

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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Most participants considered palliative care to be synonymous with end of life or death, and not as an added layer of support for people living with serious illness.

'Patient and caregiver experiences with advanced cancer care: A qualitative study informing the development of an early palliative care pathway' (p.7), in *BMJ Supportive & Palliative Care*.

Canada

An unacceptable number of people who requested medical assistance in dying received little or no quality palliative care in the months before death

POLICY OPTIONS | Online – 19 October 2020 – When a person with a failing organ, stroke or other chronic life-limiting disease has persistent suffering that goes untreated, they can become depressed and hopeless. It's a common pathway to severe distress that can lead people to request medical assistance in dying (MAiD). This is a medical error. The error is not in receiving MAiD, as the person may meet all the requirements: unbearable suffering, a grievous and permanent condition, an advanced state of decline, ability to give informed and voluntary consent. The error occurred in the months before, when the pain, shortness of breath, anxiety, feeling a burden to others began, but was not recognized and treated. Because there is no single event or "fail," the slide into despair is gradual. For example, people with advanced and severe heart or lung disease might be receiving multiple medications to help their heart function but still get breathless with minimal physical effort. To cope with the scary feeling of breathlessness, they do less and less and gradually become depressed because they are home-bound and feel useless. Most chronic illness clinics rely on clinicians – doctors, registered nurses, nurse-practitioners – to identify and treat symptoms and help people cope with

illness, but this requires time and knowledge of palliative care, which they may not have. The concept of untreated suffering is a medical error. <https://bit.ly/2lMetzJ>

Healthcare costs in Canada dropped after assisted dying became legal

GLOBAL NEWS | Online – 20 October 2020 – Since Canada's law on MAiD came into effect more than four years ago, healthcare costs have dropped millions of dollars, according to a Parliamentary Budget Officer (PBO) report.¹ The report on assisted dying said since becoming legal on 17 June 2016, Canada's healthcare costs have dropped \$86.9 million. Many studies have shown that healthcare costs in the last year of life, and especially the last month, are "disproportionately high," the PBO report stated. The costs represent between 10-20% of total healthcare costs despite those patients representing about 1% of the population. The report emphasized that the numbers should "in no way be interpreted" as suggesting assisted dying be used to reduce healthcare costs. <https://bit.ly/37vlnnr>

1. 'Cost Estimate for Bill C-7: Medical Assistance in Dying,' Parliamentary Budget Officer, October 2020. Download/view at: <https://bit.ly/3ocsk2D>

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Noted in Media Watch 4 May 2020 (#664, p.12):

- **MEDICAL HYPOTHESES**, 2020;142:109727. **‘Hastened death due to disease burden and distress that has not received timely, quality palliative care is a medical error.’** The authors’ hypothesis is that some requests for hastened death (known as medical assistance in dying or MAiD in Canada) are driven by lack of access to palliative care (PC) or lack of quality in the PC attempting to address disease burden and distress such that the resulting provision of hastened death is a medical error. The root cause of the error is in the lack of quality PC in the previous weeks, months and years of the disease trajectory – a known therapy that the system fails to provide. The authors present three cases of request for assisted death that could be considered medical error. **Full text:** <https://bit.ly/2YdajXr>

U.S.A.

Hospices respond to influx of COVID-19 patients, keep families connected

HOSPICE NEWS | Online – 20 October 2020 – As the healthcare system strives to care for the legions of patients suffering from COVID-19, hospices have accepted an influx of patients who are infected with the virus. With hospice and palliative care patients among the most vulnerable to coronavirus disease infection, providers have ramped up infection control efforts to protect those at highest risk. In the midst of this, hospices have had to get creative as to how they help infectious patients safely maintain contact with their families. The virus has significantly impacted end-of-life care as hospices respond to the challenging needs of COVID-19 patients and their families. Nearly 11,000 COVID-19 patients died in their homes thus far in the pandemic, according to a report from the U.S. Centers for Disease Control & Prevention.¹ The proportion of those patients who were receiving hospice care is currently unknown, but more than 6,000 COVID-related deaths nationwide have occurred in a hospice facility. <https://bit.ly/37t2H7O>

1. ‘Weekly Updates by Select Demographic and Geographic Characteristics: Provisional Death Counts for Coronavirus Disease 2019 (COVID-19),’ U.S. Centers for Disease Control & Prevention, October 2020. <https://bit.ly/2HnL4uW>

Study finds room for improvement when hospital patients transition to hospice care

MEDICALXPRESS | Online – 19 October 2020 – Terminally ill patients referred to hospice care from a hospital setting tend to be on hospice for shorter periods than those who enter hospice while living at home or in a residential care facility. These findings by Oregon State University College of Pharmacy researchers are an important step toward improving the care experiences of dying patients and their loved ones. In general, more time on hospice is better for patients than less time, research has shown. “It’s well established that hospice care reduces symptom burden and improves quality of life for patients nearing the end of life and for their caregivers,” said Jon Furuno, an associate professor and the interim chair of the Depart-

Specialist Publications

‘Organizational characteristics of assisted living communities with policies supportive of admitting and retaining residents in need of end-of-life care’ (p.5), in *American Journal of Hospice & Palliative Medicine*.

‘Variation in the design of do not resuscitate orders and other code status options: A multi-institutional qualitative study’ (p.7), in *BMJ Quality & Safety*.

‘Rethinking the role of advance care planning in the context of infectious disease’ (p.9), in *Journal of Aging & Social Policy*.

‘Goals-of-care conversations don’t fit in a box: Hospice staff experiences and perceptions of advance care planning quality measurement’ (p.9), in *Journal of Pain & Symptom Management*.

‘End-of-life wishes among non-Hispanic, Black and White middle-aged and older adults’ (p.10), in *Journal of Racial & Ethnic Health Disparities*.

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ment of Pharmacy Practice. But Furuno's recent research points out some key variations in hospice transitions and experiences, opening the door to changes that could make important, positive differences for patients and families.¹ Patients can be referred to hospice care from any location, but little is known about differences between referrals from different care settings; i.e., hospitals, nursing homes, assisted living facilities or the someone's home. **Full text:** <https://bit.ly/3561dNG>

1. 'Variation in hospice patient and admission characteristics by referral Location,' *Medical Care*, published online 10 September 2020. **Abstract:** <https://bit.ly/35b4b3z>

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 20 October 2020 – '**Operationalizing burdensome transitions among adults at the end of life: A scoping review.**' Care transitions at the end of life (EoL) are associated with reduced quality of life and negative health outcomes, yet up to half of patients in developed countries experience a transition within the last month of life. A variety of these transitions have been described as "burdensome" in the literature, however there is currently no consensus on the definition of a burdensome transition. Definitions varied based on time before death, setting of cohorts, and study population. These definitions can be helpful in identifying and subsequently preventing unnecessary transitions at the EoL. **Abstract (w. bibliography):** <https://bit.ly/3kpcG1s>

Noted in Media Watch 6 January 2020 (#647, p.2):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 December 2019 – '**Healthcare worker perceptions of gaps and opportunities to improve hospital-to-hospice transitions.**' Three areas of gaps in hospital-to-hospice transitions were identified in interviews with healthcare workers from three hospitals and three hospice programs: 1) Low literacy about hospice care; 2) Changes in medications; and, 3) Hand-off information related to daily care. Specific concerns included hospital providers giving inaccurate descriptions of hospice; discharge orders not including comfort medications for the transition and inadequate prescriptions to manage medications at home; and lack of information about daily care hindering smooth transition and continuity of care. **Abstract:** <http://bit.ly/2trNcL4>

International

Implementation Plan for the National Palliative Care Strategy 2018

AUSTRALIA | Australian Government (Department of Health) – 20 October 2020 – The implementation of the Strategy primarily rests with the Commonwealth, state and territory governments and the Implementation Plan provides the vital link between the higher-level vision and priorities in the Strategy and the palliative care (PC) activities funded or undertaken by Commonwealth and state and territory governments to realise the goals of the Strategy. While the Strategy does not have a timeframe, this Plan identifies action areas to progress the goals and priorities in the Strategy over the next five years. The way in which action areas are implemented may differ across jurisdictions to reflect local needs and resources. Recognising that this is the first time a nationally-endorsed Plan has been undertaken, four national action areas have been identified that provide a starting point to progress the priorities of the National Strategy. Each action area does not attempt to address every priority in the Strategy, but

rather provides direction for the collaborative efforts of governments over the next five years of

Specialist Publications

'Implementation of primary palliative care in five Belgian regions: A qualitative study on early identification of palliative care needs by general practitioners' (p.8), in *European Journal of General Practice*.

'Refusing and withdrawing treatment at the end of life: Ethical complexities involving patients who lack decision-making capacity' (p.11), in *Medicina y ética: Revista internacional de bioética, deontología y ética médica*.

'Spiritual diversity, spiritual assessment, and Māori end-of-life perspectives: Attaining *ka ea*' (p.13), in *Religions*.

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the Strategy. The Commonwealth and each jurisdiction will provide an annual update via the Palliative Care & End of Life Care Reference Group under the Health Services Principal Committee. This reporting will summarise the activity that is planned or underway to support each of the four action areas. This annual reporting, along with the key data indicators being developed by the Palliative Care & End of Life Care Data Development Working group, will inform the monitoring and evaluation of the Strategy. Planned activities outlined in available state, territory and Commonwealth PC documents were mapped against the 37 priorities that underpin the seven goals in the Strategy. Outcomes from the mapping exercise were then discussed with state, territory and Commonwealth government stakeholders to inform the creation of a draft Plan which was then circulated to jurisdictions for feedback. Feedback on the draft Plan was synthesised and incorporated into the development of this final version for endorsement by all jurisdictions. **Download/view at:** <https://bit.ly/34hPmNr>

Noted in Media Watch 1 June 2020 (#668, p.5):

- AUSTRALIA | Palliative Care Australia – 26 May 2020 – ‘**Calls for palliative care reform in post COVID-19 world.**’ A new report calls for an overhaul of the palliative care (PC) system in Australia, calling for an additional annual investment of \$365 million to bring the system up to speed in a post COVID-19 world.¹ The report calls for a national agreement on PC between the Commonwealth and the states and territories, and a new full-time Palliative Care Commissioner to help create the best experience possible for those with life-limiting conditions and those around them. The report found that if people can be supported with PC outside of institutional settings, they can live well and die in a place of their choosing, for example, at home. In practice however, very few Australians are achieving this. <https://bit.ly/3eyXBqE>

1. ‘Investing to Save – The economics of increased investment in palliative care in Australia,’ Palliative Care Australia, May 2020. **Download/view at:** <https://bit.ly/3d8DFL2>

COVID-19: Two thirds of hospices facing redundancies as government help runs out

U.K. (England) | ITV News (London) – 19 October 2020 – Two thirds of hospices in England have started planning for redundancies as the COVID-19 pandemic continues to hit funding for end of life care (EoLC), ITV News has learned. Extra government support to help the sector through the coronavirus crisis stopped in the summer, leaving hospices on the brink of cuts to the care they provide. Last month, ITV News reported that a third of England’s hospices – 56 out of 169 – are at financial risk and are being forced to contemplate redundancies. Hospice UK, the national charity for hospices and palliative care, has been working with National Health Service England to identify the most cash-strapped providers of EoLC to see if local clinical commissioning groups can step in to help. ITV News has now learned that number has doubled, with two in three hospices in England now reporting financial concerns that are forcing them to plan for redundancies. <https://bit.ly/348CUiW>

Noted in Media Watch 28 September 2020 (#685, p.4):

- U.K. (England) | ITV News (London) – 24 September 2020 – ‘**Coronavirus: Third of hospices on brink of redundancies and service cuts ahead of “surge in demand.”**’ A third of all hospices in England are on the brink of making redundancies and cutting back services for end-of-life care (EoLC) as the pandemic continues to plunge the sector deeper into a funding crisis. ITV News has learned that 56 of England’s 169 hospices are at financial risk and are being forced to contemplate service cuts and redundancies, just as the sector prepares for a second wave of COVID-19. Hospice UK, the national charity for hospices and palliative care, is working with National Health Service England to identify the most cash-strapped providers of EoLC to see if local clinical commissioning groups can step in to help. <https://bit.ly/33UBirT>

Deaths at home from Alzheimer’s and heart disease soar amid COVID-19 pandemic

U.K. (England & Wales) | *The Telegraph* (London) – 19 October 2020 – One hundred extra deaths at home a day are occurring from illnesses such as heart disease and Alzheimer’s because of the coronavirus pandemic, new figures have revealed.¹ Experts have warned that people could be dying avoidably or without proper end-of-life care because they cannot access National Health Service services or feel discouraged

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from trying. Overall, the number of deaths in private homes in England between 28 December and 11 September was 108,842, up 25,472 on the five-year average, according to the Office for National Statistics (ONS). These figures included huge increases in people dying at home with dementia and Alzheimer's – 79% – and heart disease, at 26%. Deaths from cerebral palsy, heart rhythm problems, diabetes and Parkinson's disease also increased by more than 70%. Meanwhile, the number of people dying in hospital since the start of the pandemic is below the five-year average. In Wales, the number of deaths in private homes registered between 28 December 2019 and 11 September 2020 was 7,440; this was 1,624 deaths more than the five-year average for the same period. The new ONS data came to light after *The Telegraph* published an analysis of 200 health conditions which has seen hospital admissions plummet by up to 90%. <https://bit.ly/37mrvyq>

1. 'Deaths in private homes, England and Wales (provisional): Deaths registered from 28 December 2019 to 11 September 2020,' Office for National Statistics, 19 October 2020. <https://bit.ly/2HgOiAF>

Specialist Publications

Organizational characteristics of assisted living communities with policies supportive of admitting and retaining residents in need of end-of-life care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 22 October 2020 – There has been a rapid increase [in the U.S.] in the number of residential care/assisted living communities (RC/AL) that allow residents to die in place. A majority of residential care facilities 73.7% report admitting and retaining residents at end of life (EoL). Yet, levels of skilled nursing care were generally low with 60.9% of these RC/AL communities reporting that registered nurses were not available, including hospice staff. In multivariable, multinomial regression models, organizational characteristics such as skilled nursing, hands-on contact hours from personal care aides, and policies allowing exemptions to self-evacuation rules were associated with increased likelihood of RC/AL communities admitting/retaining residents in need of EoL care. Despite overall low levels of skilled nursing care, a nationally representative survey revealed that a majority of RC/AL communities admit and retain residents in need of EoL care. Staffing and exemptions from self-evacuation policies appear to be central characteristics associated with the provision of these services in RC/AL communities. **Abstract (w. list of references):** <https://bit.ly/2TIA0kU>

N.B. Selected articles on EoL care in assisted living communities in the U.S. noted in Media Watch 8 June 2020 (#669, pp.4-5).

Psychotherapeutic considerations for patients with terminal illness

AMERICAN JOURNAL OF PSYCHOTHERAPY | Online – 22 October 2020 – Dignity has gained increasing attention as a vital component of quality of life and quality of end-of-life (EoL) care. This article reviews psychological, spiritual, existential, and physical issues facing patients at the EoL as well as practical considerations in providing therapy for this population. The authors reviewed several evidence-based treatments for enhancing EoL experience and mitigating suffering, including a primary focus on dignity therapy and an additional review of meaning-centered psychotherapy, acceptance and commitment therapy, and cognitive-behavioral therapy. Each of these therapies has an emerging evidence base, but they have not been compared to each other in trials. Thus, the choice of psychotherapy for patients at the EoL will reflect patient characteristics, therapist orientation and expertise with various approaches, and feasibility within the care context. Future research is needed to directly compare the efficacy and feasibility of these interventions to determine optimal care delivery. **Abstract:** <https://bit.ly/3kydot6>

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Related:

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 21 October 2020 – ‘**Medical stress and fear of death and dying in a medical patient population.**’ Participants in this study identified their level of stress related to their medical condition, their level of fear of death and dying, and what treatments they would most prefer for addressing any fear of death and dying as well as their medical illness-related stress. Overall, reported medical illness-related stress was not significantly correlated with fear of death and dying. 75% of participants reported preferring psychotherapy or mindfulness interventions for addressing their stress. Psychotherapy, anti-anxiety medications, and meditation were the top three choices for addressing fear of death and dying. **Abstract (w. list of references):** <https://bit.ly/31CPNQR>

Family experiences with palliative care for children at home: A systematic literature review

BMC PALLIATIVE CARE | Online – 24 October 2020 – The results of this systematic review underpin the lack of research on the sick children and their siblings’ perspectives on palliative care (PC) at home. Children in PC should be given an opportunity to express and communicate their experiences, feelings and needs themselves, and not only through their parents. Their experience is important for optimising the quality of care at the end of life, and identifying the needs of these vulnerable children is crucial. There is a gap in the knowledge about children’s needs that further research should address. Furthermore, few countries are represented in the literature on families’ experiences with PC for children at home, with most studies stemming from North America, Canada and the U.K. Based on the experiences of the families in this review, the authors highlight five areas that deserve more attention. First of all, the families need organised, individualised support from a skilled pediatric PC team. Secondly, respite care is necessary in order to manage a demanding home-care situation. Further, parents need help with and support for siblings both because the siblings need attention, but also to reduce the parents’ bad conscience in relation to giving them less attention. Privacy to be a family is a further need, and, finally, many families need financial support. **Full text:** <https://bit.ly/3mj0Q9H>

Related:

- *PALLIATIVE MEDICINE* | Online – 24 October 2020 – ‘**The support needs of parent caregivers of children with a life-limiting illness and approaches used to meet their needs: A scoping review.**’ Support needs of parent caregivers of children with life-limiting illnesses are substantial and heterogeneous. While studies report evidence of burden and distress in parent caregivers, this rarely translates into improvements in practice through the development of interventions. A systematic and regular assessment of individual parent caregiver support needs is required by using instruments appropriate to use in clinical practice to move the focus to palliative care interventions and improved services for parents. **Abstract (w. list of preferences):** <https://bit.ly/37ChpZX>
- *PEDIATRIC BLOOD & CANCER* | Online – 21 October 2020 – ‘**Palliative care considerations and practices for adolescents and young adults with cancer.**’ Younger adolescents and young adults (AYAs) ... are often cared for within pediatrics. In caring for AYAs with cancer, there are unique considerations that become even more important to recognize, acknowledge, and address in AYAs with life-threatening cancer receiving palliative care (PC). This review highlights important factors such as psychosocial development, cultural considerations, and support structure, which should be considered when providing PC to AYAs with cancer during the various stages of care: introduction of PC; symptom management; advanced care planning; end-of-life care; and, bereavement. **Abstract:** <https://bit.ly/35jikfc>



[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>

Variation in the design of do not resuscitate orders and other code status options: A multi-institutional qualitative study

BMJ QUALITY & SAFETY | Online – 20 October 2020 – U.S. hospitals typically provide a set of code status options that includes full code and do not resuscitate (DNR), but often includes additional options. Although U.S. hospitals differ in the design of code status options, this variation and its impacts have not been empirically studied. The code status options at each [of 7 participating hospitals] varied widely with regard to the number of code status options, the names and definitions of code status options, and the formatting and capabilities of code status ordering menus. DNR orders were named and defined differently at each hospital studied. The authors identify five key design characteristics that impact the function of a code status order. Each hospital's code status options were unique with respect to these characteristics, indicating that code status plays differing roles in each hospital. Physician participants[in this study] perceived that the design of code status options shapes communication and decision-making practices about resuscitation and life-sustaining treatments, especially at the end of life. The authors identify four potential mechanisms through which this may occur: framing conversations, prompting decisions, shaping inferences and creating categories. **Full text:** <https://bit.ly/2Hj5JAA>

Patient and caregiver experiences with advanced cancer care: A qualitative study informing the development of an early palliative care pathway

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 19 October 2020 – This study highlights current gaps in advanced cancer care related to the delivery of cancer care and early palliative care (PC) in Alberta [Canada] and provides suggestions from the perspectives of patients and family caregivers (FCGs) on how these gaps can be addressed. The priorities mentioned by patients and FCGs provide support for integration of an early PC approach in advanced cancer care. Patients and FCGs highlighted the importance of communication in their experiences of cancer care, specifically communication that is respectful and compassionate. Communication between provider-patient is necessary for building good interpersonal relationships between healthcare providers and patients/families. Most participants communicated with their cancer team consistently, and thus were able to develop a trusting relationship with their cancer team. Those patients who had a negative experience regarding their diagnosis (e.g., diagnosis delay), or did not communicate often with their family physician, were reluctant to receive care from their family physician. This study highlights a misunderstanding of PC. Most participants considered PC to be synonymous with end of life or death, and not as an added layer of support for people living with serious illness. This study identified patient and caregiver priorities for a provincial pathway to deliver early PC integrated with advanced cancer care. **Full text:** <https://bit.ly/35c5aAK>

Life and death in Canadian penitentiaries

CANADIAN FAMILY PHYSICIAN, 2020;66(10):759. Currently, 25% of the individuals incarcerated in federal prisons are older than 50 years of age, and this percentage is increasing at an alarming rate. Incarcerated individuals have higher rates of mortality and morbidity for most illnesses. In addition, they go through a process of accelerated aging (i.e., they have the health problems of someone 10 to 15 years older than them in the community). As a result, their life expectancy is around 62 years, compared with the Canadian average of 82 years. The aging of the incarcerated population creates unexpected challenges. These include high rates of comorbidities, and illnesses and symptoms commonly associated with aging, such as dementia, which has now reached a rate of 5% in older prisoners. Prisons were never meant to be nursing homes, and yet they are increasingly asked to perform this function. The resulting situation is inhumane, unethical, and legally problematic. **Full text:** <https://bit.ly/34fvScI>

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Palliative Care Network
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Knowledge & Technology
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Noted in Media Watch 25 May 2020 (#667, p.12):

- *MCGILL JOURNAL OF LAW & HEALTH*, 2020;14(1):1-50. **‘End-of-life care for federally incarcerated individuals in Canada.’** The authors review the current legislation, policies, and practices related to end-of-life care (EoLC) for federally incarcerated individuals as set out in statutes, guidelines, and government reports and documents that were either publicly available or obtained through Access to Information requests from the Parole Board of Canada and Correctional Service of Canada (CSC). They describe the *status quo*, identify gaps, and offer reflections and raise concerns regarding EoLC for federally incarcerated individuals. There are significant information gaps about the number of people seeking EoLC and about how CSC is managing provision of such care. **Full text (click on pdf icon):** <https://bit.ly/3cQVH4t>

N.B. EoLC in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, etc., noted in past issues of the weekly report can be downloaded/viewed on the Palliative Care Network website at: <http://bit.ly/2RdegnL>

Implementation of primary palliative care in five Belgian regions: A qualitative study on early identification of palliative care needs by general practitioners

EUROPEAN JOURNAL OF GENERAL PRACTICE | Online – 20 October 2020 – GPs expressed a desire for therapeutic freedom. In all seven focus groups, family practitioners were worried that imposing guidelines and standardisation of palliative care (PC) according to theoretical ideals would reduce the creativity of “tailor-made care.” More than in PC protocols, GPs are interested in feedback and peer review methods to improve their own PC skills. The phrase “palliative care” is still used with difficulty in all five regions. Some GPs never use these words while others have a personal mission to diminish the PC taboo. A third group uses the words “palliative care” if they feel the patient and the family can handle hearing them. For many GPs, life expectancy is not the main concern when they are starting PC, whether it is called PC or comfort care. GPs are worried about all their patients in complex care, living with a frail health balance and needing to face the biopsychosocial and spiritual needs of PC patients. GPs often struggle with collaboration issues: with other GPs, with paramedical professionals, with hospital-based professionals and so on. The main problem is the difficulty to guarantee continuity of care. **Full text:** <https://bit.ly/35iLMSG>

Care of the dying person before and during the COVID-19 pandemic: A quality improvement project

FUTURE HEALTHCARE JOURNAL, 2020;7(3):e50-e53. The current COVID-19 pandemic has necessitated the redeployment of National Health Service staff to acute-facing specialties, meaning that care of dying people is being provided by those who may not have much experience in this area. This report details how a plan, do, study, act (PDSA) approach was taken to implementing improved, standardised multidisciplinary documentation of individualised care and review for people who are in the last hours or days of life, both before and during the COVID-19 pandemic. The documentation and training produced is subject to ongoing review via the specialist palliative care team’s continuously updated hospital deaths dashboard, which evaluates the care of patients who have died in the trust. The authors hope that sharing the experiences and outcomes of this process will help other trusts to develop their own pathways and improve the care of dying people through this difficult time and beyond. **Full text:** <https://bit.ly/3ojlmHR>

What’s new in meaning reconstruction?: Advancing grief theory and practice

GRIEF MATTERS: THE AUSTRALIAN JOURNAL OF GRIEF & BEREAVEMENT, 2020;23(1). Considerable research has confirmed the proposition that meaning reconstruction is a key process in grieving as survivors attempt to find orientation in a life challenged by loss. This article reviews ... this literature, organising studies into those bearing on processing the “event story” of the death itself, and those focused on accessing the “back story” of the relationship with the deceased. In numerous populations, struggle or success in making meaning of the loss mediates the impact of risk factors for complicated grief, ranging from violent death bereavement to attachment insecurity. The growing evidence for the relevance of meaning reconstruction in the wake of loss carries practical implications for grief therapy, leading to the development of promising treatment protocols and procedures. **Abstract:** <https://bit.ly/2HvgzUa>

Palliative care for persons living with Parkinson disease

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 20 October 2020 – Medical advances have led to significant progress in treating Parkinson disease (PD). However, these advances have limits, and no curative treatments are currently available. Recent research has shown that integration of palliative care (PC) and PD improves quality of life and reduces the severity and burden of symptoms. PC in PD involves treatment of non-motor symptoms such as pain, fatigue, and depression. It also consists of treating difficult emotions, such as caregiver stress, demoralization, and grief. Practical challenges, such as getting more help at home, and advance care planning are also explored. There is no right time for starting PC. Some services, such as talking about the future, are best done early because advanced PD can affect communication skills. PC is not yet a standard part of care for PD. Use of PC does not mean that a patient must give up their treating PD neurologist. A PC team and neurologist work together, often along with a pharmacist, nurse, chaplain, and/or social worker. They provide support primarily to the person with PD but also offer support to family members. **Full text:** <https://bit.ly/3m0bmT8>

N.B. Selected articles on PC for patients living with PD noted in Media Watch 13 July 2020 (#674, p.10).

Goals-of-care conversations don't fit in a box: Hospice staff experiences and perceptions of advance care planning quality measurement

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 20 October 2020 – With rising concerns about quality of care in hospice, federal agencies in the U.S. recently began mandating quality measurement in hospice, including measures of advance care planning (ACP). The objective of this study was to characterize hospice providers' experiences with ACP quality measurement and their reflections on ways to improve it. Participants included fifty-one hospice staff from various clinical backgrounds and organizational roles in four geographically diverse non-profit, community-based hospices in the U.S. There were four key findings: 1) Variation (within and across organizations, participants applied a variety of processes to measure ACP quality; exposure to and experiences with quality measurement varied based on organizational role); 2) Barriers (ACP quality measurement was impeded by limited resources, technological problems, and measurement challenges); 3) Attitudes (participants' opinions of recently implemented federally mandated requirements for ACP quality measurement highlighted numerous downsides, unintended consequences, and few upsides); and, 4) Recommendations (improvements included personalizing ACP quality measures, elevating the importance of quality measurement, and stream-

lining processes). Hospice staff take ACP quality measurement seriously, but insufficient organizational resources and regulatory bureaucracy create challenges. Efforts to enhance ACP quality measure nuance and assess outcomes are needed to improve care. **Abstract (w. list of references):** <https://bit.ly/3m6LuoO>

Rethinking the role of advance care planning in the context of infectious disease

JOURNAL OF AGING & SOCIAL POLICY | Online – 20 October 2020 – Advance care planning (ACP) for medical decision-making at the end of life (EoL) has developed around the expectation of death from long-term, progressive chronic illnesses. The authors reexamine ACP in light of the increased probability of death from COVID-19, an exemplar of death that occurs relatively quickly after disease onset. They draw several conclusions about ACP in the context of infectious diseases: interpersonal and socio-structural barriers to ACP are high; ACP is not well-oriented toward decision-making for treatment of an acute illness; and, the U.S. healthcare system is not well positioned to fulfill patients' EoL preferences in a pandemic. Passing the peak of the crisis will reduce, but not eliminate, these problems. **Abstract:** <https://bit.ly/3ocwuaz>

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Noted in Media Watch 19 October 2020 (#688, p.10):

- *PALLIATIVE MEDICINE REPORTS*, 2020;1(1):216-220. ‘**The pitfalls of utilizing “goals-of-care” as a clinical buzz phrase: A case study and proposed solution.**’ The phrase “goals-of-care” is often utilized as a buzz phrase that lacks a shared understanding of its clinical relevance. The authors present a case example in which breakdowns in communication occurred between a patient and clinicians due to misunderstandings of the meaning of the phrase “goals-of-care.” They propose a unified definition of “goals-of-care” in hopes to minimize differences in what this phrase implies in clinical practice. The authors also seek to introduce a standardized process for establishing goals-of-care that may offer a more reliable and measurable method to promote goal-concordant care. **Full text:** <https://bit.ly/3jPM49G>

Related:

- *MEDICAL DECISION MAKING* | Online -22 October 2020 – ‘**Extent and predictors of decision regret among informal caregivers making decisions for a loved one: A systematic review.**’ The authors identified factors that may influence decision regret, including older childhood age of care recipients, family or medical antecedents, adult care recipients being male, informal caregivers manifesting an initial desire to avoid the decision, decisional conflict, perception of effective decision making and support, and treatment complications. Further research could elucidate links between phases of decision-making and the presence of decision regret and determine whether decision support can reduce or alleviate decision regret if provided at all phases of decision-making: before... **Full text:** <https://bit.ly/2HjdFSF>

Top ten tips palliative care clinicians should know about caring for Jewish patients

JOURNAL OF PALLIATIVE MEDICINE | Online – 21 October 2020 – Judaism, one of the world’s oldest religions, claims an estimated 14.3 million members worldwide. There is great diversity in terms of identity, practice, and belief among people who identify as Jewish. As of 2017, 40% of the global Jewish community resided in the U.S., making it essential for palliative care clinicians to understand religious and cultural issues related to their serious illness care. In this article, the authors discuss 10 important concepts relevant to the inpatient care, advance care planning, and bereavement needs of Jewish patients and families. **Abstract:** <https://bit.ly/3dMO686>

End-of-life wishes among non-Hispanic, Black and White middle-aged and older adults

JOURNAL OF RACIAL & ETHNIC HEALTH DISPARITIES | Online – 19 October 2020 – Although some research has been done on end-of-life (EoL) preferences and wishes, knowledge of racial differences in the EoL wishes of non-Hispanic White and non-Hispanic Black middle-aged and older adults is limited. Previous studies exploring such racial differences have focused mainly on EoL decision-making as reflected in advance healthcare directives concerning life-sustaining medical treatment. This study focuses on racial differences in non-decision-based aspects of EoL care, that is, EoL care that incorporates patients’ beliefs, culture, or religion. Non-Hispanic Blacks reported more EoL non-decision-based desires and wishes than non-Hispanic Whites. In addition to gender, age, and education other determinants of EoL non-decision-based medical desires and wishes included perceived and objective health status, spirituality, and medical trust. Poverty level, perceived discrimination did not correlate with EoL medical wishes. Non-Hispanic Blacks desired a closer relationship with their providers as well as a higher level of respect for their cultural beliefs and values from their providers compared with their White counterparts. Awareness, understanding, and respecting the cultural beliefs and values of older non-Hispanic Black patients, that usually are seen by non-Hispanic Black providers, is the first step for meaningful relationship between non-Hispanic Black patients and their providers that directly improve the EoL quality of life for this segment of our population. **Abstract (w. list of references):** <https://bit.ly/2TlekFf>

N.B. Selected articles on disparities in the provision and delivery of hospice and palliative care for racial/ethnic minorities in the U.S. noted in Media Watch 31 August 2020 (#681, p.3).



Would the article above be of interest to a colleague?

Twelve tips to teach culturally sensitive palliative care

MEDICAL TEACHER | Online – 17 October 2020 – With an increasingly ageing population there will be a rising demand for palliative care (PC), including from older migrants and ethnic minorities. While many (future) physicians are unfamiliar with specific needs of older migrants and ethnic minorities regarding care and communication in PC, this may be challenging for them to deal with. Moreover, even many medical teachers also feel unprepared to teach PC and culturally sensitive communication to students. The authors suggest twelve tips to teach culturally sensitive PC to guide the development and implementation of teaching this topic to medical students. Drawn from literature and the authors' own experiences as teachers, these twelve tips provide practical guidance to both teachers and curriculum designers when designing and implementing education about culturally sensitive PC. **Full text:** <https://bit.ly/2ID0EU4>

Refusing and withdrawing treatment at the end of life: Ethical complexities involving patients who lack decision-making capacity

MEDICINA Y ÉTICA: REVISTA INTERNACIONAL DE BIOÉTICA, DEONTOLOGÍA Y ÉTICA MÉDICA, 2020;31(4):1019-1041. Obtaining valid, free and informed consent is not always very easy. It presupposes on the one hand disclosure of fair, clear and appropriate information, and on the other hand the capacity to understand as properly as possible, and then to take a decision. So when a patient has long-term cognitive impairments and lacks the capacity independently to make or communicate a decision and



when this decision is about his or her end of life, the consent may be very complex. How to do it right? This article does not give *the* solution but it discusses the issue in the French legal and ethical framework. The challenge is to find a crest line between beneficence, respect for autonomy and the refusal of *unreasonable obstinacy* (which defines futility in French Law). Beneficence might mean withdrawing (or with holding) ongoing medical treatments (i.e., chemotherapy, radiotherapy, etc.) when they become increasingly ineffective and furthermore, are aggressive and intrusive for the patient (leading to a decrease in his quality of life). But when the patient cannot consent or seems to disagree, how can we go forward? The struggle is to know what truly matters to the dying person in order to respect his or her wishes. **Full text (click on 'Full Text' icon):** <https://bit.ly/3jayVXA>

N.B. English language article.

Noted in Media Watch 25 May 2020 (#667, p.11):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 15 May 2020 – '**Advance care planning: The future.**' The authors summarize the evidence about what advance care planning (ACP) is and how it should be conducted. They address its barriers and facilitators and discuss current and future models of ACP, including a wider look at how to best integrate those who have diminished decisional capacity. Different models are analysed, including new work in Wales (future care planning which includes best interest decision-making for those without decisional capacity)... While ACP is a joint responsibility of patients, relatives and healthcare professionals, more clarity on how to apply best ACP practices to include people with diminished capacity will improve patient-centred care. **Abstract:** <https://bit.ly/3fXLtBa>

Noted in Media Watch 8 July 2019 (#621, p.4):

- *AMA JOURNAL OF ETHICS*, 2019;21(7):E587-593. '**Who makes decisions for incapacitated patients who have no surrogate or advance directive?**' While there is no perfect solution to the problem of making medical decisions for such vulnerable patients, three different approaches are noted in the literature: 1) A physician approach; 2) An ethics committee approach; and, 3) A guardianship approach. Recent policies and laws in the U.S. have required an approach that is "tiered" with respect to both who is involved and the gravity of the medical treatment questions at issue. In a general sense, some variant of a tiered approach is likely the best possible solution for jurisdictions and health institutions ... to the challenging puzzle of treating unrepresented patients. **Full text:** <http://bit.ly/2J3CEaG>

Cont.

Noted in Media Watch 5 February 2018 (#549, p.9):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 1 February 2018 – ‘**Medical decision-making for adults who lack decision-making capacity and a surrogate: State of the science.**’ Adults who lack decision-making capacity are a vulnerable, voiceless population in healthcare. Little is known about how medical decisions are made for this patient population. The findings of this study revealed: 1) Various terms are used to refer to adults who lack decision-making capacity; 2) The number of “unbefriended” adults is sizable and likely to grow; 3) Approaches to medical decision-making in different healthcare settings varies; and, 4) Professional guidelines and laws to address the issues related to this population are inconsistent. **Abstract (w. list of references):** <http://bit.ly/31sParj>

Palliative care in Sweden

The 6S-model for person-centred palliative care: A theoretical framework

NURSING PHILOSOPHY | Online – 22 October 2020 – Palliative care (PC) is provided at a certain timepoint, both in a person’s life and in a societal context. What is considered to be a good death can therefore vary over time depending on prevailing social values and norms, and the person’s own view and interpretation of life. This means that there are many interpretations of what a good death can actually mean for an individual. On a more general level, research in PC shows that individuals have basic common needs, for example physical, mental, social and spiritual well-being. Therefore, in today’s pluralistic Western society, it becomes important that PC is person centred to enable individuals to receive, as far as can be achieved, care that promotes as good a life as possible based on the person’s own needs and preferences, and in accordance with evidence and current laws. For many years a research group, consisting nurse researchers together with nurses working in PC, has developed a model for person-centred PC, the 6S-model. The model’s central concept is Self-image, where the starting point is the patient as a person and their own experience of the situation. The other concepts: Self-determination, Symptom relief, Social relationships, Synthesis and Strategies are all related to the patient’s self-image, and often to each other. The model’s development, value base and starting assumptions are reported in this article, as are examples of how the model is applied in PC in Sweden. The model has been, and still is, constantly evolving in a collaboration between researchers and clinically active nurses, and in recent years also with patients and close relatives. **Abstract:** <https://bit.ly/3e5n649>

Clinician perspectives on implementing video visits in home-based palliative care

PALLIATIVE MEDICINE REPORTS, 2020;1(1). Despite the increasing use and acceptance of technology in healthcare, there is limited evidence on the usefulness and appropriate use of telehealth in home-based palliative care (HBPC). As part of the process evaluation of a pragmatic trial of video visits in HBPC, the authors assessed clinician experience with video visit implementation. Clinicians (36 physicians and 48 registered nurses) generally had favorable attitudes toward video visits and telehealth. Respondents felt confident in the skills needed to make their role in video visits successful. Clinicians were neutral on whether video visits were useful for their practice or enhanced the patient-caregiver experience. Clinicians found video visits to be most appropriate for follow-up care (as opposed to start of care). The interviews yielded two themes that complemented the survey findings: 1) Factors enhancing the value proposition (positive responses from patients and families and convenience); and, 2) Factors diminishing the value proposition (issues related to the technology and scheduling). The authors provide insights into clinicians’ experiences with implementing remote video physician consultations, facilitated by a nurse in the patient’s home in the pre-COVID-19 era. Clinician views about video visits may have shifted with the pandemic, which occurred after our data collection was complete. **Full text:** <https://bit.ly/3m1zrJ6>

Cont. next page



Media Watch: Behind the Scenes
<http://bit.ly/2MwRRAU>

Related:

- *CANCER NURSING*, 2020;43(6):429-430. 'How the COVID-19 pandemic could reshape palliative care into high-tech and high-touch care: An ethics of care perspective.' COVID-19 disrupted palliative care and other healthcare services as health systems were quickly overwhelmed with patients and by public health measures requiring social distancing and restricting face-to-face contact. These challenges have spurred the adoption of digital health (DH) in many health systems across the globe. DH is mainly concerned with the use of routine and innovative forms of information and communications technology to address health needs. DH has become an umbrella term that encompasses eHealth, telemedicine, mobile health (or mHealth)... **Full text:** <https://bit.ly/3kna58c>

N.B. Selected articles on the role of telemedicine in HBC noted in Media Watch 19 October 2020 (#688, pp.5-6).

Providing care to parents dying from cancer with dependent children: Health and social care professionals' experience

PSYCHO-ONCOLOGY | Online – 22 October 2020 – Health and social care professionals' perceptions of the challenges faced by many families when a parent is dying from cancer included: parental uncertainties surrounding if, when and how to tell the children that their parent was dying, the demands of managing everyday life, and preparing the children for the actual death of their parent. Many of the thirty-two participants in this study felt ill-equipped to provide care to parents at end of life (EoL) concerning their children. The results are discussed under two themes: 1) Hurdles to overcome when providing psychological support to parents at EoL; and, 2) Support needs of families for the challenging journey ahead. **Abstract:** <https://bit.ly/3oh7zmf>

N.B. See 'The Crossroads of Grief: Understanding Grief & Diversity,' Children & Youth Grief Network, Ontario, Canada, 2018. Scroll down to 'Complete Literature Review' for 'Parental; Illness, Dying & Death' (p.13) and 'Death of a Parent' (p.30). **Download/view at:** <http://bit.ly/2OB4Y6C>

Spiritual diversity, spiritual assessment, and Māori end-of-life perspectives: Attaining *ka ea*

RELIGIONS | Online – 20 October 2020 – The contemporary world is endowed with increasingly diverse spiritual and cultural perspectives, yet little is known about the spiritual concerns and spiritual resilience of Māori from Aotearoa New Zealand at the end of life (EoL). A context is provided for the value of spiritual assessment and identification of spiritual needs or concerns. Spiritual concerns and the desire to attain a state of *ka ea* (fulfillment, gratitude, or peace) may point to interventions, helping activities, or referrals that guide treatment. The authors reflect on qualitative findings from the 2017-2020 Pae Herenga study of 61 caregiving families, their helping professionals, and religious/spiritual leaders. They explore essential spiritual values and practices that support *kaumātua* (older tribal people) who have a life-limiting illness in achieving a sense of satisfaction and fulfilment at the EoL. Three themes emerged: the relational is spiritual, the need to live into the future, and value of spiritual EoL care. While some scholars have lamented the lack of culturally appropriate rapid assessment instruments, The authors suggest that a more open-ended assessment guide is better suited to understand key elements of spiritual diversity and spiritual concerns, particularly the spiritual strengths and resources that lead to well-being and even thriving at life's end. Finally, learning about spiritual diversity can assist others to reconnect to lost meanings and regain a more holistic and centred view of life. **Full text:** <https://bit.ly/31CkXl1>

N.B. Additional articles on Māori beliefs and practices in the context of the EoL and EoL care noted in Media Watch 17 August 2020 (#679, p.4).

Media Watch: Access on Online

International



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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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