

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.

8 March 2021 Edition | Issue #707



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Compiled & Annotated by Barry R. Ashpole

The pandemic of COVID-19 has undoubtedly placed unprecedented pressure in healthcare systems across the globe, it has, however, further deepened the divide between the practice of medicalization and compassionate care central to palliative care.

'An ethical conundrum: Palliative care in the COVID-19 pandemic' (p.12), in *Palliative & Supportive Care*.

U.S.A.

Death doulas give time to those running out of it

WYOMING | Wyoming Public Radio & Media (Laramie) – 5 March 2021 – Death doulas are also called death midwives or end-of-life doulas, but whatever you call them, their numbers have blossomed in the last decade. There's a few in every state, but Colorado is a hotspot in the Mountain West. Beyond being a doula, Cindy Kaufman leads the Colorado End-of-Life Collaborative. "End-of-life doulas fill what we believe is a gap," she said. That gap is the space between hospices, which provide necessary medical care, and what she does – help someone with the actual process of dying. Since the hospice industry started in the '70s and '80s, Kaufman said, it's become more of a business with certain hours and staff caring for multiple clients. While they started as non-profits, the majority of hospices are now for-profit institutions. "We don't carry those kinds of case-loads, we work for (ourselves)," she said, comparing death doulas with hospice staff. "We

don't fall under insurance, we're private pay." Kaufman said death doulas can bring ritual back into dying, and make it easier to say good-bye. They can help plan legacy projects, say late-night prayers, figure out what kind of burial or cremation someone wants. For some, they just sit with people, right up to the end. And death doulas are incredibly diverse, not only in what they offer but with their backgrounds. There's no licensing requirement or mandatory training. Kaufman said some people use their own culture to inform how they practice as death doulas, and they don't want more regulations. <http://bit.ly/3sSptNI>

Specialist Publications

'Palliative care education and research at U.S. cancer centers: A national survey' (p.7), in *Cancer*.

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Noted in Media Watch 14 December 2020 (#696, p.11):

- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 7 December 2020 – ‘**Describing the end-of-life doula role and practices of care: Perspectives from four countries.**’ Contemporary concerns about the end of life (EoL) within the global North are driven by healthcare system restructuring; changing epidemiological, demographic, and social trends; ideologies of choice, autonomy, and person-centered holistic care; and, the desires of individuals, families, and communities to demedicalized dying. EoL doulas evidence a new response to these complexities of modern dying. This study contributes substantially new information to the small body of empirical research about the EoL doulas role and their practices of care, and is the first to employ an international comparative perspective. **Full text:** <https://bit.ly/2lsp6bb>

Noted in Media Watch 10 August 2020 (#678, p.11):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 3 August 2020 – ‘**End-of-life doulas: A qualitative analysis of interviews with Australian and international death doulas on their role.**’ Seven themes emerged: what a death doula (DD) offers, what a DD does, challenges and barriers, occupational preferences, family support, contract of service/fee and regulation. There is a perception that healthcare professionals do not understand what it is that DDs do. The lack of a DD business model sees inconsistencies in what services each DD offers and what patients and families can expect. EoL is complex and confusing for patients and families and there is a need to further explore the DD role and how it can work when there are many inconsistencies in working practice. **Abstract:** <https://bit.ly/30speh6>

International

Dignity in life and death: Commission recommends more nurses and palliative care

AUSTRALIA (New South Wales) | *The Sydney Morning Herald* – 1 March 2021 – The Aged Care Royal Commission’s final report calls on the government to recognise that palliative care (PC) and end-of-life care, like dementia care, is a “core business” for aged-care providers.¹ Given that almost a third of people using residential aged care will die within one year of entering care, the report said PC should not be seen as an optional extra. “Residential aged care is often a person’s final place of residence before they die. People at the end of their lives should be treated with care and respect. Their pain must be minimised, their dignity maintained, and their wishes respected,” the report stated. Yet the Commission heard people were coming in “older, sicker, frailer, [with] multimorbidities and are needing much more care, and ... because of that ... significant numbers of them need PC in the first instance.” The report said they had “heard examples where the care

provided to people in their last weeks and days of life was severely lacking.” It singles out PC as one of four areas that should come under urgent scrutiny by the aged care regulator... It recommends all aged care workers should be trained in dementia and PC, and funding should be increased. <http://bit.ly/2Och9cs>

Specialist Publications

‘**Inequalities in end-of-life palliative care by country of birth in New South Wales, Australia: A cohort study**’ (p.13), in *Australian Health Review*.

‘**Understanding the needs of Australian carers of adults receiving palliative care in the home: A systematic review of the literature**’ (p.13), in *Sage Open Nursing*.

1. ‘Car Dignity & Respect,’ The Royal Commission into Aged Care Quality & Safety, March 2021. **Download/view report at:** <http://bit.ly/3r50V3J>

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Related:

- AUSTRALIA | *The Conversation* – 3 March 2021 – **‘We all hope for a “good death.” But many aged-care residents are denied proper end-of-life care.’** Death is inevitable, and in a civilised society everyone deserves a good one. It would therefore be logical to expect that aged-care homes would provide superior end-of-life care (EoLC). But sadly, palliative care (PC) options are often better for those living outside residential aged care than those in it. In truth, we have already known about the PC problem for years. In 2017, the Australian government’s Productivity Commission reported that EoLC in residential aged care needs to be better resourced and delivered by skilled staff, to match the quality of care available to other Australians.¹ <http://bit.ly/3rp8YYY>

1. ‘Reforms to Human Services,’ Productivity Commission, Australian Government, March 2018. [Draft of the report noted in Media Watch 5 June 2017 (#515, p.4)]. <http://bit.ly/3q9Q1s8>

Noted in Media Watch 1 March 2021 (#706, p.3):

- AUSTRALIA (New South Wales) | PM Glynn Institute – 24 February 2021 – **‘A Snapshot of Palliative Care Services in Australia.’** The current debate on voluntary assisted dying (VAD) naturally prompts a discussion of the current state of palliative care (PC) in Australia. Ensuring access and equity, both underlying principles of social justice, is essential. This means that PC should not only be available to everyone who needs it, but also available to members of society who are more disadvantaged than others. In light of this, and with VAD having been legalised in Victoria in 2018, in Western Australia in 2019, and being under consideration in other states, it is important that before other parliaments follow suit, they first ensure that quality PC is accessible and equitable... **Download/view report at:** <http://bit.ly/37KQmkV>

Noted in Media Watch 8 February 2021 (#703, p.2):

- AUSTRALIA | Palliative Care Australia – 3 February 2021 – **‘Government urged to increase investment in palliative care.’** Palliative Care Australia (PCA) has called on the Commonwealth Government to invest a further \$365 million to meet the growing palliative care (PC) needs of people in the community, in hospitals and in residential aged care. Three key funding initiatives are contained in PCA’s ‘Pre-Budget Submission’ and form a comprehensive suite of funding measures designed to address a system that is failing to meet the demand for PC in Australia.¹ PCA’s recommendations are informed by a KPMG report ‘Investing to Save: The Economics of Increased Investment in Palliative Care in Australia,’ commissioned by PCA in 2020.² <http://bit.ly/2MRgOvn>

1. ‘Pre-Budget Submission: Palliative Care – its more than you think,’ Palliative Care Australia, February 2021. **Download/view submission at:** <http://bit.ly/2MwsIL5>
2. ‘Investing to Save: The Economics of Increased Investment in Palliative Care in Australia,’ KPMG Australia, May 2020. [Noted in Media Watch 1 June 2020 (#668, p.5)] **Download/view report at:** <https://bit.ly/3d8DFL2>

Shortfalls in palliative care must be addressed in advance of any legislation around assisted dying

IRELAND | Irish Hospice Foundation – 1 March 2021 – It is imperative that the Government address shortfalls on palliative care (PC) in advance of any national debate on assisted dying. The organisation believes that fundamental supports for persons nearing end-of-life are not universally in place across Ireland and any move to legislate for assisted dying would be premature until this is addressed. PC supports are required to underpin any future decision to legislate on the matter and as it currently stands several counties have no access to specialist PC inpatient unit or hospice beds. The counties of Laois, Offaly, Longford, Westmeath, Louth and Meath, for example, have no [PC] beds, no planned beds and no funds to build any specialist inpatient or hospice unit. The Foundation believes that there has not yet been a sufficiently detailed and diverse debate and consultation in Ireland on assisted dying. The coming months provide an opportunity for open and inclusive debate on the matter and all voices must be heard. Central to any discussion on the matter is respect for the diversity of opinions that exist to enable an informed decision which will have implications for the society we live in. <http://bit.ly/3r7NcsD>

Cont.

Noted in Media Watch 17 February 2020 (#653, p.7):

- **BMC HEALTH SERVICES RESEARCH** | Online – 14 February 2020 – ‘**End-of-life experience for older adults in Ireland: Results from the Irish longitudinal study on ageing.**’ Ireland is ranked among the leading countries for end-of-life care provision yet significant gaps and difficulties in experience for older people are observable. People with cancer are more likely to die at home or in hospice, contrary to policies recommending palliative care as a component of all serious chronic disease management. High proportion of hospital deaths ... indicates inadequate community and home care supports. Unpaid informal care accounts for 37% of all care received but access to this care ... may be adversely affected by living alone or in a rural area. **Full text:** <http://bit.ly/2SvtiJf>

Noted in Media Watch 10 February 2020 (#652, p.7):

- **HRB OPEN RESEARCH** | Online – 3 December 2019 – ‘**Population-based palliative care planning in Ireland: How many people will live and die with serious illness to 2046?**’ The number of people in Ireland dying from a disease associated with palliative care (PC) need is estimated to increase 68% between 2016 and 2046 if levels of need stay constant. Under assumptions of changing need, increases are estimated in the range 78-84% depending on projection method employed. The equivalent estimates for England & Wales between 2015 and 2040 are 25% with constant needs and up to 47% with changing needs.¹ The number of people living with a disease associated with PC need outnumber those in the last year of life with a relevant diagnosis. **Full text:** <http://bit.ly/2OzrhJJ>

1. ‘How many people will need palliative care in 2040? Past trends, future projections and implications for services,’ *BMC Medicine*, published online 18 May 2017. [Noted in Media Watch 22 May 2017 (#513, p.11)] **Full text:** <http://bit.ly/2IHcYCi>

Noted in Media Watch 26 August 2019 (#628, p.4):

- **HEALTH RESEARCH BOARD (Dublin, Ireland)** | Online – 21 August 2019 – ‘**Out-of-hours specialist and generalist palliative care service provision. An evidence review.**’ Inadequate community supports and deficiencies in access to services outside of regular office hours have been linked to poor outcomes for patients with life-limiting illness. Policymakers, researchers, providers, patients, and carers in Ireland have all identified out-of-hours care as a key deficit in current service provision. The Department of Health commissioned this review to inform the revision of national palliative care (PC) policy and address the recognised challenges in providing out-of-hours PC. Therefore, the purpose of this evidence review was to synthesise evidence regarding the provision of out-of-hours PC for adults. **Download/view at:** <http://bit.ly/2L4gPYh>

Parliamentary inquiry into poor housing at the end of life calls for evidence

U.K. | *Charity* – 1 March 2021 – A cross-party group of MPs is calling for evidence for an inquiry into the effects of unsuitable housing and fuel poverty on the care and support people receive at the end of life (EoL). More than two-thirds of people say they would prefer

to die at home, and dying at home is often used as an indicator that someone has had a “good death.” This inquiry, from the All-Party Parliamentary Group (APPG) for Terminal Illness, will explore the extent to which the experience of living in unsuitable housing, including the experience of fuel poverty, affect people living with terminal illness, their families and carers, and whether it impacts someone’s ability to die at home if that is their wish. The APPG’s work follows its previous inquiry, which found that inadequate income can lead to considerable financial strain, stress, anxiety and health impacts on people at the EoL, and a report on fuel poverty by the EoL charity, Marie Curie, which concluded that the impact of fuel poverty could hasten the death of some people with a terminal illness. The period of consultation will run until Friday, 2 April 2021. <http://bit.ly/3b8ODIm>



All Party Parliamentary Group
for Terminal Illness

N.B. All-Party Parliamentary Group (APPG) for Terminal Illness secretariat website: <http://bit.ly/2XJTXp8>



Would the *Charity* article be of interest to a colleague?

Hospice UK says Welsh leaders have responsibility to ensure people in Wales have sufficient, dignified care at the end of life as it launches its 2021 manifesto priorities

U.K. (Wales) | Hospice UK – 1 March 2021 – Hospice UK has launched its 2021 Senedd election manifesto priorities, calling for politicians to take action to ensure people in Wales living with a terminal or life-shortening condition, and their carers, receive the support they need. Of the 170,000 to die during the next Senedd, approximately 80% will benefit from palliative and end-of-life (EoL) care. Current estimates suggest as many as one in four Welsh people are missing out on the right care at the EoL. The charity urges all political parties to: 1) Reach every child and adult with palliative care (PC) needs in Wales by tackling the inequalities that lead to people missing out on vital care and by widening access to it in the community, which includes enabling access to children and their families across Wales to be cared for at home, and increasing the capacity of the adult and children’s community workforce skilled in PC; 2) Plan to meet increased need for EoL care into the future, with better understanding of where people die, to support essential resource allocation and service development where there is increased need of palliative and EoL care, such as in care homes and people’s own homes, which also means encouraging individuals across Wales to plan for their death by promoting open conversations about death, dying and bereavement; 3) Resource a sustainable palliative and EoL care sector; as demonstrated by the COVID-19 pandemic, the fragility of funding for essential palliative and EoL care providers, such as charitable hospices and care homes, threatens their ability to continue when the care they provide is most in need and under pressure; and, 4) Build capacity and resilience in communities to care for people at the EoL and to support bereaved families through the lasting impact of COVID-19, to uphold Wales’ ambition of becoming the first “Compassionate Country.” <http://bit.ly/3bRivli>

N.B. Link to ‘Manifesto priorities: Senedd election 2021’ embedded in Hospice UK report.

Noted in Media Watch 25 November 2019 (#641, p.4):

- U.K. (Wales) | Deeside.com (Flintshire) – 20 November 2019 – ‘**One in four people in Wales denied access to end-of-life care.**’ North Wales Assembly Member Mark Isherwood, Chair of the Assembly’s Cross-Party Group on Hospices & Palliative Care, has called on the Welsh Government to take action to help radically improve access to hospice and palliative care (PC) for everyone across Wales. While approximately 23,000 people in Wales have a PC need at any one time, around 1 in 4 – approximately 6,000 people – don’t get access to the end-of-life care they need: “As the Cross Party Group on Hospices & Palliative Care’s report found, despite some progress in widening access to hospice and PC in Wales, there remains significant unmet need and under-met need.”¹ <http://bit.ly/35qtGkGb>

1. ‘Inequalities in access to hospice and palliative care,’ Cross-Party Group on Hospices & Palliative Care, National Assembly of Wales, July 2018. [Noted in Media Watch 16 July 2018 (#572, p.4)] **Download/view at Hospice UK:** <http://bit.ly/35nDg2Y>



[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>



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

Specialist Publications

Palliative sedation, compassionate extubation, and the principle of double effect: An ethical analysis

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 4 March 2021 – Palliative sedation (PS) is a well-recognized and commonly used medical practice at the end of life for patients who are experiencing refractory symptoms that cannot be controlled by other means of medical management. Given concerns about potentially hastening death by suppressing patients' respiratory drive, traditionally this medical practice has been considered ethically justifiable via application of the ethical doctrine known as the principle of double effect (PoDE). And even though most recent evidence suggests that PS is a safe and effective practice that does not hasten death when the sedative medications are properly titrated, the PoDE is still commonly utilized to justify the practice of PS and any risk ... it may entail of hastening the death of patients. One less common clinical scenario where the PoDE may still be appropriate ethical justification for PS is when the practice of PS is pursued concurrently with the active withdrawal of life-sustaining treatment – particularly the practice of compassionate extubation. This case study describes an unconventional case of PC with concurrent compassionate extubation where PoDE reasoning was effectively employed to ethically justify continuing to palliatively sedate a patient during compassionate extubation. **Abstract (w. list of references):** <http://bit.ly/3rgEs3F>

N.B. Search back issues of Media Watch for additional articles on PS at: <http://bit.ly/2ThijkC>

Hong Kong's growing need for palliative care services and the role of the nursing profession

ASIA PACIFIC JOURNAL OF HEALTH MANAGEMENT, 2021;16(1):40-46. This viewpoint paper explores the growing emphasis and social need for palliative care (PC) from a global perspective, juxtaposed against the Hong Kong *status quo* and its increasing need for such services. It further highlights that the role of nursing within PC is central to patients receiving the best quality of care. Hong Kong's current delivery models are generally insufficient and can be improved by the adoption of five recommended policy changes, which reinforce the position of nurses as vital to creating a better service. These recommendations will enable nurses to take the lead in future PC delivery frameworks, enabling more efficient planning of future management of patients' pain and other symptoms, social, spiritual, or emotional needs that arise during assessment. Its value may extend to other countries and settings. **Abstract:** <http://bit.ly/3ejefOb>



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.16.

Research Matters

'Measuring goal-concordant care in palliative care research' (p.13), in *Journal of Pain & Symptom Management*.

'Survey will provide national-level information to help researchers identify important issues and better understand what it means to provide quality care in the home setting' (p.14), posted on the website of the U.S. National Hospice & Palliative Care Organization.

'Applying evidence-based symptomatic treatments from other clinical disciplines to palliative care' (p.14), in *Palliative Medicine*.

'End-of-life childhood cancer research: A systematic review' (p.14), in *Pediatrics*.

'Research and social media: A dangerous cocktail or a winged messenger?' (p.15), in *ScienceNordic*.

“A silent epidemic of grief”: A survey of bereavement care provision in the U.K. and Ireland during the COVID-19 pandemic

BMJ OPEN | Online – 3 March 2021 – Bereavement care is a central aspect of the work of a wide range of health and social care professionals yet remains a low priority within healthcare policy. The COVID-19 pandemic has highlighted this important area of patient care, creating both major challenges to bereavement support provision and opportunities for practitioners and policymakers to address this neglected aspect of clinical care. Bereavement is one of the long-term impacts of COVID-19: if left unaddressed it may lead to significant physical and mental health morbidity and create a further burden on health and social care services. This study highlights the profound impact of the pandemic on bereaved people, yet much remains unknown about how individuals,

communities, and the health and social care system will respond. While further research is urgently needed in this area, we already know that action is needed now to ensure equity of provision across ethnic groups, ages and marginalised groups, and equity of care for all bereaved people whether from COVID-19, from other conditions or those bereaved prior to the pandemic. **Full text:** <https://bit.ly/3ret88f>

[Corrections & Clarifications](#)

An abstract of this article was included in Media Watch 1 March 2021 (#706, p.5), noted as ‘In print.’

Related:

- *PEDIATRICS* | Online – 1 March 2021 – ‘**Grief and bereavement in fathers after the death of a child: A systematic review.**’ The grief experience of fathers appears to be unique and is likely influenced by the cultural, societal, and religious contexts within their respective lived experiences. Despite evolving gender roles across the past several decades, many fathers remain anchored to the belief that men should deal with loss through stoicism, a “stiff upper lip,” self-isolation, and hard work. Yet the literature suggests that, for some fathers, these coping mechanisms may be inadequate for navigating their grief. Better understanding of paternal grief and bereavement has the potential to lead directly to clinical improvements in the care and support of fathers after the death of a child. **Full text:** <http://bit.ly/3b7T71M>
- *PLOS ONE* | Online – 4 March 2021 – ‘**It’s like being in a war with an invisible enemy’: A document analysis of bereavement due to COVID-19 in U.K. newspapers.**’ This study of online newspapers in the public domain has implications for how health-related and death-related news is communicated and how the media response to deaths could be improved in this and future mass bereavement events. There appears to be a delicate balance required in using fear-based narratives that can help generate action and solidarity without increasing fear in a way that may exacerbate the situation or negatively affect bereaved people. As noted in relation to other “sensationalist” topics and suicide, the media have a role to play in nuanced reporting. **Full text:** <http://bit.ly/3qh2nhV>

Palliative care education and research at U.S. cancer centers: A national survey

CANCER | Online – 4 March 2021 – Palliative care (PC) education and research are essential to developing a skilled workforce and evidence base to support the delivery of quality cancer care. The current state of PC education and research at U.S. cancer centers is unclear. In this national survey, the education and research programs of the National Cancer Institute (NCI)-designated and non-designated cancer centers and the changes between 2009 and 2018 are compared. There were 52 of 61 (85%) NCI-designated and 27 of 38 (71%) non-designated cancer centers that responded. NCI-designated centers were more likely than non-designated centers to have a PC fellowship program, training for advanced practice providers, PC research program, peer-reviewed funding, and philanthropic grants. There were few significant improvements in PC education or research between 2009 and 2018 for both groups, notable exceptions include an increase in PC fellowships and mandatory PC rotations for medical oncology fellows at NCI-designated cancer centers. PC education and research are more developed at NCI-designated cancer centers. Despite some progress over the past decade, it is relatively slow and suboptimal. **Abstract:** <https://bit.ly/3c2ilro>

Effectiveness of a family-caregiver training program in home-based pediatric palliative care

CHILDREN | Online – 26 February 2021 – Caretakers of children with life-limiting conditions show high skills and knowledge in the tasks that are needed to develop their role. An educational program may strengthen these capabilities and improve levels of confidence. This study shows that the provided intervention had a particularly positive effect in caretakers' self-perception and confidence about the outstanding caring skills they already had. Although the number of out-of-hours telephone calls from the caregivers to the pediatric palliative care (PC) team after the intervention did not decrease, they were more focused on the description of symptoms. Psycho-educational space emerged in the authors' school for parents of children with complex healthcare needs in the setting of home-based PC that allowed them to share their experience of daily care for their children. **Full text:** <http://bit.ly/3bgfYSJ>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 4 March 2021 – **'Teaching empathic communication to pediatric interns: Immediate and 3-month impact.'** The authors evaluated pediatric intern self-reported preparedness to deliver serious news, express empathy, and medical error disclosure after a one-day simulation based-empathic communication training. They evaluated self-reported use of communication skills and describe the clinical scenarios in which the skills were used. A one-day simulation-based reflective teaching course for pediatric interns is an effective way to teach empathic communication skills. They feel more prepared to deliver serious news, respond with empathy and disclose a medical error. **Abstract (w. list of references):** <http://bit.ly/2Okc1TO>
- *CHILD* | Online – 22 February 2021 – **'Important aspects influencing delivery of serious news in pediatric oncology: A scoping review.'** Identified aspects of communication were categorized into six thematic groups: 1) Initial setting; 2) Physician's approach; 3) Information exchange; 4) Parental role; 5) Illness related aspects; and, 6) Age of the ill child. The importance of the aspects is perceived differently by parents, patients, siblings and physicians. This scoping review highlights that delivering serious news requires an individualized approach towards the patient and the family. Ten key objectives built upon the results of the literature review offer guidance for daily clinical practice in communication with pediatric patients and their families. **Full text:** <http://bit.ly/3c5Ck8C>
- *JOURNAL OF PEDIATRIC NURSING* | Online – 26 February 2021 – **'Spiritual needs of Brazilian children and adolescents with chronic illnesses: A thematic analysis.'** Meeting spiritual needs is essential for finding meaning, purpose and hope in the experience of living with chronic illnesses and at the end of life (EoL), based on their faith, beliefs and interpersonal relationships. Two themes emerged in this study. The first, entitled 'Spiritual needs,' encompasses five types of needs: 1) Need to integrate meaning and purpose in life; 2) Need to sustain hope; 3) Need for expression of faith and to follow religious practices; 4) Need for comfort at the EoL; and, 5) Need to connect with family and friends. The second theme was the "definition of spiritual care." **Abstract (w. list of references):** <https://bit.ly/304L6hn>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 1 March 2021 – **'End-of-life communication among caregivers of children with cancer: A qualitative approach to understanding support desired by families.'** Bereaved caregivers were recruited through a closed social media group to complete an online survey providing retrospective reports of end of life (EoL) communication with their child and preferences for communication support from healthcare providers. Most respondents spoke with their child about their prognosis and death. Half of children asked about death, particularly older children. Asking about dying was related to having conversations about prognosis and death. Most caregivers wanted support to talk to their children. **Abstract:** <http://bit.ly/3dYEklw>



Abstract Watch: Hospice and palliative care workforce, research priorities, and spirituality

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Online – 3 March 2021 – This contribution to the Association's blog focuses on three distinct aspects of end-of-life care: the hospice and palliative care workforce, research priorities, and spirituality with summaries of selected journal articles noted in Media Watch during the past year. <http://bit.ly/3uRqXJJ>

“It is not a scientific number it is just a feeling”: Populating a multi-dimensional end-of-life decision framework using deliberative methods

HEALTH ECONOMICS | Online – 1 March 2021 – The capability approach is potentially valuable for economic evaluation at the end of life (EoL) because of its conceptualization of wellbeing as freedom and the potential for capturing outcomes for those at EoL and those close to persons at the EoL. For decision making, however, this information needs to be integrated into current evaluation paradigms. This research explored weights for an integrated economic evaluation framework using a deliberative approach. Twelve focus groups were held (38 members of the public, 29 “policymakers,” seven hospice volunteers); budget pie tasks were completed to generate weights. Constant comparison was used to analyze qualitative data, exploring principles behind individuals’ weightings. Average weights elicited from members of the general population and policymakers for the importance that should be given to close persons (vs. patients) were very similar, at around 30%. A “sliding scale” of weights between health gain and the capability for a good death resulted from the policymaker and volunteer groups, with increasing weight given to the capability for a good death as the trajectory got closer to death. These weights can be used in developing a more comprehensive framework for economic evaluation at EoL. **Full text:** <https://bit.ly/3sW1UDC>

Comparison of palliative care delivery in the last year of life between adults with terminal non-cancer illness or cancer

JAMA NETWORK OPEN | Online – 4 March 2021 – This cohort study of 145,709 adults [who died between January 2010 and December 2017 in Ontario, Canada] ... found important differences in the delivery of palliative care (PC) across different types of serious illness for patients with cancer compared with those with chronic organ failure or dementia. In general, patients dying of cancer were younger, had a lower burden of medical comorbidity, and had lower prior healthcare use compared with patients dying of terminal non-cancer illness. PC was also initiated earlier and in the hospital or clinic setting for patients with cancer. For patients with cancer, PC was more often delivered by PC specialists across multiple locations. More patients with cancer also received PC from both general practitioners and physicians with subspecialty training compared with patients with chronic organ failure and dementia. These findings identify patient-level disparities in access to PC, which may be associated with the presence of established PC programs in cancer centers to provide multidimensional care for patients with cancer. These findings also suggest practitioner-level deficiencies in PC for patients with terminal non-cancer illness that may be associated with differences in specialist self-rated knowledge of end-of-life care or recognition of their patient’s palliative needs and subsequent referral during their illness. **Full text:** <http://bit.ly/2NXvpGy>

Palliative care practices in a rural community: Cultural context and the role of community health worker

JOURNAL OF HEALTH CARE FOR THE POOR & UNDERSERVED, 2021;32(1):550-564. In many communities in South Africa, no palliative care (PC) services exist. One strategy for increasing access to PC services is to integrate community health workers (CHWS) into PC practice. The purpose of the study was to describe the PC practices of CHWS. A qualitative, explorative descriptive design guided the study. Thirty-four people participated. Mean age of the participants was 53.7 years old, 98% were female, and 100% were affiliated with non-governmental organizations. The mean numbers of years in practice was 10.2 and 36.5 for the CHWS and professional nurses, respectively. After analysis of the data three major themes emerged: 1) The influence of the Vha-venda cultural context; 2) Home-based PC practices, and the lack of PC resources & supplies. Despite a lack of resources, CHWS play an important role in PC by providing physical comfort, providing spiritual comfort, educating patient-family, and supporting medication management. **First page view:** <http://bit.ly/3c9CTOR>

N.B. The Venda (Vha-venda or Vhangona) are a Southern African Bantu people living mostly near the South African-Zimbabwean border.

Drug information needs of healthcare professionals in palliative care: A retrospective evaluation of a palliative care drug information service

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 27 February 2021 – Drug therapy is an integral part of palliative care (PC), but pharmacotherapy can be challenging for healthcare professionals. Access to information is essential for healthcare providers to choose the best drug treatment for an individual patient. A drug information service can support healthcare professionals to obtain appropriate, unbiased information. During the study period, 477 enquiries reached the drug information service, mostly from physicians (59%), followed by pharmacists (31%). Ketamin was the most discussed drug (11%)... Application techniques (26%) was the most relevant category... The information needs on PC pharmacotherapy seem to be particularly high among physicians. The demand for information in the area of application technology is particularly apparent and demonstrates a therapeutic gap in terms of availability of suitable preparations as well as necessary information. **Abstract (w. list of references):** <http://bit.ly/300BBjb>

What are the emotional experiences of being a volunteer in palliative and end-of-life care settings? A systematic review and thematic synthesis

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 26 February 2021 –Previous research has focused on the risks of stress, burnout and the impact on general emotional well-being in paid palliative care (PC) staff, however volunteers in patient-facing roles are exposed to similar stressors. Volunteers increasingly provide emotional support to patients and families but receive little formal support for themselves. It is important to understand volunteers' emotional experiences of their role to identify strategies that could be implemented to support them effectively. From the 22 included studies, four themes were developed: 1) Intrinsic challenges (e.g., conflicting feelings); 2) Extrinsic challenges (e.g., resources and expectations); 3) Personal gain (e.g., learning and self-growth); and, 4) Developing relationships (e.g., appropriate boundaries). Challenges included personal feelings related to their role for example uncertainty, not being "good enough" and feeling drained as well as frustrations within the PC system. Volunteers face unique challenges but also positive impacts that can affect their emotional well-being. It is important to monitor how volunteers are coping and provide appropriate support. **Abstract (w. list of references):** <https://bit.ly/301NJk4>

Mindfulness-based compassion training for health professionals providing end-of-life care: Impact, feasibility, and acceptability

JOURNAL OF PALLIATIVE MEDICINE | Online – 5 March 2021 – Health professionals who care for patients and their families at the end of life may experience gratitude, and enhanced spirituality and meaning in life, yet they are also at increased risk of psychological distress, compassion fatigue, and occupational burnout given the stressors they encounter in their work. Participants in this study reported that the sessions were useful, relevant, easy to understand, and that they gave them sufficient knowledge to implement the strategies learned. Levels of anxiety, compassion fatigue (burnout only), and emotional exhaustion decreased over time with some decay in effects at follow up, and levels of compassion satisfaction and self-compassion increased with time. **Abstract:** <https://bit.ly/3rm7EWU>

Dignity therapy for end-of-life care patients: A literature review

JOURNAL OF PATIENT EXPERIENCE | Online – 25 February 2021 – Dignity therapy as an intervention has been used for individuals receiving palliative care (PC). The goal of this review is to explore the current state of empirical support to its use for end-of-life care patients. Results revealed the feasibility, acceptability, satisfaction, and effectiveness of dignity therapy for life-limiting cases/conditions of patients in different age groups. It also highlighted the importance of the therapy setting and the need to apply this in the cultural context. The meaning of dignity therapy to patients and their family care members also emerged. Findings showed most patients displayed the need to leave a legacy and from this their core values surfaced. This review highlights the contribution of dignity therapy to the holistic care of patients who hope to leave a legacy. The therapy was also relevant to decrease the anxiety; depression, and burden of family members throughout the PC period of their loved ones. **Full text:** <http://bit.ly/3b9Tin4>

Muslim perspectives on advance care planning: A model for community engagement

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 27 February 2021 – The authors aimed to organize a community-based event on advance care planning (ACP) to better understand the Islamic views on ACP and end-of-life care and to encourage dialogue between healthcare professionals and the Islamic community. There have been several initiatives on engaging and educating the public on ACP. The British Columbia Center for Palliative Care (BCCPC) conducted a project using peer-facilitated group activities to improve public engagement in ACP. Rather than using health professionals, this study investigated the role of the public in providing support and education as peers. They concluded that peer-facilitated workshops on ACP were effective in increasing participants' knowledge of ACP and encouraging them to participate in ACP activities. Other studies have also explored using community volunteers as a method to introduce ACP. Projects examining specific religious and cultural groups' views on ACP have also been conducted. For example, the BCCPC is currently exploring promoting ACP in the South Asian community. Trained volunteers will conduct educational ACP sessions in Punjabi and address cultural and societal issues related to ACP. Other groups have also explored views on ACP within the South Asian and other major religious communities. **Full text:** <http://bit.ly/2MwO6Qu>

What defines the comprehensive assessment of needs in palliative care? An integrative systematic review

PALLIATIVE MEDICINE | Online – 1 March 2021 – The comprehensive assessment of needs in palliative care (PC) identifies where patients most want attention to guide clinical decisions that tailor care provision from their first encounters. Forty-nine articles met the authors' inclusion criteria for original articles in English or Spanish reporting comprehensive assessment of needs of adult patients receiving PC. The majority (41/49) of studies were moderate to high quality. Two themes were identified: 1) How a comprehensive assessment of needs should be carried out in PC, which reflected a preference to develop structured tools for assessment; and, 2) What needs of patients should be assessed in the comprehensive assessment of needs in PC, which conveyed a trend to assess beyond core domains – physical, psychological, social, spiritual – with information and practical most prevalent, but with substantial variation in specifying and classifying needs into domains. The assessment of needs in PC is comprehensive but lacks consensus on the needs and domains that should be assessed by the PC team. Future studies should better define what needs can be standardized into the assessment to improve process of care and patient satisfaction. **Abstract (w. list of references):** <http://bit.ly/2Of2bm6>



The impact of COVID-19 on palliative care workers across the world: A qualitative analysis of responses to open-ended questions

PALLIATIVE & SUPPORTIVE CARE | Online – 2 March 2021 – The pandemic has had a huge impact on palliative care (PC) workers' ability to deliver services, their financial status, and their workloads. It has made them particularly vulnerable to infection, resulting in distress and burnout and affecting their emotional wellbeing. Counseling and networks are important resilience building buffers. Coping strategies such as team and family support strengthen workers' capacity to adapt and respond. Since traditional models of PC delivery do not apply during the pandemic, priorities have to shift, and tasks have to be reallocated in order for systems to continue functioning. Providers are being forced to reconsider and redefine PC delivery models when physical contact and in-person communication with patients and family members is limited or non-existent. Adaptation, creativity, and flexibility and the use of inexpensive technologies such as telehealth, have become increasingly important. The experiences shared by participants may be transferable to others facing similar challenges. Government officials, academia, providers, and affected populations should work together to develop and implement steps to ensure the integration of PC into pandemic response and preparedness plans so as not to leave anyone behind, including health workers. Enhancing the resilience, capacity, and ability to adapt as well as implementing measures that could protect the most vulnerable and prevent suffering are paramount. **First page view:** <http://bit.ly/3bfNPLo>



An ethical conundrum: Palliative care in the COVID-19 pandemic

PALLIATIVE & SUPPORTIVE CARE | Online – 1 March 2021 – The medical uncertainties and ethical complexities in the current COVID-19 pandemic added substantial responsibilities on frontline healthcare professionals (HCPs) in making decisions regarding clinical rationing. However, there has not been much discussions addressing the psychological intricacies for HCPs in making decisions with respect to the allocation and withdrawal of intensive care resources; furthermore, who should be accountable for making such intricate decisions and what are the safeguards? The purpose of recommendations issued by various agencies, e.g., the Italian College of Anaesthesia, Analgesia, Resuscitation & Intensive Care (SIAARTI), the World Health Organization, the Pan American Health Organisation and the Centers for Disease Control & Prevention (CDC), is to facilitate and support decision-making for HCPs. However, it is challenging to ensure all institutions across the globe would adopt the same ethical principle when confronted with resource scarcity under the exceptional circumstances of the COVID-19 pandemic. With respect to safeguarding, for patients who do not meet the criteria for life-sustaining treatments, palliative care (PC) is recommended by the SIAARTI as well as the CDC as a priority to maximize comfort. However, resources for PC services are known to be inadequate, and the outbreak of COVID-19 has further amplified resource scarcity in PC. This circumstance raises ethical concern over the appropriateness of the utilitarian ethical perspective in maximizing collective welfare in the pandemic, when there is already a known gap of care provision of the alternative care option for those excluded from receiving life-sustaining treatments. How then can the decision for PC as an alternative be ethically justified? **Full text:** <http://bit.ly/3q6Mw5J>

Noted in Media Watch 15 June 2020 (#670, p.4):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 9 June 2020 – ‘**Integration of palliative care into COVID-19 pandemic planning.**’ The COVID-19 pandemic is expected to surpass the healthcare system’s capacity to provide intensive care to all patients who deteriorate as a result of the disease. The authors describe some of the important palliative care (PC) considerations that need to be incorporated into COVID-19 pandemic planning. The main aspects to be considered include decision algorithms for rationing care, training on effective symptoms management, alternative delivery methods of PC services such as telemedicine and finally death and bereavement support for surviving family members who are likely to be isolated from their loved one at the moment of death. **Full text:** <https://bit.ly/2YsIIlRp>

Noted in Media Watch 30 March 2020 (#659, p.11):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 March 2020 – ‘**What should palliative care’s response be to the COVID-19 epidemic?**’ Widespread transmission of COVID-19 in the U.S. could translate into large numbers of people needing medical care at the same time. This will push many health systems to the point of rationing limited resources such as ICU beds and life-sustaining machinery, as has occurred in Italy. Patients and their families at the peak of the pandemic will face symptoms, emotional distress, and decision-making in the face of uncertainty and limited options. No one is more prepared to handle these needs than providers on palliative care (PC) consult teams. However, PC consult teams are themselves a limited resource. **Full text:** <https://bit.ly/2xtZkxh>

A national collaborative to spread and scale paramedics providing palliative care in Canada: Breaking down silos is essential to success

PROGRESS IN PALLIATIVE CARE | Online – 4 March 2021 – A national collaborative has been launched in Canada to spread and scale up the Paramedics Providing Palliative Care model. This builds on the knowledge that paramedics in the 9-1-1 (emergency/unscheduled) and scheduled models of care are both historically and currently asked by the public to provide urgent symptom relief within the context of a palliative approach, and that approximately 40% of dying people visit the emergency department in the last two weeks of life despite 70% wishing to die at home. A model of care including a palliative care (PC) clinical practice guideline or protocol, specific training, and a mechanism for sharing of goals of care, has been proven to improve the palliative and end-of-life experience for patients with PC needs and their families. It increases the comfort and confidence of paramedics and has benefits to the broader health system. Meaningful and very broad stakeholder engagement and intersectoral collaboration is absolutely essential to the success of this innovative approach to care. **Abstract:** <https://bit.ly/3uVk8XB>

Understanding the needs of Australian carers of adults receiving palliative care in the home: A systematic review of the literature

SAGE OPEN NURSING | Online – 24 February 2021 – This systematic review highlights the gap in the literature examining Australian original research published between 2008 and 2020 on the topic of understanding the needs of carers of adults receiving palliative care (PC) in the home in Australia. It highlights that multiple support systems are needed to support the carer to enable them to undertake their role. Carers need to be supported both physically and emotionally, including timely respite, practical assistance, education and bereavement care. Many carers who used formal palliative support services were very satisfied with the care provided to both themselves and the patient, but social stigma around the meaning of PC, cultural barriers or geographical issues were some reasons for poor uptake of support services. An early understanding of the disease trajectory and what to expect on the caring journey would assist the carers to prepare ahead, both physically and emotionally. Open and clear communication between all parties would enable carers to feel validated, empowered and an important part of the team, thus enabling them to continue their role of providing PC in the home which would in turn, reduce the burden on the health system.

Full text: <http://bit.ly/3sBbgEA>

Related:

- *AUSTRALIAN HEALTH REVIEW*, 2021;45(1):117-123. '**Inequalities in end-of-life palliative care by country of birth in New South Wales, Australia: A cohort study.**' This retrospective cohort study of 73,469 patients investigated variation in in-hospital palliative care (PC) according to the decedent's country of birth. There are differences in in-hospital PC at the end of life between population groups born in different countries living in Australia. The implementation of culturally sensitive PC programs may help reduce these inequalities. Further studies are needed to identify the determinants of the differences observed in this study and to investigate whether these differences persist in the community setting. **Abstract (w. list of references):** <http://bit.ly/3rastoj>

Research Matters

Measuring goal-concordant care in palliative care research

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 2 March 2021 – Goal-concordant care is a priority outcome for palliative care (PC) research, yet the field lacks consensus on optimal methods for measurement. The authors sought to: 1) Categorize methods used to measure goal-concordant care; and, 2) Discuss strengths and limitations of each method using empirical examples from PC research. They categorized measurement methods for goal-concordant care, and identified empirical examples of each method to illustrate the strengths, limitations, and applicability of each method to relevant study designs. The authors defined four methods used to measure goal-concordant care: 1) Patient- or caregiver-reported; 2) Caregiver-reported after death; 3) Concordance in longitudinal data; and, 4) Population-level indicators. Patient or caregiver-reported goal-concordant care draws on strengths of patient-reported outcomes, and can be captured for multiple aspects of treatment; these methods are subject to recall bias or family-proxy bias. Concordance in longitudinal data is optimal when a treatment preference can be specifically and temporally linked to actual treatment; the method is limited to common life-sustaining treatment choices and validity may be affected by temporal variation between preference and treatment. Population-level indicators allow pragmatic research to include large populations; its primary limitation is the assumption that preferences held by a majority of persons should correspond to patterns of actual treatment in similar populations. Methods used to measure goal-concordant care have distinct strengths and limitations, and methods should be selected based on research question and study design. Existing methods could be improved, yet a future gold standard is unlikely to suit all research designs. **Abstract (w. list of references):** <https://bit.ly/3bWwkyS>

Survey will provide national-level information to help researchers identify important issues and better understand what it means to provide quality care in the home setting

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION (NHPCO) | Online – 2 March 2021 – The nation's hospice community is changing at an unprecedented rate. Last year the field faced its biggest challenge – COVID-19. This combined with patient access and staffing shortages are forcing provider organizations to redefine themselves. To do this, national-level research is needed that will guide programmatic efforts and help define what it means to provide healthcare in the home. A unique feature of the survey is the collaboration between national associations. Co-sponsors joining NHPCO include National Association of Home Care and Hospice (NAHC), NAHC Forum of State Associations, LeadingAge, Home Care Association of America, and Council of State Home Care & Hospice Associations. The 2021 National Healthcare at Home Best Practices & Future Insights Study will help identify best practices that agencies can implement to position themselves for future success. The results promise to be the largest and most comprehensive ever released on the delivery of home health and hospice in the U.S. <http://bit.ly/3bcX27n>

Noted in Media Watch 16 November 2020 (#692, p.5):

- *JOURNAL OF AGING RESEARCH* | Online – 5 November 2020 – ‘**Gaps in hospice and palliative care research: A scoping review of the North American literature.**’ Despite the importance of the topic and an increase in hospice and palliative care utilization, there still are gaps in research and evidence within the field. Major themes were identified: 1) Clinical; 2) System access to care; 3) Research methodology; and, 4) Caregiving related research gaps. Findings include strategies for engaging stakeholder organizations and funding agencies, implications for other stakeholder groups such as clinicians and researchers, and highlight implications for policy (e.g., national framework discussion) and practice (e.g., healthcare provider education and training and public awareness). **Full text:** <https://bit.ly/2InDL7a>

Applying evidence-based symptomatic treatments from other clinical disciplines to palliative care

PALLIATIVE MEDICINE | Online – 27 February 2021 – In evidence-based practice, application of knowledge to clinical decisions relies on the researchers' ability to target a defined and reproducible population representative of broader populations or clinical care settings to optimise generalisability, and the clinicians' ability to determine sufficient similarities between the population studied and the individual patient to optimise applicability. Formal frameworks have been proposed to maximise the researchers' ability to describe the palliative care (PC) populations in their studies so clinicians can make more informed decisions when applying the findings to their practice. There is a need for similar formal methods to maximise the clinicians' ability to make informed decisions about the applicability of interventions where the evidence has been developed in disciplines other than PC. Applicability is applying research findings to a patient, ultimately asking “will this person react in a similar way to the intervention for a similar net clinical effect (benefits and harms)?” Applicability of findings across disciplines (or “clinical transferability”) relies on evaluating the therapeutic intervention in the context of the population and setting in which the intervention was studied. Assessing applicability requires clinicians to have critical appraisals skills to interpret the relevance of each study's findings for the patients they serve, and incorporate relevant findings into their own practice. **Full text:** <http://bit.ly/3b1IRBZ>

End-of-life childhood cancer research: A systematic review

PEDIATRICS | Online – 1 March 2021 – The authors selected 24 articles published in English that examined perceptions or experiences of research participation for children with cancer at the end of life (EoL) from the perspectives of children, parents, and health professionals (HPs). Eight themes were identified: 1) Seeking control; 2) Faith, hope, and uncertainty; 3) Being a good parent; 4) Helping others; 5) Barriers and facilitators; 6) Information and understanding; 7) The role of HPs in consent and beyond; and, 8) Involvement of the child in decision-making. Some families participate in EoL research seeking to gain control and sustain hope, despite uncertainty. Other families choose against research, prioritizing quality of life. Parents may perceive research participation as the role of a “good parent” and hope to help others. HPs have positive views of EoL research, but fear that parents lack understanding of the purpose of studies and the likelihood of benefit. The authors identify barriers to research participation and informed consent. **Abstract:** <http://bit.ly/3b8uaNm>

Research and social media: A dangerous cocktail or a winged messenger?

SCIENCENORDIC | Online – 1 March 2021 – Research is usually considered trustworthy. Many would probably argue that research published in scientific papers is as close as we can get to truthful knowledge about the world. We usually do not consider “fake news” to be a problem to the scientific community. In research, findings about the world are primarily reported through scientific papers which undergo peer-review processes to ensure trustworthiness and credibility of said findings. While scientific publishing is a rather slow process, social media platforms operate with blazing speed in comparison. And while both arenas can be used to disseminate knowledge, different rules apply to each. As scientific papers are increasingly also being disseminated through social media platforms, the distribution and reach of research is to some extent put in the hands of tech giants and social media algorithms. The implications of this mix of science and social media is the subject of discussion in this article. **Full text:** <http://bit.ly/3q8gar9>

Media Watch: Editorial Practice

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Distribution

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Something Missed or Overlooked?

IF YOU ARE AWARE OF A CURRENT REPORT, ARTICLE, ETC., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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