n8ZHIN>

Noted in Media Watch 20 March 2017 (#504, p.14):

- *RURAL & REMOTE HEALTH* | Online – 8 March 2017 – ‘**Training generalist doctors for rural practice in New Zealand.**’ This article adds to existing knowledge by describing the structure and evolution of a rural hospital medicine training program, highlighting the key features of its success. New Zealand’s rural population is spread thinly over a terrain that is not vast but is rugged. Also, its institutions and communities of interest are relatively small. **Full text:** <https://goo.gl/cz12ly>



Media Watch: Behind the Scenes

<http://goo.gl/XDjHxz>



Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

How to distinguish medicalization from over-medicalization?

MEDICINE, HEALTH CARE & PHILOSOPHY | Online – 27 June 2018 – Is medicalization always harmful? When does medicine overstep its proper boundaries? The aim of this article is to outline the pragmatic criteria for distinguishing between medicalization and over-medicalization. The consequences of considering a phenomenon to be a medical problem may take radically different forms depending on whether the problem in question is correctly or incorrectly perceived as a medical issue. Neither indiscriminate acceptance of medicalization of subsequent areas of human existence, nor criticizing new medicalization cases just because they are medicalization can be justified. This article: 1) Identifies various consequences of both well-founded medicalization and over-medicalization; 2) Demonstrates that the issue of defining appropriate limits of medicine cannot be solved by creating an optimum model of health; and, 3) Proposes four guiding questions to help distinguish medicalization from over-medicalization. The article should foster a normative analysis of the phenomenon of medicalization and contribute to the bioethical reflection on the boundaries of medicine. **Full text:** <https://goo.gl/TSgrv9>

Extract from *Medicine, Health Care & Philosophy* article

In secularised Western societies, medicine has in many aspects substituted religious institutions: the authority of a therapist has replaced that of a priest, and deviation started to be perceived in terms of sickness rather than sin or crime. But the fact of religious institutions being supplanted by medical institutions cannot be readily classified as a negative or positive phenomenon. Some critics of medicalized death believe that we ought to go back to the times when forthcoming death used to be an essentially religious experience, not a medical one, arguing in favour of dying at home and shifting the duty of caring for those on their deathbed from public and medical institutions back onto the family and religious community. However, the change in the conditions of dying has not been forced on societies – it originated from transformations that these societies have undergone, from evolving needs and priorities (e.g. striving to postpone the moment of death, to eliminate physical pain). Therefore, in order to effectively criticise the medicalization of a problem, one needs to find an alternative explanation and a solution that would be more adequate and helpful in a given situation.

Noted in Media Watch 4 March 2013 (#295, p.8):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2013;19(2):85-91. '**Working in a medicalised world: The experiences of palliative care nurse specialists and midwives.**' A grounded theory approach illuminated the social processes associated with caring during birth and death. Four categories were identified through thematic analysis: 1) Memories 2) One act; 3) Advocate; and, 4) Medical event. These integrated to create a core category: working to counter the pathologisation of birth and death. Study participants illustrated the impact of medicalisation on the experience of birth and death and struggle with the negative effects of this. **Abstract (w. link to references):** <https://goo.gl/8eK5rk>

The palliative care knowledge of nursing home staff

The European Union's Seventh Framework Programme Palliative Care for Older People cross-sectional survey in 322 nursing homes in six European countries

PALLIATIVE MEDICINE | Online – 4 July 2018 – This study highlights specific knowledge gaps. Although the authors found that many problematic issues are the same across countries, huge heterogeneity persists even after adjusting for confounders. Knowledge about basic palliative care (PC) issues is generally poor among nurses and care assistants in all countries, but particularly so in Poland and in Italy. A study of PC development in European care homes and nursing homes shows that there is a large variation in the degree to which PC is developed and implemented. In Poland, and particularly in Italy, hardly any initiatives exist to develop PC in these settings and there is no evidence of engagement with PC initiatives by and within the care and nursing homes. This may suggest that the degree of PC knowledge of nursing home staff is influenced by the availability of PC services and initiatives in the nursing home and by the

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extent of national policy and investment in PC development in the nursing home setting. As expected, the authors found that in all countries nurses have better PC knowledge than care assistants. This reflects differences in PC education, and differences in roles and levels of care responsibilities. Care assistants often work under the supervision of a nurse and their direct care responsibilities are limited. However, as most direct care in nursing homes is provided by care assistants, they are in an ideal position to note clinical changes and to assess and address a resident's needs, making knowledge of PC extremely relevant to them. A White Paper of the European Association for Palliative Care on PC education identifies nursing homes as a setting in which the staff, irrespective of their discipline, need to know the basic principles of PC.¹ This implies that all levels of staff need to be able to provide high-quality care to residents at the end of life. In this respect, this study shows very clearly that there is a strong need to further invest in basic PC knowledge and skills, especially for care assistants. **Full text:** <https://goo.gl/ppHxTi>

1. 'Core competencies in palliative care: White Paper on palliative care education – Part 1,' *European Journal of Palliative Care*, 2013;20(2):86-91. [Noted in the 4 March 2013 issue of Media Watch (#295, p.7)] **Journal contents page:** <https://goo.gl/kugYhG>

Related

- **MORTALITY** | Online – 4 July 2018 – “**Doing death” the Mediterranean way: End-of-life in a segregated nursing home.** This paper presents ethnographic data on a migrant-specific nursing home ward in Switzerland. It shows that the structurally pre-defined segregation of residents sharing a common characteristic affects care practices along three dimensions: 1) Performances of sameness/otherness; 2) Informalisation of relationships; and, 3) Language/understanding. Yet, “death work” showed little difference to non-segregated wards. **Abstract:** <https://goo.gl/MxPbvN>
- **NURSING ETHICS** | Online – 26 June 2018 – ‘**Ethical issues experienced during palliative care provision in nursing homes.**’ In this study, the ‘Ethical Issues in Palliative Care for Nursing Homes’ instrument was used to measure the frequency and level of distress arising from ethical issues through a cross-sectional survey... Interviews revealed three themes: 1) Ethical issues in practice; 2) Relational issues; and, 3) Organisational issues. Relational issues, primarily issues with residents and families, occurred most frequently and caused greater distress. **Abstract:** <https://goo.gl/ytnEnM>

End-of-life care in Australia

Responding to urgency of need: Initial qualitative stage in the development of a triage tool for use in palliative care services

PALLIATIVE MEDICINE, 2018;32(7):1246-1254. Palliative care (PC) services face the challenge of a workload increasing in volume and diversity. An evidence-based triage method to assess urgency of PC needs is required to ensure equitable, efficient and transparent allocation of specialist resources when managing waiting lists. Twenty PC providers were purposively sampled to ensure representation across disciplines (primary, specialist; medicine, nursing and allied health), service types (inpatient, hospital liaison and community) and locations (metropolitan and rural). A series of markers of urgency were identified, including physical and psychological suffering, caregiver distress, discrepancy between care needs and care arrangements, mismatch between current site of care and desired site of death when in terminal phase and complex communication needs. Performance status and phase of disease were reported to be less informative when considered in isolation. Interpersonal and system-based barriers to the implementation of a PC triage tool were highlighted. **Abstract:** <https://goo.gl/uGHkf6>

When bad news isn't necessarily bad: Recognizing provider bias when sharing unexpected news

PEDIATRICS | Online – 25 June 2018 – As providers, we are often part of difficult conversations in which we have to share bad news with families. Increasingly, this skill is being recognized as a necessary competency for effective clinical practice, with curricula and protocols emerging to support training in this art of breaking bad news. In parallel, we are learning more about the role implicit bias plays within our health

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care encounters, in which our lived experiences provide a lens through which we approach all interactions and unconsciously shape our understanding and behavior. In this article, the authors share a family's journey that highlights where these two concepts (breaking bad news and implicit bias) often intersect. Their purpose is to shine a light on an important lesson for providers: that often we bring our own biases to the table when we frame news as "bad" when ultimately, from a family's perspective, it may not be bad at all. In doing so, we may play an integral role in how we start a family's journey with a new diagnosis. Using one family's story as a framework, the authors aim to help providers consider when an alternative paradigm may be valuable, with a shift from "breaking bad news" toward "sharing unexpected news," and they provide tangible skills to consider when this approach may be ideal. **Full text:** <https://goo.gl/3Cquwq>

Palliative dermatology: An area of care yet to be explored

PROGRESS IN PALLIATIVE CARE | Online – 1 July 2018 – Dermatologists are rarely involved in palliative works currently, but recent literature demands an active involvement. The authors review literature linking palliative care (PC) and dermatology. They also attempt to define the need and scope of palliative dermatology as a subspecialty of PC. Policymakers of palliative medicine should seriously consider the role of dermatologists in the team and a dermatologist may avail basic training in PC as it may aid them to address certain clinical situations in a better way. **Abstract:** <https://goo.gl/6Be3n2>

Sedation and care at the end of life

THEORETICAL MEDICINE & BIOETHICS | Online – 2 July 2018 – Christianity affirms a duty to relieve unnecessary suffering yet also proscribes euthanasia. Accordingly, the question arises as to whether it is ever morally permissible to render dying patients unconscious in order to relieve their suffering. If so, under what conditions? Is this practice genuinely morally distinguishable from euthanasia? Can one ever aim directly at making a dying person unconscious, or is it only permissible to tolerate unconsciousness as an unintended side effect of treating specific symptoms? What role does the rule of double effect play in making such decisions? Does spiritual or psychological suffering ever justify sedation to unconsciousness? What are the theological and spiritual aspects of such care? This introduction describes how the authors in [a forthcoming] special issue wrestle with such questions and shows how each essay relates to the author's individual position on palliative sedation, as developed in greater detail within his contribution. **Abstract (inc. list of references):** <https://goo.gl/3fgUeJ>

N.B. Journal home page: <https://goo.gl/hiGCi6>

History and perspectives on nutrition and hydration at the end of life

YALE JOURNAL OF BIOLOGY & MEDICINE, 2018;91(2):173-176. The question of whether to provide artificial nutrition and hydration (ANH) to a patient with terminal illness or at end of life has been debated over many years. Due to the nature of the question and the setting in which it presents, prospective trials are not feasible, and the health care professional is left to work with the patient and family to make decisions. This perspectives piece addresses the issue in a format designed to inform the reader as to the pertinent considerations around ANH. The authors briefly review significant historic, religious, ethical, and legal contributions to this discussion and physiologic underpinnings. They address the beliefs of patient, family, and health care providers surrounding this issue. The authors' goal is to provide a review of the considerations for health care providers as they address this issue with patients and families in the course of compassionate care. **Full text:** <https://goo.gl/uRooZF>

N.B. Additional articles on artificial nutrition and hydration noted in the 3 July 2017 issue of Media Watch (#510, pp.10-11).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CRIMINAL LAW & PHILOSOPHY* | Online – 5 July 2018 – ‘**The practice of euthanasia and assisted suicide meets the concept of legalization.**’ This article explores attempts at legalization of the practice of euthanasia and assisted suicide (EAS). Although in many countries there have been high levels of public support for EAS, in most of them, no legislative activity has taken place concerning these practices, and there is a lack of clarity about what is permitted and what is not. The author argues that accurate definition of the relevant concepts and a clear delineation of the territory of the debate would help draw a coherent roadmap for legalization. To this end, he analyses five legal approaches to the legalization [of] euthanasia: maintenance of the *status quo*, legal defenses, de-prioritization, decriminalization, and legislation. The author concludes with a discussion of the moral and legal implications of the foregoing analysis. **Abstract:** <https://goo.gl/1KfesQ>
- *MD MAGAZINE* | Online – 7 July 2018 – ‘**Twelve myths concerning medical aid in dying, or physician-assisted suicide.**’ In an age of “alternative facts”, it’s hard to sort out myth from reality when it comes to so-called medical-aid-in-dying (MAiD) – also called physician assisted suicide (PAS). By whatever label we attach to it, this practice involves a physician’s prescribing a lethal drug for a patient with a putatively terminal illness who is requesting this “service.” Some form of MAiD/PAS is now legal in 5 states and the District of Columbia. People of good conscience, including many physicians, are sharply divided on the ethics of MAiD/PAS. Unfortunately, much of the support for this practice is founded on several myths and misconceptions regarding existing MAiD laws and practices. The case for physician-assisted suicide legislation rests on a number of misconceptions, as regards the adequacy, safety, and application of existing PAS statutes. The best available evidence suggests that current practices under PAS statutes are not adequately monitored and do not adequately protect vulnerable populations, such as patients with clinical depression. The American College of Physicians, the American Medical Association, the World Medical Association and the American Nurses Association have all registered opposition to physician-assisted suicide. It is critical that physicians inform themselves as regards the actual nature and function – or dysfunction – of medical aid in dying legislation. The first step is to recognize and challenge the many myths that surround these well-intended but misguided laws. **Full text:** <https://goo.gl/uDsJ92>
- *MEDICAL LAW REVIEW* | Online – 2 July 2018 – ‘‘**Capacity for discernment**’’ and euthanasia on minors in Belgium.’ In 2014, the Belgian Euthanasia Law was amended so as to extend the possibility of obtaining euthanasia to minors who have the capacity for discernment. The amendment led to considerable debate among Belgian legal experts, health care professionals and ethicists, in large part due to concerns about the scope and assessment of the minor’s “capacity for discernment,” a concept first introduced in Belgian medical law by the amendment. This article offers a critical legal analysis of the concept of “capacity for discernment” and its implications for euthanasia practice in Belgium. The authors do so by focusing on a ruling of the Belgian Constitutional Court of 29 October 2015, where the concept figured prominently in the examination of the constitutionality of the amendment. **Abstract:** <https://goo.gl/kwSaeZ>
- *NURSING FORUM* | Online – 4 July 2018 – ‘**Medical assistance in dying (MAiD): Canadian nurses’ experiences.**’ Nurses’ experiences of either providing care for a patient who had chosen MAiD, or declining to participate in MAiD, were explored. Findings describe three themes and eight storylines of the impact of MAiD on nurses’ view of the profession, clinical practice, and personally. While most nurses perceived MAiD as an extension of the profession and their nursing practice, a small number also expressed moral distress as they grappled with assisted dying. Narratives illustrated an ongoing sense-making process and spectrum of emotions. These findings offer insight and provide direction for nurses and managers in this new clinical and legal reality. **Full text:** <https://goo.gl/8y2TGr>

Media Watch: Editorial Practice

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

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

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

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[Scroll down to 'International Websites']

Canada

BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION: <https://goo.gl/gw5ti8>

[Click on 'National Resources,' scroll down to 'Palliative Care Network Community']



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

[Scroll down to 'Are you aware of Media Watch?']

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

[Scroll down to 'Additional Resources']

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

ONTARIO | Mississauga Halton Palliative Care Network: <https://goo.gl/ds5wYC>

[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

SASKATCHEWAN | Saskatchewan Medical Association: <https://goo.gl/5cftPV>

[Scroll down to 'Palliative Care Network Community']

Europe



EUROPEAN JOURNAL OF PALLIATIVE CARE: <https://goo.gl/KjrR6F>

[March/April 2018 issue (Scroll down to 'The homeless: A vulnerable population with poor access to palliative care.')]

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

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

South America



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

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