

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

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Compiled & Annotated by Barry R. Ashpole

It can be hoped that, as health policy analysts address the inequities uncovered by the pandemic, the plight of rural palliative patients receives equal consideration.

'Rural-urban inequities in palliative care' (p.0), in *BC Medical Journal*.

Canada

Home and Community-Based Palliative Care: Shaping the future from lessons learned during the COVID-19 pandemic

HEALTH CANADA | Online – Accessed 8 July 2021 – The Coronavirus disease 2019 (COVID-19) has caused 23,623 deaths in Canada since January 2020 at the time of printing (April 2021), and continues to pose an ongoing threat to Canadians of all ages. Early pandemic planning focused on the hospital sector and later shifted to the long-term sector as infection and death rates soared. Patient discharges from hospitals, cancellation of non-essential services and procedures, and people's reluctance to receive care in institutional care settings, led to a skyrocketing demand for home care services. COVID-19 further strained already limited palliative care (PC) resources and exposed pre-existing gaps and systemic vulnerabilities in PC delivery across in-home and community-based settings across Canada. Unprecedented demand for in-home and community-based care provided both challenges and opportunities for the PC sector. While initially largely overlooked in early pandemic planning, home and community-based PC has proven to be of paramount importance in caring for

people during this crisis. The sector demonstrated a high degree of flexibility and was able to pivot quickly to assume an essential role in the provision of increasingly complex palliative and end-of-life care. The pandemic further illuminated the importance of greater cross-sectoral collaboration and highlighted the need to ensure that equity remains a top priority in future planning. **Access at the Canadian Society of Palliative Care Physicians website:** <https://bit.ly/3r3XHhG>

Specialist Publications

'Impact of legalization of medical assistance in dying on the use of palliative sedation in a tertiary care hospital: A retrospective chart review' (p.5), in *American Journal of Hospice & Palliative Medicine*.

'Cost of futile ICU care in one Ontario hospital' (p.7), in *Inquiry: Journal of Health Care Organization, Provision & Financing*.

N.B. Facility-based care, such as nursing homes and long-term care homes, were not included in the consultations to inform this report.

New online calculator can predict how long seniors have left to live, what help they need

ONTARIO | Global News (Toronto) – 5 July 2021 – Amid a lack of proper support for Canadians receiving home-based support towards the end of their lives, a new risk calculator is helping predict how long seniors have left to live. The Risk Evaluation for Support: Predictions for Elder-Life in the Community Tool – dubbed ‘RESPECT’ for short – can predict death within six months, and was developed using data from more than 491,000 community-dwelling adults aged at least 50 years who used home care between 2007 and 2013. “The RESPECT calculator allows families and their loved ones to plan,” said Dr. Amy Hsu, investigator at the Bruyère Research Institute and lead author of the study.¹ In addition to palliative care professionals, researchers said it can be used by physicians and home care staff. Dr. Peter Tanuseputro, a physician-scientist at The Ottawa Hospital and Institute for Clinical Evaluative Sciences who also authored the study, said in a statement that knowing how long a person has to live is also “essential in making informed decisions about what treatments they should get and where they should get them.” Although most Canadians die from predictable causes and have health needs that can be met at home, only 20% of residents receive a physician home visit in their last year of life. <https://bit.ly/3hfHDG9>

Extract from Global News report

According to University of Toronto Bioethicist Kerry Bowman, implementing such a calculator to the healthcare system could potentially be an “ethical minefield.” Bowman said that while there might be some upsides to the calculator, such as advance care planning, there were quite a lot of ethical dilemmas to consider when disclosing the timeline of a person’s death. Those include whether a recipient is capable of consent, and whether or not knowing the information would change their attitude or perception. “We have learned before the pandemic and particularly with the pandemic, that there’s tremendous inherent biases within healthcare, access, distribution and algorithms for vulnerable people, racialized people, lower socioeconomic classes,” he said. “Using a tool like this without doing due diligence with social, cultural and ethical analysis is not a smart thing to do.” Lastly, if the calculator would ever be introduced to Canada’s healthcare system, Bowman believes that it would be interfaced with the country’s medical assistance in dying (MAiD), and could possibly shape the attitude of palliative care and end-of-life decisions.

1. ‘Predicting death in home care users: Derivation and validation of the Risk Evaluation for Support: Predictions for Elder-Life in the Community Tool (RESPECT),’ *Canadian Medical Association Journal*, 2021;193(26):E997-E1005. Full text: <https://bit.ly/3hzgHQJ>

U.S.A.

Planning death has gone digital: Inside the apps that prepare you for loss

NEW YORK | *The Observer* (New York) – 5 July 2021 – Over the last few years a plethora of apps and services ... have sprung up that promise to ease the process of planning for death. Whether it’s noting what healthcare that you’d like to receive, recording memories so that a curated legacy is left behind, or uploading important documents, there are plenty of options on offer. Some target a specific aspect of the death planning process ... which allows users to record messages for the people that they leave behind to access after they pass. Others ... offer a more rounded approach, guiding individuals through everything from writing a will to planning an eco-friendly funeral. In a world where much of our lives take place online, it seems only natural that death should find its own digital niche. The pandemic has boosted an already burgeoning industry, causing younger generations to reflect deeply on what they want to leave behind. Mark Taubert, a palliative care doctor who has been working throughout the pandemic told us how apps can prompt his patients to think about preferred places of death or make their wishes known ready for when they are too unwell to communicate. He describes the relationship between technology and end-of-life care as deeply complex, acknowledging that the way that we manage grief is influenced by the people around us, society, and our own experiences – and that the pandemic has been crucial in prompting us to consider how technology might play a part in both life and death. <https://bit.ly/3hlsZ09>

International

Quality of palliative care falls in Japan amid pandemic

JAPAN | *The Japan Times* (Tokyo) – 10 July 2021 – Over 70% of hospitals in Japan with palliative care (PC) units for patients with terminal cancer and other diseases believe that the quality of care has decreased due to the pandemic, a survey by a non-profit organization showed. The pandemic has forced hospitals to reduce visits to patients by family members and others to prevent infections, according to Hospice Palliative Care Japan, a non-profit based in Kanagawa Prefecture. The March survey covered 376 hospitals and asked them about their measures taken between December and February. Valid responses were collected from 174 hospitals. About 33% of responding hospitals said that the quality of PC has “greatly decreased” due to the pandemic, while 39% said that it has “decreased somewhat.” Only 25% said that the quality of care has not decreased. <https://bit.ly/36sN9PC>

Specialist Publications

‘Call the *rezadora*: Aiding Latino families at the end of life’ (p.6), in *Hispanic Health Care International*.

‘A literature review of possible barriers and knowledge gaps of general practitioners in implementing advance care planning in Ireland: Experience from other countries’ (p.7), in *International Journal of Medical Students*.

‘A framework for adult bereavement care in Ireland. Policy and planning response in a COVID and post-COVID-19 Ireland’ (p.10), in *Palliative Care & Social Practice*.

‘Remote area nurses’ perceptions of the enablers and barriers for delivering end-of-life care in remote Australia to Aboriginal people who choose to pass away on their traditional lands’ (p.12), in *Rural & Remote Health*.

Organizational readiness found to be main driver for good quality end-of-life care in hospitals

AUSTRALIA | *News Medical* – 8 July 2021 – How prepared and engaged a hospital is to provide end-of-life care (EoLC) is pivotal to the quality of care provided, a new Flinders University study has found.¹ With many deaths occurring in hospitals in Australia every year, hospitals are one of the main providers of end-of-life care. And with the number of Australians who die each year projected to double by 2040, the need for safe and quality EoLC in hospitals is an ongoing concern. Now, a recent study conducted by the Flinders University Research Centre for Palliative Care, Death & Dying has sought to identify the best practices and organizational requirements for delivering excellent EoLC in hospitals. The study also identified the measures needed to support patients and families during a pandemic. Led by Deb Rawlings from Flinders University’s College of Nursing & Health Sciences, the study was commissioned by the Australian Commission on Safety & Quality in Health Care in order to inform an update to the National Consensus Statement for safe and quality EoLC. Using a rapid review of literature, the study found that organizational readiness is a main driver for good quality EoLC. <https://bit.ly/2TPoNNe>



**Research Centre
for Palliative Care
Death & Dying**

1. ‘Rapid Review of the Literature to Inform the Development of Quality & Safety Indicators for End-of-Life Care in Acute Hospitals,’ Australian Commission on Safety & Quality in Health Care, June 2021. **Download at:** <https://bit.ly/3hviqrg>

“Six months to live” rule for dying people to claim benefits scrapped from next year

U.K. | *The Daily Mirror* (London) – 8 July 2021 – Dying benefit claimants will no longer have to show they have six months to live as cruel rules are finally axed. Special Rules for Terminal Illness will be reformed in a victory for campaigners, ministers announced today – two years after saying they were not fit for purpose. But it’s thought the changes could take up to two years to be fully implemented. Ten people a day die while

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waiting for a decision on a Personal Independence Payment claim. The Special Rules allow terminally ill claimants to access fast-track benefits. But the current rules say claimants must get their GP to fill out a form confirming they can “reasonably be expected” to die within six months. The Department for Work & Pensions has now confirmed the arbitrary six-month rule will be scrapped and eligibility will be widened to those who might be expected to die within 12 months. <https://bit.ly/3e16FH8>

Prisoners near death housed in “unsuitable” environment

IRELAND | *The Irish Times* (Dublin) – 6 July 2021 – Some prisoners in Irish jails were so fragile and close to death they were unable to use a telephone yet little or no palliative care (PC) was being provided to them, a prison chaplain’s report reveals. It details how “many” prisoners in the Midlands Prison – the largest jail in the Republic – were “elderly men” who “need specialist PC and at some stage may need end-of-life care.” While the medical staff and carers working in the prison “do a wonderful job,” a prison environment was not suitable for men clearly approaching the end of their lives. The chaplains’ reports for all of the jails in the Irish prison system have been published by the Department of Justice. <https://bit.ly/3dREXfQ>



Seirbhís Phríosúin
na hÉireann
Irish Prison Service

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report, last updated 1 May 2021, can be downloaded at the Palliative Care Network website: <http://bit.ly/2RdegnL>

Palliative care needs to include spiritual care

AFRICA (South Africa) | *Mail & Guardian* (Johannesburg) – 5 July 2021 – Palliative care (PC) ... is gaining momentum in South Africa. Spiritual care is slowly being recognised as an important component of PC and hospice work. Spirituality is particularly important in Africa but it is the most neglected pillar of PC. Priority is given to the medical component of PC, as it should be, because a central aim of PC is to provide pain relief and symptom control. The other two pillars of PC – psychosocial and bereavement care – are prioritised next. Spiritual care, largely for resource reasons, tends to be neglected. Where spiritual care is offered it is commonly through the use of community resources such as volunteers and nongovernmental organisations. Most African countries cannot afford a professional PC service as is offered in the Global North, nor is it clear in the African context that a fully professionalised service would necessarily provide the best and most appropriate care. Resource constraint is a significant stumbling block to holistic.¹ Research has found that in South Africa most spiritual care services are provided by volunteers who come from varied academic, cultural, and socioeconomic backgrounds. There appears to be no clear entry requirement and most of the work is learnt through experience, through passed-down family traditions, on-the-job-training and mentoring by professionals such as nurses and social workers and by faith-based organisations. <https://bit.ly/3qMWN90>

1. ‘Challenges and opportunities for spiritual care practice in hospices in a middle-income country,’ BMC Palliative Care, published online 22 April 2021. [Noted in Media Watch 3 May 2021 (#715, p.7)] **Full text:** <https://bit.ly/3tQW07O>



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://bit.ly/2RPJy9b>

Specialist Publications

Impact of legalization of medical assistance in dying on the use of palliative sedation in a tertiary care hospital: A retrospective chart review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 5 July 2021 – This study demonstrates an increase in the use of palliative sedation (PS) in one hospital's palliative care (PC) unit following the legalization of medical assistance in dying (MAiD) in Canada... While some confusion persists outside the PC profession about PS versus MAiD, the authors believe that the legal, mainstream presence of MAiD may have promoted an increased recognition of the two options as distinct entities. They believe that rates of PS increased not because of its use in place of MAiD, but rather may have been driven by greater awareness about patient choice at end-of-life (EoL) and increased comfort with EoL options generally. Future research should expand work to other clinical environments and geographical regions to determine if findings are replicated in other settings. Future studies could also seek to explore how MAiD has altered the attitudes and practices of PC physicians who administer PS. **Full text:** <https://bit.ly/3k1sNVN>

Rural-urban inequities in palliative care

BC MEDICAL JOURNAL, 2021;63(6):255. There are significant inequities in the delivery of palliative healthcare between rural and urban populations in British Columbia (BC). These inequities have, like many other areas of healthcare, been amplified by the current [COVID-19] pandemic. According to Statistics Canada, on average, BC's rural populations are older, poorer, and have a higher chronic disease burden than urban populations. It might be thought, therefore, that the Ministry of Health and health authorities would recognize this inequity and assign palliative care (PC) resources accordingly. In fact the opposite is true, and like many other inequities, the COVID-19 pandemic has worsened this divide. Both the 2018 Health Canada Framework on Palliative Care and the BC Centre for Palliative Care address the need for equity in the delivery of PC services.^{1,2} Under its guiding principles, the Centre states that "All individuals and families have equal access to hospice PC services when they need it and where they need it: at hospitals, long-term care facilities, hospices, and the home." Unlike other healthcare services (e.g., neurosurgery), PC services can only be effectively delivered in a patient's home community. There are many reasons why this is currently not being achieved equally across the province... **Full text:** <https://bit.ly/3qX89re>

1. 'Framework on Palliative Care in Canada,' Health Canada, 2018. [Noted in Media Watch 10 December 2018 (#593, p.1)] **Download/view at:** <http://bit.ly/2AVEghF>
2. 'Palliative Care is a Public Health Issue,' BC Center for Palliative Care, August 2015. (See Chapter 3: 'Palliative care is an increasingly important public health issue.') **Download at:** <https://bit.ly/3wk8vsZ>

Research Matters

'Historic abuses, present disparities, and systemic racism: Threats to surrogate decision-making for critical care research enrollment' (p.13), in *Annals of the American Thoracic Society*

'Dealing with death as an outcome in supportive care clinical trials' (p.13), in *JAMA Internal Medicine*.

'Pragmatic considerations in incorporating stakeholder engagement into a palliative care transitions study' (p.13), in *Medical Care*.

'Research cooperative groups in pediatric palliative care research' (p.13), in *Palliative Medicine Reports*.

What do we know about patients' perspectives and expectations relating to palliative and end-of-life care in advanced liver disease? A systematic review of qualitative literature using ENTREQ guidelines

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 7 July 2021 – Liver disease, a major cause of death worldwide, affects younger people compared with other major causes of death. Palliative and end-of-life (EoL) care for these patients are often overlooked. Guidelines are emerging on what good EoL care in liver disease should look like, but there is a dearth of research into patients' perspectives even though they are most affected by these guidelines. Only eight articles met the authors' criteria. Themes demonstrated repeated hospital admissions towards the EoL, lack of coordinated care in community and barriers in discussion about PC in end-stage liver disease due to lack of confidence among professionals and a negative view about PC among patients and carers. Emotional, financial and disability-related needs of patients and their carers are often neglected. Lack of coordinated community support and honest conversations around PC leads to reduced quality of life. More primary research from diverse population is needed to improve PC and EoL care in end-stage liver disease. **Abstract:** <https://bit.ly/3dYIOc6>

Virtual reality in hospice: Improved patient well-being

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 2 July 2021 – Virtual reality (VR) technology as a therapeutic intervention has been gaining attention in healthcare settings in recent years. Studies suggest that using the technology can help alleviate symptoms such as pain and anxiety, and induce positive emotions for people in hospital. Managing symptoms and promoting emotional and psychological well-being are core palliative care goals of relieving suffering of people with life-limiting illness. Accordingly, VR may be highly beneficial for use in hospice care yet remains underdeveloped in such settings. Nineteen hospice patients successfully tried an immersive VR experience. The majority of participants enjoyed the experience. Many expressed joy and delight at the process. VR holds possibilities for relieving symptoms such as pain and anxiety frequently experienced by people in hospices. Furthermore, the technology offers the capacity to reconnect with a previous sense of self and to allow respite through the capacity to transcend current reality and connect with another meaningful reality. This exploratory study offers a starting point for larger studies to investigate the utility of VR for hospice patients. **Abstract:** <https://bit.ly/3hgshRP>

Noted in Media Watch 22 February 2021 (#705, p.4):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 15 February 2021 – **'The potential of personalized virtual reality in palliative care: A feasibility trial.'** Virtual Reality (VR) can help alleviate symptoms in a non-palliative care (PC) population. Personalized therapy can further alleviate these symptoms. There is little evidence, however, in a PC population. This is a novel study in the U.K. investigating personalized VR, over repeated sessions, for people with a terminal illness. This research suggests it is feasible to recruit people with advanced illness, in a hospice setting, for a repeated VR trial. While preliminary findings suggest a reduction in Edmonton Symptom Assessment System-Revised scores, there were no statistically significant findings. **Full text:** <http://bit.ly/3bat3LQ>

N.B. Additional articles on VR in PC and hospice noted in this issue of Media Watch (pp.4-5).

Call the *rezadora*: Aiding Latino families at the end of life

HISPANIC HEALTH CARE INTERNATIONAL | Online – 5 July 2021 – The *rezadora*, a lay spiritual leader, provides support to Latino families as they provide end-of-life (EoL) care for loved ones. The purpose of this study was to learn about the work of the *rezadora* in Guatemala as a resource for Latinos with serious illness in the U.S. An ethnographic exploratory case study was conducted during summer 2018 in rural Guatemala. The authors interviewed three *rezadoras* who resided in two villages. The study yielded two cases, the single case and the paired case, which allowed for a holistic view of how the *rezadora* serves the community. Analysis led to two themes: 1) Essence of being called; and 2) Power of prayerful song.

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Essence of being called was represented by the prominence of the *rezadora* and their perpetual faith work. Power of prayerful song was characterized through the mission, customs, and the presence of the *rezadora*. As the Latino population ages in place, the need for palliative and EoL care services will increase. Lay spiritual leaders could enhance the palliative care teams in these communities and improve the quality of life for Latinos with serious illness. **Abstract (w. references):** <https://bit.ly/2UvSyCU>

Noted in Media Watch 31 October 2016 (#485, p.6):

- *JOURNAL OF TRANSCULTURAL NURSING* | Online – 21 October 2016 – ‘**At the grave we make our song: A palliative care study in rural Guatemala.**’ The overarching theme was “relief from suffering,” reinforced by three support systems: 1) The family; 2) Community *rezadora*; and, 3) Priest. The family made decisions and provided physical care. The *rezadora* sang prayers and prepared the home altar. The priest provided traditional sacraments. The role of the *rezadora* should be considered in providing palliative care to Guatemalans. Some have difficulty understanding the role of the nurse in palliative and end-of-life care (EoLC). The authors suggest training opportunities using international resources to enhance the role for nurses in EoLC. **Abstract (w. references):** <https://bit.ly/2SUKZtx>

Cost of futile ICU care in one Ontario hospital

INQUIRY: JOURNAL OF HEALTH CARE ORGANIZATION, PROVISION & FINANCING | Online – 5 July 2021 – This study supports previous American and Australian study findings of significant costs associated with the delivery of futile care across differing healthcare models. Together these findings demonstrate that use of healthcare funding to provide futile care is widespread and represents a global economic issue. There are both financial and non-financial opportunity-costs associated with providing futile care. On top of the economic burden and significant loss of patient quality of life is the moral injury sustained by ICU healthcare providers including physicians and nurses. Moral injury, a term originating in the military context, refers to experiences of serious inner conflict arising from what one takes to be grievous moral transgressions that can overwhelm one’s sense of goodness and humanity. In the medical context, it is increasingly used to describe situations where providers feel that they are causing a patient pain and suffering without any hope of benefit to the patient, thereby causing inner conflict. Accordingly, the literature suggests that the potential suffering involved in futile care delivery is often not fully understood at the time of decision-making. **Full text:** <https://bit.ly/3xkEY3J>

A literature review of possible barriers and knowledge gaps of general practitioners in implementing advance care planning in Ireland: Experience from other countries

INTERNATIONAL JOURNAL OF MEDICAL STUDENTS, 2021;9(2);145-156. Advance care plans (ACP) have been employed into medical practices worldwide; however, they remain largely uncompleted by general practitioners (GPs), regardless of their benefits to patients and their families with respect to EoL care. Furthermore, ACP will soon be implemented into clinician practices across Ireland, as part of the Assisted Decision Making (Capacity) Act 2015. This review aimed to explore the literature to examine challenges GPs may face in employing ACP into clinical practice. Fourteen studies were condensed and critically appraised through CASP (Critical Appraisal Skills Program), which concluded that the quality of the studies was high. Through this review, knowledge gaps and barriers for GPs regarding ACP were identified. Barriers for implementing ACP into practice were categorized into three major themes: 1) Barriers for the GPs; 2) Barriers in the healthcare system; and, 3) Barriers regarding the patient. These included insufficient time, complexity of the ACP documents themselves, uncertainty of the disease prognosis, and the ultimate fear of inducing anxiety and loss of hope in patients. **Full text:** <https://bit.ly/3qLFFjQ>



Media Watch: Access 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.14.

Generating key practice points that enable optimal palliative care in acute hospitals: Results from the OPAL project's mid-point meta-inference

INTERNATIONAL JOURNAL OF NURSING STUDIES ADVANCES | Online – 6 July 2021 – The authors identified and confirmed three categories of care that enable optimal inpatient palliative care PC: 1) Person-centred care; 2) Expert care; and, 3) Optimal environment for care. Within these three overarching categories are 14 domains of importance for inpatients with PC needs and their families. Many components within each domain are also likely to be important for other inpatient populations. However, there are some unique requirements for inpatients with PC needs that warrant careful consideration, particularly in relation to the inpatient who is imminently dying. Furthermore, this meta-inference provides a clear set of practice points aligned to each domain and category to inform optimal inpatient PC. Understanding how to drive reform to enable this care, within the busy and varied environments of hospitals caring for diverse populations across metropolitan and rural contexts, is an important next step. **Full text:** <https://bit.ly/36klOOg>

Carving in hospice to Medicare Advantage – potential unintended consequences

JAMA HEALTH FORUM, 2021;2(7):e212269. Since the creation of the Medicare hospice benefit in 1982, Medicare Advantage has grown rapidly. In 2011, only about 1 in 5 Medicare decedents aged 66 years or older were cared for under a Medicare Advantage plan. In 2018, 1 in 3 Medicare decedents were enrolled in a Medicare Advantage plan at the time of death. In 10 states, Medicare Advantage provides medical care to between 38.3% and 52.3% of Medicare decedents. Among that top 10, Michigan experienced the largest growth in decedents who were on Medicare Advantage at the time of death, increasing from 19.8% to 38.3% (i.e., 93.4% growth). In the top 3 states (Hawaii, Rhode Island, and Oregon), about half of decedents were enrolled in a Medicare Advantage plan when they died. If these trends continue, Medicare Advantage will become the predominant provider of care for seriously ill persons at the end of life in the U.S. Since the hospice benefit's creation, Medicare Advantage has not covered hospice care of its enrollees, and such care remains excluded from Medicare Advantage plans. This carve-out resulted from the lack of data regarding how best to calculate payment. Concerns over the carve-out include not only administrative complexity but also issues related to coordination and continuity of care. The Medicare Payment Advisory Commission in 2014 recommended an innovation: carving hospice back into Medicare Advantage to improve coordination of care, as well as offering access to palliative care services other than hospice. This innovation is being tested by a Centers for Medicare & Medicaid Services demonstration program, the Value-Based Insurance Design Model Hospice Benefit, and the results of this important demonstration will guide policy. If the

approach is successful, the challenge is to anticipate the potential unintended consequences, both those “that can be seen” and those “that must be foreseen.” **Full text:** <https://bit.ly/2TrS-SIZ>

Extract from *JAMA Health Forum* article

Changing the financial incentives from the hospice carve-out, in which costs of hospice terminal care are the responsibility of traditional Medicare and not the Medicare Advantage program, to hospice “carve-in,” in which Medicare Advantage is responsible for the all the costs of hospice care, has the potential for unintended and unwanted consequences. Such consequences should be anticipated as a possibility, based on the experience of the now-canceled Liverpool Care Pathway for the Dying Patient in the U.K. The initiative aimed to provide actively dying persons in hospitals with improved end-of-life care (EoLC) based on the principles and practices of hospice. However, the Liverpool Care Pathway (LCP) was eliminated from U.K. hospitals in 2013 based on an independent review led by Baroness Julia Neuberger; the review was conducted after a national public scandal erupted with the discovery that some patients placed on the pathway were not appropriate candidates for EoLC because they had reversible conditions, such as medication adverse effects, rather than terminal conditions. With the history of the LCP experience in mind, one should anticipate that payment policy changes that carve in a hospice benefit with Medicare Advantage plans now responsible for reimbursing hospice care might also lead to unintended consequences, and thus monitoring for unwanted effects should be in place.

N.B. Selected articles on the LCP noted in Media Watch 23 September 2019 (#632, pp.13-14).

Paid carers' understanding and experiences of meaningful involvement in bereavement for people with intellectual disability when a significant other is dying

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Online – 8 July 2021 – Most of the paid carers interviewed recognised that the people with intellectual disabilities were impacted by the death of a fellow resident. However, the level to which it was thought to be an issue varied amongst them, and some did not think it would have an impact at all. Paid carers found it challenging to know how much the individuals understood about death and dying. They were not comfortable having direct conversations, particularly in relation to a fellow resident. Other words were often used to describe the situation, such as “going to heaven” or “going up to the sky.” This has been found in other research with staff reporting feeling scared and unprepared to have conversations and deal with death in general... Tuffrey-Wijne *et al* highlighted that there is a high level of skill and confidence needed to communicate about death and dying, but there is no standardised requirement for training.¹ Furthermore, the care certificate that many paid carers work towards does not contain a standard on this topic. **Full text:** <https://bit.ly/3xyXtBI>

1. ‘Communicating about death and dying with adults with intellectual disabilities who are terminally ill or bereaved: A U.K.-wide survey of intellectual disability support staff,’ *Journal of Applied Research in Intellectual Disabilities*, published online 19 February 2020. [Noted in Media Watch 24 February 2020 (#654, p.8)] **Abstract:** <http://bit.ly/38KREvG>

Development of a palliative telehealth pilot to meet the needs of the nursing home population

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 2 July 2021 – Many older adults will spend their final days in a skilled nursing facility because of multiple complex conditions. Patients with unclear goals of care (GoC) are at higher risk of rehospitalization and burdensome care at end of life. Palliative care (PC) has been shown to improve outcomes for this patient population; however, access is limited because of the small number of boarded specialists nationwide. Telehealth offers the ability to expand the reach of PC to both underserved geographies and community settings. This quality improvement pilot project details the development and implementation of a telehealth PC program available to nursing home residents. Eight nursing homes, in the New England region of the U.S., participated in the 4-month pilot. The palliative telehealth program offered real-time access to a PC specialist able to provide symptom management, GoC discussions, and Medical Orders for Life-Sustaining Treatment (MOLST) completion. The pilot shows promising outcomes including code status change, MOLST form completion, and reduced hospitalizations supporting the benefit of comprehensive GoC discussions for frail older adults living in a nursing home. As healthcare moves into the digital age, telemedicine plays a large role in the delivery of essential patient care. Provision of palliative specialists by telehealth allows the opportunity to address the unmet needs of this frail population. **Abstract:** <https://bit.ly/2VfqkN0>

N.B. Search back issues of Media Watch for additional articles on “telemedicine” in PC at: <http://bit.ly/2ThijkC>

Uncertainty in faith, fear of death? Transitions in religious doubt and death anxiety in later life

OMEGA – JOURNAL OF DEATH & DYING | Online – 5 July 2021 – While religiosity is usually associated with lower death anxiety, holding doubts about one’s faith are associated with higher death anxiety. This study examines within-individual changes in religious doubt and death anxiety. Results from lagged dependent variable models suggest that compared to older adults who did not experience any doubt about their faith, those holding consistently high doubt or increasing or decreasing doubt reported greater death anxiety. Lingering religious doubt was associated with higher death anxiety among weekly religious attenders. Findings suggest that being more assured in one’s faith and spiritual understanding may lead to a more peaceful experience when confronting thoughts about one’s own mortality, especially for older adults holding a stronger religious identity. The authors situate their findings within the literature on the “dark side” of religion and well-being in later life. **Abstract (w. references):** <https://bit.ly/3hHbGWe>



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A framework for adult bereavement care in Ireland. Policy and planning response in a COVID and post-COVID-19 Ireland

PALLIATIVE CARE & SOCIAL PRACTICE | Online – Accessed 6 July 2021 – The COVID-19 pandemic has challenged how we address bereavement and grieving in Ireland. Understanding how grief impacts in the intermediate and long-term is an issue of national importance. Planning will be required to meet emergent needs and to support communities. This project aimed to develop a national public health framework for bereavement care design, methods, and approach taken. The framework was based on literature and developed through a national collaborative process with organisations and people at all levels of bereavement care, including state and voluntary sectors across Ireland. A working group of 16 representatives of organisations drafted the framework and supporting materials. The 4-level public health framework sets out needs and responses for all, some and few bereaved people. A national consultation was held. The national consultation received 56 responses from a wide range of professionals working in bereavement care in Ireland. An overwhelmingly positive response was received; 96% to 100% of respondents reported that they understood the framework and 94% could place their service within the tiered framework. This national framework provides a structure for planning short-term and more long-term responses and services to meet bereaved people's needs in a COVID and post-COVID-19 Ireland. However, we need a whole of government response to coordinate, progress, and embed innovative, evidence-based solutions to issues which arise. Specific to the COVID experience there are opportunities for public grief education and first-line services. Based on predictions for difficulties in grief through lack of social support and other complexity there is also a requirement for investment in skills training and services at Levels 2, 3, and 4 of the bereavement model. The Irish Hospice Foundation has set out 7 policy-pillars to shape an approach to policy on end of life (EoL) and bereavement issues in Ireland. They advocate for the development of a new robust strategy taking into consideration the views of the public, the State, and those dealing professionally with EoL in all care settings, in palliative and bereavement care. **Abstract:** <https://bit.ly/36gvA5b>

N.B. Irish Hospice Foundation's Bereavement & Loss Hub: <https://bit.ly/3vUH8FO>

Related:

- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – Accessed 6 July 2021 – **'Public health approaches to bereavement care: Through the lens of the pandemic.'** Until recently, we had surprisingly little data about bereavement as it is lived out in everyday life. We were well informed about the minority who seek support from professional services, but not about the majority who do not. Bereavement was understood as a problem to be solved rather than an experience to be engaged. Perceptions/strategies for all were largely shaped by the complications that can arise for some, and we paid correspondingly less attention to the experience and resources used by the majority, those who learn to live with their loss. The public health model of bereavement support has changed this landscape... **Abstract:** <https://bit.ly/3wgj8gt>

Palliative care in the emergency department: A qualitative study exploring barriers, facilitators, desired clinician qualities, and future directions

PALLIATIVE & SUPPORTIVE CARE | Online – 8 July 2021 – Palliative care (PC) providers perceived as successful in their work in the emergency department (ED) were described as autonomous, competent, flexible, fast, and fluent in ED language and culture. Barriers to ED-PC integration included the ED environment, lack of access to PC providers at all times, the ED perception of PC, and the lack of a supporting financial model. Facilitators to ED-PC integration included proactive identification of patients who would benefit from PC, ED-focused PC education and tools, PC presence in the ED, and data supporting ED-PC. Increased primary PC education for ED staff, increased automation, and innovative ED-PC models were seen as areas for future growth. The authors' findings provide useful information for PC programs considering expanding their ED presence, particularly as this is the first study to their knowledge that examines traits of successful PC providers in the ED environment. Their findings also suggest that, despite growth in the arena of ED-PC, barriers and facilitators remain similar to those identified previously. Future research is needed to evaluate the impact that ED-PC initiatives may have on patient and system outcomes, to identify a financial model to maintain ED-PC integration, and to examine whether perceptions of successful providers align with objective measures of the same. **Abstract (w. references):** <https://bit.ly/3e1f0KJ>

Autonomy and control in the wish to die in terminally ill patients: A systematic integrative review

PALLIATIVE & SUPPORTIVE CARE | Online – 7 July 2021 – Personal autonomy and control are major concepts for people with life-limiting conditions. Patients who express a wish to die (WTD) are often thought of wanting it because of loss of autonomy or control. The research conducted so far has not focused on personal beliefs and perspectives; and, little is known about patients' understanding of autonomy and control in this context. The aim of this review was to analyze what role autonomy and control may play in relation to the WTD expressed by people with life-limiting conditions. After a screening process, 85 full texts were included for the final analysis. Twenty-seven studies, recording the experiences of 1,824 participants, were identified. The studies were conducted in Australia, Canada, U.S., The Netherlands, Spain, Sweden, Switzerland, Finland, Germany, and the U.K. Three themes were identified: 1) The presence of autonomy for the WTD; 2) The different ways in which autonomy is conceptualized; and, 3) The socio-cultural context of research participants. Despite the importance given to the concept of autonomy in the WTD discourse, only a few empirical studies have focused on personal interests. Comprehending the context is crucial because personal understandings of autonomy are shaped by socio-cultural-ethical backgrounds and these impact personal WTD attitudes. **Abstract (w. references):** <https://bit.ly/3qQm6Hn>

Noted in Media Watch 21 January 2019 (#598, p.13):

- *PLOS ONE* | Online – 17 January 2019 – **'Wishes to die at the end of life and subjective experience of four different typical dying trajectories. A qualitative interview study.'** The motivations that lead to wishes to die (WTD) in palliative care patients with cancer are relatively well studied. But little is known about WTD in other pathologies and the relation between subjective understandings of dying trajectories and a WTD. In addition to personal motivations, the authors found that people in their study population dealing with similar trajectories were often confronted with similar questions and concerns due to similar challenges. For four trajectories the authors show typical patterns, similarities and differences that should be considered when talking with patients about their WTD. **Full text:** <https://goo.gl/BAA5i8>

Supporting children with complex chronic conditions and their families at the end of life

PEDIATRIC CRITICAL CARE MEDICINE, 2021;22(7):669-671. Pediatric intensivists frequently care for children with complex chronic conditions (CCCs), defined as conditions expected to last greater than one year, involving multiple organ systems with severity of one system necessitating subspecialty pediatric care and tertiary-care center hospitalization. Children with CCC are increasingly admitted to the hospital and represent greater than 50% of children who are admitted to the pediatric intensive care unit (PICU). These children often use PICU resources disproportionately when compared with children without CCC. Their parents, in turn, become superusers of the healthcare system, learning to undertake medical caregiver roles in the home and to navigate complex systems to advocate for their children. During illness and recovery, parents describe feeling unprepared for the transition between hospital and home and are overwhelmed with frequent healthcare visits, care coordination, and advocacy. Parents face intense home care demands, competing family obligations, lack of training and support, and barriers due to insurance, access, or other healthcare systems issues. Clinicians often work in a siloed environment, without communication between and among primary care providers and subspecialists, exacerbating the family's sense of being overwhelmed with poorly coordinated medical advice. **Full text:** <https://bit.ly/3jLH88q>

Related:

- *PALLIATIVE MEDICINE* | Online – 5 July 2021 – **'A good death in the child with life-shortening illness: A qualitative multiple-case study.'** No previous study addressed perceptions of a good death in children across both cancer and non-cancer groups. A predominant focus on suffering (mostly in the physical dimension) in related studies as a proxy for good death remains flawed. This study attempts to address those gaps. Reference to a good death is prevalent in the adult setting, but its application within paediatrics can be problematic. Some perceive a child's death as unnatural and could never be good. Prior reviews on a good death in a similar group of children either drew heavily on adult literature or focused on a specific group like cancer. **Full text:** <https://bit.ly/36c7Ejt>

Cont.

- *PALLIATIVE MEDICINE* | Online – 5 July 2021 – ‘**Organizational and individual barriers and facilitators to the integration of pediatric palliative care for children: A grounded theory study.**’ The results of this study highlight the importance of organizational and individual factors that functioned as both facilitators and barriers to the integration of pediatric palliative care (PC) within a context of an accessible, well-run public healthcare system. Allocating organizational resources dedicated to primary PC and managing the existing ones effectively is critical to providing pediatric PC... On the individual level, significant barriers to the integration of pediatric PC included pediatric oncologists’ attitudes toward PC, the impact of personality, and the emotional burdens of healthcare providers. **Full text:** <https://bit.ly/36ecM6C>
- *SUPPORTIVE CARE IN CANCER* | Online – 6 July 2021 – ‘**Palliative home-based care to pediatric cancer patients: Characteristics and healthcare delivered.**’ This retrospective study describes the heterogeneity of a large series of children with cancer attended by the pediatric palliative care unit in Madrid, Spain. This care took place mainly at the patients’ homes. Most patients needed several medical devices and suffered a high number of symptoms caused by the underlying disease. Despite this, the authors observed a low rate of hospital admissions, and 70% of the patients died at their homes. Further and large studies should be done in order to obtain and analyze the validity of the authors’ findings. **Full text:** <https://bit.ly/3jOs4XU>

Remote area nurses’ perceptions of the enablers and barriers for delivering end-of-life care in remote Australia to Aboriginal people who choose to pass away on their traditional lands

RURAL & REMOTE HEALTH | Online – 5 July 2021 – This research shows that communication and acknowledgement of each party’s requirements, needs, wants, expectations and limitations, and brainstorming both formally and informally about these needs, could lead to fewer barriers. Overall, it seems that when those involved from the community and the remote area nurses came together, they were able to deliver what they considered a successful service to patients, families, communities and themselves, enabling end-of-life care (EoLC) to occur on traditional homelands. Unfortunately, this does not happen often and is not always enabled by the healthcare provider. This research confirms that, while there remain limitations in providing EoLC to Indigenous peoples on their homelands, remote area nurses can be very resourceful and try extremely hard to overcome those limitations. The research shows remote area nurses have the will to provide this care, and, with more support from the care providers, this may happen more frequently and with more ease. **Full text:** <https://bit.ly/3jGkeiV>

Noted in Media Watch 2 December 2019 (#642, p.15):

- *RURAL & REMOTE HEALTH* | Online – 30 November 2019 – ‘**Passing on wisdom: Exploring the end-of-life wishes of Aboriginal people from the Midwest of Western Australia.**’ Indigenous patients with life-limiting conditions have complex needs, experience reduced access to and uptake of treatment, and have lower utilisation of palliative care (PC) services than the general population. Lack of understanding of the role of PC and poor availability of culturally safe specialist PC services impact on Indigenous people’s end-of-life (EoL) decision-making. Aboriginal people were engaged to talk frankly about their wishes and concerns around EoL. The community consultations raised considerable discussion about wills, where to die, burial versus cremation, and the cost of funerals. **Full text:** <http://bit.ly/37RtZ5g>

Rehabilitation and palliative care: Histories, dialectics and challenges

WELLCOME OPEN RESEARCH | Online – 2 July 2021 – Rehabilitation and palliative care (PC) are healthcare fields with separate histories, but some recent convergences. Both have been identified as components within universal health coverage and each is the subject of a supportive World Health Assembly Resolution. The authors draw on the historiography of the two specialties, a recent systematic review of their engagement with each other as described in 62 studies, and critical policy perspectives to examine how rehabilitation and PC have been framed as potential partners in care. They examine the changing patient groups served by each field and the organizational forms that combined rehabilitation and PC may take. The authors explore the implications of such collaboration for the underlying goals and values of the two specialties, where each is the subject of changing definitions with differing responsibilities for regulating access to services as well as assuring and documenting quality. To be effective combined rehabilitation and PC must adapt to the highly segmented and specialized systems in which it is required to operate, recognizing that rehabilitation and PC are themselves co-constructors of such segmentation and specialization, but also potential agents for change. **Full text:** <https://bit.ly/3dOhQ5W>

Research Matters

Historic abuses, present disparities, and systemic racism: Threats to surrogate decision-making for critical care research enrollment

ANNALS OF THE AMERICAN THORACIC SOCIETY, 2021;18(7):1118-1120. Anyone who has attempted to recruit critically ill patients into clinical trials recognizes the challenges that lie therein. Critically ill patients often lack decisional capacity and must rely on surrogate decision-makers (SDMs) to make both clinical and research enrollment decisions. The SDM role is both cognitively and emotionally burdensome. Furthermore, it is frequently performed by a close family member who is already under the tremendous stress inherent in having a loved one in the intensive care unit. Therefore, it may be unsurprising that many SDMs suffer long-term psychological morbidity, including anxiety, depression, and symptoms of post-traumatic stress disorder. These effects may be exacerbated by being asked to consider enrollment into research.

Full text: <https://bit.ly/3e4IA3m>

Dealing with death as an outcome in supportive care clinical trials

JAMA INTERNAL MEDICINE, 2021;181(7):895-896. The past decade has witnessed a dramatic expansion in the number of randomized clinical trials (RCTs) testing palliative and other supportive care interventions, including methods to improve advance care planning, specialist and generalist palliative care delivery, and caregiver and clinician decision-making for patients with serious illnesses. However, like many welcome advances, this expansion in supportive care RCTs has engendered novel ethical and regulatory questions. Foremost among these questions is how to conceptualize and monitor mortality as an end point in trials of supportive care interventions. **Abstract:** <https://bit.ly/3bf7laf>

Pragmatic considerations in incorporating stakeholder engagement into a palliative care transitions study

MEDICAL CARE, 2021;59(Suppl 4):S370-S378. Stakeholder involvement in healthcare research has been shown to improve research development, processes, and dissemination. The literature is developing on stakeholder engagement methods and preliminarily validated tools for evaluating stakeholder level of engagement have been proposed for specific stakeholder groups and settings. This article describes the methodology for engaging a Study Advisory Committee (SAC) in research and reports on the use of a stakeholder engagement survey for measuring level of engagement. The trial's SAC is composed of 18 members from three stakeholder groups: patients and their caregivers; patient advocacy organizations; and, healthcare payers. The SAC monitors research progress and provides feedback on all study processes. The stakeholder engagement survey reveals improved engagement over time as well as continued challenges. **Abstract:** <https://bit.ly/3dSttJ4>

Research cooperative groups in pediatric palliative care research

PALLIATIVE MEDICINE REPORTS | Online – Accessed 6 July 2021 – Research cooperative groups aim to facilitate collaborative and rigorous palliative care (PC) research. The purpose of this article is to demonstrate how cooperative groups are taking formal and sustainable steps with commitment to pediatric PC research programs and provide an example of how one cooperative group is implementing these innovative efforts to partner with programs to integrate pediatrics on an expanding scale. Details are described for how pediatric studies can benefit from cooperative group infrastructure and expertise. In turn, the authors describe how cooperative groups can benefit from collaborating on pediatric studies through broadening of data dictionaries, data repositories, and reach in PC research communities. **Full text:** <https://bit.ly/2TF01zk>



Palliative Care Network
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