

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

As we witness the older population grow, the dying population change and conversations about how we choose to die unfold, architects have a responsibility to work alongside healthcare professionals, co-producing environments that can positively contribute to holistic experiences of dying.

'The dying patient: Taboo, controversy and missing terms of reference for designers – an architectural perspective' (p.12), in *Medical Humanities*.

Canada

Associations between the receipt of inpatient palliative care and acute care outcomes: A retrospective study

STATS CANADA | Online – Accessed 16 November 2020 – Canada continues to have a hospital-centric care system for those who are dying, despite the preference of most individuals to die in their community and other home-like settings. In 2015, 58% of decedents in Canada were hospitalized more than once in their last year of life and 61% of Canadians died in hospital. Under a hospital-centric system, the health-care costs associated with dying are high. Despite the prominence of hospital care near the end of life (EoL), little is known about the characteristics of those who are admitted to hospital during this period and the types of inpatient care being provided. Hospitalizations in the final year of life may provide an opportunity to initiate palliative care (PC) or continue a PC treatment plan established prior to hospitalization. While most Canadians die of causes with predictable trajectories, many do not receive PC or adequate support prior to death. The impacts of receiving community-based PC on EoL outcomes are well-documented, including lower healthcare costs, acute care use (e.g., emergency room visits, hospitalizations with and

without intensive care unit admissions) and improved patient satisfaction with care. Yet, according to the Canadian Institute for Health Information, of the two-thirds of decedents in Alberta and Ontario who used home care in their final

Specialist Publications

'**Involvement of palliative care in patients requesting medical assistance in dying**' (p.7), in *Canadian Family Physician*.

'**Canadian best practice recommendations for the management of amyotrophic lateral sclerosis**' (p.8), in *Canadian Medical Association Journal*.

'**Challenges of providing palliative and end-of-life care to refugee claimants in Canada: A case report**' (p.9), in *Journal of Palliative Medicine*.

'**Grieving in the digital era: Mapping online support for grief and bereavement**' (p.13), in *Patient Education & Counselling*.

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year of life, only half received formal EoL support prior to death.¹ Although non-palliative home care services include a wide range of valuable in-home assistance, formal identification of PC needs and an EoL designation are often associated with increased hours of services provided and improved patient and health system outcomes, including fewer days in hospital, death outside of acute care settings and lower cost to the healthcare system. Similar challenges may be observed in the acute care sector, where conversations about PC and advance care planning often happen late in a patient's dying trajectory, with nearly half of patients who died in hospital receiving a designation for PC only after their symptoms worsened or when curative treatments were terminated. **Full text:** <https://bit.ly/38UAabK>

1. 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, Ottawa, Ontario, September 2018. [Noted in Media Watch 24 September 2018 (#582, p.1)] **Download/view at:** <http://bit.ly/2MqmCYO>

Noted in Media Watch 3 February 2020 (#651, p.13):

- *PLOS ONE* | Online – 31 January 2020 – '**Does early palliative identification improve the use of palliative care services?**' In this propensity-score matched cohort study of patients who were likely to die within one year, the authors found that actively identifying patients who may benefit from a palliative care (PC) approach increased the utilization of PC services and community-based care such as home care, physician home visits, and outpatient opioid use. Earlier access to PC is in line with quality standards for quality care in the province of Ontario. Nevertheless, the most recent data from the Canadian Institute for Health Information shows that in Ontario and Alberta, fewer than 15% receive PC at home. The results of this study are also congruent with other end of life studies. **Full text:** <http://bit.ly/31gyd3N>

Noted in Media Watch 10 February 2020 (#652, p.1):

- *THE CATHOLIC REGISTER* | Online – 5 February 2020 – '**Palliative care in Canada: Harsh facts, sad realities.**' A guaranteed right to doctor-assisted death in Canada has still not been matched with a right to palliative care (PC) as the vast majority of Canadians continue to die among strangers in institutions, either without PC or with too little PC delivered too late in their disease trajectory... Of Canadians who died at home in 2016-2017, even though two-thirds received home care during their last year, less than one-in-six received PC, according to the Canadian Institutes of Health Information. Just 22% of long-term care residents with less than six months to live received PC. Only 15% of Canadians die at home... In contrast, over 40% of medical aid in dying procedures provide death at home. <http://bit.ly/3bgP1Mk>

U.S.A.

Growing number of hospices pursuing trauma-informed care

HOSPICE NEWS | Online – 17 November 2020 – When a hospice patient suffering from dementia began to hoard milk and other fluids, he was almost asked to leave the skilled nursing facility caring for him. But hospice staff trained in trauma-informed care recognized his fear response and pursued interventions, bringing the patient relief and allowing him to remain in the place he called home. Due to scenarios like these, hospices increasingly are beginning to embrace the concept of trauma-informed care. Individual trauma results from events or circumstances that an individual experiences as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and well-being, according to the Substance Abuse & Mental Health Services Administration (SAMHSA). While confronting their mortality is inherently traumatic for patients, hospices are seeing

that some who have gone through extreme events may need an extra layer of support in order to address their psychological and emo-

Specialist Publications

'**Urgent creation of a palliative care team in a small hospital during the COVID-19 crisis**' (p.14), in *American Journal of Hospice & Palliative Medicine*.

'**End-of-life care for persons under guardianship**' (p.11), in *Journal of Pain & Symptom Management*.

'**Children at the intersection of pediatric palliative care and child maltreatment: A vulnerable and understudied population**' (p.11), in *Journal of Pain & Symptom Management*.

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tional symptoms, including veterans or victims of past abuse, among others. The need for trauma-informed services may be rising due to the COVID-19 pandemic. One recent study examined trauma-informed palliative care during COVID-19 and indicated that an increasing wave of trauma response from patients, caregivers and clinicians was likely.¹ <https://bit.ly/36GtFqo>

1. 'COVID-19 lessons: The alignment of palliative medicine and trauma-informed care,' *Journal of Pain & Symptom management*, published online 18 May 2020. [Noted in Media Watch 25 May 2020 (#667, p.10)]
Full text: <https://bit.ly/2ylk8YM>

Noted in Media Watch 28 September 2020 (#685, p.12):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 22 September 2020 – 'Practice considerations for trauma-informed care at end of life.' Trauma-related symptoms may complicate care, making it an important subject of clinical attention for interdisciplinary hospice team members. As part of this team, social workers are particularly well suited to provide more targeted interventions where indicated, though all members of the team should take a trauma-informed approach. This article reflects on the need for organizations to take a systems-level approach when implementing trauma-informed care and suggests implications for practice through a universal approach to trauma and the need for trauma-specific assessments and interventions... **Abstract:** <https://bit.ly/3iVlprz>

Painful ethical choices in 2020 vs 2010: How has thinking changed?

MEDSCAPE | Online – 17 November 2020 – Much has changed in the 10 years since *Medscape's* first survey on what physicians would do when faced with painful choices in patient care. A new report shows that physicians' value judgments have shifted in many respects, sometimes as a result of increased regulations and fears of litigation.¹ Several of the questions in the survey revolved around end-of-life decisions, and in some cases, the differences seen in just a decade were striking. One example concerned life support decisions in the context of a family's choices [see sidebar]. <https://wb.md/2UxHNwj>

Extract from *Medscape* survey

Far more physicians in 2020 would provide futile therapy at the family's request than a decade ago. Concern over a malpractice lawsuit and potential negative patient/family online reviews are factors that play into this change. Also, patients and family members participate more in medical decisions than a decade ago.

1. 'Ethics 2020: Life, Death & Painful Dilemmas,' *Medscape*, November 2020. <https://wb.md/35DV90D>

A nudge helps doctors bring up end-of-life issues with their dying cancer patients

STAT | Online – 16 November 2020 – Imagine this scenario, one that's not uncommon for people diagnosed with incurable cancer: You and your cancer doctor decide that you should try chemotherapy to prolong your life. Six months later, that chemotherapy and several other treatments not only haven't slowed the cancer but have caused burdensome side effects – some so bad you needed to be hospitalized. Finally, at this point, the doctor asks, "What matters most if you were at the end of your life?" Would having that conversation about your end-of-life (EoL) wishes earlier have helped you make the most of your last days? And if your doctor had believed you may not survive past six months, would you have wanted to know? When conversations about goals and EoL wishes happen early, they can improve patients' quality of life and decrease their chances of dying on a ventilator or in an intensive care unit. Yet doctors treating cancer focus so much of their attention on treating the disease that these conversations tend to get put off until it's too late. This leads to costly and often unwanted care for the patient. This can be fixed, but it requires addressing two key challenges. <https://bit.ly/2IDX8sP>

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Noted in Media Watch 6 July 2020 (#673, p.2):

- *STAT* | Online – 1 July 2020 – ‘**An experiment in end-of-life care: Tapping AI’s cold calculus to nudge the most human of conversations.**’ The daily email that arrived in physician Samantha Wang’s inbox ... contained a list of names and a warning: These patients are at high risk of dying within the next year. This list of names was generated by an algorithm that had reached its conclusions by scanning the patients’ medical records. The email was meant as a nudge, to encourage Wang to broach a delicate conversation with her patient about his goals, values, and wishes for his care should his condition worsen. A handful of hospitals and clinics around the country are deploying cutting-edge artificial intelligence models in palliative care. <https://bit.ly/38g2Auu>

Noted in Media Watch 5 August 2019 (#625, p.8):

- *JOURNAL OF MEDICINE & PHILOSOPHY*, 2019;44(4):403-422. ‘**On nudging’s supposed threat to rational decision-making.**’ Nudging is a tool of libertarian paternalism. It involves making use of certain psychological tendencies in order to help people make better decisions without restricting their freedom. However, some have argued that nudging is objectionable because it interferes with, or undermines, the rational decision-making of the nudged agents. Opinions differ on why this is objectionable, but the underlying concerns appear to begin with nudging’s threat to rational decision-making. Those who discuss this issue do not make it clear to what this threat to rationality amounts. In this article, the author evaluates what effect nudging has on decision-making... **Full text:** <http://bit.ly/2LQ8t9g>

International

Support Australians who are dying to talk

AUSTRALIA | Palliative Care Australia – 19 November 2020 – Dying should be seen as a normal part of life, with grief and bereavement supported in the community and within workplaces. Death literacy across the community needs to be improved significantly so people are more comfortable talking openly about death and dying. Older Australians also need to be supported to understand what good palliative care (PC) means for them regardless of their prognosis. Work done across the community to normalise discussion of death and dying, and grief and bereavement, will make care planning discussions more common and more accepted. It will also result in an understanding of PC and how PC contributes to health and healthy dying. This will, in turn, support the aged care workforce to be better able to facilitate advance care planning within aged care services. Aged care policy is currently focussed on wellness and enablement. While this is very important, this focus must not shut down conversations and planning for a person’s inevitable death. Both PC, and wellness and enablement, share the common goal of maximising quality of life, and

both should be able to exist equally within aged care. Our health services are often so focussed on keeping people alive, that they can forget that everyone dies and this is not a failure on their part. Unrealistic expectations of modern medicine can also result in delayed referrals to PC services and militate against a healthy approach to death and dying. <https://bit.ly/3IP10G7>

Specialist Publications

‘**Why have advance directives failed in Spain?**’ (p.7), in *BMC Medical Ethics*.

‘**Can migration background be a boundary in palliative care at the end of life?**’ (p.9), in *Deutsche Medizinische Wochenschrift*.

‘**Taking care of dying patients through an “interprofessional ecosystem”**: A grounded theory study on the experience of an interprofessional team in palliative care’ (p.14), *Scandinavian Journal of Caring Sciences*.



Palliative Care Network

Palliative Care for Everyone, Everywhere

Closing the Gap Between
Knowledge & Technology
<http://bit.ly/2DANDFB>

National Institute for Health & Care Excellence publishes draft quality standards for end-of-life care

U.K. | *Medscape* (Univadis) – 19 November 2020 – The new draft quality standard for adult end-of-life (EoL) services describes high-quality care in priority areas for improvement. This quality standard updates the existing standard, which was published in November 2011. The quality statements are: 1) Adults who are likely to be approaching the EoL are identified using locally developed systems; 2) Adults approaching the EoL have opportunities to discuss advance care planning; 3) Carers providing EoL care to people at home are supported to access local services that can provide assistance; 4) Adults approaching the EoL receive care that is coordinated between health and social care practitioners within and across different services and organisations; and, 5) Adults approaching the end of their life have access to support 24 hours a day, seven days a week. The draft guidance is now open for consultation and the Institute is asking particularly for comments on a number of areas, including: 1) Does the draft accurately reflect the key areas for quality improvement? Are local systems and structures in place to collect data for the proposed quality measures? Do you think each of the statements above would be achievable by local services given the net resources needed to deliver them? Do you think EoL care service delivery (excluding the last days of life) has substantially changed during the COVID-19 pandemic ...and, can you describe any positive changes? Full text: <https://bit.ly/2UKPwr3>

Daily Express launches crusade to save Britain's hospices struggling through pandemic

U.K. | *The Daily Express* (London) – 17 November 2020 – The newspaper is calling for urgent action from the government to help thousands struggling financially in the face of the pandemic. A legion of hospices ... find themselves under unimaginable pressure as winter bites. The average adult hospice in England gets 32% of its funding from health budgets while children's hospices get 17%. It means most rely heavily on community fundraising events to keep their heads above water – activities decimated by COVID-19. A recent survey by Hospice UK found 93% of facilities feared people with end-of-life (EoL) needs could miss out on vital support. This is largely as a result of social distancing measures and a drop in community fundraising. More than two-fifths said they would have to slash services to people with palliative and EoL needs. At the height of the first wave of the pandemic hospices were caring for 24,000 people a day – three times more than the same period in 2019. In the first month alone hospices had lost £70 million as fund-raising all but stopped following the national lockdown. The Government gave hospices a £200 million handout to help get through the crisis, but it is clear that more needs to be done. Hospice UK said almost three quarters were having to reduce day services in hospices as a result of the pandemic, while 43% feared they could reduce them by up to a half. <https://bit.ly/2IjtnqM>

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 Coronavirus 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 ... 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>

Noted in Media Watch 13 April 2020 (#661, p.3):

- U.K. | *Civil Society News* – 7 April 2020 – ‘**Sue Ryder warns it may be forced to close hospices.**’ One of the U.K.'s largest hospice charities has warned that it is on “the brink of closure” as a result of the Coronavirus crisis. Sue Ryder, which provides end-of-life care for 5,000 people each year, says that it faces a £12 million financial black hole over the next three months. It has launched an emergency appeal for public donations and called for urgent funds from the government. Without that support, the charity warns that it may be forced to close its hospices and end its services helping terminally ill people in their own homes. The charity says that its investment fund has lost £2 million since the crisis began, as a result of falling stock market values. <https://bit.ly/3e0gTWx>

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Noted in Media Watch 3 February 2020 (#651, p.4):

- U.K. | *The Daily Mirror* (London) – 30 January 2020 – **“We must act now to save our hospices – or children will go without care.”** As part of its long-term plan, National Health Service England has pledged to raise funding for children’s hospices to £25 million in 2023-2024, and the Conservative Party pledged to “support our precious hospices” in its election manifesto. A report from Together For Short Lives, a charity which represents hospice users, warns of a “children’s palliative care (PC) workforce crisis.”¹ It says services are at “breaking point” because of a growing shortage of PC doctors and nurses. The report shows there are just fifteen children’s PC consultants in the U.K. when there should be forty to sixty. <http://bit.ly/2GCXwU9>

1. ‘Open letter delivered to Secretary of State,’ Together for Short Lives, January 2020. **Download/view** at: <http://bit.ly/2OgFIT3>

Covid-19: Families “let down” by children’s hospices funding

U.K. (Wales) | BBC News (Cardiff) – 17 November 2020 – Families with children who have life-limiting conditions “urgently need more access to respite care,” a report has found.¹ More than 130 families across Wales’ seven health boards who use children’s hospices contributed to the critical Family Voices report. They want better access and more money for Wales’ two hospices. The Welsh Government said it was working with hospices “to understand their future funding requirements.” Tŷ Hafan, near Cardiff, and Tŷ Gobaith, near Conwy, provide specialist one-to-one care and outreach services to children and their families, including end-of-life and crisis care, plus respite help to full-time carers. The report found paediatric palliative care “needs to be improved,” with almost three-quarters of families saying they faced barriers when it came to accessing support. <https://bbc.in/3IEgnRx>

1. ‘Our lifeline,’ Family Voices, November 2020. **Download/view** at: <https://bit.ly/38XHZgK>

Noted in Media Watch 9 March 2020 (#656, p.4):

- U.K. (Wales) | BBC News (Cardiff) – 4 March 2020 – **“Welsh children’s respite care cut due to hospice funding “crisis.”** Funding for Wales’ children’s hospices is reaching “crisis point” amid calls for more public funding to stop them cutting respite care for sick children. They get on average less than 10% of funding from the Welsh Government, lower than for other U.K. countries. The Welsh Government said it was discussing funding needs with hospices. Children’s hospices in Scotland get more than half of their funding from the Scottish government while England’s children’s hospices get 21% of their cash from the public purse. The two children’s hospices in Wales, Ty Hafan near Cardiff and Ty Gobaith near Conwy, rely on public donations to survive. <https://bbc.in/39rARH2>

Specialist Publications

Consulting with young people: Informing guidelines for children’s palliative care

ARCHIVES OF DISEASE IN CHILDHOOD | Online – 18 November 2020 – This article presents the findings of a consultation with young people commissioned by the [U.K.’s] National Institute for Health & Care Excellence (NICE) to inform clinical guidelines for paediatric palliative care...The topics explored were pre-defined by NICE: information and communication; care planning; place of care; and psychological care. Four overarching themes were identified, cutting across the predetermined topic areas: being treated as individuals with individual needs and preferences; quality of care more important than place; emotional well-being; and, living as a young person. Importantly, care planning was viewed as a tool to support living well and facilitate good care, and the young people were concerned less about where care happens but who provides this. Young people’s priorities differ from those of parents and other involved adults. Incorporating their priorities within policy and practice can help to ensure their needs and preferences are met and relevant research topics identified. **Abstract:** <https://bit.ly/3fifqMf>

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Related:

- *ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 16 November 2020 – ‘**Experiences of healthcare, including palliative care, of children with life-limiting and life-threatening conditions and their families: A longitudinal qualitative investigation.**’ This study describes how children with life-limiting and life-threatening conditions and their family members perceive healthcare services, providing insights into their varied experiences of palliative care. The children tended to accept their conditions as part of life, were not always keen to engage in discussions about their conditions and wanted some control over when they talked about their illness. Children and families had an awareness of the fragility of the child’s life, but the possibility of dying was rarely spoken about. **Full text:** <https://bit.ly/38T8vZ0>

Why have advance directives failed in Spain?

BMC MEDICAL ETHICS | Online – 16 November 2020 – Although there has been a specific legislative framework governing advance directives (ADs) in Spain for 20 years, and bioethics has developed in recent decades, the implementation of ADs has failed. ADs have not fulfilled their purpose, because they have hardly any impact on clinical decisions, and therefore they have not been a useful tool to help honor patients’ autonomous decisions about their future care. Studies indicate that there are four reasons for this failure: 1) The lack of proper training for healthcare professionals on the end of life (EoL) and ADs, in terms of the conceptual framework, existing legislation and legal implementation; 2) Lack of a public process to increase awareness about ADs documents, which has led to a great lack of knowledge about ADs among patients, and thus only certain groups especially sensitive to EoL issues (e.g., chronic and terminally ill patients, as well as their families, caregivers and certain ideological groups) are fully aware of them and register ADs properly; 3) Excessively cumbersome bureaucratic documentation and implementation procedures, which are a barrier for patients to prepare them and for professionals to consult them when necessary; and, 4) The continued existence of a paternalistic medical culture, both among patients and healthcare professionals, which makes it difficult to reach shared decisions with patients and their relatives. **Full text:** <https://bit.ly/35x7fZf>

Involvement of palliative care in patients requesting medical assistance in dying

CANADIAN FAMILY PHYSICIAN, 2020;66(11):833-842. Despite its proven benefits in alleviating pain and suffering, this study found that there is still a gap in the provision of palliative care (PC) among the patients who requested medical assistance in dying (MAiD). Although PC should be offered when MAiD is requested, there are no guidelines or legislation mandating a referral to PC, and no guidance on when, how, and where such PC should be delivered. For the MAiD process at The Ottawa Hospital, it is an expectation that the most responsible physician has provided information about PC to the patient and family, but that information is not standardized or well documented. Multi-centre studies over a longer follow-up period and a larger sample size are needed to further explore the observations in this study and determine the role of PC and its effect on patients requesting MAiD. **Full text:** <https://bit.ly/2KpCKfR>



[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>

Canadian best practice recommendations for the management of amyotrophic lateral sclerosis

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 16 November 2020 – High-quality evidence is lacking for most topics in amyotrophic lateral sclerosis (ALS) management; most recommendations provided are based on expert consensus among the working group. The need for further research in ALS management remains, and more evidence-based recommendations will be critical for improving the standards of patient care in Canada and internationally. This guideline can help point the clinical research community, nationally and internationally, to areas of research priorities on disease management. The development of the first Canadian ALS guideline is an important step forward for improving the lives of patients with ALS living in Canada. The predominance of expert consensus statements relative to evidence-based statements in this guideline not only highlights the need for more

research in ALS management but also emphasizes the challenges ALS clinicians face in managing patients with a severe disabling disease. **Full text:** <https://bit.ly/3f24jXC>

Extract from *Canadian Medical Association Journal* article

Expert opinion supports early integration of palliative care (PC) for patients with ALS. However, palliative and end-of-life care are sensitive topics and variably received by patients. Therefore, early introduction of PC must be initiated with consideration of the patient's evolving needs and expectations. At the very least, experts have advocated that it is appropriate to initiate discussions about PC if the topic is raised by patients or caregivers, and if there are indications of advanced disease or disability.

Noted in Media Watch 2 March 2020 (#655, p.8):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 February 2020 – ‘**Top ten tips palliative care clinicians should know about amyotrophic lateral sclerosis.**’ Amyotrophic lateral sclerosis (ALS) is a rapidly progressive and fatal neurodegenerative disorder with enormous palliative care (PC) needs that begin at the time of diagnosis. Although it is an uncommon disease, clinicians who work in PC or hospice are likely to encounter ALS somewhat frequently given the needs of patients with ALS with regard to psychosocial support, symptom management, advance care planning (ACP), caregiver support, and end-of-life care. As such, PC clinicians should be familiar with the basic principles of ALS symptoms, treatments, disease course, and issues around ACP. **Abstract:** <http://bit.ly/32v8KEI>

Noted in Media Watch 24 February 2020 (#654, p.10):

- *JOURNAL OF PALLIATIVE CARE* | Online – 17 February 2020 – ‘**Engaging specialist palliative care in the management of amyotrophic lateral sclerosis: A patient-, family- and provider-based approach.**’ Stakeholders’ [i.e., study participants] general impressions of specialist palliative care (PC) were highly variable. Many expressed limited or inaccurate understandings of PC’s definition and purpose. Perceptions of PC as hospice were common. Stakeholders generally supported the integration of specialist PC into amyotrophic lateral sclerosis (ALS) management, and many recognized the value of early integration of palliative services in both the community and the clinical setting. **Abstract (w. list of references):** <http://bit.ly/3bGBi1E>

N.B. Additional articles on PC for people living with ALS noted in this issue of Media Watch.



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 p.15.

IPCRC.NET International Palliative
Care Resource Center

Search Back Issues of Media Watch @
<http://bit.ly/2ThijkC>

Can migration background be a boundary in palliative care at the end of life?

DEUTSCHE MEDIZINISCHE WOCHENSCHRIFT | Online – 17 November 2020 – According to current research data, individuals with migration background rarely utilize palliative care (PC) services. The potential reasons remain largely unclear, with cultural differences being suggested most frequently. This study focuses on the needs of cancer patients with migration background in Germany and provides an overview of the care problems encountered. Arriving in PC, severely ill patients with migration background experienced social exclusion. This migration-specific effect has a negative impact on coping with the disease and on palliative treatment and end-of-life (EoL) care. Relatives and medical care providers face a challenge when they fail to meet the patients' expectations. Many problems are attributed to cultural differences although patients nearing EoL tend to articulate rather generic needs. Individuals with migration background frequently receive PC without their caregivers having any specific knowledge of their migration biography. In order to do justice to societal effects, the support given must go beyond the mere medical expertise. **Full text:** <https://bit.ly/2IS97Tp>

N.B. German language article.

Noted in Media Watch 28 January 2019 (#599, p.7):

- *BMC PALLIATIVE CARE* | Online – 21 January 2019 – ‘**Experts’ views on palliative care provision for patients with migration background in Germany.**’ There are migration-specific aspects that can influence care provision at the end of life. Migration should be regarded as a biographical experience that has a severe and ongoing impact on the life of an individual and their family. Legal aspects concerning migration status can influence access to and provision of care. Language barriers have to be considered, especially regarding patients’ right to informed decision-making. Babitsch *et al* stated that to ensure culturally sensitive and competent healthcare, institutions have to consider and accept cultural diversity, and provide access to professional medical interpreters.¹ **Full text:** <http://bit.ly/2CQToO0>

1. ‘Doctor’s perception of doctor-patient relationships in emergency departments: What roles do gender and ethnicity play?’ *BMC Health Services Research*, published online 11 April 2008. **Full text:** <https://bit.ly/35HdyK0>

The Neonatal Comfort Care Program: Origin and growth over 10 Years

FRONTIERS IN PEDIATRICS | Online – 30 October 2020 – The objective of perinatal palliative care (PC) is to provide holistic and comprehensive healthcare services to women who are anticipating the birth of a neonate diagnosed prenatally with a life-limiting condition and to continue supportive interventions for the mother and neonate after the birth. The nature of pregnancy, with two patients requiring medical care, requires clinicians from different specialties to engage with one another, the patient, and her chosen family members. Following birth, additional skill sets to treat the medical and comfort needs of the neonate, as well as the psycho-emotional and medical needs of the mother, are required. An interdisciplinary team is necessary to assist families throughout the pregnancy and postnatal journey, and coordination of such care

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Challenges of providing palliative and end-of-life care to refugee claimants in Canada: A case report

JOURNAL OF PALLIATIVE MEDICINE | Online – 16 November 2020 – Refugees are a highly vulnerable marginalized population with unique medical and psychosocial needs. Unfortunately, the Interim Federal Health Program (IFHP) in Canada partially covers the medical needs of refugee claimants, but does not include hospice or home-based palliative care (PC). This report describes the case of a refugee claimant cancer patient who was admitted to an inpatient tertiary cancer center medical oncology ward in Ontario, Canada, due to insufficient community-based PC resources available for patients covered by the IFHP. This case report highlights the differences in PC coverage between the provincial healthcare coverage, Ontario Health Insurance Plan, and federal healthcare coverage for refugees, from a practical point of view, how this can affect the PC available for patients and their families, and the impact on the Canadian healthcare system. **Abstract:** <https://bit.ly/35DrldA>

is an integral component of PC services. The number of PC programs is increasing, but little is written about the origins of such programs, their subsequent growth, and how transitions of care occur within the programs. The authors present data garnered from interdisciplinary team members of a single organization, the Neonatal Comfort Care Program at Columbia University Irving Medical Center, and how they provide care for families throughout the pregnancy and postnatal trajectory. They address the origin and growth of the program, the development of the interdisciplinary team, and the strategies used for high-quality communication and their respective impact on care continuity. The authors provide specific recommendations from data gathered from team members, examine the role of formal and informal education, and identify barriers and future opportunities. **Full text:** <https://bit.ly/35BoBnL>

Noted in Media Watch 18 May 2020 (#666, p.6):

- *ADVANCES IN NEONATAL CARE* | Online – 6 May 2020 – ‘**Conceptually redefining neonatal palliative care.**’ The purpose of this article is to suggest a conceptual definition of neonatal palliative care (NPC) that encompasses all the essential concepts as a way of moving NPC forward by having a consistent approach. Following a review of the NPC literature, a thematic analysis as a method for identifying, analyzing, and interpreting patterns of meaning in the definitions (“themes”) within the literature was undertaken. The major themes identified included philosophies of care, support, culture and spirituality, the team, and clinical management. At the heart of NPC is the primacy of maintaining quality of life, while providing ethical and humane care that supports a “good death.” **Abstract:** <https://bit.ly/2LsFvKJ>

Noted in Media Watch 10 August 2015 (#422, p.8):

- *AMERICAN JOURNAL OF MATERNAL CHILD NURSING*, 2015;40(1):44-50. ‘**Clinician perspectives of barriers in perinatal palliative care.**’ Physicians and nurses [i.e., study participants] differ significantly in the barriers that they report. Nurses expressed more obstacles at the healthcare systems level reporting difficulty in their ability to garner interdisciplinary support and gain administrative backing. Physicians were more confident in their ability to counsel patients than nurses. Members of both disciplines expressed similar feelings of distress and helplessness when caring for families expecting a fetal or neonatal demise. The study participants also reported a lack of societal support and understanding about perinatal palliative care. **Abstract:** <https://bit.ly/3e3Gpu4>

What do positive and negative experiences of patients, relatives, general practitioners, medical assistants, and nurses tell us about barriers and supporting factors in outpatient palliative care? A critical incident interview study

GERMAN MEDICAL SCIENCE, 2020;18:Doc08. GP-centered care at the end of life (EoL) was highly desired by all participating healthcare providers, patients, and relatives. This collaborative model [discussed by the authors] has already been established successfully in England and The Netherlands, where patients see their GP as first point of contact for most health concerns. The GP works as a gatekeeper, before patients are referred to specialists. International experience also shows that GP-centered care at the EoL, especially when additional out-of-hour services are provided, leads to decreased numbers in hospital and emergency admissions. An evaluation of weekend face-to-face inpatient assessments by hospital specialist palliative care (PC) services showed that visits were mostly valued as highly appropriate and necessary. Essentially no misuse was detected. Although a GP-centered care system has been tested to reduce healthcare costs in Germany, it could not be established for the long term. Successful PC was experienced when the GP had a clear responsibility and was the first contact for patients and relatives. Separation of responsibility was identified as a significant barrier to successful continuity of care in the international literature. Study participants highlighted the need for a framework of care that is well adapted for patients and their relatives. These time-consuming demands are often experienced to be in conflict with the high GP caseload, and this results in competing priorities. Requirements such as an out-of-hours availability for patients and relatives can be incompatible with other demands for a GP in everyday practice. Other negative PC experiences, such as a lack of regional or local care infrastructure, are hard to address, although teamwork and cooperation with other PC service providers could unburden the capacity of GPs. **Full text:** <https://bit.ly/3pUN53N>

A survey of hospice and palliative care nurses' and holistic nurses' perceptions of spirituality and spiritual care

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 16 November 2020 – The provision of spiritual care is referred to in professional practice guidelines and mandated in nurses' ethical codes. Still, a gap exists regarding essential training in spiritual conversation and assessment, leaving some healthcare providers feeling uncomfortable when assessing spiritual support needs. It is assumed that the standards of care for hospice and palliative nurses and holistic nurses stipulate that spirituality is addressed within the framework of their specialties and provide education for spiritual care, thus making these nurses proficient in providing spiritual care. This study found that given adequate resources and education, nurses can be positioned to address the spiritual needs of patients and provide appropriate care. This study adds to an emerging body of evidence suggesting that training in spiritual care should be an important component of the foundational nursing curriculum. **Abstract:** <https://bit.ly/2KojMWU>

End-of-life care for persons under guardianship

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 16 November 2020 – Guardians are surrogate decision-makers appointed by a court when other healthcare decision-makers are unable, unwilling, or unavailable to make decisions. Prior studies suggest that persons under guardianship may experience delays in transitions of care. In this study, 167 persons under guardianship who died between 2003-2019 within the Veterans Healthcare Administration (VHA) in Massachusetts and Connecticut were matched on a 1:1 basis to persons without guardians. The groups were compared on treatment specialty at death, days of hospice and ICU care, and receipt of palliative care (PC) consultation. Persons under guardianship were as likely as patients in the comparison group to receive PC consultation..., but were more likely to have ethics consultation ... and have longer lengths of ICU admission... Qualitative findings suggest that issues related to family conflict, fluctuating medical course, and limitations in guardian authority may underlie extended lengths of stay. Guardianship appears to be rare, and as a rule those under guardianship have equal access to hospice and PC within VHA. Guardianship may be associated with healthcare challenges in a small number of cases, and this may drive perceptions of adverse outcomes. **Abstract (w. list of references):** <https://bit.ly/2UwBzwN>

N.B. Selected articles on end-of-life decision-making and treatment for patients with professional guardians noted in Media Watch 23 September 2019 (#632, p.4).

Children at the intersection of pediatric palliative care and child maltreatment: A vulnerable and understudied population

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 13 November 2020 – Concerns for child maltreatment can complicate the provision of pediatric palliative care (PPC). Little is known about the vulnerable population of children with life-threatening conditions involved with PPC and state Child Protective Services (CPS) or hospital Child Protection Teams (CPT). Among 1,804 children followed by PPC [i.e., patient population studied], 189 (10.4%) had documented CPS/CPT involvement. Among those, 113 (60%) had CPT involvement, 88 (47%) had concerns of medical neglect, and 100 (53%) had simultaneous CPS/CPT and PPC involvement. Goals of PPC consultation varied by clinical characteristics and concerns for medical neglect. Frequency of CPT involvement and physical abuse concerns also varied by child clinical characteristics. PPC practitioners regularly encounter children with CPS/CPT involvement. PPC practitioners should be aware of the risk of maltreatment in their patients. Although rare in the general pediatric population, medical neglect is a relatively frequent maltreatment concern in children cared for by PPC. PPC practitioners have an opportunity to aid in proper evaluation of medical neglect in children they care for. Closer PPC collaboration with CPS/CPT may further optimize care. **Abstract (w. list of references):** <https://bit.ly/2UBINj2>

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Noted in Media Watch 23 July 2018 (#573, p.11):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2018;56(3):309-317. '**Prior trauma exposure and serious illness at end of life: A national study of children in the U.S. foster care system from 2005-2015.**' Children in foster care suffer with serious illness at the end of life (EoL). However, the relationship between prior trauma exposure and serious illness has received little empirical attention. Sixty-eight percent of children [i.e., the patient population studied] experienced maltreatment, 28% exposure to parental drug/alcohol misuse, and 39% psychosocial stressors before entering foster care. These findings suggest that trauma-informed EoL care may be a critical need among children in foster care with serious illness. **Full text:** <https://bit.ly/3pzMlv7>

Introduction to sex-positive palliative care: Best practices and interventions

JOURNAL OF PALLIATIVE MEDICINE | Online – 20 November 2020 – Discussing difficult and personal topics is not new to those practicing palliative care (PC). Specialty-level consultation is often sought to facilitate complex and uncomfortable conversations on death and dying. PC providers focus on patient and family needs through the lens of whole-person care. Sexuality is an important component of every person's identity, yet providers often avoid this topic. Avoiding conversations about sexuality is especially strong when the patient has a serious illness. PC providers are recognized communication experts, although current curricula offer little training on how to incorporate discussions regarding this important aspect of personhood. Using case discussions, the authors offer strategies for examining sexuality and incorporating sex-positive interventions into practice. By highlighting how sexuality and PC intersect, we hope to foster a community of interdisciplinary PC providers who practice what we have termed sex-positive palliative care.

Abstract: <https://bit.ly/35ND6VH>

N.B. Additional articles on sexuality in advanced disease and at the end of life from the perspective of palliative care professionals noted in Media Watch 14 September 2020 (#683, p.10).

The dying patient: Taboo, controversy and missing terms of reference for designers – an architectural perspective

MEDICAL HUMANITIES | Online – 16 November 2020 – Contemporary society has grown seemingly detached from the realities of growing old and subsequently, dying. A consequence, perhaps, of death becoming increasingly over-medicalised, nearly one in two U.K. nationals die institutional deaths. In this article the authors, two architectural scholars engaged in teaching, research and practice and a nurse and healthcare scholar with a focus on end-of-life (EoL) care and peoples' experiences, wish to draw attention to a controversy resulting from a paucity in current literature on the terms of reference of the dying "patient" as we navigate the future implications of the **COVID-19** pandemic. This contributes to a relative lack of touchstones for architects to refer to when designing person-centred palliative care (PC) environments. Unlike common building types, architects are extremely unlikely to have lived experience of PC environments as patients; and, therefore, require the help of healthcare professionals to imagine and empathise with the requirements of a person dying away from home. This article includes a review of ageing and dying literature to understand, and distil from an architectural perspective, who, design professionals, are designing for and to remember the nuanced characteristics of those we hold a duty of care toward. The authors ask readers to heed the importance of accurate terms of reference, especially when commissioning and/or designing environments of PC. Furthermore, they put forward an appeal for interdisciplinary collaboration to develop a framework for codesigning positive experiences of person-centred care and environments at the EoL. **Full text:** <https://bit.ly/36CXo3i>

N.B. Selected articles on the relationship between the architecture of healthcare facilities and the quality of hospice and PC noted in Media Watch 10 October 2020 (#687, p.6).

The perspectives of children and young people affected by parental life-limiting illness: An integrative review and thematic synthesis

PALLIATIVE MEDICINE | Online – 19 November 2020 – The review has shown that children facing parental life-limiting illness strive to maintain their agency. Despite the emotional impact and additional caregiving responsibilities associated with having a seriously ill parent, children continue to make independent choices and adopt strategies to manage their changed social world. Children maintaining agency in the face of parental life-limiting illness is a useful conceptualisation of their experience, and may be beneficial to healthcare professionals. There is international recognition that children have a fundamental right to be involved in matters affecting them, and a changed perspective on children's rights by professionals may facilitate this. Regarding children as active participants when a parent is dying, even considering them to have the status of a carer, might provide professionals with a novel perspective on children's role and position in families. Parents will be inclined towards overprotection and shielding, and professionals are able to use the evidence within this review to show how this is unhelpful, contrary to children's wishes and may lead to long-term emotional problems. The review has reinforced an unequivocal message that healthcare professionals can utilise in their interactions with dying parents: children want to know what is happening and want to play an active role. **Full text:** <https://bit.ly/36XklhQ>

Noted in Media Watch 2 November 2020 (#690, p.8):

- *EUROPEAN JOURNAL OF ONCOLOGY NURSING* | Online – 27 October 2020 – '**Going against patients' will? A qualitative study of how palliative healthcare professionals handle competing considerations when children are excluded from parental illness and death.**' The Norwegian Health Personnel Act obliges healthcare professionals to contribute to meeting children's need for information about their parents' illness and prognosis. This study supports the findings of previous research... It contributes to this established knowledge by investigating the healthcare professionals' ways of handling the moral problem that occurs when parents withhold information about their illness and impending death from their minor children. **Full text:** <https://bit.ly/2TzJIWg>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 27 October 2020 – '**Parents with advanced cancer: Worries about their children's unspoken concerns.**' Parents struggle initiating conversations with their children about the cancer. When parents do not have the tools to talk with their children, they silently watch their children attempt to navigate their illness, but can only wonder but not know what their children are thinking. The authors describe the worries and concerns parents wonder their child holds, but has not spoken, about the parent's cancer, adding to an understanding of the magnitude of the emotional burden parents with advanced cancer carry as they struggle to balance their diagnosis and treatment and their life as parents. **Abstract (w. list of references):** <https://bit.ly/3ouXVfW>

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>

Grieving in the digital era: Mapping online support for grief and bereavement

PATIENT EDUCATION & COUNSELLING, 2020;103(12):2515-2524. The authors of this multi-centre study describe the landscape of digital resources available for grief and bereavement, and explore cultural variations through the analysis of patterns in three languages with a multinational repartition (English, French and Spanish). For each language, websites were collected through a systematized approach and classified according to their category (governmental, health, educational, social media, conventional media, spiritual), their country of origin, and the type of support they offered (practical support, services, peer support, informational support, resources). A total of 2,587 websites (English: 1,003; French 678; Spanish: 906) were analyzed. Cultural variations were observed both for the websites' categories and the types of support. Half of the websites presented at least one type of support, informational support being the most prevalent, followed by practical support. English websites presented significantly more support than Spanish websites,

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with French websites in between. By using an extensive survey, the authors' results allow for a general mapping of online websites that is comparable across languages, but also unveil digital dynamics unknown to date. The results of this study further the multicultural understanding of digital support for grief and bereavement, propose an innovative and operational typology for online support, and raise awareness of the current support landscape. **Abstract:** <https://bit.ly/3nsis3m>

Paramedic care of the dying, deceased and bereaved in Aotearoa, New Zealand

PROGRESS IN PALLIATIVE CARE | Online – 17 November 2020 – Paramedics play an essential and distinct role as providers of care to the dying, deceased and bereaved in Aotearoa, New Zealand and around the world. The authors highlight what is known about the features, barriers and facilitators of quality end-of-life (EoL) care by emergency ambulance personnel. They identify priorities for future policy and practice, education and research in this area. Paramedics provide urgent and after-hours support to those with known life-limiting illness and their caregivers, but also attend sudden deaths, from unexpected or unknown causes. Paramedic care at the EoL may involve attempted resuscitation; challenging decision-making and communication; symptom relief; recognition of irreversible dying; provision of compassionate, culturally responsive support for co-responders, bystanders and the bereaved. There is an insufficient acknowledgement of the critical and unique role of paramedics, as providers of urgent care to the dying deceased and bereaved. Ambulance personnel around the world want better preparation and support for EoL care. **Abstract:** <https://bit.ly/36HJVr8>

N.B. Additional articles on the role of paramedics in EoL care noted in Media Watch 15 June 2020 (#670, p.10).

Taking care of dying patients through an “interprofessional ecosystem”: A grounded theory study on the experience of an interprofessional team in palliative care

SCANDINAVIAN JOURNAL OF CARING SCIENCES | Online – 17 November 2020 – The interprofessional approach is part of the philosophy in palliative care (PC), and its benefits are already documented. However, there is no evidence regarding the process through which the interprofessional team faces the process of the patient's end-of-life (EoL) and how this experience might be of value for the team's development itself. The aim of this study was to analyse and understand the psychosocial processes that occurs when an interprofessional team accompanies patients and their families to death in PC, with the ultimate aim to develop a substantive theory to describe this phenomenon. Fourteen healthcare professionals – belonging to different disciplines (doctor, nurse coordinator, nurse, nurse assistant, psychologist) – were interviewed in a Northern Italy PC facility. The core category of this study was identified to be the process of accompaniment of the dying patient as an interprofessional ecosystem. Moreover, the results showed four main factors determining the development of the core psychosocial process: from professionals' 'Hidden Amaze-ment' to 'Onerous Happiness' where 'Weaving of Professional Resources' and 'Work Meaning' are the underlying conditions to catalyse the process itself. Interprofessional care appears an essential value, which becomes the source of the team's strength when facing EoL experiences. Health policies and organisations should take the importance of the characteristics of the work environment more carefully. The meaning that professionals attribute to their work and to the team itself, indeed, it may have impact on the overall quality of care and contribute to sustain work engagement, even in stressful situations like EoL care. **Abstract:** <https://bit.ly/2UB7IDw>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 19 November 2020 – '**Urgent creation of a palliative care team in a small hospital during the COVID-19 crisis.**' The COVID-19 pandemic created a global health emergency that has changed the practice of medicine and has shown the need for palliative care (PC) as an essential element of hospital care. In the authors' small South Florida hospital, a PC service was created to support the frontline caregivers. Thanks to the hospital support, the team was formed rapidly. It consisted of three advanced care practitioners, a pulmonary physician with PC experience and the cooperation of community resources such as hospice and religious support. **Abstract (w. list of references):** <https://bit.ly/2UHZbyA>

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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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