

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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Advance care planning: Scroll down to [Specialist Publications](#) and ‘Dilemmas adult children face in discussing end-of-life care preferences with their parents’ (p.6), in *Health Communications*.

Canada

Study finds homeless, vulnerable, finally get care when at death’s door

BRITISH COLUMBIA | CTV News (Victoria) – 1 November 2018 – The lives of 25 homeless or marginally housed people in Victoria only started to get better when they were close to death, says a University of Victoria study.¹ Researchers followed the people for two years during the study, which concluded that many of them received the best health care available only when they had reached the end of their lives. Kelli Stajduhar, a professor at the university’s school of nursing and Institute on Aging & Lifelong Health, said 13 people died during the study and the health status isn’t known for the 12 who survived while the research was underway. The study ... finds that people living on the streets are in a world of unmet needs, multiple losses, persistent grief and trauma. Stajduhar said the study recommends better training throughout the healthcare system to inform providers about the barriers to care endured by marginalized people, including end-of-life support. It called for improved policies to help health workers understand why the homeless avoid care and aren’t getting treatment for life-threatening conditions until it’s too late. Stajduhar said many participants said they were often told by doctors and health providers that their lifestyles of addiction, poverty and homelessness could lead to an early death, but early diagnosis of potential health conditions was limited. <https://goo.gl/4Stk5C>

1. ‘Too Little, Too Late: How we fail vulnerable Canadians as they die and what to do about it,’ Institute on Aging & Lifelong Health, November 2018. **Download/view at:** <https://goo.gl/SZ2qWc>

Noted in Media Watch 8 October 2018 (#584, p.17):

- **OMEGA – JOURNAL OF DEATH & DYING** | Online – 2 October 2018 – ‘**Bearing witness: Exploring the end-of-life needs of homeless persons and barriers to appropriate care.**’ This review summarizes the burgeoning gray and academic literature on end-of-life (EoL) care for homeless persons. Six themes emerged: 1) Characteristics of homeless persons who require EoLC; 2) Preferences and concerns of homeless persons approaching the EoL; 3) The role of spirituality for homeless persons at the EoL; 4) Barriers to care at the patient, provider and institutional or structural levels; 5) Inclusive models of PC; and, 6) Implications for policy and practice. **Abstract:** <https://goo.gl/uD9YCb>

N.B. Additional articles on palliative and end-of-life care for the homeless in Canada noted in 30 July 2018 issue of Media Watch (#574, p.1).

More united approach needed to provide a “good death” to rural residents who wish to die at home

ALBERTA | *Folio* (University of Alberta) – 29 October 2018 – Rural communities have to take the lead in giving their terminally ill residents a “good death” at home rather than relying solely on the government, says a University of Alberta expert. It’s becoming a keenly felt issue for many small, under-resourced hamlets and towns hit by shrinking health care like doctor shortages and hospital closures, said University of Alberta community planning researcher Kyle Whitfield. “We aren’t planning ahead. We’re reacting – and we’re reacting much too slowly to the need that’s growing quickly.” In a case study of one Alberta town, Whitfield found that volunteers had to take on the work of planning hospice care for their families, friends and neighbours to stay in the community to die.¹ “It’s a phenomenon that’s occurring at a high rate; in Alberta you’re going to find hospice societies made up of citizens coming together to plan for their own communities. They are really having to come together to plan for their own health-care needs because of the downloading of government support onto the shoulders of these people. They are having to find ways to provide support for end-of-life care, because it isn’t there,” said Whitfield... Yet the need is growing for meaningful hospice care ... that allows people a good death: being surrounded by loved ones in their home communities during their final days. The number of people choosing to die in hospitals is dwindling, Whitfield noted. <https://goo.gl/qoNQq2>

1. ‘A case study exploring the implications of one Alberta rural community’s experience with planning their own hospice care,’ *Journal of Rural & Community Development*, 2018;13(1):1-12. [Noted in 5 March 2018 issue of Media Watch (#553, p.10)]. **Full text:** <https://goo.gl/3aURCH>

Noted in Media Watch 16 May 2016 (#462, p.18):

- *SOCIAL SCIENCE & MEDICINE* | Online – 7 May 2016 – ‘**Palliating inside the lines: The effects of borders and boundaries on palliative care in rural Canada.**’ Borders and boundaries can be used to define a variety of differing spaces such as the familial, social, economic, political, as well as issues of access – including access to health services. Despite the implicit connection between borders, boundaries and health, little research has investigated this connection from a health geography perspective. This analysis contributes to addressing this notable gap by examining how borders and boundaries are experienced and perceived to impact access to palliative care in rural Canada from the perspectives of the formal and informal providers of such care. **Abstract:** <http://goo.gl/9vyVH7>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 31 October 2018 – ‘**Early draft of report on medically assisted dying examines ethics of advance requests.**’ Allowing Canadians to request a medically assisted death weeks or even years ahead of time would be less ethically fraught if limited to patients who have already been approved to receive the procedure imminently, according to an early draft of a report prepared for the federal government. Permitting advance requests for patients with dementia – especially in cases where years elapse between the formal application and the lethal injection – would be much more complicated and would require extensive safeguards, says the draft, obtained by *The Globe and Mail*. The Council of Canadian Academies, an independent not-for-profit organization, was asked by Ottawa nearly two years ago to produce reports on three types of patients who don’t qualify for an assisted death under the law, including those who want a doctor to end their lives after they’ve lost the capacity to say yes at the moment of death. <https://goo.gl/gziV35>

[Specialist Publications](#)

‘Of dilemmas and tensions: A qualitative study of palliative care physicians’ positions regarding voluntary active euthanasia in Quebec, Canada’ (p.16), in *Journal of Medical Ethics*.

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- MONDAQ | Online – 30 October 2018 – **‘Medical assistance in dying: Canadian registry recommendations.’** This highlights the need to establish a national Canadian standard for data collection, without which researchers, the federal government, and others are prevented from conducting comprehensive research and analyzing trends in basic and reliable information that could otherwise improve preventative initiatives, societal understanding, and end-of-life care across the country. The first section discusses the value that comprehensive data collection brings to understanding medical assistance in dying (MAiD) in Canada. The second section provides an overview of the legal framework in which MAiD operates in Canada, as well as a brief discussion on where data collection is currently failing, as evidenced by the first three interim government reports on MAiD. The authors propose that the federal government should set up a national MAiD registry for MAiD cases successfully or unsuccessfully carried through, based on the current structure of the Canadian cancer registry system. Setting up a system that assembles valid, consistent, reliable, and uniform data on all known MAiD patients in defined populations whose demographic characters are known will ensure that future policies are based on accurate and reliable evidence. **Full text:** <https://goo.gl/FaHJQ1>

U.S.A.

The ways inequality affects black Americans at the end of life

PUBLIC BROADCASTING SYSTEM (‘Next Avenue’) | Online – 2 November 2018 – It’s no secret that wage gaps, discrimination and institutional racism limit black Americans’ access to health equity. However, what’s discussed a lot less frequently is that these factors impact the way this group experiences death, too. Nearly one in four black Americans live in poverty as compared to one in 10 white Americans, and for older black Americans, that number is even larger. Nearly 64% of older black Americans are on the cusp of poverty. Because of financial insecurity, preoccupation with daily survival can take priority over death-related planning like writing advance directives (ADs) and funeral planning for black Americans. Studies suggest around 24% of older black Americans have ADs as compared to 44% of older white Americans. Black Americans predominantly live in states that refused the Medicaid expansion. Those who face financial obstacles are disproportionately impacted by a lack of coverage. The black community has an uninsured rate of 12%, which can make health conditions more difficult to manage. Black Americans report higher rates of

dissatisfaction with medical and end-of-life (EoL) care options like hospice than white Americans. The medical system’s historical mistreatment of black Americans impacts trust in EoL providers. Only 38.3% of black American Medicare patients enrolled in hospice care prior to their deaths, compared to 51% of white patients. <https://goo.gl/XEzJVs>

Specialist Publications

‘Palliative care consultation trends among hospitalized patients with advanced cancer in the U.S., 2005 to 2014’ (p.5), in *American Journal of Hospice & Palliative Medicine*.

‘Racial and ethnic disparities in palliative care: A systematic scoping review’ (p.8), in *Families in Society*.

‘A systematic review in support of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care’ (p.9), in *Journal of Pain & Symptom Management*.

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



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.17.

Rethinking death in America

U.S. TODAY & WORLD NEWS | Online – 31 October 2018 – For decades, the idea of a funeral service has generated images of burial on a gated lot with a manicured lawn punctuated by markers of marble or granite after a religiously oriented service involving wreaths of flowers and black-clad mourners. With 2.7 million Americans – as many as the population of the city of Chicago – dying each year, it only stands to reason that those lots will become more crowded and that at some point the graves will become overwhelming – especially in urban areas. That's already happening in some places in the world. London has been forced to try out grave-sharing, Venice is booting bodies from burial plots to make space for the more recently deceased. Israel is building multi-story underground tunnels to house the departed. At the same time, graveyards hosting centuries-old dead are looking for inventive ways to stay relevant and to fund necessary upkeep as streams of visitors dwindle with each passing generation. Florida's state government estimated in a recent report that each of its counties has hundreds of cemeteries that are abandoned or have fallen into disrepair. So it may come as little surprise that the share of people in the U.S. opting to be cremated after they die is increasing and even – for three straight years – narrowly outpacing the share of people getting buried, according to recent funeral industry statistics. <https://goo.gl/DrRF1Z>

Exploiting the elderly: Study questions lucrative care for dying patients

PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 30 October 2018 – Nursing home residents hovering on the brink of death are increasingly being pushed into intensive physical rehabilitation that is unnecessary and unproductive for the patient and, at the same time, exceptionally lucrative for the nursing home. A study by the University of Rochester analyzed data from hundreds of nursing home facilities and thousands of patients who had been long-term residents of those nursing homes before they died in the facilities.¹ The results were bone-chilling. In the last days of their lives, many patients were subjected to senseless rehabilitation treatment. Medicare defines ultrahigh intensity rehab as more than 12 hours of therapy services per week. The Rochester university study, which looked at the final 30 days of patients' lives, found some residents were treated to the highest concentration of rehabilitation during the last week of their lives. The study also found that for-profit nursing homes were twice as likely to use high to ultrahigh intensity therapy than non-profit homes. <https://goo.gl/dMzXAd>

1. 'Rehabilitation therapy for nursing home residents at the end-of-life,' *Journal of the American Medical Directors Association*, published online 1 October 2018. [Noted in the 8 October 2018 issue of *Media Watch* (#584, p.16)]. **Abstract:** <https://goo.gl/xYVNtG>

International

Government must assess the “damaging” impact of National Health Service award on charitable hospice providers

U.K. (England) | PoliticsHome (London) – 31 October 2018 – The three-year National Health Service (NHS) award negotiated earlier this year between NHS employers and the trade unions was welcomed for finally lifting our much valued NHS staff out of the constraints of the 1% public sector pay cap. However, one unintended consequence of this pay deal is the adverse impact upon the charitable sector which is commissioned to provide NHS services. The majority of hospices are funded mainly by charitable donations and fundraising with an average of only around 30% of their funding coming from the NHS. The Department of Health & Social Services has announced that the NHS pay award will not be funded for the charitable sector unless they employ staff on Agenda for Change terms and conditions, the national agreed deal for NHS staff. The Department has acknowledged that most charitable hospices do not employ staff on NHS terms and conditions, as these staff are not NHS employees. However, as hospices recruit their staff from the same local pool as the NHS, they have little option but to mirror the pay award made for NHS staff in order to recruit and retain the staff they need. In terms of the potential impact on

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charitable hospices, Hospice UK has estimated that over the course of the three-year NHS pay deal, charitable hospices will be faced with an additional bill of somewhere between £60 million and £100 million.¹ In the absence of any additional government support, hospices are faced with a difficult choice – they must either ask their local communities to donate more to fund the pay award, or they must look at options to reduce services proportionately to cover the cost. Neither of these are palatable options either for the hospices or for the communities they serve. <https://goo.gl/QbjpcG>

1. 'Charities warn that National Health Service pay award could hit hospices hard,' Hospice UK, 10 July 2018. [Noted in 16 July 2018 issue of Media Watch (#572, p.4)] <https://goo.gl/PYPZW2>

Specialist Publications

How should clinicians respond when patients are influenced by celebrities' cancer stories?

AMA JOURNAL OF ETHICS, 2018;20(11):E1075-E1081. Despite the prodigious medical literature on cancer care, some patients rely on celebrity narratives as frameworks for understanding their experiences of cancer and as benchmarks for decision making. Regardless of whether these narratives are appropriate sources of health information for patients, it has been shown that celebrity narratives influence patterns of care. Three cases – John McCain, Angelina Jolie, and Jimmy Carter – are presented to illustrate how media coverage of cancer can have unforeseen consequences on individual patients exposed to these kinds of stories. For this reason, clinicians should become familiar with these narratives and comfortable with discussing how celebrity narratives can shape patients' views and decisions. **Full text:** <https://goo.gl/kuj4Et>

Noted in Media Watch 27 August 2018 (#578, p.2):

- U.S. (California) | *The San Diego Union-Tribune* – 25 August 2018 – **'Why hospice care should start sooner rather than later.'** As much as we need celebrities and respected persons to announce their decision to seek hospice or palliative care, the gap between “enters hospice care” and “dies after a battle with X” is too often way too short: Harmon Killebrew, four days; Lari White, three days; Joan Mondale, one day; B.B. King, 10 days; George McGovern, five days; Jarrod Lyle, six days; and, Barbara Bush, two days. With luminaries like these passing in days, and the median length of stay in hospice just a little over three weeks, the public could be forgiven for thinking that “hospice is where you go to die.” <https://goo.gl/eS2zya>

Palliative care consultation trends among hospitalized patients with advanced cancer in the U.S., 2005 to 2014

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 1 November 2018 – Although palliative care (PC) services are increasing in the U.S., disparities exist in access and utilization. PC consultations were recorded in 9.9% of 4,732,172 weighted advanced cancer hospitalizations and increased from 3.0% to 15.5% during 2005 to 2014. Factors associated with higher PC consultations were increasing age, ≥80 years; black race; private insurance coverage; West region; large hospitals; high income; do-not-resuscitate (dying patients) status; and in-hospital radiotherapy. PC consultations were lower in patients with chemotherapy. Many demographic, socioeconomic, health-care, and geographic disparities were identified in PC consultations. Additionally, PC resources were underutilized by hospitalized patients with advanced cancers and commonly utilized by patients who are dying. Healthcare providers and policy makers should focus on these disparities in order to improve PC use. **Abstract:** <https://goo.gl/S12Tks>



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“Terminal” dehydration (Part 2): Medical indications and therapeutic approach

DER ANAESTHESIST | Online – 26 October 2018 – The approach in the clinical fluid management of the dying is still controversially discussed in specialist circles and also in the general population. In this article the importance of establishing the therapeutic indications is emphasized against the background of a lack of evidence. Options to achieve non-invasive objectification of assumed dehydration as well as assessment of the reversibility of the symptoms are shown and the importance of monitoring of all therapeutic actions is discussed. The pathophysiological foundation of reversible disorders of fluid homeostasis are described and distinguished from the irreversible disorders leading to terminal dehydration. If clinically assisted hydration is indicated, the hydration status must be assessed individually as well as in advance and all therapeutic measures must be constantly adjusted to the results of non-invasive monitoring procedures. **Full text:** <https://goo.gl/L85BW1>

N.B. “Terminal” dehydration (Part 1): Differential diagnosis and body of evidence, *Der Anaesthesist*, 2018; 67(9):709-722. **Full text:** <https://goo.gl/MJnnP9>. German language articles.

A randomised controlled trial of an advance care planning intervention for patients with incurable cancer

BRITISH JOURNAL OF CANCER | Online – 29 October 2018 – The authors modified and evaluated an advance care planning (ACP) intervention, which had been shown to improve compliance with patient’s end-of-life (EoL) wishes, in a different patient population. Patients with incurable cancer, and a family member (FM), were randomised one-to-one to usual care or usual care plus an ACP intervention, between April 2014 and January 2017. Oncologists and participants were non-blinded. ACP was based on the Respecting Patient Choices® model, with an offer to provide individualised ranges for typical, best-case and worst-case scenarios for survival time. Seven facilitators (two oncology nurses, two nurses and three allied health professionals) delivered the intervention within 2 weeks of study enrolment. The primary outcome measure, assessed by interviewing the FM 3 months after patient death, was the FM perception that the patient’s wishes were discussed, and met. Six hundred and sixty-five patients from seven Australian metropolitan oncology centres were referred for consideration by their oncologists, 444 (67%) met the study inclusion criteria and were approached by a study researcher. Two hundred and eight patients (47%) and their FM entered the trial as dyads. Fifty-three (46%) dyads in the ACP group and 63 (54%) dyads in the usual-care group had complete primary outcome data. Seventy-nine patients and 53 FMs attended an ACP discussion. Mean length of discussion was 57 min. FMs from 23 (43%) dyads allocated to ACP and 21 (33%) dyads allocated usual care reported the patient’s EoL wishes were discussed and met... There

were no differences in EoL care received, patient satisfaction with care, FM satisfaction with care or with death or FM well being. Rates of palliative care referral were high in both groups (97% vs 96%). A formal ACP intervention did not increase the likelihood that EoL care was consistent with patients’ preferences. **Abstract (inc. list of references):** <https://goo.gl/Xqsrp6>

Dilemmas adult children face in discussing end-of-life care preferences with their parents

HEALTH COMMUNICATION | Online – 30 October 2018 – This study explored the perceived goals, barriers, and strategies that characterize family interactions about advance care planning (ACP), which is instrumental in guiding end-of-life (EoL) care. Discussions within the family context can significantly improve EoL decision making but are complicated, partly because participants are attempting to achieve multiple, and often competing, goals. Participants [in this study] responded to a hypothetical scenario about a conversation with a parent about ACP by completing an anonymous online survey. Respondents described their conversational goals, anticipated barriers, and strategies they thought would be helpful. Thematic data analysis identified four dilemmas participants faced while attempting to achieve multiple, conflicting goals: 1) The desire to make the parent feel wanted while discussing them not being around; 2) The need to be gentle but still direct; 3) The practical necessity of designating one decision-maker without provoking family conflict; and, 4) The desire to lessen the burden on the designated decision-maker by providing necessary information while still placing them in a decision-making role. **Abstract:** <https://goo.gl/ZSdlhe>

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Noted in Media Watch 29 October 2018 (#587, p.12):

- *PALLIATIVE MEDICINE* | Online – 26 October 2018 – ‘**The conceptual models and mechanisms of action that underpin advance care planning for cancer patients: A systematic review of randomised controlled trials.**’ No systematic review has focused on conceptual models underpinning advance care planning (ACP) ... and the mechanisms of action in relation to the intended outcomes. Nine randomised controlled trials were included, with only four articulated conceptual models. Conceptual models identify the individual behavioural change. Strengthening patients’ motivation and competence in participating ACP discussions are key mechanisms of change. **Abstract:** <https://goo.gl/T8ttjE>

Noted in Media Watch 6 August 2018 (#575, p.14):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 30 July 2018 – ‘**State of advance care planning research: A descriptive overview of systematic reviews.**’ Advance care planning (ACP) related research focuses on nine main topics. There are major knowledge gaps about ACP initiation, timeliness, optimal content, and impact because of the low quality and fragmentation of the available evidence. Research has mostly focused on discrete aspects within ACP instead of using a holistic evaluative approach that takes into account its intricate working mechanisms, the effects of systems and contexts, and the impacts on multilevel stakeholders. **Abstract (inc. list of references):** <https://goo.gl/RaB4FG>

Noted in Media Watch 2 July 2018 (#570, p.11):

- *PALLIATIVE MEDICINE* | Online – 29 June 2018 – ‘**Advance care planning: A systematic review about experiences of patients with a life-threatening or life-limiting illness.**’ The authors identified three themes in patients’ experiences with advance care planning (ACP): 1) “Ambivalence” refers to patients simultaneously experiencing benefits from ACP as well as unpleasant feelings; 2) “Readiness” for is a necessary prerequisite for taking up its benefits, but can also be promoted by the process of ACP itself; and, 3) “Openness” refers to patients’ need to feel comfortable in being open about their preferences for future care towards relevant others. **Full text:** <https://goo.gl/H5f4dk>

Noted in Media Watch 1 January 2018 (#539, p.12):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 December 2017 – ‘**Respecting Choices® and related models of advance care planning: A systematic review of published evidence.**’ The authors found that there is a low level of evidence that Respecting Choices® (RC) and derivative models increase the incidence and prevalence of advance directive and Physician Orders for Life-Sustaining Treatment (POLST) completion. The evidence is mixed, inconclusive and too poor in quality to determine whether RC and derivative models change the consistency of treatment with wishes and overall health-care utilization in the end of life. **Abstract:** <https://goo.gl/pnq22k>

Differences in attitudes towards end-of-life care among intensivists, oncologists and prosecutors in Brazil: A nationwide survey

CRITICAL CARE | Online – 26 October 2018 – There is great variability in end-of-life care (EoLC) and the legal context may interfere with decisions on limitation of medical treatment. In Brazil, EoLC was initially regulated in 2006, but legal controversies still continue. Even though physicians do not need authorization from the judiciary system to act, those controversies may cause uncertainty regarding seemingly competing professional duties (caring for patients’ best interests versus maintenance of life), possibly hampering good medical care. In this study, the authors sought to compare the attitudes of physicians (intensivists and oncologists) and prosecutors from the Ministerio Publico da Uniao (MPU) towards common concepts in EoLC in Brazil, such as patient autonomy and withholding/withdrawal of care. The authors evaluated MPU prosecutors because they may be responsible for investigation of deaths due to limitation of medical treatment. **Full text:** <https://goo.gl/RXYxyY>

Racial and ethnic disparities in palliative care: A systematic scoping review

FAMILIES IN SOCIETY | Online – 29 October 2018 – Despite the advances and spread of palliative care programs, communities of color remain significantly underserved. Although these disparities are widely known, there is a marked lack of empirical evidence. The authors conducted a systematic scoping review that synthesized the literature since 2000 about racial and ethnic disparities in palliative and end-of-life care (EoLC). Findings lend support to extant literature that social-environmental barriers and disparities distinctly affect access to care for these populations. The review expands upon understanding of how social determinants drive disparities in palliative and EoLC and suggests implications for practice, policy, and research in promoting health equity in serious illness. **Abstract:** <https://goo.gl/UR6VEZ>

Strengthening the interdependence of palliative care and social work

FAMILIES IN SOCIETY | Online – 25 October 2018 – This special issue of *Families in Society* is focused on the robust intersections of social work knowledge, values, and skills with palliative care (PC), a comprehensive approach to health care for people of all ages who are living with or affected by serious, life-threatening illnesses, at any point along the disease continuum and in combination with other disease-related treatments. Over the past several decades, as the evidence base of its benefits has grown steadily, the scope of PC has also expanded, moving it from the relative fringes of medicine to the center stage of interprofessional health care and humanitarianism. This is very good news for the tens of millions of children and adults that are conservatively estimated to need this care now as well as for the markedly larger number of people that are projected to need it in the next few decades. An ample body of rigorous research now documents that PC not only improves symptom burden and quality of life, but can also minimize unnecessary use of health services, including hospital admissions; shorten the length of hospital admissions when they occur; and reduce hospital costs. In addition to better outcomes for patients and cost effectiveness of care, some findings indicate that when PC is provided early in the course of illness, it might even extend survival. In short, research has demonstrated that superior care can cost less. Social workers, who have been long-standing champions of PC through the realms of advocacy, policy, public and professional education, research, and direct service to individuals and families, are key members of interdisciplinary PC teams and have been essential to the achievement of these outcomes. **Full text:** <https://goo.gl/FpguWZ>

N.B. Access articles in this special issue of *Families in Society* at: <https://goo.gl/ekwgu1>

Extended care unit: A feasible economic solution for longer-term palliative inpatients

INTERNAL MEDICINE JOURNAL | Online – 1 November 2018 – Palliative patients who cannot go home are placed into nursing homes. This involves moving between up to five locations in the final weeks of life. The authors censored all inpatients on a single day from a large tertiary centre to investigate the feasibility of a proposed extended care unit to accommodate patients with a prognosis of less than 90 days, unable to return home, and with nursing home referral process commenced. This study identifies a present demand for an extended care unit (15 patients identified), outlines admission criteria, and proposes a funding model that is predicted to save hospital costs (savings of \$207.70 per patient, per bed day). This patient-focused approach is a feasible economic solution to the current unmet needs of this patient demographic. **Abstract:** <https://goo.gl/XP46Mn>

The motivations and consequences of dying at home: Family caregiver perspectives

JOURNAL OF HOUSING FOR THE ELDERLY | Online – 25 October 2018 – Although ample research suggests individuals prefer to die at home, the realities of a home death experience, from the perspective of family members, are not well understood. This study addresses this gap in knowledge via a narrative analysis about the process of dying at home. Five family caregivers participated in semi-structured interviews about their experiences witnessing and supporting the end-of-life process of an older family mem-

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ber who died at home. Their stories paint a vivid picture about the motivations and consequences of the experience, including themes such as caregivers' immense feelings of uncertainty regarding their caregiving abilities and decision making, the significance of the home environment as a symbol of comfort and security, the influence of family and social networks, and "dying well" as a social justice issue. Overall, the caregivers' narratives support the notion that being at home is considered an essential aspect of "dying well." However, the narratives also demonstrate that dying at home presents many challenges for family members, especially to those with limited resources and social support. The authors caution against viewing the home death as a proxy for a good death. **Abstract:** <https://goo.gl/qKNK7X>

A systematic review in support of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 31 October 2018 – This systematic review highlights the large and varied body of research that exists in palliative care (PC). Most promising areas in terms of structure and process of care are home-based PC, interdisciplinary team care, and telehealth approaches. There is documented evidence for comprehensive PC and music/art therapy addressing physical and psychological aspects of care. The existing evidence base for social needs assessments and culturally sensitive care remains very limited. There is documented evidence for life review/dignity therapy in the area of spiritual assessment approaches. Grief/bereavement support services appear to improve key outcomes for caregivers, but the evidence base for effective approaches for care in the last days of life is very limited. Evidence for ethics consults and advance directive/physician order interventions show the strongest evidence in the ethical and legal aspects of care domain. This comprehensive review underscores the importance of targeting future research toward building high-quality evidence in key areas of clinical practice and patient/caregiver needs. **Full text:** <https://goo.gl/mPvUuq>

Engaging multidisciplinary stakeholders to drive shared decision-making in oncology

JOURNAL OF PALLIATIVE CARE | Online – 1 November 2018 – Although recognized as best practice, regular integration of shared decision-making (SDM) approaches between patients and oncologists remains an elusive goal. It is clear that usable, feasible, and practical tools are needed to drive increased SDM in oncology. To address this goal, the authors convened a multidisciplinary collaborative inclusive of experts across the healthcare delivery ecosystem to identify key principles in designing and testing processes to promote SDM in routine oncology practice. They describe 3 best practices for addressing challenges associated with implementing SDM that emerged from a multidisciplinary collaborative: 1) Engagement of diverse stakeholders who have interest in SDM; 2) Development and validation of an evidence-based SDM tool grounded within an established conceptual framework; and, 3) Development of the necessary roadmap and consideration of the infrastructure needed for engendering patient engagement in decision-making. The authors believe these 3 principles are critical to the success of creating SDM tools to be utilized both within and outside of clinical practice. **Abstract:** <https://goo.gl/pcxFzQ>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 November 2018 – '**Did a goals-of-care discussion happen? Differences in the occurrence of goals-of-care discussions as reported by patients, clinicians, and in the electronic health record.**' The authors examined three methods to assess occurrence of a goals-of-care (GoC) discussion ... at a clinic visit for seriously ill patients and determine whether each method is associated with patient-reported receipt of goal-concordant care. 52% of patients reported occurrence of a GoC discussion at the clinic visit; clinicians reported occurrence of a discussion at 66% of visits. Neither occurrence of a discussion by clinician report nor by electronic health record documentation was associated with goal-concordant care. **Abstract:** <https://goo.gl/PZzaL3>



Media Watch: Behind the Scenes
<http://goo.gl/XDjHxz>

Lasting legacy: Maternal perspectives of perinatal palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 2 November 2018 – Many of the leading causes of infant mortality are diagnosed prenatally, presenting providers with the ability to present perinatal palliative care (PC) planning as an option. In the initial phase of this study, results revealed differences regarding the infant's end-of-life trajectory, including location of death, number of invasive procedures, and death in the setting of withholding versus withdrawing life-sustaining treatment. Highlighting that without a perinatal PC plan in place, the default treatment for infants with prenatally diagnosed life-limiting conditions is likely to be invasive and painful with often times minimal likelihood of long-term survival. Analysis of interview and focus group data revealed three themes: care, choice, and legacy. The authors used their experience with the health care system to draw implications for practice from the focus group and interview data, which care can serve to promote women feeling cared for and cared about, as well as promote opportunities for hope during a fragile pregnancy. **Abstract:** <https://goo.gl/tNveyz>

Comparing health care provider-perceived barriers to pediatric palliative care fifteen years ago and today

JOURNAL OF PALLIATIVE MEDICINE | Online – 2 November 2018 – Study findings were similar between 2002 and 2017, particularly in the extremes of the most and least commonly cited barriers. Barriers to palliative care (PC) for hospitalized children persist and commonly include perceptions that families deny, prefer, or have discomfort with forgoing life-sustaining treatments. Increasingly, studies have shown that families can be simultaneously hopeful and aware of their child's worsening health. Further PC education and research about these barriers and their impacts are necessary to support seriously ill children and their families. **Abstract:** <https://goo.gl/wGNPX7>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 November 2018 – **'Provision of palliative and hospice care to children in the community: A population study of hospice nurses.'** Approximately 500,000 children in the U.S. suffer from life-limiting illnesses each year, many of whom are hospice eligible each year. Few hospice agencies, however, offer formal pediatric programs. A total of 551 respondents across 71 hospices completed surveys. The majority of nurses reported no training in pediatric palliative or hospice care (89.8%), with approximately half reporting < 5 years of hospice experience (53.7%) and no pediatric hospice experience (49.4%). **Abstract:** <https://goo.gl/mhEkV4>

Facilitators and barriers to interdisciplinary communication between providers in primary care and palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 2 November 2018 – Community-based palliative care (CBPC) plays an integral role in addressing the complex care needs of older adults with serious chronic illnesses, but is premised on effective communication and collaboration between primary care providers (PCPs) and the providers of specialty palliative care (SPC). Optimal strategies to achieve the goal of coordinated care are ill-defined. Thirty semi-structured interviews were conducted with primary and palliative care interdisciplinary team members in academic and community settings. Major categories emerging from the data that positively or negatively influence optimal provision of coordinated care included feedback loops and interactions; clarity of roles; knowledge of palliative care, and workforce and structural constraints. Facilitators were frequent in-person, e-mail, or electronic medical record-based communication; defined role boundaries; and, education of PCPs to distinguish elements of generalist palliative care (GPC) and more complex elements or situations requiring SPC. Barriers included inadequate communication that prevented a shared understanding of patients' needs and goals of care, limited time in primary care to provide GPC, and limited workforce in SPC. The authors' findings suggest that processes are needed that promote communication, including structured communication strategies between PCPs and SPC providers, clarification of role boundaries, enrichment of non-specialty providers' competence in GPC, and enhanced access to CBPC. **Abstract:** <https://goo.gl/Jdu3Ud>

Physician visits and recognition of residents' terminal phase in long-term care facilities: Findings from the PACE cross-sectional study in 6 European Union countries

JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE | Online – 23 October 2018 – The authors describe the relation between physician visits and physicians' recognition of a resident's terminal phase in long-term care facilities (LTCFs) in Belgium, England, Finland, Italy, The Netherlands, and Poland. In each country, a cross-sectional study was conducted across representative samples of LTCFs. Participating LTCFs reported all deaths of residents in the previous 3 months, and structured questionnaires were sent to several proxy respondents including the treating physician. Number of physician visits, the resident's main treatment goal, whether physicians recognized the resident's terminal phase and expected the resident's death, and resident and physician characteristics. The number of physician visits to residents varied widely between countries, ranging from a median of 15 visits in the last 3 months of life in Poland to 5 in England, and from 4 visits in the last week of life in The Netherlands to 1 in England. Among all countries, physicians from Poland and Italy were least inclined to recognize that the resident was in the terminal phase (63.0% in Poland compared to 80.3% in The Netherlands), and residents in these countries had palliation as main treatment goal the least (31.8% in Italy compared to 92.6% in The Netherlands). Overall, however, there were positive associations between the number of physician visits and the recognition of the resident's terminal phase and between the number of physician visits and the resident having palliation as main treatment goal in the last week of life. **Abstract (w. link to references):** <https://goo.gl/sQL1Cd>



Noted in Media Watch 9 July 2018 (#571, p.14):

- *PALLIATIVE MEDICINE* | Online – 4 July 2018 – ‘The European Union’s Seventh Framework Programme Palliative Care for Older People cross-sectional survey in 322 nursing homes in six European countries.’ Although the authors found that many problematic issues are the same across countries, huge heterogeneity persists even after adjusting for confounders. Knowledge about basic palliative care (PC) issues is generally poor among nurses and care assistants in all countries, but particularly so in Poland and in Italy. A White Paper of the European Association for Palliative Care on PC education identifies nursing homes as a setting in which the staff, irrespective of their discipline, need to know the basic principles of PC.¹ **Full text:** <https://goo.gl/ppHxTi>

1. ‘Core Competencies in Palliative Care: White Paper on Palliative Care Education...’ *European Journal of Palliative Care*, 2013;20(2):86-91. [Noted in 4 March 2013 issue of Media Watch (#295, p.7)] **Journal contents page:** <https://goo.gl/kugYhG>

N.B. PACE website: <https://goo.gl/kWsvLo>

Grief tied to death: Dying of a broken heart is a real phenomenon

MEDSCAPE MEDICAL NEWS | Online – 25 October 2018 – The death of a loved one is a tragic and ultimately unavoidable experience that we all eventually face. Stories of spouses dying within days or even hours of each other are not uncommon. A recent study may explain why.¹ Researchers from Rice University, Houston, Texas, found that individuals who struggle to overcome grief caused by the loss of a loved one may experience levels of inflammation high enough to cause heart damage. “I was struck by how often people who had lost a loved one, like a spouse, were at much greater risk of suffering an often fatal heart attack than other people. They seemed to literally be ‘dying of a broken heart.’ I wanted to understand why this was the case,” lead investigator Chris Fagundes, PhD, who is an assistant professor of psychological sciences at Rice University, told *Medscape Medical News*. “In a previous paper, we found inflammation was significantly higher in bereaved individuals.² In this study, what we looked at is if level of bereavement could predict those most at risk,” said Fagundes. **Full text:** <https://goo.gl/rRCK3C>

1. ‘Grief, depressive symptoms, and inflammation in the spousally bereaved,’ *Psychoneuroendocrinology*, published online 11 October 2018. **Abstract (w. Link to references):** <https://goo.gl/u2tbTC>
2. ‘Impaired mental health and low-grade inflammation among fatigued bereaved individuals,’ *Journal of Psychosomatic Research*, published online 21 July 2018. **Abstract (w. link to references):** <https://goo.gl/L85BW1>

Tellable and untellable stories in suffering and palliative care

MORTALITY | Online – 30 October 2018 – The relief of patients' suffering – both physical and non-physical – is a primary aim of palliative care (PC), and has been described as an obligation and ethical duty for PC providers. The author suggests that common approaches to relieving patients' non-physical suffering – such as creating opportunities to make meaning, achieve personal growth, and hone one's resiliencies – comprise the larger, more tellable part of the PC discourse. A more marginal, less tellable part of the discourse acknowledges that some non-physical suffering cannot necessarily be relieved. Inspired by Foucauldian writings, the author suggests that PC discourse may be disciplining the relief of non-physical suffering, with unintended ramifications for front-line practice. Making more space for both the tellable and untellable stories of patients' non-physical suffering holds potential for an evolved PC discourse; one that un-disciplines dying. **Abstract:** <https://goo.gl/mDt8n9>

Health and social care professionals' experiences of supporting parents and their dependent children during, and following, the death of a parent: A qualitative review and thematic synthesis

PALLIATIVE MEDICINE | Online – 29 October 2018 – Children need to be prepared for the death of a parent and supported afterwards. Parents seek support from health and social care professionals to prepare their children. Support is not always forthcoming. The search yielded 15,758 articles. Fifteen met the [authors'] inclusion criteria. A total of 13 included professionals' experiences of supporting parents and children before parental death. Two included experiences of supporting surviving parents and children afterwards. Three analytical themes identified as follows: 1) Aspiring to deliver family-focussed care.; 2) Health and social care professionals' behaviours and emotion; and, 3) Improving connections with parents and children. Professionals struggle to connect empathically with parents and their children to prepare and to support children when a parent is dying and afterwards. Awareness of professionals' needs would enable provision of appropriate support for parents and children. **Abstract:** <https://goo.gl/L5JWsZ>

End-of-life care in Austria

“Being there”

PALLIATIVE MEDICINE IN PRACTICE, 2018;12(3):131-134. Volunteer hospice teams are part of the nationwide Austrian concept of a 'Graded Hospice & Palliative Care System.' This three-level system was commissioned by the Ministry of Health and developed by GÖG/ÖBIG [Austrian Federal Institute of Health], a national research and planning institute for health care, in joint cooperation with Hospice Austria in 2004. By the end of 2016, there were 3,528 hospice and palliative care (PC) volunteers in Austria. 2,929 volunteers belonged to one of the 162 hospice teams and were involved in direct patient care, 599 volunteers were performing other tasks in their hospice teams or were working within coordinating organizations in their federal state (e.g., as board members, helping with fundraising, etc.). 86% of the volunteers were female. Volunteers contributed in total 405,204 hours. 256,325 (63%) of these were spent in direct patient care in all kinds of settings at home, in PC units, in day hospices, inpatient hospices and also in nursing homes. Volunteers in direct patient care are required to undergo a training based on a standard curriculum developed by Hospice Austria and are organized in teams with a (paid) coordinator. Abstract (inc. list of references): <https://goo.gl/3g6W9R>

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>



Supporting the health care transition from adolescence to adulthood in the medical home

PEDIATRICS, 2018;142(5):e20182587. Risk and vulnerability encompass many dimensions of the transition from adolescence to adulthood. Transition from pediatric, parent-supervised health care to more independent, patient-centered adult health care is no exception. The tenets and algorithm of the original 2011 clinical report, 'Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home,' are unchanged. This updated clinical report provides more practice-based quality improvement guidance on key elements of transition planning, transfer, and integration into adult care for all youth and young adults. It also includes new and updated sections on definition and guiding principles, the status of health care transition preparation among youth, barriers, outcome evidence, recommended health care

transition processes and implementation strategies using quality improvement methods, special populations, education and training in pediatric onset conditions, and payment options. The clinical report also includes new recommendations pertaining to infrastructure, education and training, payment, and research. **Full text:** <https://goo.gl/Ro2JWf>

Extract from *Pediatrics* article

For patients receiving pediatric palliative care or end-of-life care, timing of transition to adult health care depends on the youth's anticipated disease trajectory and overall goals of care.

Noted in Media Watch 24 September 2018 (#582, p.15):

- *PATIENT EDUCATION & COUNSELING*, 2018;101(10):1723-1724. **'Shared decision making's adolescence and transition into adulthood.'** The seven articles comprising the special section in this issue are thematically linked through their interest in how patients and clinicians perceive decisions and shared decision making. Yet they are diverse in many ways including populations, methodologies, and diseases. The articles represent work done in several countries, with qualitative and quantitative methodologies, from small studies on decision making perceptions and desires to large investigations of real-world experience in decision making, and from children and adolescents to older cancer survivors. **Abstract (w. link to references):** <https://goo.gl/Fj2Dzo>

N.B. Journal contents page: <https://goo.gl/U4XKYA>

Noted in Media Watch 30 July 2018 (#574, p.13):

- *JOURNAL OF ADVANCE NURSING* | Online – 25 July 2018 – **'Conflicting realities experienced by children with life-limiting and life-threatening conditions when transitioning to adult health services.'** In this study, six conflicting realities were identified: 1) Planning to live and planning to die with different illness trajectories that misaligned with adult service models; 2) Being treated as an adult and the oldest "patient" in children's services compared with being treated as a child and the youngest "patient" in adult services; 3) Being a "child" in a child's body in children's services compared with being a "child" in an adult's body in adult services for those with learning impairments; 4) Being treated by experienced children's professionals within specialist children's services compared with being treated by relatively inexperienced professionals within generalist adult services; 5) Being relatively one of many with the condition in children's services to being one of very few with the condition in adult services; and, 6) Meeting the same eligibility criteria in children's services but not adult services. Inequity and skills deficits can be addressed through targeted interventions. **Advance:** <https://goo.gl/G6QnJB>

N.B. Additional articles on transitioning to adult health services noted in this issue of Media Watch.



Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

Who should provide care for patients receiving palliative chemotherapy? A qualitative study among Dutch general practitioners and oncologists

SCANDINAVIAN JOURNAL OF PRIMARY HEALTH CARE | Online – 30 October 2018 – This study provides insight into the views of GPs and oncologists about current practice in care for patients receiving palliative chemotherapy. It shows partially contrasting perspectives on who ideally should provide different aspects of care. The findings raise awareness about differences in the reasoning of GPs and oncologists and in their approach to specific aspects of palliative care. In general, oncologists put more emphasis on topics such as understanding the prognosis and treatment options, whereas GPs focused more on the social network around the patient, knowledge of their past medical history, and their ability to keep an eye on the situation at home, which creates continuity of care. Awareness of these different points of view and of current communication and information transfer deficits between GPs and oncologist, should

help to provide better individualized care for patients. Future research should look for methods to clarify the role distribution, to optimize interdisciplinary communication and jointly improve the quality of care for patients with advanced cancer. **Full text:** <https://goo.gl/V6BqMv>

AJGP

Australian Journal of General Practice

Palliative care is the focus of the current issue of the journal of the Royal Australian College of General Practitioners. **Contents page:** <https://goo.gl/P76nQu>

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 1 November 2018 – ‘**General practitioners and end-of-life care: A qualitative study of Australian GPs and specialist palliative care clinicians.**’ Factors affecting GPs’ involvement in end-of-life care (EoLC) included: 1) Continuity of care, long-term relationships with patients, knowledge and skills in EoLC, resource limitations and work patterns; 2) Communication and collaboration between GPs and the acute healthcare system; and, 3) Communication and collaboration between GPs and specialist PC clinicians. GPs could be encouraged in this role by providing them with education and practical experience in EoLC, making changes to remuneration structure, formalised arrangements for shared care and encouraging continuity of care and developing long-term relationship with their patients. **Abstract:** <https://goo.gl/S12Tks>

Care, coercion and dignity at the end of life

STUDIES IN CHRISTIAN ETHICS | Online – 25 October 2018 – End-of-life (EoL) debates in medical ethics often centre around several interrelated issues: improving care, avoiding coercion, and recognising the dignity and rights of the terminally ill. Care ethics advocates relational autonomy and non-abandonment. These commitments, however, face system pressures – economic, social and legal – that can be coercive. This article takes up two related aspects in this domain of ethics. Firstly, that competence and communication are core clinical ethics principles that can sidestep the overplayed dichotomies in EoL care. And secondly, it questions the assumption that advance directives are universally benevolent – comparing the provisions of the Council of Europe’s 1999 recommendations on protection of human rights and dignity of the dying within the framework of the Irish context. The article also registers the unintended impacts of changing legal frameworks in relation to euthanasia and assisted suicide in Europe, including recent proposals in The Netherlands. A focus on human dignity can provide a theologically and philosophically shared normative orientation that argues for present directives rather than only advance directives, and a presumption in favour of “living up to death.” Dignity approaches not only grant rights but secure them by supporting ongoing initiatives that honour, rather than erode, the “longevity dividend.” **Abstract:** <https://goo.gl/dTpfdB>

Cont.

Noted in Media Watch 8 January 2018 (#545, p.6):

- *BIOETHICS* | Online – 28 December 2017 – ‘**Manipulation, salience, and nudges.**’ Not surprisingly, healthcare practitioners and public policy professionals have become interested in whether nudges might be a promising method of improving health-related behaviors without resorting to heavy-handed methods such as coercion, deception, or government regulation. Many nudges seem unobjectionable... Other nudges influence decision-making in ways that do not involve providing more and better information. Nudges of this sort raise concerns about manipulation. **Abstract:** <https://goo.gl/TR7cYa>

Noted in Media Watch 20 June 2016 (#467, p.12):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 15 June 2016 – ‘**Compromised autonomy: When families pressure patients to change their wishes.**’ A case example, based on a clinical ethics consultation, is used to highlight the complexities of compromised autonomy secondary to family coercion and manipulation at the end of life. Decision making in the context of family involvement and relational autonomy is explored along with effects of caregiver stressors, patient/family disagreements, and the nuances of substituted judgment. **Abstract:** <http://goo.gl/WguFRf>

How much time is left? Associations between estimations of patient life expectancy and quality of life in patients and caregivers

SUPPORTIVE CARE IN CANCER | Online – 1 November 2018 – It is unclear whether life-expectancy estimates of patients with advanced cancer and their caregivers are associated with patient existential, social, or emotional quality of life (QoL) or caregiver emotional QoL. [In this study] pessimistic life-expectancy estimates are associated with worse existential QoL in patients and worse emotional QoL in caregivers. Prospective research to establish causal relationships is needed, and interventions to address the relationship between beliefs about life expectancy and existential and emotional QoL should be considered. Providing these interventions to patients and caregivers receiving information on life expectancy may mitigate the negative impact of life-expectancy information on patient existential quality of life. **Abstract (inc. list of references):** <https://goo.gl/A2UWz5>

End-of-life care in a multicultural framework: To treat or not to treat

UNIVERSITY OF TORONTO MEDICAL JOURNAL, 2018;95(3):43-44. Canada’s growing immigrant population is increasing demands for a culturally sensitive healthcare system. There are visible disparities in end-of-life care (EoLC) treatment when Canadian residents are compared to immigrants. This may be due to differences in patient preferences, influenced by culture, however is more likely associated to the physicians approach surrounding conversations about EoLC. Physicians may be clouded by preconceived notions of what patients may want based on their cultural heritage. It is essential for physicians to be inclusive and accepting of patient preferences and to address issues, such as familial involvement and non-disclosure of diagnoses. Ultimately, integration of clinical tools that will build rapport and allow open dialogue between physicians and patients is the first step towards treatment plans that provide benefits and less harm to their recipients. **Abstract:** <https://goo.gl/hPouXn>



Photo: Lori Waselchuk. Philadelphia, PA

Updated 11.01.2018

Prison Hospice: Background

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>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CUADERNOS DE BIOÉTICA*, 2018;29(97):257-268. ‘**Hastening death by voluntary stopping of eating and drinking. A new mode of assisted suicide?**’ The new catch phrase “voluntary stopping of eating and drinking” has made its appearance in the medical and bioethical literature. The practice, whose “primary intention” is to hasten the death of a person who does not want to continue living, has been proposed as an alternative to euthanasia and assisted suicide. Some authors present it as a valid option from both the ethical and legal point of view arguing that it is basically a “natural death” in the same line as a limitation of treatment and does not involve suicide. The authors present a critical review of the recent literature and reach the conclusion that it is very difficult to consider this practice as anything other than a type of suicide. In consequence, healthcare workers should consider it alien to medical ethos and good clinical practice. **Abstract (via PubMed):** <https://goo.gl/X9PYSX>

N.B. Spanish language article.

- *JOURNAL OF MEDICAL ETHICS* | Online – 30 October 2018 – ‘**Of dilemmas and tensions: A qualitative study of palliative care physicians’ positions regarding voluntary active euthanasia in Quebec, Canada.**’ In 2015, the Province of Quebec, Canada passed a law that allowed voluntary active euthanasia (VAE). Palliative care (PC) stakeholders in Canada have been largely opposed to euthanasia, yet there is little research about their views. The research question guiding this study: “How do PC physicians in Quebec position themselves regarding the practice of VAE in the context of the new provincial legislation?” Participants positioned themselves in opposition to euthanasia. Their justifications were framed within their professional commitment to not hasten death, which sat in tension with the value of patients’ autonomy to choose how to die. Participants described VAE as unacceptable if it impeded opportunities to evaluate and alleviate suffering. Further, they contested government rhetoric that positioned VAE as a way to improve end-of-life care. Participants felt that VAE would diminish the potential of PC to relieve suffering. Dilemmas were apparent in their narratives, about reconciling respect for patient autonomy with broader PC values, and the value of accompanying and not abandoning patients who make requests for VAE while being committed to neither prolonging nor hastening death. This study provides insight into nuanced positions of experienced PC physicians in Quebec and confirms expected tensions between an important stakeholder and the practice of VAE as guided by the new legislation. **Abstract:** <https://goo.gl/j7MWk6>
- *KŌTUITUI: NEW ZEALAND JOURNAL OF SOCIAL SCIENCES* | Online – 24 October 2018 – ‘**The euthanasia debate: Synthesising the evidence on New Zealander’s attitudes.**’ New Zealand is considering a change in law to permit euthanasia and/or assisted dying (EAD). The authors reviewed 20 years of research to investigate New Zealanders’ attitudes towards EAD, including those of health professionals. They identified 21 quantitative and 5 qualitative studies. The authors reviewed the circumstances under which people think that EAD should be accessible, and which forms of EAD they support. All public attitude studies reported that the majority (68%) of respondents support EAD. There are few statistically significant demographic associations with attitudes toward EAD; exceptions include religiosity, educational attainment, and some ethnic groups. Health professionals’ attitudes varied by speciality. Qualitative research was analysed for reoccurring themes; “feeling like a burden” was evident across most studies. The authors conclude that public attitudes are stable and a majority are open to legislative change. However, the qualitative research reveals the complexity of the issue and indicates a need for careful consideration of any proposed law changes. It is unclear what safeguards people expect if the law changes. The authors found little research involving vulnerable and marginalised populations. **Full text:** <https://goo.gl/eHTFMB>

[Media Watch: Editorial Practice](#)

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Cont.

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

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

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