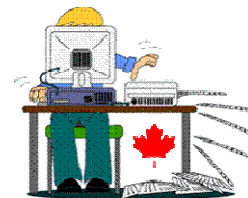


Media Watch...

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

Hospice and palliative care social work: Scroll down to [Specialist Publications](#) and 'Discovering people's strengths and resources at the end of life' (p.10), in *European Journal of Palliative Care*.

Canada

Ontario law to require drug firms to reveal funds paid to doctors' groups, patient advocates

ONTARIO | *The Globe & Mail* (Toronto) – 22 February 2018 – Pharmaceutical companies will have to reveal in detail the payments they make to patient-advocacy groups and professional medical societies in Ontario as part of the province's efforts to pull back the curtain on money in medicine. The lack of transparency has meant that health charities and non-profits have had no mandatory obligation to reveal which companies are funding them and in what amounts. Right now, Canadian patient-advocacy groups can disclose as much or as little as they like about the donations they receive from drug or device makers. Some make detailed disclosures on their websites; most do little more than putting the names or logos of their industry sponsors online. In draft regulations, the Ontario government laid out how the health-sector transparency law it passed last year will work, including listing the 31 categories of funding recipients who will be covered by the new disclosure system, the first of its kind in Canada. These changes will allow anyone to search the name of a health charity or non-profit in an online database to access funding information. <https://goo.gl/KKpY3F>

N.B. Ontario Health Sector Payment Transparency Act, 2017. **Download/view at:** <https://goo.gl/KoXJah>

Easing suffering: Ontario nurse practitioners given authority to prescribe high-dose painkillers

ONTARIO | CBC News (Toronto) – 21 February 2018 – A change in the scope of practice for some nurse practitioners (NPs) in Ontario will allow them to offer greater pain relief to people nearing the end of life. The provincial government has granted NPs, who are trained in palliative care (PC), the authority to independently prescribe high-strength, long-acting opioids. Up to 9 February 2018, only physicians registered under the ministry of health's PC facilitated access program could independently prescribe high-strength, long-acting opioids such as morphine (200 mg tablets and capsules) and hydromorphone (24 mg and 30 mg capsules) to people receiving PC. <https://goo.gl/68q5jr>

Doctors say he's dead. Jewish laws say he's alive. Can a hospital turn off life support?

ONTARIO | CBC News (Toronto) – 15 February 2018 – To the doctors at Humber River Hospital, 25-year-old Shalom Ouanounou is dead. He has no capacity for consciousness, no brainstem reflexes, and no ability to breathe on his own. But to his devoutly religious family, who adhere to a interpretation of Jewish law that defines death as cardiac and respiratory failure, Ouanounou is very much alive. Since November, when an emergency injunction was obtained to stop the hospital from ending Ouanounou's life support a few weeks after he was pronounced dead, he's lain in a bed in the west-end hospital as machines support his respiratory and cardiac systems. What becomes of him is now in the hands of an Ontario judge, Justice Glenn Hainey, who heard arguments for and against the continuation of his life support. "Ontario has no legal definition of death. Some provinces do, but Ontario doesn't," said Mark Handelman, a lawyer representing Ouanounou via his father, who is acting as his substitute decision maker. Handelman argues that removing life support for Ouanounou, a committed Orthodox Jew, would violate his charter right to free-

dom of religion. Meanwhile, a group of three doctors and the Humber River Hospital make the argument that despite the lack of a fixed legal definition, in practice, neurological death is "death at law in Ontario." <https://goo.gl/CK1Bj4>



On Calgary streets: Dignity, at the end of life

ALBERTA | *The Calgary Herald* – 23 February 2018 – For a person on the street struggling every day to find food and shelter, a terminal diagnosis is a crushing burden. A nurse and doctor have founded a program which provides support to Calgary's vulnerable citizens, where they need it most. <https://goo.gl/iGzXer>

N.B. Articles on programs for the homeless of Halifax (Nova Scotia), Montreal (Quebec), and Toronto (Ontario), noted in the 22 January 2018, and 15 May and 23 January 2017 issues of *Media Watch* (#547, pp.1-2, #512, p.2 and #496, p.2, respectively).

N.B. Representative sample of the news media coverage of the Shalom Ouanounou case noted in the 13 November 2017 issue of *Media Watch* (#538, pp.1-2). Selected articles on medical decision-making, with specific reference to the highly publicised cases of Baby K., Baby Joseph, Jahi McMath and Charlie Gard, noted in the 1 January 2018 issue of *Media Watch* (#544, p.25). Additional articles on defining "brain dead" noted in the 20 November 2017 issue of *Media Watch* (#539, p.1).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC NEWS | Online – 25 February 2018 – **'Watchdog calls for "compassionate" parole as prison system adopts new assisted death policy.'** The federal prison watchdog is urging more "compassionate" parole options and a ban on medically assisted death behind bars as Canada's prison system manages an increasingly sick, mentally ill and elderly inmate population. Correctional Investigator Ivan Zinger said new guidelines brought in on 29 November 2017 allow the prison system to act as a "facilitator or enabler" of death, breaching the system's legal and ethical obligations. <https://goo.gl/s7Ejah>

Specialist Publications

'Physicians are not solely responsible for ensuring access to medical assistance in dying' (p.18), in *Canadian Medical Association Journal*.

'Implementation of Medical Assistance in Dying (MAiD): A scoping review of health care providers' perspectives' (p.19), in *Journal of Pain & Symptom Management*.

Cont.

- BRITISH COLUMBIA | BC Local News (Surrey) – 21 February 2018 – ‘**Langley Hospice issues formal statement opposing MAiD directive.**’ Langley Hospice society’s board of directors has weighed in on the issue of Medical Assistance in Dying (MAiD). The board issued a formal statement opposing the Fraser Health Authority (FHA) directive – which allows physician assisted death to be carried out within hospice facilities – and outlining a list of concerns related to the practice, including what it describes as a lack of consultation between hospice and the FHA. The previous policy – replaced by the December 2017 directive – stated that a patient already in hospice requesting MAiD was to be transferred to a designated facility equipped to perform the procedure. This policy was acceptable to hospice palliative care, noted Langley Hospice Society Board President Kathy Derksen in an email. “Since the (latest) directive there has been a groundswell of opposition from members of our Langley community and we have found ourselves in an extremely difficult position.” <https://goo.gl/hwzhXC>

U.S.A.

CPR survival rates are lower than most people think

REUTERS | Online – 23 February 2018 – The majority of people believe cardiopulmonary resuscitation (CPR) is successful more often than it tends to be in reality, according to a small U.S. study.¹ This overly optimistic view, which may partly stem from seeing happy outcomes in television medical dramas, can get in the way of decision-making and frank conversations about end-of-life care with doctors, the research team writes... Whatever the cause of cardiac arrest, restarting the heart as quickly as possible to get blood flowing to the brain is essential to preventing permanent brain damage. More often than not, cardiac arrest ends in death or severe neurological impairment. <https://goo.gl/VSEu8D>

1. ‘Public knowledge and perceptions about cardiopulmonary resuscitation (CPR): A multicenter survey,’ *American Journal of Emergency Medicine*, published online 3 February 2018. <https://goo.gl/s78cyc>

Noted in Media Watch 31 August 2015 (#425, p.15):

- *RESUSCITATION* | Online – 18 August 2015 – ‘**Revisiting CPR survival rates depicted on popular TV shows.**’ Public perceptions of cardiopulmonary resuscitation (CPR) can be influenced by the media. Nearly two decades ago, a study found the rates of survival following CPR were far higher in popular TV shows than actual rates.¹ **Abstract:** <http://goo.gl/4jZmLk>

1. ‘Resuscitation on television: Realistic or ridiculous? A quantitative observational analysis of the portrayal of cardiopulmonary resuscitation in television medical drama,’ *Resuscitation*, 2009;80(11):1275-1279. [Noted in the 24 February 2014 issue of Media Watch (#346, p.6)] **Abstract:** <http://goo.gl/2Z4F9O>

Hospice group feels squeeze from competition

MASSACHUSETTS | *The Cap Code Times* (Hyannis) – 17 February 2018 – When nurse Mary E. McCarthy founded Hospice of Cape Cod in 1980, it was the only hospice program on the peninsula. Nearly 40 years later, in its new incarnation as HopeHealth, the program faces fierce competition for patients from eight other hospice organizations serving Cape Cod. The recent layoff of 18 people in HopeHealth’s Hyannis office “was a direct result of lower census,” said Diana Franchitto, president and CEO of HopeHealth. “Throughout the country, hospice is a very competitive market,” Franchitto said, noting that 70 hospices operate in Massachusetts. <https://goo.gl/6sX7a4>

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>



International

End-of-life care in England

Swindon National Health Service pilot involving Prospect Hospice will improve end-of-life care – and potentially save £780,000

U.K. (England) | *The Swindon Advertiser* – 23 February 2018 – Prospect Hospice and Swindon National Health Service (NHS) Clinical Commissioning Group plan to launch a pilot project aimed at improving end-of-life (EoL) care. They say that a new computer system, Black Pear, will make it easier for doctors, nurses and carers to share important details about patients' care. And a "24 hour palliative care (PC) response team" will be staffed with nurses able to give round-the-clock support. It could potentially see savings to NHS services elsewhere, with one estimate suggesting that these could amount to more than £780,000. Every year, 1,590 people in Swindon are predicted to need EoL or specialist PC. This is set to increase, by 2020 rising to 1,685. <https://goo.gl/Puj8d4>

Compassionate Communities

The town that's found a potent cure for illness – community

U.K. (England) | *The Guardian* (London) – 21 February 2018 – It could, if the results stand up, be one of the most dramatic medical breakthroughs of recent decades. It could transform treatment regimes, save lives, and save health services a fortune. Is it a drug? A device? A surgical procedure? No, it's a new-fangled intervention called community. This week the results from a trial in the Somerset town of Frome are published informally...¹ We should be cautious about embracing data before it is published in the academic press, and must always avoid treating correlation as causation. But this shouldn't stop us feeling a shiver of excitement about the implications, if the figures turn out to be robust and the experiment can be replicated. What this provisional data appears to show is that when isolated people who have health problems are supported by community groups and volunteers, the number of emergency admissions to hospital falls spectacularly. While across the whole of Somerset emergency hospital admissions rose by 29% during the three years of the study, in Frome they fell by 17%. Julian Abel, a consultant physician in palliative care and lead author of the draft paper, remarks: "No other interventions on record have reduced emergency admissions across a population." <https://goo.gl/Mnokfg>

1. 'Tackling loneliness and isolation reduces health bill,' *Resurgence & Ecologist*, Issue #307, 2018. **Full text:** <https://goo.gl/68ngwg>

Noted in Media Watch 10 July 2017 (#520, p.7):

- *BMC PALLIATIVE CARE* | Online – 3 July 2017 – '**Piloting a compassionate community approach to early palliative care.**' Volunteer navigators were skilled and resourceful in building connections and facilitating engagement. Although it took time to learn the navigator role, volunteers felt well-prepared and found the role satisfying and meaningful. Benefits cited by clients were making good decisions for both now and in the future, having a surrogate social safety net, supporting engagement with life, and ultimately, transforming the experience of living with illness. **Full text:** <https://goo.gl/2vvZe6>

N.B. Additional articles on the concept of "compassion communities," particularly in the context of palliative and end-of-life care, noted in this issue of Media Watch.

Specialist Publications

'Population-based, person-centred end-of-life care: Time for a rethink' (p.8), in *British Journal of General Practice*.

'New U.K. general practice core standards for advanced serious illness and end-of-life care' (p.8), in *British Journal of General Practice*

'Low uptake of palliative care for COPD patients within primary care in the U.K.' (p.13), in *European Respiratory Journal*.

'Family perceptions of care at the end of life in U.K. nursing care homes' (p.16), in *Journal of Research in Nursing*.

'Nursing Standard-Marie Curie survey uncovers how end-of-life care is being compromised' (p.8), in *Nursing Standard*.

Parents lose legal fight to keep Liverpool toddler on life support

U.K. (England) | *The Guardian* (London) – 20 February 2018 – The parents of Alfie Evans, a seriously ill 20-month-old boy, have lost a legal fight to keep their son alive after a judge ruled further treatment would harm his “future dignity.” The toddler ... is in a semi-vegetative state and has a degenerative neurological condition that has never been definitively diagnosed by doctors. Sitting at the Royal Courts of Justice in London, Mr. Justice Hayden said he had accepted medical evidence which showed further treatment would be futile... The judge said: “Alfie’s need now is for good-quality palliative care. He requires peace, quiet and privacy in order that he may conclude his life as he has lived it, with dignity.” Hayden said Alfie had lost the capacity to hear, see, smell or respond to touch other than reflexively owing to the catastrophic degeneration of his brain. <https://goo.gl/2VRhcg>

N.B. Selected articles on medical decision-making, with specific reference to the cases of the highly publicised cases of Baby K., Baby Joseph, Jahi McMath and Charlie Gard, noted in the 1 January 2018 issue of *Media Watch* (#544, p.25).

Palliative care in China

Easing their pain: The center providing hospice care to orphans

CHINA | Sixth Tone (Shanghai) – 18 February 2018 – At the start of 2014, the Nanjing Rainbow Center was established for orphans with severe and terminal diseases. The three-story center, located on the outskirts of Nanjing ... is currently home to around 20 children. For every three kids, there’s one caregiver, usually referred to as “Mama.” All of the young patients [aged between just a few weeks and 10 years old] have been diagnosed with severe and often incurable conditions, like congenital heart diseases or severe hydrocephalus... In the last four years, more than half of the 50 children whom the center accepted passed away. Even palliative care institutions for the elderly are rare in China due to cultural taboos around death, and the prevailing attitude is still to insist on aggressive treatment rather than accepting that end-of-life care would provide more comfort. Similar services for children are even scarcer. As the Rainbow Center is operated by the Nanjing Children’s Welfare Institute and financed by charities and private donors, only terminally ill children who have been orphaned or abandoned by parents end up at the center. <https://goo.gl/jjfUE6>

N.B. Nanjing Rainbow Center website: <https://goo.gl/s543we>

End-of-life care in England

Chalkney House care home failing to give residents “comfortable and dignified pain free death”

U.K. (England) | *The Halstead Gazette* – 18 February 2018 – A care home is letting down some residents at the end of their lives, a care report has revealed. Among a number of comments, from Care Quality Commission inspectors about the failing Chalkney House home, was “not all people using the service were provided with the support they needed to experience a comfortable and dignified pain free death.” The home ... was visited by inspectors following five complaints, three safeguard alerts and two whistleblowers getting in touch. Inspectors found the home “required improvement” when it came to safety, effectiveness, being caring or leadership. It was rated “inadequate” at responding to concerns and was also in breach of the Health & Social Care Act. <https://goo.gl/rxjsEp>



Related

- U.K. (England) | Kent online (Rochester) – 18 February 2018 – ‘**Kent & Canterbury Hospital introduces “compassion signs” for dying patients.**’ Hospital patients just hours or days from death will have “compassion” symbols placed near their beds to alert staff and visitors. The initiative – designed to encourage dignity and respect – has been devised by the east Kent hospitals trust and the Pilgrim’s Hospice to provide further comfort to those receiving end-of-life care and their families. It is operating in about 50 wards across the trust, including at the Kent & Canterbury Hospital. <https://goo.gl/SYvXcG>

Specialist Publications

Assessment and treatment considerations for post traumatic stress disorder at end of life

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 20 February 2018 – Post traumatic stress disorder (PTSD) may first emerge, re-emerge, or worsen as individuals approach end of life (EoL) and may complicate the dying process. Lack of awareness of the occurrence and/or manifestation of PTSD at EoL can lead to PTSD going unaddressed. Even if PTSD is properly diagnosed, traditional evidence-based trauma-focused treatments may not be feasible or advisable with this group as many patients at EoL often lack the physical and mental stamina to participate in traditional psychotherapy. This article reviews the clinical and empirical literature on PTSD at EoL, as well as

discusses assessment and psychotherapy treatment issues with this neglected population.

Abstract: <https://goo.gl/iCznXB>

Journal Watch

'Best practices of medical journalism: Role of editors, peer reviewers, and authors' (p.19), in *Journal of Marine Medical Society*.

'Choosing and communicating with journals' (p.19), in *Journal of Public Health & Emergency*.

Noted in Media Watch 31 July 2017 (#523, p.10):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 28 July 2017 – **'Stepwise psychosocial palliative care: A new approach to the treatment of posttraumatic stress disorder at the end of life.'** Although evidence-based therapies for posttraumatic stress disorder (PTSD) exist for physically healthy populations, these often do not adequately address PTSD in dying patients. These interventions require 8-16 weekly sessions, and the median stay in U.S. hospices is 17.5 days. There is a potentially serious timing mismatch. Moreover, these treatments may temporarily increase trauma symptoms, resulting in some patients dying in greater distress than had they not received care. **Abstract:** <https://goo.gl/f6dZnQ>

Palliative care specialists' perceptions concerning referral of haematology patients to their services: Findings from a qualitative study

BMC PALLIATIVE CARE | Online – 21 February 2018 – Study participants identified a range of barriers and facilitators influencing the referral of patients with haematological malignancies to specialist palliative care (SPC) services. They included: the characteristics and pathways of haematological malignancies; the close patient/haematology team relationship; lack of role clarity; late end-of-life discussions and SPC referrals; policy issues; and, organisational issues. Main facilitators identified were: establishment of interdisciplinary working patterns ... and enhanced understanding of roles; timely discussions with patients and early SPC referral; access to information platforms able to support information sharing; and, use of indicators to "flag" patients' needs for SPC. This is the first U.K. study to explore SPC practitioners' perceptions concerning haematology patient referrals **Full text:** <https://goo.gl/tqGTet>

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

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

N.B. French language article.

End-of-life care in Australia

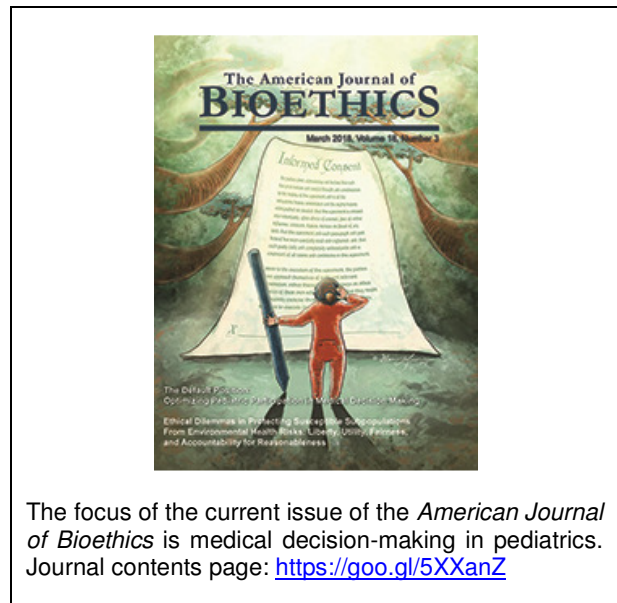
The contribution of a Massive Open Online Courses to community discussions around death and dying

BMC PALLIATIVE CARE | Online – 20 February 2018 – The Dying2Learn Massive Open Online Courses provides a rare opportunity to explore community views and attitudes around death and dying within a learning environment rather than a health context. Enrolment rates [in this study] demonstrated significant community interest and willingness to participate. Those who enrolled in the course were generally active with large number of participants viewing pages and completing activities. The completion rate of activities remained strong at around 30-40% across the four modules. The group who chose to participate included a large cohort of health professionals and the whole cohort was comfortable talking about death and dying at commencement. Even so, and despite the ceiling effect, there was an increase in the comfort in talking about death and dying at the end of the course. **Full text:** <https://goo.gl/RQfFB0>

N.B. Dying2Learn website: <https://goo.gl/zXy9HK>

Patterns of paediatric end-of-life care: A chart review across different care settings in Switzerland

BMC PEDIATRICS | Online – 19 February 2018 – The aim of this study was to comprehensively describe, explore and compare current practices in paediatric end-of-life care in four distinct diagnostic groups across healthcare settings including all relevant levels of healthcare providers... In this nationwide retrospective chart review study, data from paediatric patients who died in the years 2011 or 2012 due to a cardiac, neurological or oncological condition, or during the neonatal period were collected in 13 hospitals, two long-term institutions and 10 community-based healthcare service providers throughout Switzerland. Ninety-three (62%) of the 149 reviewed patients died in intensive care units, 78 (84%) of them following withdrawal of life-sustaining treatment. Reliance on invasive medical interventions was prevalent, and the use of medication was high, with a median count of 12 different drugs during the last week of life. **Full text:** <https://goo.gl/8CuQuD>



Noted in Media Watch 16 October 2017 (#534, p.4):

- SWITZERLAND | Swissinfo.ch (Geneva) – 11 October 2017 – **‘Paediatric palliative care still hard to find.’** The fact that the Geneva team was set up only due to a volunteer effort by a group of pioneering professionals, and the fact that the hospital [i.e., Geneva University Hospitals] does not currently have an official paediatric palliative care unit, reflects the situation in Switzerland as a whole. There are only three hospitals (St. Gallen, Zurich and Lausanne) that have such units. <https://goo.gl/C3YoRh>

Related

- *CHILDREN* | Online – 20 February 2018 – **‘Pediatric palliative care for children with progressive non-malignant diseases.’** A substantial number of children cared for by pediatric palliative care physicians have progressive non-malignant conditions. Some elements of their care overlap with care for children with cancer while other elements, especially prognosis and trajectory, have nuanced differences. **Abstract:** <https://goo.gl/HD15iv>

Cont.

- *CHILDREN* | Online – 20 February 2018 – ‘**Palliative care for children in hospital: Essential roles.**’ Palliative care (PC) for children in pediatric hospitals is a vital part of the network of services supporting children with severe illness. This has been recognized, with a trend over the past decade for an increased number of pediatric PC services established in pediatric hospitals. The inpatient team is in the unique position of influencing the early identification of children and their families, across the age and diagnostic spectrum, which could benefit from PC. **Full text:** <https://goo.gl/JWjx28>
- *CHILDREN* | Online – 19 February 2018 – ‘**Paediatric palliative care in resource-poor countries.**’ Globally it is estimated that 21.6 million children need access to palliative care (PC), with 8.2 needing specialist services. PC has been identified as important within the global health agenda, e.g., within universal health coverage, and a recent *Lancet* commission report recognised the need for paediatric PC.¹ However, a variety of challenges have been identified to paediatric PC development globally such as: access to treatment, access to medications... **Abstract:** <https://goo.gl/dBTGi7>
 1. ‘Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,’ *The Lancet*, published online 12 October 2017. [Noted in the 16 October 2017 issue of *Media Watch* (#534, p.14)] **Full text:** <https://goo.gl/i7r9M1>
- *JOURNAL OF PEDIATRIC NURSING* | Online – 14 February 2018 – ‘**Becoming a team: The nature of the parent-healthcare provider relationship when a child is dying in the pediatric intensive care unit.**’ *Becoming a team* explores the changes that occurred to the parent-healthcare provider relationship when parents realized their child was dying and attempted to become part of their child’s care team. When the focus of care changed from “life-saving” to “end-of-life,” parents’ perspectives and desires of their and the healthcare providers’ roles changed. **Abstract:** <https://goo.gl/wkVPd3>

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

Population-based, person-centred end-of-life care: Time for a rethink

BRITISH JOURNAL OF GENERAL PRACTICE, 2018;68(668):116-117. The way we care for people in the last chapter of their lives has been said to be a litmus test for our society. Lifespan now outstrips health span and, with increasing complexity, symptom burden, and rising mortality, the context of end-of-life care (EoLC) is changing and broadening. It is time for a new approach – a reframed, inclusive, big-picture population-based approach to EoLC to meet the challenges of the 21st century. The year 2017 marked 50 years of the U.K.’s outstanding hospice and palliative care services. Building on this, yet addressing the challenges of today, there is a shift in thinking towards reframing concepts of EoLC to meet the growing needs of the ageing population, and fully integrating EoLC into mainstream care by all providers. People now live longer, with more complex conditions into old age, and with post-baby-boomer demographics our morbidity and mortality rates are rising. The era of the single disease is over and with increasing frailty and multi-morbidities, the focus shifts from pure survival to outcomes that matter to people. For many people quality of life is more important than quantity of life. With increased access to complex interventions towards the end of life, with potential over-medicalisation and “physician-assisted survival,” we face a new tipping point – just because we can, doesn’t mean we should. There is a delicate balance here for all clinicians, particularly general practitioners, in orchestrating appropriate care, avoiding both over-use of hospital interventions and under-provision of care and support. **Introductory paragraphs:** <https://goo.gl/QkE6zE>

Related


- *BRITISH JOURNAL OF GENERAL PRACTICE*, 2018;68(668):114-115. ‘**New U.K. general practice core standards for advanced serious illness and end-of-life care.**’ The authors introduce the new standards, which will be piloted at selected practices in spring 2018, with subsequent wider implementation from autumn 2018. **Abstract:** <https://goo.gl/oESXHb>
- *NURSING STANDARD* | Online – 21 February 2018 – ‘**Nursing Standard-Marie Curie survey uncovers how end-of-life care is being compromised.**’ This infographic reveals how more than nine in ten respondents have seen dying patients stranded in hospital because of delays in providing the funding or care that would allow them to return to the community.¹ **Abstract:** <https://goo.gl/biM2Lu>
 1. ‘Survey reveals how National Health Service pressures put further strain on end-of-life care,’ *Nursing Standard*, published online 21 February 2018. **Abstract:** <https://goo.gl/mKAZvZ>

Palliative care for movement disorders

CURRENT TREATMENT OPTIONS IN NEUROLOGY | Online – 20 February 2018 – Studies of patients with movement disorders and their family caregivers suggest that these patients have significant unmet needs under current models of care, including under-recognition and treatment of non-motor symptoms, inadequate psychosocial support, and suboptimal end-of-life care. The authors describe how a palliative care (PC) approach can empower clinicians, patients, and families to reduce common sources of suffering and optimize quality of life. This field recognizes the importance of primary PC – palliative skills useful for any clinician caring for persons caring for serious illness – as a foundation of the PC approach and complementary to specialist PC. The authors focus on primary PC skills for movement disorder specialists including providing a diagnosis and prognosis with compassion, discussing goals of care, complex symptom management, caregiver support, spiritual and emotional well-being, and referral to hospice and specialist PC. **Abstract (w. list of references):** <https://goo.gl/6LwRXD>

N.B. Articles on integrating palliative care into neurology services noted in the 19 February 2018 issue of Media Watch (#551, p.8).

Palliative medicine: Has there been mission rift?


 *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2018;25(1):6-8. With its new-found status, one of palliative medicine's first challenges was to confront the prospect of evidence-based medicine. This new paradigm suggested tradition, anecdote and theoretical reasoning be replaced by evidence from high-quality randomised control trials and observational studies. In combination with "clinical expertise," these were to provide clinicians with the knowledge to drive health-care into the new millennium. Thirty years later, other specialties have amassed an evidence base that stands tall over that of palliative medicine (PM). However, somewhat contradictorily, PM is widely regarded as offering a standard of care second to none. Within this paradox lies the answer to what really matters to people. Evidence-based medicine has its limitations. It has become distorted by vested interests, uses surrogate outcomes to establish efficacy, is a poor fit for frailty and multi-morbidity, and there are huge problems with publication bias. Despite this, we have created a volume of research and guidelines that has left us at saturation point. Compulsive reliance on evidence has created a breed of clinician trained in following a template driven approach that stifles development of the subtleties of clinical expertise. What lies beyond evidence-based medicine?

THE JOURNAL OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE

European Journal of Palliative Care

Access to the *European Journal of Palliative Care* requires a subscription. January/February issue contents page: <https://goo.gl/Y4fnQZ>

Human rights in end-of life-care: Implementation and early evaluation of a Sue Ryder training programme

 *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2018;25(1):9-14. There have been many reminders of losing sight of our humanity when delivering healthcare, including the Mid-Staffordshire Enquiry and Winterbourne View in the U.K.^{1,2} Consequently, the Care Quality Commission, which monitors, regulates and inspects care services in England & Wales, implemented a human rights approach to its regulation standards in September 2014, based on principles set out in the Human Rights Act (1998). The Act is the main law protecting human rights in the U.K. It contains a list of 16 rights taken from the articles of the European Convention on Human Rights

Cont.

(1950). These rights are relevant to everyone working in health and social care, who should understand their legal duty to respect and protect the human rights of those in their care. This Phase 1 evaluation of the Sue Ryder human rights in end-of-life (EoL) care training programme demonstrates promising early results in its aim to empower practitioners to implement human rights in practice and improve knowledge and confidence in complex decision-making at the EoL with patients and their families. The Phase 2 evaluation, which will take place over a longer time period, will continue to track knowledge and confidence and will include qualitative interviews with some participants, to determine a significant outcome.

1. 'Report of the Mid-Staffordshire National Health Service Foundation Trust Public Inquiry,' February 2013. [Noted in the 11 February 2013 issue of Media Watch (#292, p.5)] **Download/view report at:** <https://goo.gl/mYV9Jc>
2. 'Winterbourne View Hospital: Department of Health review and response: Final report into the events at Winterbourne View hospital and a programme of action to transform services,' Department of Health Care, December 2012. **Download/view at:** <https://goo.gl/ce3Uw5>

Discovering people's strengths and resources at the end of life



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2018;25(1):16-18. From the early days of hospice and palliative care social work, Elisabeth Earnshaw-Smith developed an emphasis on family care and a family-oriented service, away from "one-to-one" models. This echoed Cicely Saunders' perspective on the way in which "the modern hospice developed with its regard for the family as both the unit of care and, frequently, the caring team." This approach included members of the multidisciplinary team (MDT): seeking to understand the family, rather than a narrow clinician-patient focus; thinking from a family perspective (for example, family trees or genograms were introduced as a matter of routine practice as both an assessment and a therapeutic tool); moving away from the temptation to label one member of a family as carrying the problem to thinking about the ripple effect of illness on whole-family systems; using the understanding from, and the strategies of, family therapy and of systemic thinking (this led to one of the senior consultants at St. Christopher's training in family therapy as an adjunct to his medical input); and, having an appreciation of family dynamics. It took Earnshaw-Smith, as an experienced and skilled social worker, to recognise the potential of social work and how it could be used to enhance the range of skills of the MDT.

Related

- *BMC PALLIATIVE CARE* | Online – 17 February 2018 – '**The second patient? Family members of cancer patients and their role in end-of-life decision making.**' Although participants [in this study] recognised the important role of the family in decision-making, they also acknowledged certain challenges such as possible psychological burden of the relatives, the challenge of knowing family structures, and a strong family wish for further treatment that would seem to account for the reluctance of oncologists for a proactive position regarding family involvement in decision-making. **Full text:** <https://goo.gl/xVsVDA>
- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 20 February 2018 – '**Caring about dying persons and their families: Interpretation, practice and emotional labour.**' The importance of emotional support for dying persons and their families has been well established, yet we know less about how care workers understand emotional processes related to death and dying, or how these understandings are connected to care practices and emotional labour at the end of life. Dominant interpretive frames of a "good death" informed [study] participants' emotionally supportive practice. **Abstract:** <https://goo.gl/qUTyX2>



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.20.

Barriers to palliative care for people with severe mental illness: Exploring the views of clinical staff



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2018;25(1):20-25. People with severe mental ill-health (SMI) are disadvantaged when accessing general healthcare services, including palliative and end-of-life (EoL) care. The average life expectancy of people with SMI is 10-20 years less than that of the general population. People with SMI also experience poor physical health generally, due in part to higher rates of smoking, alcohol and substance misuse, and poor diet. Multiple barriers to providing palliative and EoL care for this patient group are identified; in particular, the lack of confidence of clinical staff was identified as a key barrier. Mental health clinicians report feeling a lack of confidence in dealing with issues surrounding death, dying and terminal illness. Those working in palliative care report feeling a similar lack of confidence in meeting the needs of people with SMI.

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

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

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

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

Psychological ideas in palliative care: Distress, adjustment and coping



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2018;25(1):26-31. Distress is common at the end of life, but for a sub-group of patients and carers it is clinically significant. The size of that sub-group depends on how distress is defined and measured. In clinical practice, judgements about distress need to consider the context and trajectory, because patients typically adjust over time. Adjustment is the process of reconfiguring thoughts, activities, and practical and social environments to re-establish equilibrium following a change. Adjustment can be facilitated by having a candid and strengths-focused discussion about coping strategies.

N.B. This is the seventh article in the journal's series ‘Psychology in palliative practice.’

The role of volunteers supporting people with life-limiting illness at home



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2018;25(1):33-35. This evaluation highlights the important role that volunteers can perform in people's homes and how this can alleviate pressure on paid staff. Volunteers provide valuable social and emotional support to clients. This support may enable people with advanced illness to stay in their own homes for longer and potentially support them to fulfil their wish to remain at home as long as possible. Although boundary issues have been reported for hospice volunteers, this is likely to be more problematic

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and harder to manage in people's homes. Utilising volunteers working alone within people's homes may present challenges that are less of an issue when volunteers undertake their roles more visibly within hospices and hospitals and while working closely with qualified staff. This evaluation highlights the need for accountability and explicit safe practice expectations in order to protect both volunteer and client. Since this study, an European Association of Palliative Care taskforce White Paper has been published – it provides useful definitions and reflections on the volunteer role.¹

1. 'Defining volunteering in hospice and palliative care in Europe,' *European Journal of Palliative Care*, 2016;23(7):184-191. [Noted in the 1 August 2016 issue of Media Watch (#473, p.12)]

N.B. Additional articles on the role of volunteers in hospice and palliative care noted in the 11 December 2017 issue of Media Watch (#542, p.13).

End-of-life care in Ireland

The dementia patient's pathway through the specialist palliative care services (Part 1)



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2018;25(1):37-39. This study aimed to explore carers' and health care professionals' (HCPs) understanding of the role of specialist palliative care (SPC) services and the dementia patient's journey through the service. HCPs [i.e., study participants] acknowledged the positive aspects of having SPC advice and support for dementia patients. HCPs face numerous challenges in delivering a palliative care approach to this cohort of patients. While referral and access criteria for patients with life-limiting conditions to SPC services is available in Ireland, there needs to be greater awareness of these guidelines among general HCPs. Dementia has not always been viewed as a life-limiting condition or terminal condition. However, there is an increasing demand on SPC services to offer support for these patients.

Related

- *BMC MEDICAL ETHICS* | Online – 20 February 2018 – '**Advance directives as a tool to respect patients' values and preferences: Discussion on the case of Alzheimer's disease.**' Few and not conclusive data exist on the potential positive impact of advanced directives on the treatment of patients with severe cognitive impairment or dementia... This requires concrete policies and actions to make directives known and effective, particularly in a context of increased possibility of early diagnosis of Alzheimer's disease (AD) paired with lack of effective treatments. **Full text:** <https://goo.gl/iUAV3j>

Can rationing through inconvenience be ethical?

THE HASTINGS REPORT, 2018;48(1):10-22. The authors provide a comprehensive analysis and a normative assessment of rationing through inconvenience as a form of rationing. By "rationing through inconvenience" in the health sphere, they refer to a non-financial burden (the inconvenience) that is either intended to cause – or has the effect of causing – patients or clinicians to choose an option for health-related consumption that is preferred by the health system for its fairness, efficiency, or other distributive desiderata beyond assisting the immediate patient. The authors argue that under certain conditions, rationing through inconvenience may turn out to serve as a legitimate and, compared to direct rationing, even a preferable tool for rationing; they propose a research agenda to identify more precisely when that might be the case and when, alternatively, rationing through inconvenience remains ethically undesirable.

Abstract: <https://goo.gl/m9yFb4>

N.B. Commentary on 'Can rationing through inconvenience be ethical?' – 'Rationing care through collaboration and shared values,' *The Hastings Report*, 2018;48(1):22-24. **Abstract:** <https://goo.gl/T3uT26>

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Noted in Media Watch 24 October 2016 (#484, p.10):

- *JOURNAL OF MEDICAL ETHICS* | Online – 12 October 2016 – ‘**Rationing conscience.**’ Decisions about allocation of limited healthcare resources are frequently controversial. These decisions are usually based on careful analysis of medical, scientific and health economic evidence. Yet, decisions are also necessarily based on value judgements. There may be differing views among health professionals about how to allocate resources or how to evaluate existing evidence. **Full text:** <https://goo.gl/npU73M>

Noted in Media Watch 20 April 2015 (#406, p.10):

- *THE HASTINGS REPORT*, 2015;45(2):15-19. ‘**Why it’s not time for health care rationing.**’ Discussion of health care rationing, which was hotly debated in the nineties, has become much more muted. Is health care rationing *passé*? The author contends that debates about health care rationing have waned not because the need to ration has dwindled nor because ethical debates about how or whether to ration have been resolved. **Abstract:** <https://goo.gl/uLZoDG>

Grieving with humor: A correlational study on sense of humor and professional grief in palliative care nurses

HOLISTIC NURSING PRACTICE, 2018;32(2):98-106. The aim of this study was to explore the relationship between humor and professional grief. Findings confirm that these are not independent phenomena. Using humor as a coping mechanism emerged as a response to death-related work. Likewise, positive attitudes toward humor seem to alleviate the distress associated with end-of-life care. **Abstract:** <https://goo.gl/3qyyEG>

A new way of organising palliative care for patients with severe chronic obstructive pulmonary disease

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING | Online – 22 February 2018 – Patients with chronic obstructive pulmonary disease (COPD) often live with unmet palliative needs and low quality of life, although several guidelines recommend that those with COPD should be offered early and integrated palliative care (PC). However, none of the guidelines describe how these recommendations can be operationalised and the current literature offers little information about experiences with developing and implementing new PC services. This article offers insight into the experience of developing and implementing a new palliative outpatient structure for patients with severe COPD. All patients are assigned to a nurse who has overall responsibility for establishing and maintaining an individualised relationship with the patient and identifying their needs for care and treatment. Routine outpatient visits are replaced by *ad hoc* consultations, and patients are seen by pulmonary specialists only when there is a need for medical assessment and treatment or a planned advanced care planning dialogue. The new service was successfully implemented; however, the changes required good multidisciplinary collaboration, dedicated health professionals and managerial support. This paper highlights the need for further studies to investigate the effectiveness of new PC interventions for patients with COPD. **Abstract:** <https://goo.gl/JVPrHx>

Related

- *EUROPEAN RESPIRATORY JOURNAL* | Online – 14 February 2018 – ‘**Low uptake of palliative care for COPD patients within primary care in the U.K.**’ Mortality and symptom burden from chronic obstructive pulmonary disease (COPD) and lung cancer are similar, but there is thought to be an inequality in palliative care support (PCS) between diseases. [In this study] there were 92,365 eligible COPD patients, of which 26,135 died. Only 7.8% of the whole cohort and 21.4% of deceased patients received PCS. Only 16.7% of deceased COPD patients without lung cancer received PCS compared with 56.5% of deceased patients with lung cancer. **Abstract:** <https://goo.gl/38awyG>

N.B. Selected articles on palliative and end-of-life care for people living with chronic obstructive pulmonary disease noted in 4 September and 2 January 2017 issues of Media Watch (#528, p.13 and #493, p.9, respectively).

Palliative care consultation should be routine for all children who enroll in a Phase I trial

JOURNAL OF CLINICAL ONCOLOGY | Online – 14 February 2018 – Because Phase I trials do not have a therapeutic intent as their primary objective, children are only eligible for participation after conventional therapeutic options have been unsuccessful at curing their cancer. Most children who enroll in Phase I trials face a significant possibility that they will die as a result of their disease. Although an individual patient's risk of death is not necessarily increased by participation in a Phase I trial, investigators still have an ethical responsibility to act in the child's best interest by acknowledging the likelihood of death and by taking all reasonable measures to support families through it. The authors propose that, as a new standard of care, all children who enroll in a Phase I trial should also have a palliative care consultation, if they have not already had one. **Full text:** <https://goo.gl/Zsndhf>

What does the implementation of peer care training in a U.K. prison reveal about prisoner engagement in peer caregiving?

JOURNAL OF FORENSIC NURSING, 2018;14(1):18-26. The number of aging and chronically ill prisoners continues to rise within the U.K. prison demography; consequentially, many institutions face health and social care crises of immense proportions. The needs of this group are both complex and costly, and in the U.K., this is set to a backdrop of overcrowding, increasing violence, and public spending cuts in line with government austerity targets. In this context, the development of prisoner peer caregiving is proposed as an approach to mitigating the effects of aging, disability, and illness. A qualitative study was implemented to design, deliver, and evaluate a peer care training intervention within a U.K. prison. **Abstract:** <https://goo.gl/E9WxCj>

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 (last updated 1 February 2018) can be downloaded/viewed at Palliative Care Network-e: <https://goo.gl/YLckx6>

American Academy of Hospice & Palliative Medicine

Our differences make us stronger

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 23 February 2018 – To improve the quality of hospice and palliative care, the American Academy of Hospice & Palliative Medicine (AAHPM) models inclusion and embraces diverse backgrounds and perspectives of those with whom we work and the patients and families we serve. In 2015, AAHPM initiated a multi-year strategic plan to guide efforts to increase the Academy's commitment to diversity and inclusion both within the organization and in the broader field of hospice and palliative medicine.¹ The authors define diversity as referring to the composition of a group of people from any number of demographic backgrounds, identities (innate and selected), and the collective strength of their experiences, beliefs, values, skills and perspectives. **Abstract:** <https://goo.gl/yYWqTM>

1. 'Diversity & Inclusion,' American Academy of Hospice & Palliative Medicine, 2015. **Download/view at:** <https://goo.gl/ZFL2H3>

Information framing reduces initial negative attitudes in cancer patients' decisions about hospice care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 20 February 2018 – Negative attitudes toward hospice care might prevent patients with cancer from discussing and choosing hospice as they approach end of life. When making a decision, people often naturally focus on either expected benefits or avoidance of harm. Behavioral research demonstrated that framing information in an incongruent manner with patients' underlying motivational focus reduces their negative attitudes toward a disliked option. This finding suggests a new theory-driven approach to conversations with cancer patients who may harbor negative reactions toward hospice care. **Abstract:** <https://goo.gl/veyKSn>

Exploring factors contributing to medication errors with opioids in Australian specialist palliative care inpatient services: A multi-incident analysis

JOURNAL OF PALLIATIVE MEDICINE | Online – 23 February 2018 – Opioid errors have the potential to cause significant patient harm. These high-risk medications are used in high volumes in palliative care (PC) services to manage pain and other symptoms. Palliative patients are at greater risk of harm from opioid errors, as they are generally older and taking numerous medications to manage multiple comorbidities. Understanding factors contributing to opioid errors in inpatient PC services is a largely underexplored, yet, essential aspect of patient safety. The authors undertook an analysis of opioid errors reported over three years in two Australian specialist PC inpatient services. A total of 78 opioid errors were reported. The majority (76%) of these errors occurred during opioid administration, primarily due to omitted dose (34%) and wrong dose (17%) errors. Eighty-five percent of reported errors reached the patient resulting in opioid underdose for over half (59%) of these patients. Over one-third (37%) of errors caused patient harm, which required clinical intervention. Error contributing factors included: non-compliance with policy; individual factors such as distraction; poor clinical communication systems; and, workload. **Abstract:** <https://goo.gl/DWVHbf>

Noted in Media Watch 15 January 2018 (#546, p.5):

- *SUPPORTIVE & PALLIATIVE CARE* | Online – 4 January 2018 – ‘**Opioid errors in inpatient palliative care services: A retrospective review.**’ Of 55 opioid errors identified, 84% reached the patient. Most involved morphine or hydromorphone. Opioid administration errors accounted for 76% of reported opioid errors, largely due to omitted dose or wrong dose errors. Patients were more likely to receive a lower dose of opioid than ordered as a direct result of an opioid error, with errors adversely impacting pain and/or symptom management in 42% of patients. **Abstract:** <https://goo.gl/pyCmYA>

Noted in Media Watch 16 November 2015 (#436, p.10):

- *PALLIATIVE MEDICINE* | Online – 4 November 2015 – ‘**Quantifying the burden of opioid medication errors in adult oncology and palliative care settings: A systematic review.**’ This review highlights the paucity of the literature examining opioid error incidence, types and patient impact in adult oncology and palliative care (PC) settings. Defining, identifying and quantifying error reporting practices for these populations should be an essential component of future oncology and PC quality and safety initiatives. **Abstract (inc. a list of references):** <https://goo.gl/McZMaB>

The British contribution to the development of hospice and palliative care in Poland

JOURNAL OF PALLIATIVE CARE | Online – 20 February 2018 – This article focuses on British contribution to the development of palliative and hospice care in Poland in the 1980s and beyond. It is based on archival research in the hospices in Cracow and Poznan and broad-scoped Polish journals’ review. The social background of the hospice movement in Poland is described. The authors explore the role of inspiration and help of Dame Cicely Saunders and other British leaders in the transfer of British hospice philosophy and practice of palliative care to the medical community in Poland. This study demonstrates the importance of institutions for the formal exchange of medical information. **Abstract:** <https://goo.gl/Pjnzq8>

Noted in Media Watch 25 April 2016 (#459, p.9):

- *ARCHIVES OF MEDICAL SCIENCE*, 2016;12(2):457-468. ‘**How much does care in palliative care wards cost in Poland?**’ Palliative care (PC) units struggle with low incomes from the National Health Fund (NHF). This study shows a significant difference between the actual cost of PC units and the level of refund from the NHF. Based on the analysis of costs, the application has been submitted to the NHF to change the reimbursement amount of PC services. **Full text:** <http://goo.gl/9gb7eb>

N.B. Poland was ranked 26th of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit. [Noted in the 12 October 2015 issue of Media Watch (#431, p.6)] **Download/view at:** <https://goo.gl/PPu7rG>

Family perceptions of care at the end of life in U.K. nursing care homes

JOURNAL OF RESEARCH IN NURSING | Online – 15 February 2018 – Over a fifth of the population of developed countries die in care homes. While studies are emerging on the outcomes of care in the last few weeks of life, few report on the experience as perceived by the family members. As part of a wider study to improve the delivery of end-of-life care (EoLC), bereaved relatives of residents who had died in a care home/hospital were sent the Family Perception of Care Scale (FPCS) questionnaire to evaluate their experience of care provision for their relative in the last month of life. A global question within the FPCS looking at the overall satisfaction with the quality of EoLC indicated that bereaved relatives were satisfied with the care provided. Qualitative responses from family members highlighted some excellent care, although issues in relation to medical input, professional teamwork, last days of life, and spiritual care remain problematic. **Abstract (w. list of references):** <https://goo.gl/jcZJY3>

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

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

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

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

Patient safety after death

JOURNAL OF THE ROYAL SOCIETY OF MEDICINE, 2018;111(2):39. When does patient safety end? A research paper in this month’s issue of the journal suggests that death may not quite be the final cure for life’s ills that Socrates imagined, and finds that lessons from patient safety work need to be applied to mortuary care. Previous reports of people being treated without due dignity and respect after death ... were met with public dismay and outrage. Liam Donaldson and colleagues analysed a national database over a ten-year period to evaluate the frequency of serious incidents after death.¹ They found 132 incidents relating to the storage, management or disposal of deceased patient remains. Fifty-four incidents were classified as storage problems, such as disfigurement or loss of a body part. Forty-three were issues with management, including errors of post-mortem examination and post-mortems on the wrong side of the body. A further 31 were errors in disposal of bodies, for example, nine were buried or cremated by the wrong family. While the number of incidents may seem small in relation to the total number of deaths over the study period, the distress that even one incident will cause families and carers is obvious. **Full text:** <https://goo.gl/c8weNV>

1. ‘Serious incidents after death: Content analysis of incidents reported to a national database,’ published online 23 November 2017. [Noted in the 27 November 2017 issue of Media Watch (#540, p.16)] **Full text:** <https://goo.gl/WBcVnw>

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Noted in Media Watch 10 July 2017 (#520, p.14):

- *NURSING MANAGEMENT*, 2017;24(4):23-27. '**Improving interdepartmental communication following a patient death.**' This article describes a tick-box-style death-in-department checklist introduced in a London hospital to increase and improve communication and information sharing between the emergency department, the mortuary, and the bereavement office. **Abstract:** <https://goo.gl/tcwSfd>

Noted in Media Watch 23 December 2013 (#337, p.10):

- *BEREAVEMENT CARE*, 2013;32(3):124-130. '**A missing link? The role of mortuary staff in hospital-based bereavement care services.**' The authors of this article argue that anatomical pathology technologists have been overlooked as a key group of healthcare practitioners who have a role to play in bereavement care. **Abstract:** <https://goo.gl/vQtkRp>

Pain management: Time to minimize variations in practice

PALLIATIVE CARE: RESEARCH & TREATMENT | Online – 20 February 2018 – The authors observe, in clinical care, a disconnect between the science, including pharmacology, of the use of opioids and the practice of pain management. The biggest variable seems to be clinical culture. The World Health Organization (WHO) stepladder was introduced in 1986 as a global tool to improve patient outcomes by facilitating a common approach to the practice of pain management. The 3 steps provide guidance to clinicians in identifying the right pain medication based on its intensity. These guidelines were developed primarily for patients with cancer pain. More than 30 years later, pain continues to be sub-optimally treated. This is true not only for patients with a diagnosis of cancer; more studies are providing evidence of pain being under-recognized and inadequately treated in patients with other diagnoses. In addition, the WHO stepladder intended to address pain from a physical perspective – in applying the principles of palliative care; we know that pain is multidimensional and requires a more holistic approach to incorporate aspects such as psychological and spiritual realms to adequately manage it. Even when limiting the focus to managing the physical aspect of pain, there is great variation in treatment practices. Variations exist between individuals within a team, the measurement of symptoms, the choice of opioids to manage pain, the frequency and manner of dosage escalation, and the personal choices and comfort in the use of opioid conversions. **Full text:** <https://goo.gl/Mbx2BH>

A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals

PALLIATIVE MEDICINE | Online – 19 February 2018 – Palliative care (PC) patients are often described as complex, but evidence on complexity is limited. We need to understand complexity, including at individual patient-level, to define specialist PC, characterise PC populations, and meaningfully compare interventions/outcomes. Semi-structured interviews [were conducted] across six U.K. centres with patients, family, professionals, managers and senior leads, sampled by experience, background, location and setting (hospital, hospice and community). Participants provided an understanding of complexity, which extended far beyond the commonly used physical, psychological, social and spiritual domains. Complexity included how patients interact with family/professionals, how services respond to needs and societal perspectives on care. “Pre-existing,” “cumulative” and “invisible” complexity are further important dimensions to delivering effective palliative and end-of-life care. The dynamic nature of illness and needs over time was also profoundly influential. Stakeholders found it acceptable to capture complexity at the patient-level, with perceived benefits for improving PC resource allocation. **Full text:** <https://goo.gl/jthL2S>

Noted in Media Watch 8 January 2018 (#545, p.8):

- *BMC PALLIATIVE CARE* | Online – 4 January 2018 – '**What does “complex” mean in palliative care? Triangulating qualitative findings from three settings.**' Palliative care services need to recognize that while complexity may be defined by inherent patient needs, in one of more dimensions of care, which are difficult to manage, it is also perceived by clinicians considering referral. Perceived complexity is highly dependent on individual factors such as time constraints, training, alternative treatments and referrals, resources and relationships with specialists. **Full text:** <https://goo.gl/qPfoSt>

End-of-life care in Thailand

Roles and needs of caregivers for patients with end of life in a specific setting for palliative care

RAMATHIBODI NURSING JOURNAL | Online – 19 February 2018 – This study aimed to describe roles and needs of caregivers for patients with end of life in a specific setting for palliative care (PC). The participants included 9 primary caregivers both female and male aged over 20 years who took the majority of care for end-of-life (EoL) patients before and during PC service at Mahavajiralongkorn Thanyaburi Hospital. Data were collected by conducting two focus groups and then performing in-depth interview in 4 individuals by using questionnaire and interview guidelines on roles and needs of caregivers for EoL patients. The results indicated that there were three major roles of caregiver: 1) Direct patient care which included physical, psychological, social, and spiritual; 2) Preparation for the EoL care; and 3) Role adaptation along with self-care of their own. Caregivers' needs were composed of four aspects which were: 1) Information need about EoL care management; 2) Coordination need for accessing to EoL care; 3) Helping need for patient care; and, 4) Financial support need. The findings can be used as information to design guidelines for helping the caregiver for the end of life patients in the specific setting for PC. **Full text:** <https://goo.gl/PcFoLq>



N.B. Thai language article. Additional articles on end-of-life care in Thailand noted in the 3 April 2017 issue of Media Watch (#506, pp.6-7).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2018;190(7):E181. **'Physicians are not solely responsible for ensuring access to medical assistance in dying.'** Patients' rights to access to medical assistance in dying (MAiD) trumps the religious rights of physicians under the Canadian Charter of Rights & Freedoms – or so says the Ontario Superior Court of Justice. But ensuring equitable access to health care is a societal responsibility and does not rest solely on the individual physician. Surely there is a way forward that ensures access for patients requesting MAiD without trampling on physician rights enshrined in law. On 31 January 2018, the court upheld the College of Physicians & Surgeons of Ontario's regulations that physicians provide an "effective" or direct referral for MAiD. Several physician organizations had challenged two of the college's policies (Medical Assistance in Dying and Professional Obligations & Human Rights) on the grounds that they violated the charter. The court came down firmly on the side of patients' rights over physician rights. For many, this decision was a victory, reaffirming the centrality of the patient in our health care system. Yet the court agreed that these policies impeded the religious rights of physicians who object to providing referrals for MAiD. **Full text:** <https://goo.gl/HUCL1D>
- *DEVELOPING WORLD BIOETHICS* | Online – 15 February 2018 – **'New developments in India concerning the policy of passive euthanasia.'** Euthanasia and assisted dying are illegal in India according to Sections 306 and 309 of the Indian Penal Code (IPC), and Article 21 of the Constitution of India. There have been a number of cases where the Indian High Courts and Indian Supreme Court issued differing verdicts concerning the right to life and the right to die. Nevertheless, on 7 March 2011, a paradigm shift happened as a result of the Indian Supreme Court's judgment on involuntary passive euthanasia in the case of Aruna Shanbaug. In its judgment, the Supreme Court requested the government to prepare a law on euthanasia. Accordingly, the 241st Report of the Law Commission of India proposed a bill to permit passive euthanasia. In May 2016 the Ministry of Health and Family Welfare issued the draft bill for public comment in order to create an informed decision. The Indian people are divided on the issue of euthanasia. The majority of the scientific community welcome it, while some religious groups oppose it. **Abstract:** <https://goo.gl/bufS7C>

Cont.

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 22 February 2018 – ‘**Implementation of Medical Assistance in Dying (MAiD): A scoping review of health care providers’ perspectives.**’ Perspectives of nurses, physicians, mental health providers, pharmacists, social workers and medical examiners were explored. Professional roles included consulting/supporting patients and/or other staff members with requests, assessing eligibility, administering/dispensing the lethal drugs, providing after-care to bereaved relatives, and regulatory oversight. Challenges included lack of clear guidelines/protocols, role ambiguity, evaluating capacity/consent, conscientious objection, and lack of inter-professional collaboration. Evidence from various jurisdictions highlighted a need for clear guidelines and protocols that define each profession’s role, scope of practice and legal boundaries for MAiD. Comprehensive models of care that incorporate multidisciplinary teams alongside improved clinician education may be effective to support MAiD implementation. Little is known about health care providers’ perspectives in handling requests, especially outside physician practice and nursing. **Abstract:** <https://goo.gl/v3FUfr>

Journal Watch

Best practices of medical journalism: Role of editors, peer reviewers, and authors

JOURNAL OF MARINE MEDICAL SOCIETY | Online – 13 February 2018 – Medical writing is an art which requires a fine blend of new scientific information and rhetorical skills. An article in a reputed journal ensures recognition and career advancement, and there has been a rush among doctors to publish their research work. Several indexed “predatory” journals have mushroomed and are accepting articles without a blinded peer review. The standard impact factor (IF) scoring for a journal has been debatable and so has been the authenticity of indexing. Awareness regarding standard guidelines is required for reliable and valid research. Evidence from a scientific research is the need of the day for an emerging economy like India to help build universal health coverage and meet sustainable

developmental goals. This article analyses the concepts of IF and indexing and discusses the best practices for the editors, peer reviewers, and authors. **Full text:** <https://goo.gl/XphCbd>

Extract: Journal impact factor

The impact factor (IF) has become a tool for determination of merit of a journal. Several controversies, however, have erupted as to the reliability and statistical prudence of IF, validity of IF as a measure of journal importance, and possible manipulation by reputed journals to increase IF like publishing more review articles and editorials which attract more citations than a research article and coercive citations.

Choosing and communicating with journals

JOURNAL OF PUBLIC HEALTH & EMERGENCY | Online – 9 February 2018 – Publishing your research requires knowing about the business practices of journals, what journal editors and peer reviewers want, and how the publication process works. For example, journals that have to make money for their owners have different needs and requirements than journals funded by government agencies or universities, and journals that receive advertising have different needs and requirements than journals that receive article processing charges from authors. Some journals are directed to readers in several public health disciplines, whereas others are directed to specialists or subspecialists. Finally, some journals are directed to international audiences, whereas others are directed to national or regional audiences. The quality or impact of a journal also has to be assessed before submitting a manuscript and when evaluating articles and authors who have published in it. Each of these characteristics should be considered when choosing a target journal. Likewise, most journals follow strict ethical standards when accepting, reviewing, and publishing articles, but other “predatory” journals do not, which can cost unsuspecting authors money and never result in a legitimate publication. Many authors, especially those early in their careers, are unfamiliar with the strengths and weaknesses of the various forms of peer review and how to respond to reviewers’ comments. The author reviews the scientific publishing process, including what authors need to know about journals, manuscript preparation and submittal, publication ethics, peer review, and other journal requirements. **Full text:** <https://goo.gl/4LXmrg>

Worth Repeating

Hearing the voices of people with high support needs

JOURNAL OF AGING STUDIES, 2013;27(1):52-60. This study explores the personal aspirations of a small diverse sample of hitherto un-researched people living in different parts of the U.K. Most were over 85 years of age, with varied ethnicity, health status, social care needs, financial status and lifestyle. Many were receiving input from statutory health and social care services and were perceived by others and often themselves to have high support needs. Accessible research methods were used to enable participants to specify those factors for well-being most central to their own lives and preferences. The study found commonalities of aspiration in relation to physical, social and psychological aspects of their lives, but also unique descriptions of their individual concerns. In striving to maintain a sense of self worth, participants accepted that some choices were not realistic for them personally. Positive relationships with caregivers were an essential enabler for some. In many cases negotiation has the potential to

produce simple and cost effective ways of addressing individual aspirations and improving quality of life. [Noted in the 7 January 2013 issue of *Media Watch* (#287, p.10)] **Abstract:** <https://goo.gl/2sXwss>

Highlights

- ▶ Little is known about the personal aspirations of people with high support needs.
- ▶ People with high support needs are primarily older, but may be younger.
- ▶ Using a specially modified tool we facilitated discussion about their preferences.
- ▶ Participants share some aspirations but differ in others.
- ▶ Negotiation should enable people with high support needs to achieve many wishes.

Media Watch: Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/C7qLhA>

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

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

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

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

Asia

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

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

Canada



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

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

Cont.

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

[Scroll down to 'Additional Resources']

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

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

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

Europe



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

[January/February 2018 issue (Scroll down to 'Paediatric palliative care; the patient's voice']

HUNGARY | Magyar Hospice Alapítvány: <http://goo.gl/5d1I9K>

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

Media Watch: Editorial Practice

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

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

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.

Cont.

[Search Back Issues of Media Watch @ http://goo.gl/frPgZ5](http://goo.gl/frPgZ5)

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Palliative Care Network

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

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