

Media Watch...

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

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Compilation of Media Watch 2008-2018 ©

Compiled & Annotated by Barry R. Ashpole

'The challenges of palliative and end-of-life care in tertiary care state psychiatric hospitals' (p.8), in *American Journal of Psychiatry*.

Canada

Measuring Up 2018: A yearly report on how Ontario's health system is performing

ONTARIO | Health Quality Ontario – 16 November 2018 – People in Ontario are, on average, seeing overall improvements in many aspects of their health, and in the care they receive. They are living longer and are less likely to die before the age of 75. More people are having cancer surgery or general surgery within the recommended wait times. And more people are receiving palliative care in their home in their last days of life. These examples show that improvement is possible, especially when there are focused and sustained efforts by many organizations in the health system to make progress on key indicators. However, while there are bright spots scattered throughout the health system, an aging population and more people with complex health needs means many parts of the system are under increased strain... **Download/view report at:** <https://goo.gl/H7JSRD>

N.B. See 'Palliative Care at the End of Life,' Health Quality Ontario, June 2016. [Noted in 4 July 2016 issue of Media Watch (#469, p.2); selected articles on palliative care in the province also noted in this issue of the weekly report.] **Download/view at:** <https://goo.gl/jTW7qa>

Extract from Health Quality Ontario report

There has been some improvement in home-based palliative care

Among people who lived in the community during their last 30 days of life, 25.8% received a home visit from a doctor in 2016-2017, compared to 20.0% in 2011-2012. For this indicator, people in the community included those who lived in their own home, a hospice, or assisted living facility, and excluded those in a hospital, long-term care home or complex continuing care facility. Also in 2016-2017, 25.5% received a palliative-specific home care service during their last month of life, compared to 22.6% in 2011-2012. The proportion who received any home care visit, including a palliative-specific visit, rose to 51.2% from 47.1%. Even with these improvements, about 3 out of 4 people who lived in the community during their final 30 days did not receive a home visit from a doctor, 3 out of 4 did not receive a palliative-specific home care visit, and about half did not receive any home care.

Specialist Publications

'The location of death and dying across Canada: A study illustrating the socio-political context of death and dying' (p.16), in *Societies*.

Caregivers vital to healthcare system, but often untrained and unsupported: Report

ONTARIO | CTV News (Toronto) – 15 November 2018 – They come from all walks of life, young and old: millions of Canadians who are unpaid caregivers for aging parents, children with a disability or a sibling with a chronic illness. Yet a survey reveals many are struggling, often in isolation, trying to fulfil a critical role with not enough support from the healthcare system.¹ Results of the Ontario-based survey of 800 caregivers aged 16 and older ... paints a picture of people often thrown unexpectedly into a role for which they typically aren't trained and one that has major effects on their physical and mental health, relationships and careers paths. The online survey ... found that caregivers overall appreciated the time spent with their loved ones and believed they were improving their lives. But 61% admitted they took on the role because

they believed they had no choice, with many at times feeling trapped, helpless, frustrated and overwhelmed. The survey found 36% of caregivers felt depressed and 33% were resentful of their role, with almost half overall saying caregiving had negatively affected their ability to have personal time, engage in travel or enjoy a social life. <https://goo.gl/u6eoyS>

Specialist Publications

“‘It’s not just the word care, it’s the meaning of the word...(they) actually care’”: Caregivers’ perceptions of home-based primary care in Toronto, Ontario’ (p.7), in *Ageing & Society*.

1. ‘Spotlight on Ontario’s Caregiver,’ The Change Foundation, November 2018. **Download/view report at:** <https://goo.gl/86YMsh>

Noted in Media Watch 27 August 2018 (#578, p.5):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – Accessed 20 August 2018 – ‘**Education, training, and mentorship of caregivers of Canadians experiencing a life-limiting illness.**’ This study involved a rapid literature review that addressed caregiver experiences, needs and issues as they related to health, quality of life and well-being. The author outlines the resources required for a suitable education, training, and mentorship of caregivers of Canadians experiencing a life-limiting illness. **Full text:** <https://goo.gl/RgXuVu>

What’s working and what’s not in Canada’s cancer system: Report points to where action is needed

CANADIAN PARTNERSHIP AGAINST CANCER | Online – 13 November 2018 –This is the latest in a series of reports that shine a light on areas of Canada’s cancer system – from prevention and screening, through to treatment, survivorship and end-of-life care – to show what’s working and where improvements are needed. Ten years ago there was little consistently available information on the quality of cancer care across Canada. Over the past nine years, the Partnership has been working with national partners, provincial cancer agencies and territorial health authorities to identify what data exist and can be measured, to drive change. The 2018 report shows where improvement is needed. **Download/view report at:** <https://goo.gl/aPXJ1j>

Extract from Canadian Partnership Against Cancer report (p.39)

Two-thirds of cancer patients die in hospital, even though many would prefer to die at home. Surveys consistently indicate patients prefer spending as many of their final days as possible in a comfortable, non-clinical environment surrounded by loved ones – which is often their home. Palliative care (PC) at home usually requires additional supports to manage symptoms adequately. However, complications of therapy and other adverse events may require a patient to be admitted to hospital in their final days. Although most patients with cancer die in hospital, the percentage decreased from 71.6% in 2008 to 65.9% in 2013. This means that slightly more patients are dying outside hospital settings, including hospices, residential care, and at home.

Indigenous interprofessional primary care team to offer traditional programs to support First Nations

ONTARIO | *Anishinabek News* (North Bay) – 13 November 2018 – Indigenous peoples in the Nipissing-Timiskaming region will have access to a full range of healthcare services now that an Indigenous health-care team has been developed. Full-service healthcare has historically been missing for most of the Indigenous population in the Northeastern region. With the Indigenous population rising, it is welcome news that a plan is now in place for the new North Bay Indigenous interprofessional primary care Team to fill the gaps in healthcare. A healthcare team will travel to the First Nations of Nipissing, Dokis, and Temagami and there will be an office in North Bay in a new Indigenous Community Hub, the founding partners along with the North Bay Indigenous Friendship Centre. The new North Bay Indigenous interprofessional primary care team will serve 5,500 Indigenous people from the Nipissing-Timiskaming region. The priority population will include status and non-status First Nations, Inuit, and Métis. Kathy Fortin, the Executive Director of the North Bay Indigenous Friendship Centre, identified traditional services and programming as a high need for the urban Indigenous population for wellness. End-of-life care is also a high priority... <https://goo.gl/XXYVQq>

N.B. Selected articles on culturally sensitive palliative and end-of-life care for Canada's Indigenous and First Nations peoples noted in 24 September 2018 issue of *Media Watch* (#582, p.5).

U.S.A.

Dress rehearsal for death: Using virtual reality to foster empathy for dying patients

MASSACHUSETTS | WBUR Radio (Boston) – 16 November 2018 – Researchers have discovered that virtual reality simulations – often called empathy machines – can make viewers more empathetic to people they embody: people of different races; the colorblind; even an avatar of an older you. The United Nations has created about 20 virtual reality films, including one about a 12-year-old Syrian refugee and another profiling a Liberian woman whose family died from Ebola. Last month, Stanford University's Virtual Human Interaction Lab, which studies the link between virtual reality and empathy, found that people who embodied a homeless person were more likely to sign a petition supporting affordable housing than people who read a narrative asking them to imagine themselves homeless. In medicine, virtual reality has been used to reduce pain, help stroke victims recover and allow doctors to plan and watch surgery. Embodied Labs is one of the first companies whose videos have allowed viewers to “experience” dying, but elsewhere, virtual reality has also been used directly with dying patients. Hospitals and hospices have fitted patients with headsets to allow them to see places on their bucket lists. At a pilot program at the Royal Trinity Hospice in London, a dying woman and her husband re-visited Venice, where they had gotten engaged. Another woman walked the beaches of the Maldives. A third re-

turned to Jerusalem, the city where she grew up. <https://goo.gl/P7RhXW>

Specialist Publications

'Palliative care for inmates in the hospital setting' (p.7), *American Journal of Hospice & Palliative Medicine*.

'Strengthening the workforce for people with serious illness: Top priorities from a national summit' (p.10), in *Health Affairs*.

'Advance care planning among American Indians' (p.11), in *Innovation in Aging*.

'Better together: Coexistence of for-profit and nonprofit firms with an application to the U.S. hospice industry' (p.12), in *Journal of Health Economics*.

'Elisabeth Kübler-Ross and the “five stages” model in a sampling of recent American textbooks' (p.15), in *Omega – Journal of Death & Dying*.

'American Medical Association: Still a 'No' on physician-assisted suicide' (p.18), *MedPage Today*.

Challenges and cultural barriers faced by Asians and Latinos at the end of life

CALIFORNIA | KALW Public Radio (San Francisco) – 15 November 2018 – Overcoming barriers and navigating cultural norms is not easy and requires health professionals and patients working together as equal partners. The end of life (EoL) is not easy for most Americans nearing death. The good news is that up to ninety percent of pain and suffering can be controlled. But the bad news is that over half of all dying Americans experience unwanted pain and suffering during their final days. And the numbers are even greater for people of color. African-Americans, Asians, and Latinos have less access to the pain medication and comfort care that hospice can provide at the EoL compared to whites. Asians, Latinos, and other ethnic minorities whose second language is English face additional challenges. Language barriers and cultural traditions can inhibit awareness of and discussions about EoL options and are often compounded by poverty and lack of education. <https://goo.gl/4hqFVQ>

Related

- CALIFORNIA | KALW Public Radio (San Francisco) – 14 November 2018 – ‘**Racial disparities in end-of-life care: How mistrust keeps many African-Americans away from hospice.**’ The end of life (EoL) is not easy for most people nearing death. Over half of all Americans experience unwanted pain and suffering during their final days. The numbers are even greater for people of color. Mistrust of the medical system is a major reason why many African-Americans avoid hospice. Overcoming mistrust is key to reducing racial disparities in accessing comfort care at the EoL. <https://goo.gl/XcBo7P>

N.B. Additional articles on racial disparities in the provision and delivery of end-of-life care in the U.S. noted in 5 November and 16 July 2018 issues of Media Watch (#588, p.3 and #572, p.5, respectively).

Bioethics in practice: To pursue life or to give in to death

STATE OF NEW YORK | *The Commentator* (Yeshiva University) – 11 November 2018 – In 1991, the government enacted the Federal Patient Self-Determination Act, which states that doctors must communicate with their patients a full report of their options in terms of their medical treatment and respect whatever decision the patient decides, regardless of what they personally believe. They are to express the complications, limitations and reality of a patient’s care, including whether or not extended care may be futile. As a doctor, this reality brings up many ethical questions. If a patient and/or their family decide to refuse treatment, they are going against the very fabric of values that holds the medical profession together. Doctors now have to properly balance respect for the wishes of their patient, regardless of their own beliefs, with the best avenue of treatment, while also thinking about medical limitations. Another problem that this brings up is the reality that long-term care has a significant cost, and there is an increasing

lack of resources. As more and more people choose to pursue end-of-life care, healthcare becomes gradually more and more unaffordable. Insurance prices increase and are becoming significantly more expensive, and those who need care but cannot pay for it are left with nothing. Doctors and hospitals now have to consider not only what to do for the patient, but also whether or not providing the care is even affordable. In the realm of *halakha* [i.e., Jewish law and jurisprudence], end-of-life care has become a very complicated and controversial topic. <https://goo.gl/da54yt>

[Specialist Publications](#)

‘End-of-life care: Law, ethical principles, and Jewish medical ethics’ (p.8), in *Annals of Longterm Care*.

Cont. next page



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Noted in Media Watch 23 January 2017 (#496, p.13):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 19 January 2017 – ‘**A systematic review of religious beliefs about major end-of-life issues in the five major world religions.**’ The authors’ search strategy generated 968 references, 40 of which were included for this review. A wide degree of heterogeneity was observed within religions, depending on the country of origin, level of education, and degree of intrinsic religiosity. This review describes the religious practices pertaining to major end-of-life (EoL) issues and explains the variations in EoL decision making by clinicians and patients based on their religious teachings and beliefs. **Abstract (w. list of references):** <https://goo.gl/0Lh72z>

Noted in Media Watch 24 August 2015 (#424, p.17):

- *THE LANCET*, 2015;386(10005):1776-1785. ‘**Controversies in faith and healthcare.**’ Improved understanding of the heterogeneity of viewpoints, both within and between faiths, and their effect on healthcare is important for clinical medicine, public-health programmes, and healthcare policy. Increased appreciation in faith leaders of the effect of their teachings on healthcare is also crucial. This article outlines some faith-related controversies, describes how they influence healthcare provision and uptake, and identifies opportunities for research and increased interaction between faith leaders and healthcare providers to improve healthcare. **Abstract:** <https://goo.gl/QqKAgF>

International

Staffing shortfall of almost 250,000 by 2030 is major risk to National Health Service long-term plan, experts warn

U.K. (England) | The King’s Fund – 15 November 2018 – Critical and lasting shortages in the healthcare workforce mean that the forthcoming National Health Service (NHS) long-term plan risks becoming an unachievable “wish list” of initiatives to improve the health service. If unaddressed, these shortages could lead to growing waiting lists, deteriorating care quality and the risk that some of the money for frontline services pledged at the Budget will go unspent, according to a new briefing published today by The King’s Fund, the Health Foundation and the Nuffield Trust. ‘The healthcare workforce in England: Make or break?’ draws on a new forecast of the staffing gaps emerging in the 1.2 million-strong NHS workforce. It predicts an increase in NHS staff shortages from over 100,000 at present to almost 250,000 by 2030, warning that this could mean that over one in six health service posts are short of an appropriate staff member by the

end of the next decade. The organisations warn these shortages could be over 350,000 if the NHS continues to lose staff and cannot attract skilled workers from abroad. **Download/view briefing at:** <https://goo.gl/vkzjSo>

Specialist Publications

‘**Identifying palliative care needs in residential care**’ (p.9), in *Australian Journal of Primary Health*.

‘**Māori: Living and dying with cardiovascular disease in Aotearoa New Zealand**’ (p.9), in *Current Opinion in Supportive & Palliative Care*.

“‘**Thou shalt not die in this place**”: **An ethno-methodological approach to an Ecuadorian hospice through symbolic interactionism**’ (p.15), in *Omega – Journal of Death & Dying*.

Noted in Media Watch 29 January 2018 (#548, pp.9-10):

- *HEALTH ECONOMICS, POLICY & LAW* | Online – 23 January 2018 – ‘**Projecting shortages and surpluses of doctors and nurses in the Organisation for Economic Co-operation & Development: What looms ahead.**’ The authors work develops a projection model for demand of doctors and nurses by Organisation for Economic Co-operation & Development (OECD) countries. They project a shortage of nearly 400,000 doctors across 32 OECD countries and shortage of nearly 2.5 million nurses across 23 OECD countries in 2030. **Abstract (inc. list of references):** <https://goo.gl/up8Hwi>

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Noted in Media Watch 9 May 2016 (#461, p.4):

- U.K. (England) | Care Appointments – 5 May 2016 – **‘Too many care providers “flying blind” about end-of-life care workforce.’** A lack of data about palliative care (PC) staff could lead to staff shortages in the next few years, a new report has said.¹ The report found a lack of data about staff working in palliative and end of life care (EoLC), making it hard to know if there will be enough staff to meet the rising need for EoLC. Based on the data it did gather, 44% of senior PC nurses were aged over 50 in 2013, and this percentage has risen in each of the last five surveys. <http://goo.gl/jbnzul>

1. ‘Staff prepared to care? Capacity and competence in the end of life care workforce,’ National Council for Palliative Care, May 2016. **Download/view at:** <http://goo.gl/HaJJB0>

Home help hours provision a “postcode lottery,” figures show

IRELAND | *The Irish Times* (Dublin) – 13 November 2018 – More than 6,200 older people are waiting for urgently required home care supports as the population ages, new figures indicate. The provision of home help hours and other care supports for older people has become a “postcode lottery,” the figures show, with huge variations in the size of the waiting list in different areas. Galway has the longest waiting list for home support services, with 674 people on the list last August, according to the figures from the Health Service Executive (HSE). Dublin North recorded 623 people on the waiting list and Wexford and Laois/Offaly each had 578 on their lists. In contrast, there were no people waiting for supports in Kerry, North Cork, North Lee in Cork city, Carlow/Kilkenny and South Tipperary. Demand for home support continues to grow and waiting lists have become a feature of the system, the HSE admits. The trend is set to continue each year and, as the number of over-65s increases, demand for new support services increases. Those already receiving help become more dependent, so additional supports are needed for existing clients, the HSE says. <https://goo.gl/sqdAhs>

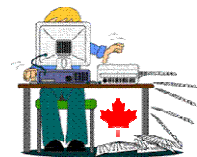
Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Queensland) | *The Brisbane Times* – 14 November 2018 – **‘Premier launches inquiry into the legalisation of voluntary euthanasia.’** Queenslanders will be asked for their views on whether the state should legalise voluntary euthanasia as part of a 12-month inquiry. Premier Anastacia Palaszczuk launched a parliamentary inquiry into the delivery of aged care, end of life and palliative care in Queensland across the health and ageing service sector. The inquiry will canvass the Queensland community and health practitioners’ views on the desirability of supporting voluntary assisted dying, including changing the law to legalise euthanasia, and safeguards to protect vulnerable people. <https://goo.gl/2HdLvH>
- NEW ZEALAND | *The Dominion Post* (Wellington) – 13 November 2018 – **‘Parliamentary tour for end-of-life choice bill comes to a close.’** After four months and more than 2000 oral submissions, the largest-ever parliamentary hearing has come to a close. Parliamentarians travelled to 14 cities to hear the country’s views on the end-of-life choice bill, which will legalise assisted death, ended on Monday. MPs will now hear from international submitters before committee staff complete the unenviable task of condensing the views expressed into a report early in 2019. The vast majority of public submissions heard were against the bill, and suggestions to amend it have MPs considering whether to confine it to terminal illness or include additional restrictions. <https://goo.gl/T9ikjY>

[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>



Specialist Publications

“It’s not just the word care, it’s the meaning of the word...(they) actually care”: Caregivers’ perceptions of home-based primary care in Toronto, Ontario

AGEING & SOCIETY, 2018;38(10):2019-2040. The frail and homebound older adult populations currently experience difficulties accessing primary care in the medical office. Given this fundamental access to care problem, and the questionable care quality that arises when navigating a labyrinthine healthcare system, these populations have typically been subject to inadequate primary care. To meet their needs better, growing research stresses the importance of providing comprehensive home-based primary care (HBPC), delivered by an inter-professional team of healthcare providers. Family caregivers typically provide the majority of care within the home, yet their perceptions of HBPC remain under-researched. Findings [of this study] suggest that, compared to the standard office-based care model, HBPC may better support unpaid caregivers, providing them assistance with system navigation and offering them the peace of mind that they are not alone, but have someone to call should the need arise. The implications of this research suggest that HBPC could be a model to help mitigate the discontinuities in care that patients with comorbid chronic conditions and their attendant unpaid caregivers experience when accessing fragmented health, home and social care systems. **Abstract (inc. list of references):** <https://goo.gl/gJv91J>

Palliative care for inmates in the hospital setting

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 November 2018 – The U.S. population of inmates continues to increase along with a rapid escalation in the number of elderly prisoners. Previous studies have demonstrated multiple barriers to providing palliative care (PC) for seriously ill inmates. The aim of this study was to assess the frequency of PC consultation and nature of consultation requests for inmates who died while hospitalized at a large tertiary care hospital. A retrospective chart review of all inmate decedents over a 10-year time period was conducted. The reason and timing of consultation was noted in addition to symptoms identified and interventions recommended by the PC team. Characteristics of patients who were transferred to the inpatient PC unit were also recorded. Forty-five percent of inmates were seen by PC prior to their death. Timing of consultation was close to the day of death. Inmates with cancer were significantly more likely to have a PC consultation prior to death. The most frequent intervention recommended was opiates for pain or dyspnea. Delirium was often missed by the primary team but was identified by the PC team. Nearly, 5000 prisoners die each year, mostly in community

hospitals. These patients exhibit similar symptoms to free-living patients. Given that the inmate population has a higher rate of comorbid conditions, there is a need for more research to identify areas of need for incarcerated patients and where PC can best serve these individuals.

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



Prison Hospice: Backgrounder

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 can be downloaded/viewed on the Palliative Care Network website at: <https://goo.gl/dqwNBA>

Photo: Lori Waselchuk. Philadelphia, PA



Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.18.

The challenges of palliative and end-of-life care in tertiary care state psychiatric hospitals

AMERICAN JOURNAL OF PSYCHIATRY (Residents' Journal), 2018;13(8):8. There is a dearth of literature on the practice of palliative and end-of-life care (EoLC) in tertiary care psychiatric hospitals, where patients can stay for extended lengths of time, even decades. Patients who stay for long periods in psychiatric hospitals, particularly geriatric patients, may find themselves in need of palliative and EoLC.¹ This includes patients with illnesses such as cancer, organ failure, and neurodegenerative diseases as well as patients with dementia, a terminal condition frequently encountered in psychiatric hospitals. Unfortunately, among family caregivers and even nursing staff, dementia is often not viewed as a terminal illness. Interestingly, a study conducted in Australia showed that around 50% of nursing staff and 60% of family caregivers did not consider dementia to be a terminal condition,² which reflects the necessity to increase awareness about palliative care needs among both healthcare professionals and care-

givers. Currently, there is no published epidemiologic study that provides data on the estimated number of patients in need of EoLC in state psychiatric hospitals. Data related to forensic patient populations are complex; however, individuals who are found not guilty by reason of insanity and persons who are classified as civilly committed sex offenders can remain hospitalized for decades. There are numerous barriers to providing EoLC for patients with severe, persistent mental illness in state hospitals. **Full text:** <https://goo.gl/zn3WDi>

The logo consists of a green rectangular background with white text. The text reads "THE AMERICAN JOURNAL OF PSYCHIATRY" in a large, bold, sans-serif font, with "RESIDENTS' JOURNAL" in a smaller, bold, sans-serif font below it.

Special issue on hospice and palliative care.
Journal contents page: <https://goo.gl/wCNa2f>

1. 'End-of-life care in a psychiatric hospital,' *BJPsych Bulletin*, 2016;40(3):149-152. **Full text (via PubMed):** <https://goo.gl/PCjxUQ>
2. 'Who knows, who cares? Dementia knowledge among nurses, care workers, and family members of people living with dementia,' *Journal of Palliative Care*, 2014;30(3):158-165. **Full text (click on pdf icon):** <https://goo.gl/m58o4X>

Noted in Media Watch 20 October 2014 (#380, p.10):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 15 October 2014 – '**Identifying patients in the acute psychiatric hospital who may benefit from a palliative care approach.**' Criteria are established that identify hospitalized medical patients who are near end of life, yet there are no criteria with respect to hospitalized patients with psychiatric disorders. The records of 276 consecutive patients admitted to a dedicated inpatient psychiatric unit were reviewed to identify prognostic criteria predictive of mortality. Twenty-two percent of patients met non-cancer criteria for dementia. Palliative care intervention should be considered when treating inpatients with psychiatric disorders, especially older patients who have a previous hospitalization or history of dementia. **Abstract:** <https://goo.gl/s6e4Np>

End-of-life care: Law, ethical principles, and Jewish medical ethics

ANNALS OF LONGTERM CARE, 2018;26(4):25-31. Consistent with appropriate clinical practice and professional regulations, Jewish medical ethics espouses beneficence, non-maleficence, justice, and autonomy. The principles of Jewish medical ethics and the intersection with secular law as it pertains to end-of-life care (EoLC) in patients are addressed. The exploration of a methodology and doctrine to cover instances when Jewish ethics clashes with clinical judgment is explored. Issues such as refusal of treatment, terminal illness, withholding and withdrawing treatment, informed consent, cardio-pulmonary resuscitation and do-not-resuscitate orders, advance directives, nutrition and hydration, and others are discussed. A comparison of Jewish and secular principles in EoLC and differences among Jewish sects is included. **Abstract:** <https://goo.gl/328AWK>

Identifying palliative care needs in residential care

AUSTRALIAN JOURNAL OF PRIMARY HEALTH | Online – 14 November 2018 – The aim of this study is to determine the accuracy, feasibility and acceptability of the surprise question (SQ) in combination with a clinical prediction tool (Supportive & Palliative Care Indicator Tool (SPICT)) in identifying residents who have palliative care (PC) needs in residential aged care facilities (RACFs) in Australia. Directors of nursing screened 187 residents at risk of dying by 12 months using first the SQ and, if positive, then the SPICT. At 12-months follow-up, deaths, hospitalisations, use of PC services, end-of-life (EoL) care and clinical indicators were recorded. The SPICT marginally increased the ability to identify residents in need of proactive EoL planning. A combination of the SQ and the SPICT is effective in predicting PC needs in residents of aged care facilities, and may trigger timely care planning. **Abstract (inc. list of references):** <https://goo.gl/1TpCQz>

Noted in Media Watch 9 October 2017 (#533, p.5):

- AUSTRALIA (Australian Capital Territory) | *Australian Ageing Agenda* (Canberra) – 4 October 2017 – ‘**A new palliative approach for residential aged care.**’ The Palliative Care Needs Rounds Checklist is undergoing a second trial in 12 facilities after a pilot at four sites in 2014-2015 showed the benefits of taking a proactive integrated approach to providing specialist palliative care within aged care facilities. Benefits of the tool include improved skills and knowledge of the care team, cost-effectiveness for the acute sector, and an increased possibility for residents to die in their preferred place with pain and suffering well managed, according to the study.¹ <https://goo.gl/F75UPn>
1. ‘Improving specialist palliative care in residential care for older people: A checklist to guide practice,’ *BMJ Supportive & Palliative Care*, published online 2 August 2017. [Noted in 7 August 2017 issue of Media Watch (#524, p.8)] **Abstract:** <https://goo.gl/vQ6PXV>

Practical strategies for optimizing and integrating palliative care in cancer

CURRENT ONCOLOGY REPORTS | Online – 13 November 2018 – Recent reforms in medical payment [in the U.S.] coupled with a rapidly evolving pharmacotherapeutic armamentarium is creating a transition in the field of oncology. This transition represents a key period for conceptual re-evaluation, providing an opportunity for furthered strategic integration of palliative care (PC) within the realm of oncology. Historically, oncologists have relied upon prognostic assessments to gauge appropriateness for referrals to specialty PC. Recent literature has elucidated on the early palliative burdens of cancer, demonstrated the importance of complexity-based palliative referrals, and begun the conversation to define provider-specific roles. The authors describe a model that overlaps complexity with oncology capacity, to target specialty services to those who could benefit most. They review the role of PC as a care philosophy, the enduring and important role of the oncologist in providing PC, and the important areas for integration of specialty services when needed. **Abstract (inc. list of references):** <https://goo.gl/TifDJU>

Related

- *CURRENT ONCOLOGY REPORTS* | Online – 13 November 2018 – ‘**Palliative care in patients with leukemia: When and how?**’ Patients with hematologic malignancies get more aggressive treatment and the end-of-life, more ICU deaths, and prolonged hospital stays. In comparison to solid tumors, their access to palliative care and hospice is less. Multiple factors seem to play a role including curative goals, different treatment options, stronger relationship between patients and oncologist, symptom burden, and limitations of hospice care. **Abstract (inc. list of references):** <https://goo.gl/upc5sj>

Māori: Living and dying with cardiovascular disease in Aotearoa New Zealand

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 13 November 2018 – Cardiovascular disease (CVD) is New Zealand's leading cause of premature deaths and disability among Māori. A projected rise in older Māori deaths within the next 30 years will require increased palliative care (PC). Māori families provide the bulk of care at end of life (EoL), but they can become fatigued with the chal-

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Challenges that accompany long-term progressive illnesses, such as CVD. They are also burdened by the financial costs associated with EoL. It is often difficult for Māori to access PC and to obtain and understand information about the illness and treatment. Navigating an unfamiliar and complex health system, low health literacy among Māori and poor relationship building and communication skills of health professionals are significant barriers. Cultural safety training would help to increase health and cardiovascular professionals' cultural understanding of Māori and their holistic EoL preferences; this could go some way to strengthen rapport building and communication skills necessary for effective engagement and informational exchanges. Increasing the Māori PC workforce and introducing cultural safety training among health professionals could help to bridge the gap. A current study to gather traditional care customs and present these to whānau and the health and PC sectors in the form of an online resource could contribute to this decolonizing objective. **Abstract:** <https://goo.gl/NoC15m>

N.B. Additional articles on Māori beliefs and practices in the context of end of life and end-of-life care noted in 27 August 2018 issue of Media Watch (#578, p.15).

Strengthening the workforce for people with serious illness: Top priorities from a national summit

HEALTH AFFAIRS | Online – 15 November 2018 – The U.S. will experience significant growth of the population older than age 65 in the coming decades, which will contribute to an increase in the number of people living with chronic and serious illnesses in the community. Field experts, policy makers, and healthcare leaders have identified the lack of an adequately prepared workforce as a critical barrier to delivering high-quality, community-based care for this population. Health professions students typically have little exposure to geriatrics and palliative care in their education, even though such exposure often draws people to pursue work with seriously ill populations. Established and emerging programs that provide rich experiences with seriously ill patients should be expanded to increase interest in geriatric and serious illness care, such as the Department of Veterans Affairs' Geriatric Scholars Program and home-based primary care programs, and Virginia Commonwealth University's student-run clinics and geriatric experiences in physical therapy and pharmacy practice. **Full text:** <https://goo.gl/vZedgP>

Elucidating the end-of-life experience of persons with amyotrophic lateral sclerosis

HOLISTIC NURSING PRACTICE, 2019;33(1):3-8. A comprehensive multi-database search retrieved 31 qualitative research articles that addressed persons with end-of-life (EoL) experiences with amyotrophic lateral sclerosis (ALS). Inclusion/exclusion criteria were applied and a critical appraisal was applied for the final 8 included articles. First-person data extraction from the final articles represented emergence of 3 themes significant to persons with ALS: 1) Decisions for life-sustaining support; 2) Coping and fear of what is to come; and, 3) Communication with providers. Tracheostomy and ventilation as a means of prolonging life were important considerations for individuals with ALS. Persons with ALS struggled emotionally with their sudden loss of control and facing their demise. Some facets in which they did exert control, such as living wills, were hindered by patient and healthcare provider communication. Effective communication in EoL circumstances is paramount to preserving patient autonomy and dignity. This can be achieved by the patients conveying their preferences with respect to EoL care in advance, as well the nurses and other healthcare providers supporting the patients emotionally as they cope with terminal illness. Understanding patients' views regarding EoL circumstances is pertinent to nurses and other healthcare providers as they plan for palliative care. **Abstract:** <https://goo.gl/o1L6iX>

Noted in Media Watch 27 August 2018 (#578, p.8):

- *EUROPEAN MEDICAL JOURNAL: NEUROLOGY*, 2018;6(1):68-76. '**Palliative care in neurology: Integrating a palliative approach to amyotrophic lateral sclerosis care.**' This narrative review examines connections between neurology, specialist palliative care (PC), and an integrated palliative approach to care for people living with neurodegenerative conditions. Amyotrophic lateral sclerosis (ALS) care and smooth care transitions between multiple services and healthcare professionals are discussed, including the timing of PC delivery in ALS; the education and training needs of healthcare professionals; and, misperceptions of PC held by healthcare professionals, patients, and families. **Full text:** <https://goo.gl/NnPabM>

Advance care planning among American Indians

INNOVATION IN AGING, 2018;2(Suppl.1):189-140. American Indians (AI) are one of the least studied populations regarding advance care planning (ACP). The available literature suggests aversion to ACP in this group. However, the available literature is based on mostly qualitative and descriptive studies, and lacks systematic investigation of ACP practice among AIs. A cross-sectional, self-administered in-person survey was conducted with a convenience sample of 200 AI and 436 non-Hispanic White older adults from two Midwestern states. Univariate analysis showed that compared with White peers, AI older adults were significantly less likely to have an end-of-life (EoL) care plan or to have completed a durable power of attorney for healthcare (DPOHC) or a living will. Multivariate analysis showed that having an EoL plan was associated with older age, some college education or more, and a greater number of chronic conditions, but not with race; whereas having a DPOHC and living will was associated with being White. Lower rates of formal ACP among AIs suggest implications for targeted, culturally sensitive approaches to promoting ACP, grounded in and understanding of indigenous cultures' health beliefs and practices, as well as high standards for quality palliative care. **Abstract:** <https://goo.gl/7XfZ2X>

Noted in Media Watch 18 December 2017 (#543, p.4):

- U.S. | National Public Radio – 12 December 2017 – ‘**Native Americans feel invisible in U.S. health-care system.**’ The life expectancy of Native Americans in some states is 20 years shorter than the national average. There are many reasons why: health programs for American Indians are chronically underfunded by Congress. And, about a quarter of Native Americans reported experiencing discrimination when going to a doctor or health clinic, according to a poll by National Public Radio, the Robert Wood Johnson Foundation, and Harvard T.H. Chan School of Public Health. <https://goo.gl/H1bKvM>

Noted in Media Watch 31 July 2017 (#523, p.11):

- *JOURNAL OF TRANSCULTURAL NURSING* | Online – 22 July 2017 – ‘**Culturally relevant palliative and end-of-life care for U.S. indigenous populations...**’ American Indians/Alaska Natives have higher rates of chronic illness and lack access to end-of-life care (EoLC). Four themes emerged in this review: 1) Communication; 2) Cultural awareness/sensitivity; 3) Community guidance for EoLC programs; 4) Barriers. Two sub-themes: 1) Trust/respect; and, 2) Mistrust. Limitations are lack of research funding, geographic isolation, and stringent government requirements. **Abstract:** <https://goo.gl/yegFi2>

N.B. Additional articles on palliative and end-of-life care for U.S. indigenous populations noted in this issue of Media Watch.

Constituents of effective support for homecare workers providing care to people with dementia at end of life

INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY | Online – 14 November 2018 – Four overarching challenges were identified [in this study]: 1) Working with clients with dementia, including clients' sometimes unpredictable responses, communication difficulties, and mood changes; 2) Caring for the dying; 3) Conflict with family members; and, 4) Working alone, which often left homecare workers at risk of exhaustion, fatigue, and a sense of isolation. When their work entailed high levels of emotion, such as a client's death or getting embroiled in a client's family conflict, they felt emotionally drained, under-prepared and overwhelmed. Supportive elements include receiving encouragement and learning from experienced peers and their feelings being acknowledged by managers at their employing homecare agency. Some workers were offered time off or encouraged to attend the client's funeral as a means of supporting the process of bereavement. There is a need to develop models of effective support to alleviate their staff's practical, emotional and interpersonal pressures. However, due to the isolating nature of homecare work, managers may not recognise early signs of their staff finding stress unmanageable and miss the opportunity to mitigate these negative effects. **Abstract:** <https://goo.gl/2Co6wQ>

**How many bereaved people hallucinate about their loved one?
A systematic review and meta-analysis of bereavement hallucinations**

JOURNAL OF AFFECTIVE DISORDERS, 2019;243(1):463-476. This first systematic review and meta-analysis of bereavement hallucinations (BHs) suggests that more than half of the bereaved people experience some kind of BH. However, there are considerable methodological limitations in the research of BHs, which is of pertinent interest as BHs have been linked to the development of a future diagnosis of clinically impairing grief. A valid measure of BHs needs to be developed and used in high-quality epidemiological research using population-based designs. **Abstract:** <https://goo.gl/Js8CJP>

“What if she was your mother?” Toward better responses

JOURNAL OF CRITICAL CARE, 2019;49(2):155-157. Critical care physicians may hear a surrogate decision-maker ask, “What would you do if she was your mother?” or “What if your father was this sick?” These kinds of questions ask more of the critical care physician than the surrogate might realize. There are deep-seated ethical, professional, and personal complexities that can challenge critical care physicians to answer these questions with honesty. This article offers practical guidance for critical care physicians who aim to respond to such queries with honesty and beneficence. The authors discuss a variety of motivations that can accompany this unique kind of question from a surrogate. The surrogate may be seeking moral guidance – the true question being, “What should I do?” The authors offer a number of questions that the critical care physician might ask of the surrogate in order to attend to both the surrogate’s moral dilemma and the patient’s values and preferences for medical interventions. They also offer a number of questions to promote contemplation of these issues by the critical care physician herself. The authors argue that until the critical care physician discovers the surrogate’s motivation, connects this motivation to patient preferences, and asks herself important questions regarding death and dying, the physician’s responses will not adequately attend to the issues prompted by such questions. **Full text:** <https://goo.gl/UnvhY9>

Better together: Coexistence of for-profit and nonprofit firms with an application to the U.S. hospice industry

JOURNAL OF HEALTH ECONOMICS, 2019;63(1):1-18. Many markets maintain a non-trivial mix of both non-profit and for-profit firms, particularly in healthcare industries such as hospice, nursing homes, and home health. What are the effects of coexistence vs. dominance of one ownership type? The authors show how the presence of both ownership types can lead to greater diversity in consumer types served, even if both firms merely profit-maximize. This is the case where firms serve consumers for multiple consumption durations, but where donations are part of a non-profit firm objective function and happen after services have been provided. This finding is strengthened if the good or service has value beyond immediate consumption or the direct consumer. The authors show these predictions empirically in the hospice industry, using data containing over 90% of freestanding U.S. hospices, 2000-2008. Non-profit and for-profit providers split the patient market according to length of stay, leading to a wider range of patients being served than in the absence of this coexistence. **Full text:** <https://goo.gl/yt2C6d>

Needs analysis and development of a staff well-being program in a pediatric oncology, hematology, and palliative care services group

JOURNAL OF HEALTHCARE LEADERSHIP | Online – 15 November 2018 – The needs analysis informed the development of a customized Oncology Staff Well-being Program with a range of strategies aligned to a PERMA framework for flourishing (positive emotion, engagement, relationships, meaning, and accomplishment). Positive emotion areas included education on topics such as well-being, resilience, responding to escalating behaviors, grief and loss, and self-care. Staff attended the available mindfulness sessions, debriefing and counselors on site, developed self-care plans, and followed a well-being Facebook Group. Engagement was supported through exploring character strengths, improving communica-

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tion, supporting innovation, and addressing frustrations and safety concerns. Relationships within the team were addressed through team building and social events. Meaning of the work was emphasized through sharing family updates and end of treatment celebrations. Accomplishments of staff were acknowledged in newsletters and meetings. The needs analysis drove a multifaceted approach to staff well-being with the development of strategies which aligned to a framework that would empower staff to flourish at work. Implementation and evaluation are ongoing and will be reported in a subsequent paper. **Abstract:** <https://goo.gl/HJj77E>

Related

- *JOURNAL OF HEALTHCARE LEADERSHIP* | Online – 15 November 2018 – ‘**Evaluation of a staff well-being program in a pediatric oncology, hematology, and palliative care services group.**’ Challenges experienced by staff in the Oncology Services Group at Queensland Children’s Hospital led to issues with staff retention, well-being, and stress on team culture. A customized program was developed through a needs analysis to improve the well-being and resilience of oncology staff, enabling them to cope with stressors and critical incidents inherent in their everyday work and to flourish. The program included education, on-site counselors, mindfulness sessions, debriefing, well-being resources, and improved engagement, support, and communication. **Abstract:** <https://goo.gl/fXGHrH>

Experiences of hospice and substance use professionals: End-of-life care for people with alcohol and drug problems

MANCHESTER METROPOLITAN UNIVERSITY | Online – 15 November 2018 –

This research set out to explore the experiences of health and social care professionals working with people with problematic substance use and who were nearing the end of their lives. While attitudes towards people with these co-existing issues were generally positive to neutral, it was clear that the professionals lacked enough knowledge to provide them with confidence for working with the “other” issue. The complexity of combined substance use and a serious health condition added to the challenges of identifying and responding to people given the fluctuating nature of both issues making it difficult to determine what belonged to the substance’s effects (or withdrawal from) and what was related to their ill health. Professionals reported difficulties asking about the “other” issue and no routine assessment thus making the identification process more difficult. They were, however, aware of the stigmatising and stereotyping of people with substance problems from other professionals and the impact this could have on referrals to services and care provision. A number of key challenges including medication and pain management, supporting family, friends and carers, and working within an emotionally challenging context were noted. At a systems level, funding cuts, limited resources and the lack of partnership working stifled innovation and practice. Training needs were identified including how to talk to people about the “other” issue, an essential requirement for accurate needs assessment. However, there was some good practice cited including supportive team working, and good individual relationships with key community and hospital-based practitioners. The lack of consistency in practice, however, suggests the need for a policy framework that can drive greater consistency across services. It also needs to ensure professionals are supported by training and practice guidance to offer the best care to all. This group of people appears to face a number of inequalities in relation to end of life care, including access to hospice care. It is time to offer this group of people dignity in dying through services that are able to deliver a package of care most suited to their needs and based on a holistic assessment process. **Download/view report at:** <https://goo.gl/rvcxs5>



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Related

- MANCHESTER METROPOLITAN UNIVERSITY | Online – 15 November 2018 – **‘End-of-life care for people with alcohol and other drug problems. Secondary analysis of interviews with family members, friends and carers bereaved through a relative’s substance use...’** The research team accessed interview transcripts of 102 people who talked about the deaths of 93 relatives/friends. This analysis explored how these families experienced their relative’s end of life, examined the extent to which services recognised or responded to the whole family’s needs, and informed design and delivery of primary qualitative data collection... **Download/view report at:** <https://goo.gl/QVocVx>

Noted in Media Watch 13 November 2017 (#538, p.14):

- JOURNAL OF PALLIATIVE CARE* | Online – 30 October 2017 – **‘Alcohol dependence in palliative care: A review of the current literature.’** Alcohol misuse affects up to 28% of palliative care (PC) in-patients. These patients may have specific PC needs such as increased susceptibility to terminal agitation, high prevalence of co-morbidities, and poor social support networks. Management may involve detoxification, controlled usage of alcohol, or treatment of alcohol withdrawal. Patients may derive clinical benefit when alcohol dependence is identified by healthcare professionals. Routine screening should be considered. **Abstract:** <https://goo.gl/TV6TWa>

Noted in Media Watch 21 November 2017 (#488, p.11)

- MENTAL HEALTH PRACTICES* | Online – 9 November 2016 – **‘End-of-life and palliative care of patients with drug and alcohol addiction.’** This literature review attempts to identify current knowledge of the end of life (EoL) care needs of patients with drug and alcohol addiction and to identify any existing good practice guidance. The author recommends a discussion about what the term recovery can mean when applied to a person with addiction at the EoL, better recognition of approaching EoL in patients with drug and alcohol addictions, and closer working relationships between palliative care and addictions services. **Abstract:** <https://goo.gl/A71TR2>

Noted in Media Watch 29 August 2016 (#477, p.7):

- BMJ SUPPORTIVE & PALLIATIVE CARE*, 2016;6(3):392-393. **‘End-of-life care for people with alcohol and other drug problems: An exploratory study.’** The problematic use of substances is linked to many forms of chronic and life-threatening conditions, the majority of which affect people in later life. In part as a consequence of population ageing and with evidence suggesting that older people’s substance use is increasing, this complex and heterogeneous group is growing. Thus greater numbers will require palliative care and present new challenges to end-of-life services. **Abstract (inc. list of references):** <http://goo.gl/EM7WcD>

Legal issues in end-of-life care: Children and young people

NURSING TIMES, 2018;114(12):49-52. When a child or young person is near the end of life (EoL), who makes decisions about their treatment? This article ... explains the legal complexities of medical decision making relating to children or young people who are nearing the EoL, or who are likely to die if they do not receive treatment. It covers capacity to consent, presumption of capacity, overruling decisions, parental responsibility, children’s best interests and the role of the courts in case of disagreement between parties. The first article in this series discussed decision making in adults and the third will discuss the legal basis around issues such as withdrawing and withholding treatment and assisted suicide.¹ **Full text:** <https://goo.gl/LGwQcb>

1. ‘Legal issues in end-of-life care: The adult patient,’ *Nursing Times*, published online 15 October 2018. **Access options:** <https://goo.gl/BEw4wg>



Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

Elisabeth Kübler-Ross and the “five stages” model in a sampling of recent American textbooks

OMEGA – JOURNAL OF DEATH & DYING | Online – 14 November 2018 – This article examines some aspects of the enduring influence of the work of Dr. Elisabeth Kübler-Ross and especially of her “five stages” model through a sampling of recent textbooks published in the U.S. in selected academic disciplines and professional fields. The following are the questions to be asked: 1) Does the “five stages” model appear without significant change in the textbooks described here? 2) Is the “five stages” model applied in these textbooks to issues involving loss, grief, and bereavement, as well as to those involving terminal illness and dying? 3) Is the “five stages” model criticized in some or all of these textbooks? 4) If so, is the criticism sufficient to argue that, while the “five stages” model might be presented as an important historical framework, it should no longer be regarded as a sound theory to guide contemporary education and practice? **Abstract:** <https://goo.gl/uqZEzo>

Noted in Media Watch 29 October 2018 (#587, p.11):

- *MORTALITY* | Online – 23 October 2018 – ‘**The “five stages” in coping with dying and bereavement: Strengths, weaknesses and some alternatives.**’ This article offers a reflective analysis of one well-known psychological theory, the so-called “five stages” in coping with dying and coping with bereavement. Despite widespread acceptance among the general public and continued presence in some forms of professional education, it is argued that the “five stages” model is less attractive than it initially appears. Significant criticisms of the theory are set forth here, as well as notable strengths of its underlying foundations. **Abstract:** <https://goo.gl/R8sMLF>
- *FAMILIES IN SOCIETY: THE JOURNAL OF CONTEMPORARY SOCIAL SERVICES* | Online – 18 October 2018 – ‘**The profession of social work and the legacy of Kübler-Ross.**’ Social work is a practice-based profession. As such, it is important to understand our roots and the basis for our interventions, to assess continuing validity, and to determine if the assumptions and methodologies we use still fit. This article focuses on the tenets put forth by psychiatrist Elisabeth Kübler-Ross 50 years ago and describes how the profession of social work extended and expanded her pioneering work to define a robust area of social work practice in palliative and end-of-life care. **Abstract:** <https://goo.gl/ZivFuT>

“Thou shalt not die in this place”: An ethno-methodological approach to an Ecuadorian hospice through symbolic interactionism

OMEGA – JOURNAL OF DEATH & DYING | Online – 14 November 2018 – Ecuador ... has a population of 16 million people. According to the National Institution of Statistics in Ecuador, every year 8 out of a 1,000 individuals die due to various causes. Palliative care and hospice are relatively new concepts for the Ecuadorian society where people usually die at home, in hospitals, or in nursing homes. In 2012, the first Ecuadorian hospice was created. According to symbolic interactionism theory, research needs to study participants’ world in order to understand the dynamic nature of human behavior. Symbolic interactionism proposes that human beings cannot be understood without the context of their interactions. Through an ethno-methodological approach, current research aims to understand the way that individuals understand and describe death while in the local hospice. Results emerge from the introspection of real stories, field notes, participant observation, and informal conversations at the hospice. This study presents major themes that emphasize the dynamic process of creating meaning of death. **Abstract:** <https://goo.gl/bjWnFg>

“I would describe myself as a deformed troll.”

Using interpretative phenomenological analysis to explore body image struggles among palliative care patients

PALLIATIVE MEDICINE | Online – 12 November 2018 – Illness adjustment is a widely studied area in the palliative care (PC) context. However, research focussing on how altered body image can affect men and women in PC is limited and unclear. Analysis of [patient] accounts indicated three superordinate themes:

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1) 'Not being me': self-discrepancy; 2) Existing in the landscape of loss; and, 3) Living and thriving in the landscape of loss. The most disturbing issues, such as appearance-focussed struggles and low body-confidence, were stemming from [study] participants' frustration over their lack of control and their attachment to their former self-image. The patients' insights demonstrated that body image distress was prevalent among all respondents regardless of gender or diagnosis. A spiral model is described showing how discrepancy-based processing (i.e., "not being me") and rigid attachment to former self can have harmful consequences on palliative patients' abilities to cope. In order to facilitate adjustment to a self-identity crisis resulting from a terminal diagnosis, it is necessary for professionals to recognise and address body image changes among PC outpatients. **Abstract:** <https://goo.gl/B61Uq2>

Addressing possible problems with patients' expectations, plans and decisions for the future: One strategy used by experienced clinicians in advance care planning conversations

PATIENT EDUCATION & COUNSELING | Online – 15 November 2018 – Giving terminally ill people opportunities to participate in advance care planning involves tensions between: endorsing and supporting patients' expectations, plans and decisions, and addressing how realistic these are. The latter risks exerting undue pressure to change plans; undermining autonomy; jeopardising therapeutic relationships. The authors describe how experienced hospice doctors raise potential/actual problems with patients' expectations, plans or decisions. Eleven episodes involving five doctors were found. In all of these, the authors identified a "hypothetical scenario sequence" where doctors raise a hypothetical future scenario wherein current plans/expectations turn out to be problematic, then engage patients in discussing what could be done about this. They describe features of this sequence and how it can circumvent the risks of addressing problems with patients' expectations and plans. This research breaks new ground, showing that by treating expectations, plans and decisions as potentially not actually problematic, practitioners can recognise and support patients' preferences whilst preparing them for possible difficulties and inevitable uncertainties. **Abstract:** <https://goo.gl/BhEJ2b>

The location of death and dying across Canada: A study illustrating the socio-political context of death and dying

SOCIETIES | Online – 9 November 2018 – This study of recent population-level hospital data revealed that only 3.5% of admissions to hospital in the 2014-2015 year ended in death and only 43.9% of all deaths that year in Canada (excluding Quebec) occurred in hospital. As such, a major shift of death and dying out of hospital has occurred in Canada since 1994, when hospital deaths peaked at 80.5%, but with considerable cross-Canada differences in end-of-life (EoL) hospital utilization identified. These differences, in addition to the differing characteristics of hospital decedents, present evidence that will help in planning EoL service improvements and advancing EoL policy to address the needs of current and future populations. Such investments offer prospects of improved well-being for patients and families throughout the dying process, as well as a reduction in healthcare system costs and opportunity costs. **Full text:** <https://goo.gl/iyXtbN>

Achievement of a good death among young adult patients with cancer: Analyses of combined data from three nationwide surveys among bereaved family members

SUPPORTIVE CARE IN CANCER | Online – 16 November 2018 – Although little improvement has been made in the survival rate among young cancer patients over recent decades, whether they have achieved a good death has never been systematically explored. The authors analyzed 245 and 5,140 responses of families of young and middle-aged patients, respectively. Less than 60% of families of young patients reported "agree/absolutely agree" regarding 9 items, which included "feeling that one's life was completed," "being independent in daily life," and "being free from physical distress." Young patients were significantly less likely to feel "one's life was completed" and "not being a burden to others" than the middle-aged. Overall, young cancer patients did not achieve a good death. Future efforts are needed to improve the quality of palliative care for young patients, focusing on psychosocial/spiritual suffering. **Abstract (inc. list of references):** <https://goo.gl/zJx5nd>

End-of-life care in the intensive care unit

SURGERY | Online – 9 November 2018 – End-of-life care in the intensive care unit (ICU) is an oxymoron. Intensive care units appeared in the 1980s only admitting patients for “intensive care.” Nowadays the ICU has become one of the few places in the hospital that can provide comfort care to the dying patient. For many doctors on ICU it remains a difficult and problematic area. Yet it is conceptually simple. The difficulty for the doctor is making the decision, for the patient and family, coming to terms with it. This article focuses on how this decision should be made and then on the care that should be provided for the patient. Many of the considerations in decision making are in the General Medical Council guidelines ... and this is essential reading before embarking of the process.¹ **Abstract:** <https://goo.gl/2muVF8>

1. ‘Treatment and Care Towards the End of Life: Good practice in decision making,’ General Medical Council, 2010. **Download/view at:** <https://goo.gl/ERXSng>

Related

- *PALLIATIVE MEDICINE* | Online – 14 November 2018 – ‘**Deep learning algorithms to identify documentation of serious illness conversations during intensive care unit admissions.**’ Deep learning algorithms identified patient care preference documentation with sensitivity and specificity approaching that of clinicians and computed in a tiny fraction of time. Future research should determine the generalizability of these methods in multiple healthcare systems. **Abstract:** <https://goo.gl/sKftW6>

N.B. Additional articles on palliative care in intensive care units noted in 12 November 2018 issue of Media Watch (#589, p.9).

‘Publishing Matters’ on p.18

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.

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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.

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *MEDPAGE TODAY* | Online – 14 November 2018 – ‘**American Medical Association: Still a ‘No’ on physician-assisted suicide.**’ The American Medical Association (AMA) stance on physician-assisted suicide (PAS) remains unchanged after its Interim Meeting, but a move to solidify the group’s opposition to the practice, also known as medical aid-in-dying (MAiD), failed to win approval. The report from the Council on Ethical & Judicial Affairs was written in response to two core resolutions: one clarifying the AMA opposition to PAS/MAiD, and a second that gives physicians the freedom to make their own decisions in states where PAS/MAiD is allowed. **Full text:** <https://goo.gl/tR22mU>

Publishing Matters

Communicating health risks in science publications: Time for everyone to take responsibility

BMC MEDICINE | Online – 13 November 2018 – Research that is poorly communicated or presented is as potentially damaging as research that is poorly conducted or fraudulent. Recent examples illustrate how the problem often lies with researchers, not press officers or journalists. The quest for publication and “impact” must not outweigh the importance of accurate representation of science. All those involved in the pipeline of research, publication and publicity have a role in ensuring that risks are clearly presented, putting their magnitude into perspective, without exaggerating their importance, and communicating their uncertainty. The authors recommend that 1) Authors should be able to justify the claims made in their papers and should work closely with press offices in ensuring accurate press releases; 2) Journals and peer reviewers enforce guidelines and damp down – rather than encourage – exaggerated claims by authors; 3) Press officers ensure that absolute risks are included in press releases and that the conclusions cannot easily be misinter-

preted; and, 4) Journalists demand that researchers put their research claims into perspective. **Full text:** <https://goo.gl/Ytn8Mf>



AMERICAN JOURNAL EXPERTS

Make a great first impression: Six tips for writing a strong abstract

The abstract is the first section that is read by journal editors when deciding whether to send your manuscript for review. Similarly, once your work is published, it is the first section that is examined by readers; in many cases, it is the only section of the manuscript that they will ever read. This is in part because literature databases index only abstracts, and, access to full-text articles is often restricted. The abstract emerges as a tool to communicate your research succinctly while highlight its most important facts. <https://goo.gl/iZAc0A>

Media Watch: Access on Online

International



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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>]

Cont.

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?']

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>

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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