

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.

20 August 2018 Edition | Issue #577



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Loss and separation: Scroll down to [Specialist Publications](#) and 'Filling the void: Hospital palliative care and community hospice – a collaborative approach to providing hospital bereavement support' (p.11), in *Journal of Social Work in End-of-Life & Palliative Care*.

[Canada](#)

Ottawa should do more to examine how medically-assisted death is working

THE GLOBE & MAIL | Online – 16 August 2018 – When the federal government authorized health care providers to deliberately end patients' lives at their request, it entered the sort of unfamiliar policy ground that merits careful monitoring. For more than two years since doctor-assisted-dying legislation was enacted, Canada has made do with an interim reporting system. It offers useful information, including the average age of Canadians who received a medically assisted death last year (73) and total number of approved requests since the law was enacted (3,714), but not nearly enough. Finally, Ottawa this month unveiled more comprehensive regulations, to come into effect on 1 November.¹ They're a big and much-needed improvement, but still don't go far enough in giving patients a chance to express contributing factors from their social lives and medical care that led them to decide their suffering was "intolerable." Starting next year, the government will have to prepare an annual report that includes data from each province on the nature of patients' suffering, whether patients consulted about their health

with other medical workers before requesting assisted death, and whether the doctors (in most cases) who provided them consulted with other health care and social workers about the requests. Useful though those figures will be in offering a sense of the scope of deliberations before decisions are made, they still fall short of where some other jurisdictions have gone in measuring whether social or medical factors that could potentially be mitigated contribute to lives being ended. <https://goo.gl/wJJDV9>

[Specialist Publications](#)

'The spectrum of end of life care: An argument for access to medical assistance in dying (MAiD) for vulnerable populations' (p.17), in *Medicine, Health Care & Philosophy*.

'Cultivating compassion: The practice experience of a medical assistance in dying coordinator in Canada' (p.17), in *Quality Health Research*.

1. 'Regulations for monitoring medical assistance in dying come into force,' *Canada Gazette*, 2018, Part II, Vol. 152, No. 16. [Noted in the 13 August 2018 issue of Media Watch (#576, p.1)] **Download/view at:** <https://goo.gl/5omKZ1>

U.S.A.

Where interpreters are scarce, immigrant health care is lost in translation

NATIONAL PUBLIC RADIO | Online – 15 August 2018 – Census data suggest as many as one in 10 working adults in the U.S. have limited English language proficiency. Meanwhile, the 1964 Civil Rights Act and subsequent orders and laws require hospitals, family practices, dentists, pharmacies and other facilities that offer medical services and receive federal funds to provide “meaningful access” to patients, so they can make informed decisions about their health. With few exceptions, this means providers must offer qualified interpreters, as well as translations for prescriptions and other medical documents. Previous research has suggested such accommodations improve clinical outcomes and reduce persistent disparities in health care overall. And yet, despite the law, and despite the obvious benefits, thousands of hospitals and other medical facilities continue to fall short, leaving patients – if they are lucky – relying on family members and friends to play *ad-hoc* interpreters of maladies and medical care. It’s an informal and imperfect form of triage that unfolds in clinics across the country every day, with potentially harrowing consequences should something be lost in translation. <https://goo.gl/nL1MX9>

Noted in Media Watch 13 August 2018 (#576, p.11):

- *MAYO CLINIC PROCEEDINGS* | Online – 9 August 2018 – ‘**Differences in code status and end-of-life decision making in patients with limited English proficiency in the intensive care unit.**’ Of the 27,523 patients admitted to 7 ICUs in a single tertiary academic medical center from 31 May 2011 through 1 June 2014, 779 (2.8%) had limited English proficiency (LEP). Patients with LEP who died in the ICU were less likely to receive a comfort measures order and took 19.1 days longer to transition to comfort measures only. **Abstract (w. link to references):** <https://goo.gl/TkQjoS>

N.B. Additional articles on patients with limited English proficiency in the context of end-of-life care noted in this issue of Media Watch.

Demographic shifts and economic necessity are leading to a change in the way families handle long-term and end-of-life care

U.S. REPORT & WORLD NEWS | Online – 15 August 2018 – By nearly all measures, the American household is shrinking. According to the Centers for Disease Control & Prevention (CDC), there were 3,853,472 births in the U.S. in 2017, “down 2% from 2016 and the lowest number in 30 years.” The total fertility rate sank to a record low of 1,754.5 births per 1,000 women, a 3% drop from 2016 and well “below replacement” – the rate at which a given generation can replace itself, which is 2,100 births per 1,000 women (according to the CDC, the rate has generally been below replacement since 1971). As the current generation of seniors continues to live much longer than the last, this data is troubling and is projected to place significant stress on a health care system that relies heavily on an invisible army of family

Specialist Publications

‘**Dying patient and family contributions to nurse distress in the ICU**’ (p.12), in *Annals of the American Thoracic Society*.

‘**Frequency of use of the religious exemption in New Jersey cases of determination of brain death**’ (p.5), in *BMC Medical Ethics*.

‘**Trends and inpatient outcomes for palliative care services in major burn patients: A 10-year analysis of the nationwide inpatient sample**’ (p.6), in *Burns*.

‘**Gynecologic oncologists’ perceptions of palliative care and associated barriers: A survey of the Society of Gynecologic Oncology**’ (p.9), in *Gynecologic & Obstetric Investigation*.

‘**Promoting patient interests in implementing the Federal Right-to-Try Act**’ (p.10), in *Journal of the American Medical Association*.

Cont.

caregivers to support those with complex, chronic conditions. Still, there is one trend – borne of a gradual shift in public perception but grounded in economics – that underscores the potential leverage of family caregivers: the rise in multigenerational households. According to a 2016 Pew Research survey, one fifth of U.S. households are now multigenerational, a proportion closer to that of the 1950s (21%) than of more recent decades (12% in 1980). Many of these households include an elder being cared for by children and grandchildren, signaling a shift from the way families handle long-term and end-of-life care (EoLC). Government financing has long fueled the growth of the U.S. education and healthcare industries – Medicaid’s long-standing payment for nearly 70% of long term care nursing facility beds is a prime example of the power of the government dollar. For nearly three generations of Americans, the nursing home became the place where elders received EoLC. Now, a combination of technology, policy, economics and changing attitudes is coalescing to return care to the home, thrusting the family caregiver back into the prominent position it once held in the American consciousness. <https://goo.gl/Jx51q9>

Related

- ILLINOIS | *The Chicago Tribune* – 16 August 2018 – ‘**The new employee perk that’s slowly taking hold: Help for those caring for aging parents.**’ As people live longer and work longer, experts expect a growing number of employees to juggle their jobs with caregiving for aging parents or ill relatives, an experience that can affect their health, productivity and finances as well as their employer’s bottom line. But even as more employers offer paid maternity and paternity leave to help new parents balance work and family, companies have been slow to accommodate those grappling with the stress that comes when family members approach the end of life. <https://goo.gl/5zTXed>

International

The awkward conversation that has seen 4 million of us experience financial hardship

U.K. (England, Northern Ireland, Scotland & Wales) | *The Daily Mirror* (London) – 17 August 2018 – “Despite many of us thinking about mortality regularly, what’s clear is that while grief and bereavement is hugely commonplace, to talk about it ‘proactively’ is a rarity, leaving many unprepared or bewildered when it comes to planning for the inevitable,” said Robert MacLachlan, of Co-op Funeralcare & Life Planning. The Co-Op has just conducted one of the largest research programmes ever into our attitudes to dying and bereavement – and the results are shocking.¹ In fact, this unwillingness to take action or even talk has contributed to an astonishing 4 million adults facing financial hardship as a result of a death. “We see increasingly that a failure to properly deal with death has a knock on impact for the bereaved, affecting mental health and also triggering financial hardship,” MacLachlan added. Some 18 million people are uncomfortable talking about death, the Co-Op found. Worse than that, though, an astonishing 81% of people have not yet saved anything towards a funeral. Almost as many (73%) haven’t made a will while 94% haven’t nominated a lasting power of attorney and 95% don’t

have a funeral plan. This lack of action means people are not prepared – one person four now faces in funeral poverty following a bereavement and has had to borrow from family and friends to cover the cost. <https://goo.gl/pwW9SR>

Specialist Publications

‘**Cardio-pulmonary resuscitation decision-making conversations in the U.K.: An integrative review**’ (p.8), in *BMJ Supportive & Palliative Care*.

‘**U.K. ambulance services: Collaborating to provide good end-of-life care**’ (p.7), in *European Journal of Palliative Care*.

‘**What is palliative care? Perceptions of healthcare professionals**’ (p.14), in *Scandinavian Journal of Caring Science*.

‘**Legalisation of euthanasia in Finland: Via a citizens’ initiative?**’ (p.16), in *European Journal of Health Law*.

1. ‘Making peace with death: National attitudes to death, dying and bereavement,’ Co-op Funeralcare Media Report, August 2018. **Download/view at:** <https://goo.gl/aCNPpj>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Australian Capital Territory) | *The Sydney Morning Herald* – 15 August 2018 – ‘**Assisted suicide bill narrowly defeated in Senate.**’ A private member’s bill that would have cleared the way for assisted suicide to be legalised across Australia has been defeated. The bill ... was defeated by 36 to 34 votes after two days of impassioned debate in the Senate. Politicians from both sides of politics rose to share divergent views, with many in support of the bill emphasising the rights of Australians who live in the territories to make their own laws. The bill proposed to overturn a federal law that removed the rights of the Australian Capital Territory and Northern Territory (NT) to legislate on euthanasia, enacted in 1997 after the NT government briefly legalised assisted dying. <https://goo.gl/buQM57>

Specialist Publications

Palliative care for older people: The psychiatrist’s role

BJPSYCH ADVANCES | Online – 10 August 2018 – In this overview, the authors discuss the palliative psychiatric care of older people towards the end of life. They briefly consider ethics, dementia care, delirium, depression, anxiety, grief and physician-assisted suicide. The authors also discuss hope, dignity, spirituality and existentialism. They hope that this article will encourage clinicians to reflect on the effects of terminal illnesses on the mental health of dying people and the current provision of palliative psychiatric care: 1) Appreciate that patient-centred care builds on providing individualised care for the dying person to meet their needs and wishes; 2) Understand the collaborative role of psychiatry in assessing the aetiology and appropriate response to patients presenting with problems of loss, grief, anxiety, depression, hopelessness, suicidal ideation, personality

change and confusion; and, 3) Recognise that maintaining hope and living with hope is a way for terminally ill patients to endure and cope with their suffering. **Summary (inc. list of references):** <https://goo.gl/Qfu7Hg>

Journal Watch

‘**British Columbia economist in grim battle against deceptive scholarship**’ (p.17), in *The Vancouver Sun*.

‘‘**“Predatory” is a misnomer in the unholy nexus between journals and plagiarism**’ (p.18), in *The Wire*.

‘**Predatory publishers: The journals that churn out fake science**’ (p.18), in *The Guardian*.

Noted in Media Watch 13 August 2018 (#576, p.15):

- *AMERICAN JOURNAL OF PSYCHIATRY*, 2018;13(8):3-5. ‘**Physician aid-in-dying: Practical considerations.**’ This article provides an overview of the current status of physician aid in dying in the U.S. and worldwide, with discussion of several practical considerations pertaining to legalization and ethics, especially with regard to patients with psychiatric disorders and the effect on the mental health care field. **Full text:** <https://goo.gl/DqJVkP>

Noted in Media Watch 6 August 2018 (#575, p.9):

- *AMERICAN MEDICAL JOURNAL OF ETHICS*, 2018;20(8):E717-E723. ‘**Four communication skills from psychiatry useful in palliative care and how to teach them.**’ In this article, the authors identify four communication skills helpful in both fields: 1) Attending to counter transference; 2) Practicing active listening and active reflection; 3) Remaining silent and neutral; and, 4) Naming the emotion. They then describe strategies for teaching these skills. **Full text:** <https://goo.gl/XoHWK7>

N.B. Additional articles on the role of psychiatry in palliative and end-of-life care noted in the 28 August 2017 issue of Media Watch (#527, pp.12-13).

Palliative care in intensive care units: Why, where, what, who, when, how

BMC ANESTHESIOLOGY | Online – 16 August 2018 – In the intensive care unit (ICU), critically ill patients receive life-sustaining therapies with the goal of restoring or maintaining organ function. Palliative care (PC) in the ICU is a widely discussed topic and it is increasingly applied in clinics. It encompasses symptoms control and end-of-life management, communication with relatives and setting goals of care ensuring dignity in death and decision-making power. However, effective application of PC in ICU presupposes specific knowledge and training which anesthesiologists and critical care physicians may lack. Moreover, logistic issues such protocols for patients' selection, application models and triggers for consultation of external experts are still matter of debate. The aim of this review is to provide the anesthesiologists and intensivists an overview of the aims, current evidence and practical advices about the application of PC in ICU. **Full text:** <https://goo.gl/3Grs6g>

Related

- *WIENER KLINISCHE WOCHENSCHRIFT* | Online – 9 August 2018 – ‘**Prioritizing information topics for relatives of critically ill patients: Cross-sectional survey among intensive care unit relatives and professionals.**’ In this study, a broad variety of topics was subjectively relevant to intensive care unit (ICU) relatives [e.g., “diagnosis,” “treatment,” “comfort,” “family” and “end of life.” There was a substantial discrepancy between relatives and ICU professionals in the subjective importance of topics: not a single top five topic for relatives featured among the top five topics for medical professionals. **Full text:** <https://goo.gl/YdLwNm>

N.B. English language article.

Frequency of use of the religious exemption in New Jersey cases of determination of brain death

BMC MEDICAL ETHICS | Online – 14 August 2018 – The 1981 Uniform Determination of Death Act established the validity of both cardio-respiratory and neurological criteria of death. However, many religious traditions including most forms of Haredi Judaism (ultra-orthodox) and many varieties of Buddhism strongly disagree with death by neurological criteria (DNC). Only one state in the U.S., New Jersey, allows for both religious exemptions to DNC and provides continuation of health insurance coverage when an exception is invoked in its 1991 Declaration of Death Act. Religious exemptions to DNC in New Jersey do occur, although they are rare. Prior to this study, there was no information on the frequency of religious exemptions. There is a need for either state or national policies that acknowledge religious objections to DNC. Allowing every individual case of religious objection to DNC to be resolved by courts is inefficient and costly. Furthermore, court rulings have not protected the religious freedom of patient families undergoing emotional ordeals when their loved one is declared dead by neurological criteria in a manner inconsistent with their religious beliefs. **Full text:** <https://goo.gl/9ebNia>

N.B. Additional articles on defining “brain death” noted in the 30 July 2018 issue of Media Watch (#574, pp.9-10).

Patient healthcare passports in community specialist palliative care: A mixed methods study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 18 August 2018 – The authors evaluated how patients, families and professionals in a specialist palliative setting use a patient held record created through close consultation with patients and carers. From September 2016 to June 2017, 550 patients were screened, 347 (63.1%) were offered records and 259 accepted (74.6%). 238 accepted a research pack, 105 returned questionnaire 1 (44.1% response rate) and 26 returned questionnaire 2 (24.8% of initial respondents). Questionnaire 1 (patients): 40% found it burdensome repeating information, and almost 70% were interested in a record to reduce this. Questionnaire 2 (patients): 74% found the record easy to use, but few (4, 15.4%) used it regularly. Over 60% stated the record was useful and would recommend it to others, despite not using it themselves. Professionals indicated that it was mainly patients and relatives who used the record, not non-palliative professionals. While initial uptake of the record was high, use appeared low. While people saw real value in the record for others, they did not generally use it themselves. This evaluation demonstrates that patient held records are unlikely to be used by palliative care patients even though they see value in the concept. **Abstract:** <https://goo.gl/89yqoG>

Music therapy in U.K. palliative and end-of-life care: A service evaluation

BMJ SUPPORTIVE & PALLIATIVE CARE, 2018;8(3):282-284. Music therapy aligns to the holistic approach to palliative and end-of-life care (PEoLC), with an emergent evidence base reporting positive effect on a range of health-related outcomes for both patient and family carer alongside high client demand. However, the current service provision and the role of music therapists in supporting individuals receiving PEoLC in the U.K. is currently unknown. A survey was distributed to the British Association for Music Therapy (BAMT) member mailing list... The respondents largely reported (84.7%) less than 10 years of experience working in PEoLC settings, with only a minority receiving statutory funding for their role. Music therapists most commonly reported supporting adults with neurological conditions, cancers and dementia. Although promising that evidence suggests provision of music therapy in U.K. PEoLC settings in the past 10 years to have increased, lack of sustainable funding suggests the role to not be consistently accessible in PEoLC. **Abstract:** <https://goo.gl/7GvYdQ>

Trends and inpatient outcomes for palliative care services in major burn patients: A 10-year analysis of the nationwide inpatient sample

BURNS | Online – 13 August 2018 – 1.9% [of the patient population studied (7,424 major burns)] received palliative care (PC) services. Independent predictors of palliative consultations included older age, larger burns, deeper burns, etc. Those receiving PC services were significantly more likely to die without surgery, with no significant difference in mortality... PC services were increasingly used during the study period. PC services in highly moribund burn patients do not impact survival and may decrease the likelihood of surgical intervention in select patients. **Abstract:** <https://goo.gl/2g8hUZ>

Is patient information on palliative care good enough? A literature review and audit

CANCER NURSING PRACTICE | Online – 14 August 2018 – This study involved three stages: 1) A literature review to identify barriers to referral; 2) An audit of patient information resources available in adult oncology services across Yorkshire and Humber (in the U.K.); and, 3) A critique of the identified information resources. The review identified patient misconceptions about palliative care (PC) as a barrier to engagement with services. The regional audit found that information about PC is not widely available to cancer patients and the information provided does not address the misconceptions reported in the literature. There is a need to improve information for cancer patients that addresses known misconceptions about PC and to make this widely available in oncology departments. **Abstract:** <https://goo.gl/cDQsEo>

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

- *SUPPORTIVE CARE IN CANCER* | Online – 9 October 2017 – ‘Palliative care content on cancer center websites.’ The authors conducted a content analysis of 62 National Cancer Institute designated cancer center websites [in the U.S.]. Ten percent had no webpage with palliative care (PC) information for patients. Among centers with information for patients, the majority (96%) defined palliative or supportive care, but 30% did not discuss delivery of PC alongside curative treatment, and 14% did not mention provision of care early in the disease process. **Abstract (inc. list of references):** <https://goo.gl/6vEYhL>



[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>

The legacy of the Northern Ireland conflict in palliative care

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2018;25(3):105-108. Between 1969 and 1998, more than 3,600 people were killed during the Northern Ireland Troubles and 40,000 people injured. This research gives an insight into the impact of the conflict on palliative care (PC) practice and the implications as Northern Ireland lives with the legacy of the Troubles. The cultural context of Northern Ireland could potentially prevent people from receiving the right care. Religious divisions, difficulties associated with addressing trauma, the implications of disclosure, and a desire to move on could be obstacles to addressing personal suffering. The PC community is well-placed to consider whether the legacy of the Troubles is a factor in the suffering of the people they are supporting. A failure to con-

sider the issue could diminish the quality of life of those being cared for.

European Journal of
Palliative Care 
A JOURNAL OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE

The journal has ceased publication. Enquiries about access, editorial or subscription matters should be addressed to the publisher at: <https://goo.gl/WQSxHE>

May/June issue contents page: <https://goo.gl/e1yqNd>

Journal's category archives: <https://goo.gl/rwp33C>

What the social sciences have to offer palliative care

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2018;25(3):109-111. A social science approach to end-of-life care (EoLC) means paying attention to the social context in which the care of the dying, and death itself, occurs. It is about considering the actions of those involved in EoLC, including the patient, their family and healthcare staff, and the social world in which these take place. This approach can be conducted at a micro level – for example, by looking at how individuals speak to each other or by examining the physical environment in which the care takes place – and may incorporate more macro considerations, such as how groups of clinicians interact or the financial pressures on healthcare organisations. Focusing on these factors provides vital understanding of how and why care is delivered as it is and is, therefore, implicit in much EoLC research. Palliative care (PC), and the end of life more generally, are widely studied themes within the social sciences. Still, the knowledge produced in these studies often remains less visible by the dominant clinical disciplines (medicine and nursing) working in palliative and EoLC. With this article, the authors seek to highlight some of the contributions made from a social science perspective, and demonstrate what we can learn from these in PC.

U.K. ambulance services: Collaborating to provide good end-of-life care

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2018;25(3):112-115. With the changing priorities in the National Health Service (NHS) of managing an increasingly ageing and complex population in the community, ambulance services are increasingly required to provide care in community settings, including for patients needing end-of-life care (EoLC). Education on EoLC is vital to help ambulance clinicians feel confident in supporting patients who reach the end of their life, and working closely with hospices and community palliative care providers is key to this. The East of England Ambulance Service NHS Trust has undertaken a number of successful collaborations with community EoLC providers and hospices, while one of the hospices works with EEASt paramedics and the local university to provide EoLC education to paramedic students. The South East Coast Ambulance Service NHS Foundation Trust has developed an improvement project, dedicated to EoLC and focusing on education, integration and collaboration of the ambulance service with the EoLC community, and improving the access to information.

N.B. Additional articles on the role of ambulance services and paramedics in palliative and end-of-life care noted in the 18 June 2018 issue of *Media Watch* (#568, pp.11-12).

STOP! Patients receiving cardiopulmonary resuscitation despite valid do not attempt cardiopulmonary resuscitation documentation

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2018;25(3):125-127. Although cardiopulmonary resuscitation (CPR) can be life saving in the arrest scenario, there is increasing recognition that it is not always appropriate and, at times, may cause harm. Making appropriate do not attempt cardiopulmonary resuscitation decisions, can help avoid unnecessary suffering and uphold dignity in death. Anticipating scenarios where CPR is inappropriate and documenting these decisions helps healthcare staff and resuscitation teams focus care effectively. Decisions need to be documented and communicated clearly, so they can be recognised by all healthcare staff involved in patient care. This is particularly important in the acute setting, with a resuscitation team who may not be familiar with the patient. In the U.K., there are a variety of Treatment Escalation Plan (TEP) documents, which are regularly updated based on new research and guidance. A TEP is a clinical decision tool to document and plan care for an acutely ill or deteriorating patient. This trust utilised a purple combined treatment escalation form with an additional yellow sticker indicating “do not attempt cardiopulmonary resuscitation” if the patient was not suitable for CPR. This form would be placed in the front of the medical notes, to be easily visible for all staff. In the event of patient deterioration, any healthcare professional could seek support from the resuscitation team.

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 1 August 2018 – ‘**Cardio-pulmonary resuscitation decision-making conversations in the U.K.: An integrative review.**’ The findings from this integrative review of the literature on patients, family and caregivers’ experience of cardio-pulmonary resuscitation decision-making discussions are at odds with the current legal state in the U.K. and are potentially challenging for health professionals, who are required to discuss do not attempt cardiopulmonary resuscitation decisions at the earliest opportunity. **Full text:** <https://goo.gl/u4zmiP>

Noted in Media Watch 30 July 2018 (#574, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 25 July 2018 – ‘**Tracey judgement and hospice do not attempt cardiopulmonary resuscitation orders: Steady as she goes or seismic change?**’ The 2014 Court of Appeals decision with respect to *Tracey vs Cambridge University Hospital* (i.e., “the Tracey judgement”) changed the requirements for discussing do not attempt cardiopulmonary resuscitation (DNACPR) decisions with patients. This study is a retrospective case note review aiming to identify any changes in practice around discussing DNACPR decisions in hospices following the judgement. **Abstract:** <https://goo.gl/xf9xWq>

The relevance of “total pain” in palliative care practice and policy

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2018;25(3):128-130. Cicely Saunders first used the term “total pain” in 1964 to describe the intertwined physical, psychological, social and spiritual dimensions of pain. This radical departure from the previous understanding of pain as purely physical provided a new interdisciplinary concept that transformed medical understanding of suffering. This concept was also critical in forging the specialty of palliative care (PC). As 2018 is the centenary year of Cicely Saunders’ birth, this seems a particularly apt time to re-engage with total pain as one of her most enduring legacies and to consider its contemporary relevance. Further consideration of total pain seems both timely and necessary. PC is promoted globally as the gold standard for end-of-life care (EoLC), but this foundational concept has undergone virtually no in-depth examination on how it has evolved or how it is understood and addressed in different clinical and cultural contexts. The authors aim to begin this conversation. First, they briefly outline key issues in defining total pain and consider some professional and system-based challenges to addressing total pain. They then suggest how the substantial knowledge gap around total pain has potentially serious consequences in clinical practice and policy development. The authors end with a review of some of the research questions about total pain that we believe need answering in order to inform practice and policy initiatives.

“
Is total pain best defined and understood as a care philosophy, a descriptor of personal experience, a relationship or a set of clinical practices? Is it even limited to end of life?
”

Access to end-of life Parkinson's disease patients through patient-centered integrated healthcare

FRONTIERS IN NEUROLOGY | Online – 30 July 2018 – The findings of this study ask for an intensive debate about advance care planning (ACP) in Parkinson's disease (PD), as currently it seems not to be adequately addressed during the course of PD. An ACP discussion might “include the individual's concerns, their important values or personal goals for care, their understanding about their illness and prognosis and their preferences for types of care or treatment that may be beneficial in the future and the availability of these.” Especially as written ACP are associated with less use of life-sustaining treatment, greater use of hospice and less likelihood of hospitalization during end of life phase. Furthermore, it was shown, that at least half of PD patients wish to discuss APC early in the course of the disease. These findings encourage the implementation of thorough ACP within integrated care structures already at early disease stages. All these different aspects ask for a further development of the integrated care model, which includes the following principles: 1) Integration of specialist palliative care (PC) knowledge at a very early point in the course of the disease with respect on the acceptance of the diagnosis (e.g., once a year from the time of the diagnosis); 2) Implementation of a clinical liaison/case manager (e.g., a PD nurse) as a patient advocate, who takes care of the patient during the course of the disease, especially in critical phases of the disease (e.g., high symptom burden, late stage, etc.); 3) Integration of nursing homes, as PD patients in nursing homes are underrepresented in neurological care; 4) Integration of general practitioners/family doctors, as they have a closer contact to patients' families and know about changing situations of care; and, 5) Dovetailing of neurological and specialist PC units and outpatient services in order to use knowledge and the best principles of both disciplines. **Full text:** <https://goo.gl/QrgWFp>

Noted in Media Watch 28 May 2018 (#565, pp.10-11):

- *JOURNAL OF APPLIED GERONTOLOGY* | Online – 22 May 2018 – ‘**A mixed-methods approach to understanding the palliative needs of Parkinson's patients.**’ Despite recommendations for a palliative approach, little is known about what palliative needs are unmet by standard care. Significant differences between physicians and patients were found [in this study] in physical, psychological, social, financial, and spiritual domains. Primary themes across interviews included: 1) Lack of healthcare education; and, 2) Need for care coordination. Secondary themes included: 1) The importance of support groups; 2) The role of spirituality/religion; and, 3) The narrow perceived role of the neurologist. **Abstract (inc. list of references):** <https://goo.gl/z5dmND>

N.B. Additional articles on the palliative care needs of patients and families living with Parkinson's disease noted in this issue of Media Watch.

Gynecologic oncologists' perceptions of palliative care and associated barriers: A survey of the Society of Gynecologic Oncology

GYNECOLOGIC & OBSTETRIC INVESTIGATION | Online – 10 August 2018 – Gynecologic oncologists frequently care for patients at the end of life with the aid of palliative care (PC) specialists. Members of the Society of Gynecologic Oncology (SGO) were invited to participate in an anonymous online survey. A total of 174 (16%) gynecologic oncologists completed the survey. The majority (75%) agreed or strongly agreed that PC should be integrated into cancer care at diagnosis of advanced or metastatic cancer. The most frequently perceived PC barriers included patients' unrealistic expectations (54%), limited access to specialty PC (25%), poor reimbursement (25%), time constraints (22%), and concern of reducing hope or trust (21%). The most agreed upon potential intervention was increased access to outpatient PC (80%). According to this cohort of SGO members, families' or patients' unrealistic expectations are the most frequent barriers to specialty PC. Understanding this communication breakdown is critically important. **Abstract (w. list of references):** <https://goo.gl/D1U7jp>

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Noted in Media Watch 15 January 2018 (#546, p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 January 2018 – ‘**Top 10 tips palliative care clinicians should know when caring for patients with ovarian cancer.**’ The authors brought together a team of gynecologic oncology and PC experts to collate practical pearls for the care of women with epithelial ovarian cancer. In this article, they use a “Top 10” format to highlight issues that may help palliative care physicians understand a patient’s prognosis, address common misconceptions about ovarian cancer, and improve the quality of shared decision making and goals-of-care discussions. **Abstract:** <https://goo.gl/MpRAuT>

Noted in Media Watch 18 December 2017 (#543, p.14):

- *CURRENT OPINION IN OBSTETRICS & GYNECOLOGY* | Online – 8 December 2017 – ‘**Palliative care in gynecologic oncology.**’ Patients with gynecologic malignancies face many difficult issues in the course of their diseases, ranging from physical symptoms to advance care planning in light of a poor prognosis. This review examines the evidence supporting integration of palliative care early in the course of disease and symptom management, and provides a framework for difficult conversations. **Abstract:** <https://goo.gl/MAAHwV>

N.B. Additional articles on palliative care in gynecologic oncology noted in the 14 August 2017 issue of Media Watch (#525, p.13).

Promoting patient interests in implementing the Federal Right-to-Try Act

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 13 August 2018 – The Food & Drug administration (FDA) has long provided seriously and terminally ill patients the ability to access investigational drugs and devices through its Expanded Access program... Unlike Expanded Access, Right-to-Try applies only to investigational drugs and does not task the FDA or institutional review boards with ensuring that the risks and benefits of treatment are reasonable. Instead, the investigational drug must simply have completed phase 1 testing and be under active development by a manufacturer. The law additionally exempts eligible investigational drugs provided to eligible patients from compliance with other FDA requirements for investigational use, such as strict standards for informed consent and adverse event reporting, but does mandate compliance with provisions regarding investigational labeling and restrictions on promoting and charging for investigational products. Further, the Right-to-Try Act grants various expansive immunities from liability not applicable to clinical trial participation or Expanded Access. As described by its primary Congressional sponsor, the law “intends to diminish the FDA’s power over people’s lives.” The recommendations suggested here are not intended to render Right-to-Try indistinguishable from Expanded Access; it is clear that lawmakers intended to create a new, distinct pathway. Instead, these recommendations may help prevent the rise of a market in unproven therapies and preserve the ability to collect critical information about investigational drugs, while enabling access as the law intended (but did not guarantee). Additionally, these recommendations are not intended to be exhaustive. For example, rigorously monitoring and enforcing the statutory requirement that manufacturers may charge only for the direct costs of their drugs under Right-to-Try also may help to deter those who would seek to exploit vulnerable patients. **Full text:** <https://goo.gl/czUu5L>

N.B. Selected articles on the issue of “right-to-try” new experimental or investigational drugs noted in the 30 July 2018 issue of Media Watch (#574, p.12).

End-of-life care for older Russian immigrants: Perspectives of Russian immigrants and hospice staff

JOURNAL OF CROSS-CULTURAL GERONTOLOGY | Online – 14 August 2018 – This pilot study examined immigrant Russian seniors and adult children’s views on end-of-life care (EoLC), and hospice staff members’ experiences providing care to diverse immigrant clients, in areas of North Carolina with a high proportion of immigrants. Findings indicate that there is little awareness of EoLC options among the Rus-

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sian immigrant community in North Carolina. EoLC is rarely discussed within the family of first generation Russian immigrants, but second-generation families are more open to doing so. First generation immigrant Russian seniors do not seem to want any specialized EoLC often due to lack of awareness, and prefer family care. Second generation seniors' attitudes are more accepting of this type of care. Results of this study suggest a great need for community outreach to immigrant groups to raise awareness of EoLC, including advance directives and hospice care and the role of interpreters in health care settings. **Abstract (inc. list of references):** <https://goo.gl/uKRdJg>

Noted in Media Watch 22 July 2013 (#315, p.7):

- *AMERICAN MEDICAL NEWS* | Online – 15 July 2013 – ‘**Palliative care’s role grows in solving end-of-life conflicts.**’ A 58-year-old Russian man with advanced esophageal cancer was admitted to a U.S. comprehensive cancer center with decreased oral intake and failure to thrive. The man’s family insisted on initiating parenteral nutrition, but the physician and other health professionals involved in his care saw that as medically contraindicated. The family of Russian immigrants insisted. They told of their struggles with food shortages in the old country and refused to consider what they saw as allowing their loved one to “starve to death.” **Full text:** <https://goo.gl/9N91jX>

Filling the void: Hospital palliative care and community hospice – collaborative approach to providing hospital bereavement support

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 15 August 2018 – Bereavement services are often provided as components of hospice and palliative care (PC) plans, including emotional, psychosocial, and spiritual support provided to individuals and families to assist with grief, loss and adjustment after the death of a loved one. Patient- and family-centered care is a hallmark of PC. Moreover, bereavement counseling is offered as a hospice care benefit that is covered [in the U.S.] by Medicare and various private insurance plans. Many bereaved persons whose loved one dies in the hospital while receiving PC services may not have access to a bereavement support program. This practice concept article describes an innovative bereavement program designed to offer support to individuals whose loved one died in the hospital while receiving PC. The bereavement team, including clinical professionals from the inpatient PC team and two community hospices, developed the University of Florida (UF) Health Bereavement Program. The interprofessional team includes social workers, volunteers, chaplains, nurses, nurse practitioners, and physicians. The bereavement program incorporates grief support workshops, follow-up with participants, via postal mail at timed intervals, website access to grief resources, staff education, and an annual evening of remembrance program. Finally, interagency collaboration has extended the reach of bereavement services beyond UF Health into our community at large. **Abstract (w. link to references):** <https://goo.gl/Qm1uAF>

Palliative care may reduce suicide risk in veterans with lung cancer

MEDICALXPRESS | Online – 10 August 2018 – Results from a large-scale patient population study ... reveal palliative care (PC) is associated with a reduced risk of suicide in veterans diagnosed with advanced stage lung cancer.¹ Of 20,900 patients with advanced lung cancer enrolled in the Department of Veterans Affairs (VA) Central Cancer Registry, 30 patients committed suicide, a rate more than five times greater than the average among all veterans who use VA health care of a similar age and gender. However, the data showed patients with lung cancer who had at least one PC visit after their diagnosis were 81% less likely to die by suicide. The psychological impact of a cancer diagnosis – particularly a lung cancer diagnosis – is underappreciated and largely overlooked in the medical community. This is the first study to explore the relationship between PC and suicide risk in cancer patients. **Full text:** <https://goo.gl/6pkYN3>

1. Incidence of suicide and association with palliative care among patients with advanced lung cancer, *Annals of the American Thoracic Society*, published online 26 July 2018. **To access this article:** <https://goo.gl/6UanNV>

How do expatriate health workers cope with needs to provide palliative care in humanitarian emergency assistance? A qualitative study with in-depth interviews

PALLIATIVE MEDICINE | Online – 16 August 2018 – Given the worldwide increase of chronic diseases, expatriate health workers on assignment with humanitarian emergency organisations can face more clinical situations that require advanced pain control or palliative care (PC). Multiple reasons can prevent the provision of this care. Fifteen expatriate health workers took part in individual in-depth interviews after their assignment with the organisation Médecins sans Frontières. Clinical situations requiring advanced pain control or PC do occur during assignments. Expatriate health workers have different levels of knowledge of pain control and PC. Lacking opioids were a main reason for inadequate pain control. The expatriates felt helpless, distressed and frustrated in such situations. Peer support was sometimes helpful. Guidelines for PC in emergency settings would have been useful. Humanitarian organisations should strengthen their capacity to provide pain control and PC by developing and applying adapted guidelines. **Abstract:** <https://goo.gl/aHsnJh>



Noted in Media Watch 14 May 2018 (#563, p.6):

- *HUMANITARIAN HEALTH DIGEST* | Online – Accessed 11 May 2018 – ‘**It’s about time for palliative care in humanitarian emergencies.**’ The Syrian crisis has shed light on a myriad of complex issues and gaps, many relating to the protracted nature of conflict and displacement outside of camp settings in middle-income countries. The importance of palliative care in such contexts is critical, but rarely discussed, never mind addressed.¹ **Full text:** <https://goo.gl/DZUKxX>

1. ‘The role of palliative care in addressing the health needs of Syrian refugees in Jordan,’ *Medicine, Conflict & Survival*, 2018;34(1):19-38. **Abstract (w. link to references):** <https://goo.gl/uHNYML>

N.B. Additional articles on the provision of palliative care during humanitarian crises or natural disasters noted in the 7 May 2018 issue of Media Watch (#562, p.11).

A positive attitude towards provision of end-of-life care may protect against burnout: Burnout and religion in a super-aging society

PLOS ONE | Online – 9 August 2018 – The authors’ findings suggest that a positive attitude towards providing end-of-life care (EoLC) is a protective factor against depersonalization. They also found considerable desire for religious intervention by Buddhist priests in long-term care (LTC) facilities. These results are very helpful in the current Japanese context of an aging society. If the increasing number of deaths in nursing care facilities was a burden on the staff, it is rational that a positive attitude would protect against burnout. A positive attitude may also relate to high goals, however, which explains why it was also linked to a feeling of lower personal accomplishment. As the number of older people increases, and more have incurable diseases such as dementia, severe frailty, and terminal cancer, the burden on nurses and care workers in LTC facilities will be heavier. This trend is likely to continue as the supply and demand gap for care workers is estimated to reach 380,000 in 2025, according to the Ministry of Health, Labour & Welfare. To support care professionals providing EoLC, the study indicated a potential role for religion. However, religious needs in LTC facilities have mainly been considered in the context with spiritual needs. **Full text:** <https://goo.gl/CmfJKi>

Related

- *ANNALS OF THE AMERICAN THORACIC SOCIETY* | Online – 10 August 2018 – ‘**Dying patient and family contributions to nurse distress in the ICU.**’ One hundred nurses who cared for 200 deceased ICU patients at two large, academic medical centers in the Northeast U.S. were interviewed about patients’ psychological and physical symptoms, their reactions to those patient experiences (e.g., emotional distress), and perceived factors contributing to their emotional distress. Patients’ emotional distress, physical distress, and their perceived quality of death were associated with nurse emotional distress. **Abstract:** <https://goo.gl/koehyJ>

Motivations for advance care and end-of-life planning among lesbian, gay and bisexual older adults

QUALITATIVE SOCIAL WORK | Online – 13 August 2018 – Lesbian, gay, and bisexual older adults are more likely than their heterosexual peers to experience health disparities, discrimination from healthcare providers based on sexual orientation, and rejection from their family of origin, all of which can complicate medical care and decision making, as well as end-of-life (EoL) arrangements. Yet, relatively few studies of lesbian, gay, and bisexual seniors have looked at motivations for advance care and EoL planning, which are strategies that can help ensure that healthcare treatment and EoL wishes are enacted as desired. The present qualitative study ... identified three themes related to motivations for advance care and EoL planning: wanting a sense of agency, learning from others, and reducing conflict and confusion for loved ones. The authors discuss the importance of these findings for social work practice with lesbian, gay, and bisexual older adults and for social work education, as well as implications for future research.

Abstract: <https://goo.gl/s2Pm7c>

Related

- *JOURNAL OF GERONTOLOGICAL SOCIAL WORK* | Online – 13 August 2018 – **“Fear runs deep”:** **The anticipated needs of LGBT older adults in long-term care.** This study adds to the existing literature about the worries of older lesbian, gay, bisexual, and transgender (LGBT) adults as they anticipate long-term care. The results suggest that they seek LGBT-inclusive residential care settings that encompass two distinct yet related aspects of LGBT-affirmative care: the procedural (e.g., culturally competent skills and knowledge of practitioners) and the implicit (e.g., the values and mission of the organization). This paper identifies implications for practice, policy, and training. **Abstract (w. link to references):** <https://goo.gl/pbBf7r>

Noted in Media Watch 13 August 2018 (#576, p.1)

- CANADA | *The Globe & Mail* – 7 August 2018 – **‘LGBTQ seniors fear renewed discrimination in long-term care.’** Improving the quality of life for queer seniors nearing the end of life is the next frontier for lesbian, gay, bisexual, transgender and queer (LGBTQ) activists. In some long-term care facilities, staff are trained and vigilant in protecting the rights of sexual minorities. In others, ignorance can lead to discrimination. If you are in your mid-60s or older, you remember when it was a crime to be gay in Canada. Now, as an increasing number of LGBTQ seniors require long-term care, some discover that the old days are back. <https://goo.gl/L2knfW>

N.B. Selected articles on palliative and end-of-life care for LGBTQ persons noted in the 25 June 2018 issue of Media Watch (#569, pp.13-14).

Palliative care: A proposal for undergraduate education in medicine

REVISTA BRASILEIRA DE GERIATRIA E GERONTOLOGIA, 2018;21(3):261-271. One of the earliest attempts to publish a curriculum for the teaching of palliative care (PC) at undergraduate level took place in Canadian medical schools in 1993. The American Academy for Hospice & Palliative Medicine subsequently published a core curriculum in 1998. The European Association for Palliative Care established a summary of a proposed curriculum, setting out the minimum of knowledge and skills that a medical student should acquire during his/her undergraduate course. In 2008 the Société Canadienne des Médecins des Soins Palliatifs proposed six items in which to divide competencies: medical expertise in pain and other symptoms, medical expertise in psychosocial and spiritual needs, and the roles of administrator, communicator, collaborator and promoter of health. Subsequently, similar projects were implemented in Japan, the U.K. and Colombia. In Brazil, the Universidade Federal de São Paulo was the first medical school to offer PC courses on an elective basis to undergraduate students in Medicine, between 1994 to 2008. In 2003, a compulsory PC discipline was created at the Universidade de Caxias do Sul. Despite these examples of approaches to PC in education, which were later followed by other universities, there is a lack of correlation between the provision of instruction in PC and the perception of its importance in

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most medical schools. Such schools have described insufficient time, a lack of faculty expertise and the time-consuming demands of multiple interests as the reasons for the lack of curricular under-representation of PC. Yet by placing the student in contact with PC during training we can help to improve patient care. **Full text:** <https://goo.gl/5wTrSt>

N.B. Click on pdf icons to access either Portuguese or English language version.

Noted in Media Watch 18 June 2018 (#568, p.12):

- *REVISTA BRASILEIRA DE EDUCAÇÃO MÉDICA*, 2018;42(2). ‘**End-of-life paradigm in medical training: Attitudes and knowledge about death and palliative care.**’ In Brazil, palliative medicine has recently been promoted to the category of medical specialty, obliging Brazilian medical schools to review the educational concepts associated to end-of-life (EoL) care. The scholar’s view of death may determine their inner disposition, values, concepts, and prejudices regarding death and dying and determine their performance as a professional. Thus, medical education programs must emphasize not only the theoretical-technical aspects in palliative care, but also the emotional climate that involves the medics’ attitudes and actions in EoL situations. **Full text:** <https://goo.gl/d2ghrQ>

N.B. Portuguese language article.

What is palliative care? Perceptions of healthcare professionals

SCANDANAVIAN JOURNAL OF CARING SCIENCE | Online – 13 August 2018 – The conceptual understanding of palliative care (PC) was perceived by the participants in an ambiguous and blurred way, reflecting the complexity of the concept. This was highlighted as a problem fifteen years ago and confirmed in subsequent research. In addition, similar concepts require clarification (e.g., “a palliative approach.” Typically, PC was identified as “end-of-life care” (EoLC), but also as “terminal care,” “last time in life,” “natural care” and so on. Previous research confirms that PC is often interpreted as EoLC. This understanding of PC also has an impact on the care provided, as previous studies have found that a blurred understanding of PC contributes to inadequate and underutilised care of people with PC needs. The authors findings also stress that education level might influence the understanding of how to interpret PC. Indeed, most participants had no special education or training within PC, which seems to be a concern among healthcare professionals in Sweden, except for those working in specialised PC units. This situation has been highlighted as a prioritised area both in Swedish and European policy documents. The results also show ambiguity about when the transition from cure to PC occurs and when it should be communicated. This ambiguity was related to the blurred boundaries between curative and PC. Several factors may influence when curative care is abandoned in favour of PC such as agreement, timing and decision-making. In a survey of over 800 physi-

cians and nurses, respondents argued that decisions to start PC were made too late. This was also emphasised in this study. **Full text:** <https://goo.gl/zfHdHk>

The socio-political debate of dying today in the U.K. and New Zealand: “Letting go” of the biomedical model of care in order to develop a contemporary *ars moriendi*

SOCIETIES | Online – 10 August 2018 – Medical practice currently maintains power over the dying individual, actualised through the selective collaboration between medicine and law as a means of subverting the individual who attempts to disrupt the contemporary accepted norms of dying. There is, however, a shift on the horizon as to whether we can make the notion of a true choice become a reality in New Zealand. This serves to offer a compelling movement towards individuals seeking control of their dying trajectory to actualise the notion of individual choice. With this shifting landscape there is an opportunity to be grasped to change how we manage our dying trajectory away from the biomedical patterns of behaviour when dying, in order to balance life decisions. To achieve this prospect, we need to engage with a framework upon which to pin the changes. The authors offer a re-framing and re-presenting approach, using illustrative examples that draw upon British and New Zealand literature, together with over 50 years of professional nursing, and the *ars moriendi* to reflect upon the self-centricity of the contemporary Western individual to access a “good death” of choice. **Full text:** <https://goo.gl/D6QZfo>

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Noted in Media Watch 23 April 2018 (#560, p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 20 April 2018 – ‘**Effects of using “palliative,” “supportive,” or “hospice” care terminology.**’ In this study, the terminology used had a large effect and, compared with alternatives, the information labeled as being about “supportive” care was significantly more likely to be selected. There may be low-cost, highly feasible changes in language choice that increase the dissemination of relevant health information. **Abstract:** <https://goo.gl/1mWwno>

Noted in Media Watch 1 July 2013 (#312, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 24 June 2013 – **Concepts and definitions for “actively dying,” “end of life,” “terminally ill,” “terminal care” and “transition of care”:** **A systematic review.**’ The authors’ findings highlight the urgent need to develop consensus definitions for these terms to facilitate daily communications related to clinical care, scientific research, education, and public policy. **Full text:** <https://goo.gl/pK7t5Y>

Noted in Media Watch 3 September 2012 (#269, p.7):

- *SUPPORTIVE CARE IN CANCER* | Online – 31 August 2012 – ‘**Concepts and definitions for “supportive care,” “best supportive care,” “palliative care,” and “hospice care” in the published literature, dictionaries, and textbooks.**’ Commonly used terms such as “supportive care,” “best supportive care,” “palliative care,” and “hospice care” were rarely and inconsistently defined in the palliative oncology literature. **Abstract (inc. list of references):** <https://goo.gl/2TE8PL>

N.B. Additional articles on terminology in the context of end-of-life care noted in the 5 October 2015 issue of Media Watch (#430, pp.15-16).

A scoping review of research to assess the frequency, types, and reasons for end-of-life care setting transitions

SCANDINAVIAN JOURNAL OF PUBLIC HEALTH | Online – 13 August 2018 – Most people approaching the end of life (EoL) develop care needs, which typically change over time. Moves between care settings may be required as health deteriorates. However, in some cases, care setting transitions may have little to do with EoL care needs and instead reflect the needs, demands, availability, or funding provisions of the country or funding body and organizations providing care. A total of 39 research articles were identified and reviewed. However, minimal useful evidence was revealed. Most articles focused solely on hospital admissions near death, and some focused on nursing home admissions, with other moves infrequently studied. This review demonstrates the need to quantify and justify EoL care setting transitions as it appears dying people are frequently moved, often as death nears. **Abstract:** <https://goo.gl/uy8AgP>

N.B. Selected articles on end-of-life care setting transitions noted in the 21 May 218 issue of Media Watch (#564, pp.6-7).

In their own words: Patient navigator roles in culturally sensitive cancer care

SUPPORTIVE CARE IN CANCER | Online – 14 August 2018 – Patient navigation has emerged as a promising strategy in reducing disparities among diverse cancer patients. However, little is known about navigators’ own perspectives on their roles in providing culturally competent care. Survey respondents described the following 11 interrelated navigator roles in the provision of culturally competent care: 1) Assess and understand patient needs; 2) Tailor care to patient; 3) Build rapport/open communication; 4) Facilitate communication between patient and health care team; 5) Educate/provide resources to the patient; 6) Advocate; 7) Self-motivated learning; 8) Address barriers to care; 9) Involve/meet the needs of family or support people; 10) Educate/support health care team; and, 11) Support patient empowerment in care. Cancer care settings should use navigators with direct knowledge of patient culture whenever possible; however, communication and cultural competence training is highly recommended for all navigators given the diversity of patient needs. **Full text:** <https://goo.gl/8GwDpg>

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Noted in Media Watch 23 April 2018 (#560, p.15):

- *PALLIATIVE MEDICINE* | Online – 18 April 2018 – ‘**How family caregivers help older relatives navigate statutory services at the end of life: A descriptive qualitative study.**’ A key challenge in meeting the palliative care needs of people in advanced age is the multiple healthcare and social service agencies typically involved in their care. The “patient navigator” model, originally developed in cancer care, is the professional solution most often recommended to address this challenge. However, little attention has been paid, or is known, about the role that family carers play in enabling their dying relatives to negotiate service gaps. **Abstract:** <https://goo.gl/2h5ueJ>

Reckoning with the last enemy

THEORETICAL MEDICINE & BIOETHICS | Online – 10 August 2018 – Developing the ethics of palliative sedation (PS), particularly in contrast to terminal sedation, requires consideration of the relation between body and soul and of the nature of death and dying. Christianly considered, it also requires attention to the human vocation to immortality and hence to the relation between medicine (as aid for the body) and discipline (as aid to the soul). The author provides a larger anthropological and soteriological frame of reference for the ethics of PS, organized by way of nine briefly expounded theses. He argues that PS, like other elements of medicine, is appropriate where, and only where, it properly orders care for the body to the requirements of care for the soul. **Abstract (inc. list of references):** <https://goo.gl/fuLsnY>

N.B. Selected articles on palliative sedation noted in the 13 August 2018 issue of Media Watch (#576, p.15).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *EUROPEAN JOURNAL OF HEALTH LAW*, 2018;25(4):407-425. ‘**Legalisation of euthanasia in Finland: Via a citizens’ initiative?**’ This article combines two legal and ethical questions: 1) The new Finnish method of citizens’ democratic participation (the citizens’ initiative); and, 2) The complex and controversial question of euthanasia. Both are currently pertinent questions in Finland. The citizens’ initiative institution is a success, especially for liberal people and human rights organisations in promoting issues which coalition governments are not ready to submit to the Parliament of Finland. The euthanasia question meets these requirements and the citizens’ initiative on euthanasia in principle has a good chance of succeeding in the parliament, but the result is unpredictable. Many members of the parliament have not yet decided their attitude to euthanasia, which is a more complicated issue than, say, same-sex marriage. **Abstract:** <https://goo.gl/iprAJ3>
- *MEDICAL LAW INTERNATIONAL* | Online – 12 August 2018 – ‘**Assisted dying challenges: Dynamic and stasis in the U.K. courts: Conway v. Secretary of State for Justice.**’ Mr. Conway’s argument, that section 2(1) Suicide Act is incompatible with his right of respect for his private life under Article 8(1) European Convention on Human Rights, adopted as a Convention right for the purposes of the Human Rights Act 1998, was dismissed. This commentary discusses four themes arising from the case. **Abstract:** <https://goo.gl/qExzSy>

Noted in Media Watch 2 July 2018 (#570, p.5):

- U.K. | Associated Press (London) – 27 June 2018 – ‘**U.K. court rules against dying man’s bid for assisted suicide.**’ Britain’s Court of Appeal has rejected an attempt from a terminally ill man to overturn the country’s blanket ban on assisted suicide, ruling that such a decision needs to be made by politicians in Parliament. Judges expressed their “deep sympathy” with Noel Conway, a 68-year-old man with motor neuron disease who is wheelchair-bound and requires nearly constant help to breathe. <https://goo.gl/14YCgd>

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- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 11 August 2018 – ‘**The spectrum of end of life care: An argument for access to medical assistance in dying (MAiD) for vulnerable populations.**’ MAiD was legalized by the Supreme Court of Canada in June 2016 and became a legal, viable end-of-life care (EoLC) option for Canadians with irremediable illness and suffering. Much attention has been paid to the balance between physicians’ willingness to provide MAiD and patients’ legal right to request medically assisted death in certain circumstances. In contrast, very little attention has been paid to the challenge of making MAiD accessible to vulnerable populations. The purpose of this paper was to examine the extant literature and resources that are available on the provision of MAiD in Canada. The authors found that the provision of EoLC in Canada offers insufficient access to palliative and EoLC options for Canadians and that vulnerable Canadians experience disproportional barriers to accessing these already limited resources. Consequently, they argue that palliative care, hospice care and MAiD must be considered a spectrum of EoLC that is inclusive and accessible to all Canadians. The authors conclude by imploring Canadian healthcare professionals, policy makers and legislators to consider MAiD as a viable EoLC option for all Canadians. **Abstract (w. list of references):** <https://goo.gl/rNy7u3>
- *QUALITY HEALTH RESEARCH* | Online – 13 August 2018 – ‘**Cultivating compassion: The practice experience of a medical assistance in dying coordinator in Canada.**’ Accessing medical assistance in dying (MAiD) became legal in Canada in June 2016. This marks a unique time in our history, as eligible persons can now opt for an assisted death and health care professionals can be involved without criminal repercussion. The author used an autoethnographic approach to explore and describe her experience of implementing and coordinating a new MAiD program in a local health authority. Part I is a self-reflexive narrative based on journal entries about my immersion in this practice role over a 6 month period. In Part II, the author shares five emergent storylines: coming to the role (the calling), embodiment (becoming the face of), immersion in clinical practice, interactions with those seeking MAiD, and self survival (sense making). The created story and storylines shine a light on new ethical practice realities, enhance understanding about MAiD as it continues to unfold, and hopefully inspire human centered, compassionate care. **Abstract:** <https://goo.gl/XVtN4k>

Journal Watch

British Columbia economist in grim battle against deceptive scholarship

CANADA | *The Vancouver Sun* – 12 August 2018 – A determined British Columbia (BC) economics professor has journeyed into the heart of a dark world where academics seeking to advance their careers have had hundreds of thousands of their articles published for a fee in journals that either deserve suspicion or are outright phoney. In academia, where the admonition to “publish or perish” is not an empty threat, it is often difficult for scholars to have their research published in legitimate journals, let alone top ones. But it’s becoming increasingly common for academics to get articles produced in questionable journals, just by forking over \$100 to \$2,500 (Cdn). Derek Pyne, a Thompson Rivers University economist who was granted tenure in 2015, is among the global academics who are exposing the deceptive journals, sometimes at a risk to their careers. Experts say these journals are chipping away at scientific, medical and educational credibility – and wasting the money of the taxpayers who largely finance public colleges and universities. Pyne’s pioneering research has been cited by *The New York Times* and *The Chronicle of Higher Education*.^{1,2} On 23 June, *The Economist*, in a piece on blacklisted journals, praised the BC scholar, remarking: “This is an area in which data are hard to come by. But one academic has been prepared to stick his neck out and investigate his own institution.”³ <https://goo.gl/WY8vYs>

1. ‘Many academics are eager to publish in worthless journals,’ *The New York Times*, 30 October 2017. [Noted in the 6 November 2017 issue of Media Watch (#537, p.13)] <https://goo.gl/wbh42J>
2. ‘Does it pay to be published in “predatory” journals?’ *The Chronicle of Higher Education*, 20 May 2017. <https://goo.gl/MEQWuy>
3. ‘What are “predatory” academic journals?’ *The Economist*, 10 July 2018. [Noted in the 16 July 2018 issue of Media Watch (#572, pp.14-15). <https://goo.gl/n4tVCM>

“Predatory” is a misnomer in the unholy nexus between journals and plagiarism

INDIA | *The Wire* (Delhi) – 10 August 2018 – The recent investigation by *Indian Express* on the proliferation and success of fake journals,¹ inappropriately called “predatory” journals, raises a few questions for the academic community: Why do the fake journals succeed? What is the role of the academicians in the whole unsavoury episode? At the outset, it is imperative to point out that it is incorrect to call them “predatory” journals because the term predatory suggests that there is a predator and a victim. The academicians who publish in these journals are not victims; most often, they are self-serving participants. The measure of success is the number of articles received by these journals. The journals provide a space to those who wanted easy credit. And a large number of us wanted this easy credit because we were, to begin with, not suitable for the academic profession and were there for the job. In essence, these journals could not have succeeded without an active participation and the connivance of some of us. We academicians engage in teaching (disseminating known knowledge) and researching (creating knowledge). The knowledge created through research is mostly disseminated through publication in appropriate forums à la journals. Those who create knowledge are generally assumed to follow certain moral guidelines, at times explicitly defined by various institutions. The success of fake journals shows that we have failed somewhere. <https://goo.gl/BkvXZ5>

1. ‘The fake academia,’ *The India Express* (Mumbai), 21 July 2018. <https://goo.gl/ymtbXm>

Predatory publishers: The journals that churn out fake science

U.K. (England) | *The Guardian* (London) – 10 August 2018 – A vast ecosystem of predatory publishers is churning out “fake science” for profit, an investigation by *The Guardian* in collaboration with German publishers NDR, WDR and *Süddeutsche Zeitung Magazin* has found [see sidebar]. More than 175,000 scientific articles have been produced by five of the largest “predatory open-access publishers,” including India-based Omics publishing group and the Turkish World Academy of Science, Engineering & Technology (WASET). But the vast majority of those articles skip almost all of the traditional checks and balances of scientific publishing, from peer review to an editorial board. Instead, most journals run by those companies will publish anything submitted to them – provided the required fee is paid. To demonstrate the lack of peer review, Svea Eckert, a researcher who worked with NDR on the investigation, successfully submitted an article created by the joke site SC1gen, which automatically generates gibberish computer science papers. The paper was accepted for discussion at a WASET conference, which Eckert attended and filmed for NDR. In British universities alone, more than 5,000 scientists have published articles through Omics and

WASET in the past five years, according to a *Guardian* analysis. <https://goo.gl/MJ516B>

5,000 German scientists have published in predatory journals

CHEMISTRY WORLD | Online – 3 August 2018 – Public broadcasters in Germany are reporting that more than 5000 of the country’s scientists have published work in what they call ‘pseudo-scientific’ or predatory journals. NDR and WDR, together with the newspaper *Süddeutsche Zeitung*, found papers authored by German researchers from across academia and industry in online publications that charge large upfront fees to publish open access work that does not undergo full peer review or proper editorial checks. In Germany, they report, the number of such publications is five times higher than five years ago and the scale of predatory publishing activity continues to grow. Globally, they estimate 400,000 scientists have been involved. They found papers published in suspect journals that had been authored by prominent German academics caught up in the scandal... They also found papers authored by employees from large German pharmaceutical companies. **Full text:** <https://goo.gl/qYSqjQ>



Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

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.

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

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE:
<https://goo.gl/T2tCWF>

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

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

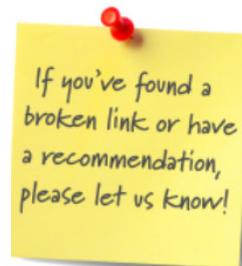
PALLIMED: <http://goo.gl/7mrgMQ>

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

Asia

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

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



Cont.

Australia

PALLIATIVE CARE WESTERN AUSTRALIA: <https://goo.gl/fCzNTL>

[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

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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