

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

Notwithstanding the increasing evidence from the literature, end-of-life care is ignored in discussions of healthcare reform, resulting in the vast majority of patients at the end of life not receiving high-quality care at their homes, hospitals, or long-term care facilities.

'How have case mix, cost and hospital stay of inpatients in the last year of life changed over the past decade? Evidence from Italy' (p.6), in *Health Policy*.

Canada

“You need not be alone anymore”: The doctor redefining palliative care

ONTARIO | *Healthy Debate* – 16 June 2021 – Last April, in a long-term care (LTC) home in Toronto devastated by a COVID-19 outbreak, 12 people had died and 89 residents had become infected in just over two weeks. So had 47 staff. Since so many staff were sick and quarantining, it was as if those remaining were “drowning,” says Russell Goldman, director of the Temmy Latner Centre for Palliative Care at Mount Sinai Hospital. “All the staff available were stretching themselves as far as they could,” recalls Ramona Mahtani, leader of inpatient palliative care (PC) at Mount Sinai. “But it just wasn’t enough.” Mahtani and Goldman were two of the physician leaders who helped manage the outbreak after Mount Sinai Hospital partnered with the LTC home on 15 April. The following day, they helped arrange the evacuation of 15 residents to the hospital’s emergency department (ED), where physicians and nurses could provide “the kind of intensive comfort care that these people needed,” says Don Melady, the leader of geriatric ED at Mount Sinai Hospital, who was working in the ED when residents arrived. While the physicians and nurses tended to the patients, the PC team helped out – even though the residents did not require end-of-life PC, Mahtani says. Instead, the PC physicians did

whatever their colleagues in the ED needed, such as assisting with alleviating symptoms and speaking with residents’ families. The PC physicians were no longer on-call consultants or experts brought in only when it became clear that a patient was forgoing curative or life-prolonging medical treatment. They became a fixture of the ED. There was a longstanding view that PC should be more integrated into the ED ... but, it took the chaos of COVID-19 to disrupt the institutional inertia that kept them apart. This “model might be a paradigm shift for how we deliver PC,” says Darren Cargill, a clinical co-lead for the Ontario Palliative Care Network. Mahtani and others, like a group of PC physicians in New York,¹ have finally “been able to create a model of integrated PC.” <https://bit.ly/3qfTEOV>

Specialist Publications

‘What should be measured to assess the quality of community-based palliative care? Results from a collaborative expert workshop’ (p.9), in *Palliative & Supportive Care*.

Cont.

1. 'A beacon for dark times: Palliative care support during the coronavirus pandemic,' *NEJM Catalyst*, published online 12 May 2020. [Noted in Media Watch 8 June 2020 (#669, p.12)] **Full text:** <https://bit.ly/2MtFBSC>

U.S.A.

“Death doulas” provide aid at the end of life

THE NEW YORK TIMES | Online – 24 June 2021 – The word “doula” comes from the Greek word meaning “woman who serves,” though most people associate it with someone who helps during birth to usher in life. In recent years, however, more people have come to recognize the need for as much assistance at the end of life as the start, part of the so-called death positivity movement that is gaining momentum in the U.S... The movement ... encourages open discussion on death and dying and people’s feelings on mortality. Unlike hospice workers, doulas don’t get involved in medical issues. Rather, they support clients emotionally, physically, spiritually and practically, stepping in whenever needed. That could be a few days before someone dies, sitting vigil

with them in their last hours, giving hand massages, making snacks. Or it could be months or even years earlier, after someone receives a terminal diagnosis, keeping them company, listening to their life stories or helping them craft autobiographies, planning funerals. Prices range from \$25 an hour on up, although many ... do it voluntarily <https://nyti.ms/3vQmE0z>

Specialist Publications

‘Specialty palliative care in COVID-19: Early experiences from the Palliative Care Quality Collaborative’ (p.8), in *Journal of Palliative Medicine*.

Related:

- *SCIENTIFIC AMERICAN* | Online – 19 June 2021 – ‘**How end-of-life doulas help ease the final transition.**’ Birth and death are the bookends of life, yet we welcome one and dread the other. Why is it that birth is celebrated, but death is taboo? End-of-life doulas work with those with serious illnesses who are facing death – and also for those who are healthy and just want to prepare for death. Doulas can advise on advance care directives, vigil planning and post-death options, and assist with life review and legacy. On more emotional matters, doulas can facilitate conversations about unresolved issues or complex family dynamics and offer space for the fears and uncertainties around death and dying. When we are prepared for death, we are better able to face it when the time comes. <https://bit.ly/2UCUIGI>

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/2Isp6bb>

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

Most hospital patients are dying “without suitable care”

AUSTRALIA | Australian National University – 24 June 2021 – A new national study shows most patients in Australia are not getting suitable end-of-life care (EoLC).¹ The paper, which looked at nine hospitals across Australia and tracked 1,693 dying patients, showed only 41% of dying patients will ever see a member of the palliative care team. The findings show a majority of patients were recognised as dying only late in their hospital stay and only 12% had an advanced care plan, which outlines patients' wishes for when they die. “At least 60% of people who die in Australia will die in a hospital setting and are at risk of not receiving appropriate EoLC,” said lead author Professor Imogen Mitchell from The Australian National University. The researchers found a

complex range of factors contribute to suboptimal EoLC, including failure to identify patients in their last months of life, substandard communication with patients and families, and failure to link medical teams. <https://bit.ly/3gRL9GL>

Specialist Publications

‘Does a hospital palliative care team have the potential to reduce the cost of a terminal hospitalization? A retrospective case-control study in a Czech tertiary university hospital’ (p.7), in *BMC Health Services Research*.

1. ‘Understanding end-of-life care in Australian hospitals,’ *Australian Health Review*, published online 2 June 2021. **Abstract (w. references):** <https://bit.ly/3gSk71W>

A bleak funding landscape could push lifeline children’s hospices to their limits

U.K. | Together for Short Lives – 22 June 2021 – Children’s hospices deliver lifeline care to the U.K.’s most vulnerable and seriously ill children and families. Caring for a seriously ill child 24/7 at home can be exhausting, lonely and isolating, and after a year of shielding from the pandemic families need the support of their hospice more than ever. Together for Short Lives has published new findings of a children’s hospice funding survey which reveals the impact of the pandemic on hospice funding and predictions for their income 2021-2022. Last year children’s hospice fundraising was hit hard by the pandemic, especially income from charity shops, community and events fundraising, and public donations. In 2020-2021 the survey found: 1) On average hospice income from charity shops and trading activities fell by over half (57%); 2) Average income from fundraising challenge events fell by over half (58%); and, 3) Income from community fundraising fell by a third (33%) and individual donations fell by 8%. Although children’s hospices received much-needed government pandemic emergency funding last year, that funding has ceased. And while the U.K. economic outlook is more positive, children’s hospices predict that fundraising will not reach pre-pandemic levels in the coming year. Children’s hospice sector faces a perfect storm. The number of seriously ill children is rising, and so is demand for hospice care, which means children’s hospices need to raise more money to provide essential care. <https://bit.ly/3xJqoSV>

N.B. Link to Together for Short Lives’ ‘Pushed to the Limits: The Impact of COVID-19 Children’s Hospice Funding, 2019/20, 2021/22’ embedded in the report above.

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>



Inequality and discrimination, even in death

U.K. | *Politics* – 21 June 2021 – When it comes to quality of death, the U.K. compares favourably with other parts of the world. It came top of 40 countries in a “quality of death” index that looks at the provision of palliative care and how it is implemented nationally.¹ So it is concerning that one in four people in the U.K. today are not able to access the palliative and end-of-life (EoL) services and support they need. Many of those missing out on basic standards of care are often people who’ve already experienced unfairness and discrimination throughout their lives, especially people from racialised and lesbian, gay, bisexual and transgender communities, and those experiencing socio-economic inequalities. A deep-rooted stigma associated with reaching out for help, language barriers and a limited understanding of support that is available are some of the main barriers to care for some parts of racialised communities. And for those experiencing homelessness, who often fall victim to discrimination, disrespect and disempowerment, their want to engage can be particularly low, altering their ability to access services. It’s certainly encouraging that inequality in accessing EoL care has been acknowledged by the Department of Health & Social Care in England since 2004, followed by the 2008 End-of-Life Care Strategy, which aimed to help all people “irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status” to access the right care. <https://bit.ly/3iWKFjM>

1. ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ The Economist Intelligence Unit (commissioned by the Lien Foundation of Singapore), October 2015. [Noted in Media Watch 12 October 2015 (#431, p.6)] **Download/view at:** <http://bit.ly/30YoDkI>

Specialist Publications

“We are taking every precaution to do our part...”: A comparative analysis of nursing, palliative and hospice care facilities’ websites during the COVID-19 pandemic

BMC HEALTH SERVICES RESEARCH | Online – 16 June 2021 – The findings of this study show that the agendas of health facilities have been seriously affected by the COVID-19 pandemic. Even if the agendas of different health facilities show similarities in the context of the pandemic, it is clear that facilities have been affected by the pandemic to different degrees, depending on the type of services they provide. This study demonstrates that the restrictions in person-to-person contact in health services has been dominant in the agendas, as circumstances have directly led to changes in visiting regulations. It further reveals that facilities sought to clearly convey that they acted in accordance with the authorities in the steps they undertook and that there is a link between the desire for social solidarity and the facilities’ demonstration of transparency to build trust among the public. The intense sharing of COVID-19-related information through websites connotes that web-based communication is considered by healthcare providers as an essential communication tool in times of public health crises. **Full text:** <https://bit.ly/3cRGH8b>

Research Matters

‘State of the science and future research directions in palliative and end-of-life care in paediatric cardiology: A report from the Harvard Radcliffe Accelerator Workshop’ (p.11), in *Cardiology in the Young*.

‘Transitioning to remote recruitment and intervention: A tale of two palliative care research studies enrolling underserved populations during COVID-19’ (p.12), in *Journal of Pain & Symptom Management*.

Publishing Matters

‘Global scientific outputs of palliative care publications: A holistic approach with bibliometric analysis’ (p.13), in *Acta Medica*.

‘Should I include studies from “predatory” journals in a systematic review? Interim guidance for systematic reviewers’ (p.13), in *JBI Evidence Synthesis*.



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Compassion fatigue and compassion satisfaction among palliative care health providers: A scoping review

BMC PALLIATIVE CARE | Online – 23 June 2021 – This review sought to identify current evidence about compassion fatigue and compassion satisfaction among palliative care (PC) health providers (PCHP). Most of the studies investigating the impacts of compassion fatigue and compassion satisfaction on PCHP were descriptive in nature. This indicates a gap in the literature that needs more investigation. Only one study identified an effective intervention to reduce compassion fatigue in PCHP. Most of the reviewed studies were correlational or exploratory in nature which affects the quality and strength of the retrieved evidence. One important aspect to be considered is the impact of compassion fatigue and compassion satisfaction on the productivity of PCHP and their ability to provide safe and compassionate care. This is an important topic especially among PC nurses since they are the largest group of PCHP and they spend a long time caring for people with life-threatening conditions and related trauma. **Full text:** <https://bit.ly/3wU5pNr>

Video hospice consultation in COVID-19: Professional and patient evaluations

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 23 June 2021 – Using video consultations (VC) during the COVID-19 pandemic facilitated the continuation of holistic support such as virtual well-being sessions, alongside remote clinical care. The authors' service evaluation illustrates that hospice support, even when involving potentially sensitive conversations, can still be provided remotely using video-conferencing technology and this is acceptable to patients and carers and consistent with recent studies. Although most health professionals (HPs) had not supported patients using video-conferencing technology prior to the COVID-19 pandemic nor had any formal training, and despite many having concerns about providing VC, the majority were successfully able to offer a range of hospice services to patients/carers including some of a sensitive nature. It was noted by HPs and patients that there were many situations, including existing medical conditions, which may present barriers or cause a patient to decline a VC. HPs therefore need to carefully consider individual patients' circumstances to optimise the use of VC. Despite HPs reporting that some patients had declined VC, most patients/carers having experienced a VC stated they would be happy to participate using VC again when appropriate. Unsurprisingly however, many stated that, given the choice, they would always prefer face-to-face consultations. **Full text:** <https://bit.ly/3gQdq03>

Related:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 23 June 2021 – '**Telehealth: Rapid adoption in community palliative care due to COVID-19 – patient and professional evaluation.**' Seventy-four patients and 22 healthcare professionals returned surveys. Both groups felt comfortable using telehealth, however, also encountered a range of issues when undertaking telehealth consultations. Despite reporting issues, the preference of both groups was for a community palliative care (PC) service model which combined face-to-face and telehealth consultations. This study is one of the first to directly address this question and as such provides useful guidance for health services when planning future community PC service models. **Full text:** <https://bit.ly/3qpo3Ug>
- *PALLIATIVE MEDICINE* | Online – 25 June 2021 – '**Virtual models of care for people with palliative care needs living in their own home: A systematic meta-review and narrative synthesis.**' The authors' search yielded 2,266 articles, of which 12 systematic reviews met their criteria. Sixteen reviews were included in total, after four reviews were found via handsearching. Other than scheduled telehealth, video-conferencing, or after-hours telephone support, little evidence was found for digital health technologies used to deliver virtual models of palliative care. There are opportunities to test new models of virtual care, beyond telehealth and/or video conferencing, such as 24-hour command centres, and rapid response teams. **Abstract (w. references):** <https://bit.ly/3zWLZcG>
- *PALLIATIVE MEDICINE* | Online – 23 June 2021 – '**The impact of digital health interventions on the psychological outcomes of patients and families receiving paediatric palliative care: A systematic review and narrative synthesis.**' Whilst a broad range of digital health interventions are becoming widely used in paediatric palliative care, only three papers, all focusing on telehealth interventions, explore their psychosocial impact. A single paper ... was added to those previously identified in existing systematic reviews. Despite the positive psychosocial impact reported in two of the three studies, the findings are disparate due to the diverse nature of the interventions. This ... limits the conclusions we are able to draw about the psychosocial impact of digital health interventions... **Full text:** <https://bit.ly/3gPEHQu>

Clinical characteristics of the end-of-life phase in children with life-limiting diseases: Retrospective study from a single center for pediatric palliative care

CHILDREN | Online – 19 June 2021 – This retrospective analysis underlines that caring for terminally ill children in the home environment is possible and often desirable. Palliative care (PC) in the end-of-life (EoL) phase of children should not only focus on oncological patients; non-oncological life-limiting diseases seem to play an increasingly important role in PC. The most common distressing symptoms at the EoL differ depending on the underlying disease of the patient. Regardless of the underlying disease, main symptoms include pain, nausea/vomiting, constipation, shortness of breath, and fear, which can be adequately addressed even in a home-care-centered PC setting. **Full text:** <https://bit.ly/3vKY3KO>

Related:

- *PEDIATRICS* | Online – 21 June 2021 – ‘**The physical health of caregivers of children with life-limiting conditions: A systematic review.**’ The impact of this caregiving on parents’ physical health is unknown. Caregiver health was negatively impacted in 84% of the 81 studies reviewed. Pain and sleep disturbance were the most common problems. Ways of measuring the physical health of caregiver varied widely. The authors found an absence of in-depth explorations of the social and economic contexts, which could potentially mitigate the impact of caregiving. Furthermore, they find health interventions tailored to this group remain largely unexplored. These findings support the need for improving access to interventions aimed at improving physical health in this population. **Abstract:** <https://bit.ly/3xDW5gE>

Developing a death literacy index

DEATH STUDIES | Online – 21 June 2021 – Performing end-of-life care can be a catalyst for developing a capacity called death literacy. This study aimed to develop a comprehensive and useable measure of death literacy that has the potential to assess interventions with individuals, communities, and societies. Using a mixed methods approach, a Death Literacy Index was developed from personal narratives and input from practitioners and experts. Refined on a sample of 1,330 Australians using exploratory and confirmatory factor analysis and structural equation modeling, a 29-item Death Literacy Index was found to be reliable and demonstrated construct validity. Further studies are needed to test predictive validity. **Abstract:** <https://bit.ly/3vOsNu8>

How have case mix, cost and hospital stay of inpatients in the last year of life changed over the past decade? Evidence from Italy

HEALTH POLICY | Online – 16 June 2021 – Results of this study showed a decrease in the average patient cost and length of hospital stays during the last year of life in 2014 compared to 2005. These effects were statistically significant also after adjustment for potential confounding factors as well as age, sex, comorbidities, disease severity, main chronic condition and setting. In particular, the average cost of inpatients in the last year of life was €9,916 in 2014 (a decrease from €10,120 in 2005), and ranged from €4,856 for inpatient palliative care to €10,898 for more expensive acute patients. This study extends the evidence from the international literature, mainly for the Canadian context and documenting the use and costs of healthcare services in the last year of life in different hybrid settings (by mixing different healthcare services/settings). Compared to a 2004-2006 British Columbia study and a 2003-2004 Saskatchewan study,^{1,2} which provided estimated average expenditure in the last year of life ranging from \$20,705 to \$31,492 Canadian dollars (€13,816 to €21,020), the authors found a lower cost per deceased patient. However, a clear comparison with these estimates is not straightforward considering that the Canadian studies used different patient inclusion criteria or healthcare services; in fact, the first study examined hospital, ambulatory, and prescription drug costs, while the second included long-term care and home care. In addition, a 2010-2013 Ontario study estimated the last-year-of-life costs of all deceased patients for all healthcare services and found an average cost of inpatient care of \$30,872 (€20,573).³ The difference between this results and the findings of previous studies can be partially explained by the exclusion of cancer patients at end of life (EoL) in our study. In this context, other previous studies have analysed EoL healthcare costs

Cont.

by focusing on specific target patients in the U.S. population, for example, adults aged ≥ 65 years or selected disease-specific cohorts, such as cancer patients and patients with heart failure. Again, the different populations studied make a clear comparison with our estimates difficult. **Full text:** <https://bit.ly/3gRKWSG>

1. 'Income inequities in end-of-life health care spending in British Columbia, Canada: A cross-sectional analysis, 2004-2006,' *International Journal of Equity in Health*, published online 16 March 2011. [Noted in Media Watch 21 March 2011 (#193, p.10)] **Full text:** <https://bit.ly/3vTqxGg>
2. 'Costs of end-of-life care: Findings from the Province of Saskatchewan,' *Healthcare Quarterly*, 2009;12(3): 50-58. [Noted in Media Watch 20 July 2009 (#106, p.8)] **Full text:** <https://bit.ly/2SkNctm>
3. 'Palliative care delivery across health sectors: A population-level observational study,' *Palliative Medicine*, 16 June 2016. [Noted in Media Watch, 20 June 2016, #467 (p.15)] **Full text:** <http://goo.gl/JyPCE6>

Related:

- *BMC HEALTH SERVICES RESEARCH* | Online – 23 June 2021 – '**Does a hospital palliative care team have the potential to reduce the cost of a terminal hospitalization? A retrospective case-control study in a Czech tertiary university hospital.**' This study provides clear evidence that integration of the hospital palliative care (PC) team during the dying phase can save substantial healthcare costs. Daily costs are three times less expensive in patients supported by a PC team. The cost savings are mainly due to the prevention of transfer to the ICU; patients with palliative team support have significantly fewer days spent in the ICU and shorter terminal hospitalizations compared to their matched controls. Moreover, PC intervention makes the context of care clear. **Full text (click on pdf icon):** <https://bit.ly/2UEafQN>
- *BMC PALLIATIVE CARE* | Online – 23 June 2021 – '**Evidence on the economic value of end-of-life and palliative care interventions: A narrative review of reviews.**' Home-based palliative care (PC) may contribute to a dual improvement in quality of care by reducing aggressive medicalization end-of-life and concomitantly reducing costs. Hospital-based PC interventions may improve patient outcomes, healthcare utilization and costs. Evidence regarding other approaches is less conclusive. This study provides a foundation for discussions between policymakers and clinical services managers regarding resource allocation and the commissioning of PC services. There is a need for greater consistency in costs and outcome measures reporting, including breadth of capture... **Full text:** <https://bit.ly/3gQkQR2>

Family narratives about providing end-of-life care at home

JOURNAL OF FAMILY NURSING | Online – 4 June 2021 – Currently, the dying process in Spain is moving to the home environment where responsibility for care falls largely on the family, thereby challenging and testing the stability of the family. Previous research has focused on the impact of illness on the primary caregiver; therefore, a knowledge gap exists. This study aimed to understand families' unitary experiences of providing home care to terminally ill family member. Using the 'Model of Interpersonal Relationship Between the Nurse and the Person/Family Cared For,' narrative research included family and individual interviews with nine families (9 groups/23 individuals). Thematic narrative analysis was used to interpret the interviews. The results highlight the impact of illness on family well-being as a whole. Family members often felt abandoned while caring for an ill family member and wished to be cared for themselves. However, their immediate community and the nurses caring for their ill family member neglected them. A paradigm shift is required by society and in home care at the end of life to better support the family. **Abstract (w. references):** <https://bit.ly/3h2f6mk>

Related:

- *PALLIATIVE MEDICINE* | Online – 25 June 2021 – '**How can we ensure the success of specialised palliative home-care? A qualitative study identifying key issues from the perspective of patients, relatives and health professionals.**' Patients, relatives, members of specialised palliative home-care teams and collaborating health professionals described six issues that are important to the success of specialised palliative home-care: the treatment of complex symptoms, comprehensive care and a sense of security, as well as a focus on the quality of relationships, respect for individuality and the facilitation of self-determination. Policymakers and service providers should consider these issues when planning, delivering and evaluating specialised palliative home-care. **Full text:** <https://bit.ly/3xRnBqX>

What affects adoption of specialty palliative care in intensive care units: A qualitative study

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 25 June 2021 – Although many patients with critical illness may benefit from involvement of palliative care (PC) specialists, adoption of these services in the intensive care unit (ICU) is variable. The authors identified three types of specialty PC adoption in ICUs, representing different phases of buy-in. The “nascent” phase was characterized by the need for education about PC services and clarification of which patients may be appropriate for involvement. During the key “transitional” phase, use of specialists depended on development of “comfort and trust,” which centered on four aspects of the ICU-PC clinician relationship: 1) Increasing familiarity between clinicians; 2) Navigating shared responsibility with primary clinicians; 3) Having a collaborative approach to care; and, 4) Having successful experiences. In the “mature” phase, ICU and PC clinicians worked to strengthen their existing collaboration, but further adoption was limited by the availability and resources of the PC team. This conceptual framework identifying distinct phases of adoption may assist institutions aiming to foster sustained adoption of specialty PC in an ICU setting. **Abstract (w. references):** <https://bit.ly/3gSJSin>

Specialty palliative care in COVID-19: Early experiences from the Palliative Care Quality Collaborative

JOURNAL OF PALLIATIVE MEDICINE | Online – 22 June 2021 – Specialty palliative care (PC) teams have served many roles in the care for patients with COVID-19 and their families. Among the preliminary findings drawn from 306 case reports submitted to the Palliative Care Quality Collaborative, the authors found a preponderance of older, male patients with underlying cardiovascular disease being the most common underlying serious illness. Surprisingly, nearly 10% of PC consults were for patients with no underlying serious illness before COVID-19. PC teams were most frequently consulted to address goals-of-care and support families. Among requests for symptom management assistance, shortness of breath was the most common, consistent with the clinical presentation of COVID-19. PC teams were also called to provide support to colleagues and staff. Shared decision-making supported by PC teams led to changes in care plans, modifications in resuscitation status preferences, and enabling of patient-family, family-clinician communication despite limitations in family visiting. Challenges related to PC delivery during the COVID-19 era included strained communication with patients resulting from masking due to personal protection equipment, significant visitation barriers for family, rapid transitions to tele-communication with family members, and limited discharge options in the community. **Full text:** <https://bit.ly/3vTOyJ9>



Patterns of stress and support in social support networks of in-home hospice cancer family caregivers

JOURNAL OF SOCIAL & PERSONAL RELATIONSHIPS | Online – 16 June 2021 – Family caregivers (FCGs) of home hospice cancer patients often experience burden and distress, which can be mitigated by perceived social support. However, less attention has been paid to the non-family sources of support within social networks, or to how sources of support may also be sources of stress. The authors describe support and stress in social networks of hospice FCGs and identify caregiving characteristics associated with classes identified in our data. They identified three classes with unique patterns of stress and support within caregivers’ support networks using a latent class analysis: 1) High support, low stress across family and non-family network members; 2) High support, high stress across family and non-family network; and, 3) High support, high stress across family network only. Caregivers in the ambivalent maximizer class reported more burden than caregivers in the supportive class. This is one of the first studies to systematically explore the role of non-family support, as well as how stress and support co-occur within relationships and across networks. **Abstract (w. references):** <https://bit.ly/3xru1wS>

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Would the *Journal of Social & Personal Relationships* article be of interest to a colleague?

Related:

- *BMC PALLIATIVE CARE* | Online – 24 June 2021 – ‘**Support received by family members before, at and after an ill person’s death.**’ The study showed that healthcare staff expressing empathy and respect in the care of dying people and their family members were important for family members’ experiences of support. The family members’ difficulty recognising that death was imminent and the importance of healthcare staff providing them with clear information were both factors expressed in connection with family members’ experiences of support at death. Finally, the study showed that follow-up conversations were valued by family members, especially if with a healthcare professional who was present at the time of death. **Full text:** <https://bit.ly/3xTa6Y0>

Engaging future healthcare professionals as caregivers to hospice patients in comfort care homes

OMEGA – JOURNAL OF DEATH & DYING | Online – 22 June 2021 – Most people wish to die at home yet significant barriers exist in accessing care in one’s home, especially for individuals with caregiver and/or housing instability. Across the U.S., residential homes for the dying are opening to address gaps in end-of-life care (EoLC) by recruiting community members to serve as caregivers to hospice patients during their final days. This article describes a blended-experiential training program, informed by both an evidence-based educational framework and transformative learning theory, that trains undergraduate students to serve as surrogate family members to hospice patients in residential care homes. This study analyzed data from a sample of undergraduate students who participated in an 8-week program. Study results indicate the program provided essential knowledge and skills in EoLC, benefiting both student learning outcomes and resident care. **Abstract:** <https://bit.ly/3j0yBxY>

What should be measured to assess the quality of community-based palliative care? Results from a collaborative expert workshop

PALLIATIVE & SUPPORTIVE CARE | Online – 22 June 2021 – Currently, there is a lack of standardized quality indicators (QIs) for palliative care (PC) delivered in the community in Canada. Three brainstorming sessions were focused on addressing the following questions: 1) What is important to measure to support quality PC, regardless of setting?; 2) Of the identified measures, are any of special importance to care provided in the home?; and, 3) What are the challenges, barriers, and opportunities for creating these measures? The experts identified four themes that are important for measuring quality, regardless of care setting, including access to care in the community by a multidisciplinary team, care for the individual with PC needs, support for the informal caregiver (e.g., family, friends), and symptom management for individuals with PC needs. Two additional themes were of special importance to measuring quality PC in the home, including spiritual care for individuals with PC needs and home as the preferred place of death. The challenges, barriers, and potential opportunities to these quality issues were also discussed. PC experts, through this collaborative process, made a substantial contribution to the creation of a standardized set of quality indicators (Qis) for community-based PC. Having a standardized set of QIs will enable healthcare professionals and decision-makers to target areas for improvement, implement interventions to improve the quality of care, and ultimately, optimize the health and well-being of individuals with a serious illness. **Abstract (w. references):** <https://bit.ly/3wNqcSx>

Noted in Media Watch 10 May 2021 (#716, p.7):

- *PALLIATIVE MEDICINE* | Online – 4 May 2021 – ‘**Factors facilitating positive outcomes in community-based end-of-life care: A cross-sectional qualitative study of patients and family caregivers.**’ Despite differences in different healthcare settings and the significance of a person-centered approach, little research has investigated facilitators of community-based end-of-life care from the perspective of service recipients. In particular, there has been limited exploration of strategies to ensure positive outcomes at an operational level. This study identified seven core themes. Improvement in service quality might be achieved through alternating the perceptions or emotional reactions of care recipients toward care providers and increased use of sensitive inquiry. **Abstract (w. references):** <https://bit.ly/3jtYAz>

Cont.

Noted in Media Watch (#708, p.7):

- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2021;27(1):18-22. **'Is the Kerala model of community-based palliative care operations sustainable? Evidence from the field.'** The uninterrupted patient services, economic-self sufficiency, and volunteering efforts are contributing to the overall sustainability of palliative care (PC) operations [in Kerala]. The replication of the Kerala model of PC in the other localities must consider these dimensions for successful implementation. Future researches can focus on exploring the economic aspects of sustainability more comprehensively through quantitative measures. Further, the sociocultural aspects that set the context of identified dimensions of sustainability also require a detailed examination from a sociological point of view. **Full text:** <http://bit.ly/3l1JmyZ>

"I decide myself": A qualitative exploration of end-of-life decision-making processes of patients and caregivers through advance care planning

PLOS ONE | Online – 18 June 2021 – The Singapore national advance care planning (ACP) programme was launched in 2011 with the purpose of ensuring that healthcare professionals are fully aware of patients' treatment preferences. There is little research assessing the performance of such programmes in ethnically diverse Asian countries; hence, the purpose of this study was to qualitatively examine patients and caregivers' experiences with the ACP programme. Participants' narratives focused on four major themes with 12 subthemes: 1) Engagement with death, factors influencing respondents' acceptance of ACP; 2) Formation of preferences, the set of concerns influencing respondents' choice of care; 3) Choice of a proxy decision-maker, considerations shaping respondents' choice of nominated health spokesperson; and, 4) Legacy solidification, how ACP is used to ensure the welfare of the family after the patient passes. These findings led to the authors' development of the directive decision-making process framework, which delineates personal and sociocultural factors influencing participants' decision-making processes. Respondents' continual participation in the intervention were driven by their personal belief system that acted as a lens through which they interpreted religious doctrine and socio-cultural norms according to their particular needs. The directive decision-making process framework indicated that ACP could be appropriate for the Asian context because participants displayed an awareness of the need for ACP and were able to develop a concrete treatment plan. Patients in this study made decisions based on their perceived long-term legacy for their family, who they hoped to provide with a solid financial and psychological foundation after their death. **Full text:** <https://bit.ly/35AfXoW>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 25 June 2021 – **'What surrogates understand (and don't understand) about patients' wishes after engaging advance care planning: A qualitative analysis.'** Multiple studies have failed to show substantial or consistent benefit from advance care planning (ACP). Understanding how and why ACP under-performs in the setting of complex medical decision-making is key to optimizing current, or designing new, ACP interventions. Helping patients and their spokespersons better anticipate decision-making in the face of prognostic and informational uncertainty as well as the emotional complexities of making medical decisions may improve the efficacy of ACP interventions. **Abstract (w. references):** <https://bit.ly/3vVoKfQ>
- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 23 June 2021 – **'Advance care planning in nursing homes: New conversation and documentation tools.'** To meet the need for context-specific advance care planning (ACP) tools to support nursing home staff in conducting ACP conversations, the authors developed the ACP+intervention. At its core, they designed three ACP tools to aid care staff in discussing and documenting nursing home resident's wishes and preferences for future treatment and care: 1) An extensive ACP conversation guide; 2) A one-page conversation tool; and, 3) an ACP document to record outcomes of conversations. These nursing home-specific ACP tools aim to avoid a purely document-driven or "tick-box" approach to the ACP... **Full text:** <https://bit.ly/3zXpkwH>

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- *MEDICAL LAW REVIEW* | Online – 23 June 2021 – ‘**Conceptualising “undue influence” in decision-making support for people with mental disabilities.**’ A crucial question in relation to support designed to enable the legal capacity of people with mental disabilities concerns when support constitutes undue influence. This article addresses this question in order to facilitate the development of law and policy in England and Wales, by providing a normative analysis of the different approaches to undue influence across decisions about property, contracts, health, finances, and accommodation. These are all potential contexts for supporting legal capacity, and, in doing so, the article compares approaches to undue influence that are rarely considered together. **Full text:** <https://bit.ly/3vWFZO0>
- *PALLIATIVE MEDICINE REPORTS* | Online – 23 June 2021 – ‘**A limited opportunity: COVID-19 and promotion of advance care planning.**’ Although the pandemic has been touted as an opportunity to elevate the importance of advance care planning (ACP), among family caregivers the authors observed only a moderate increase in the level of ACP engagement. Three barriers may impede engagement in ACP. Although one may be unique to COVID-19, it points up the value of contingency planning. All three barriers can be addressed by providing specific education and tools to guide caregivers through the process of ACP, in a way that emphasizes the need for ongoing conversations, and help achieve end-of-life experiences that match one’s values, preferences, and goals-for-care. **Full text:** <https://bit.ly/2U4B0x7>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 23 June 2021 – ‘**A third of dying patients do not have end-of-life discussions with a physician: A nationwide registry study.**’ About half (46%) of all patients in Sweden in hospitals, nursing homes, own homes, community, and palliative care units during 2015-2017 did have an end-of-life (EoL) discussion, but a third (32%) did not. Associated factors of those who did not have an EoL discussion were dementia (48.5%) or stroke (47.5%), older age (38.4%), being female (33.6%), being cared for in a nursing home (41.3%) or hospital (40.3%), having lost decision-making ability months before death (58.9%), and not having a documented decision to shift to EoL care (82.7%). **Abstract (w. references):** <https://bit.ly/2SYNCFV>

Research Matters

State of the science and future research directions in palliative and end-of-life care in paediatric cardiology: A report from the Harvard Radcliffe Accelerator Workshop

CARDIOLOGY IN THE YOUNG | Online – 24 June 2021 – Eight priorities for research were identified, including patient and family decision-making, communication, patient and family experience, patient symptom measurement and management, training and curriculum development, teamwork, family hardships and bereavement, and ethical considerations. Barriers to research in this area were also identified: lack of outcome/measurement tools, lack of research funding, small population sizes, lack of effort/protected time for research, undervalued research topic by field and colleagues, and heterogeneous research participant diversity. Priorities and barriers were mostly consistent with those reported by the field of paediatric palliative care at large. These collective, consensus-based findings from diverse, multidisciplinary leaders in the field, as well as parent representatives, provide a catalyst for scientific advancement specific to paediatric and end-of-life care in paediatric cardiology. **Abstract (w. references):** <https://bit.ly/3zTPFvJ>

Developing priorities for palliative care research in advanced liver disease: A multidisciplinary approach

HEPATOLOGY COMMUNICATIONS | Online – 16 June 2021 – Individuals with advanced liver disease (AdvLD), such as decompensated cirrhosis and hepatocellular carcinoma, have significant palliative needs. However, little research is available to guide healthcare providers on how to improve key domains related to palliative care (PC). The authors conducted a literature review using search terms related to AdvLD and key PC domains. Individual reviews of these domains were performed, followed by iterative discussions by a panel consisting of experts from multiple disciplines, including hepatology, specialty PC, and nursing. Based on these discussions, priority areas for research were identified. The authors identify critical gaps in the available research related to PC and AdvLD. They developed and shared five key priority questions incorporating domains related to PC. Future research endeavors focused on improving PC in AdvLD should consider addressing the five key priorities areas identified from literature reviews and expert panel discussions. **Full text:** <https://bit.ly/3wHC3BI>

Transitioning to remote recruitment and intervention: A tale of two palliative care research studies enrolling underserved populations during COVID-19

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 19 June 2021 – During the COVID-19 pandemic, community-based research studies experienced prolonged shutdowns unless able to pivot to remote study procedures. The authors describe the revision of two National Institutes of Health funded community-based palliative-focused clinical trials serving underserved populations to accommodate remote subject enrollment and examine its impact. Transitioning to remote processes required multiple protocol and procedural changes including: altering informed consent processes; reducing the number of surveys administered; adding internet access as an inclusion criterion. To understand technological challenges, a screening tool was developed for one study to identify potentially eligible subjects' technology abilities and accessibility. Subjects' limited access to the internet and internet-enabled devices and discomfort with technology led to changes in recruitment patterns. Lack of familiarity with technology increased the amount of time it took research team members and subjects to connect remotely. Patients with significant cognitive and/or sensory deficits were at higher risk of experiencing fatigue during remote study visits leading to streamlining of data collection. A researcher-developed technology screening tool found that potential subjects were not comfortable with videoconferencing through Zoom® expressing a preference for phone visits. Reduced travel time made scheduling remote study visits more efficient. Future community- and home-based palliative care trials must consider the best way to utilize remote recruitment, enrollment, and data collection processes to increase efficiency and reduce costs. Researchers should consider technology accessibility and train staff to ensure the greatest possible opportunity to recruit underserved populations who have traditionally been underrepresented in research studies. **Abstract (w. references):** <https://bit.ly/35FMUjD>

Palliative care intervention trials for adults living with progressive central nervous system diseases and their caregivers: A systematic review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 17 June 2021 – This review highlights there has been sparse quantitative research investigating palliative care (PC) interventions in adults living with progressive central nervous system diseases (PCNSD) published to date, and that those published demonstrated PC interventions only very modestly impacted burden of specific physical symptoms, patient quality of life and caregiver burden using patient- and caregiver-reported outcomes. There remains a significant opportunity to address the unmet need for high-quality quantitative research in those living with PCNSD and their caregivers to inform evidence-based clinical practice. Studies to date used a variety of metrics, timepoints and criteria to evaluate the effectiveness of PC interventions delivered in interdisciplinary teams whether in a specialty, integrated or primary PC model for optimizing the care of people living with PCNSD and their caregivers. Standardization of metrics, diversity of subjects enrolled and appropriate training of team members are crucial considerations when evaluating PC interventions in the context of qualitative research. Future research dedicated to optimizing outcome measurement instruments for studies involving people living with cognitive impairment impeding activities of daily living and their caregivers is needed and should include psychometric assessment and ethical considerations of the proxy-reporting approach. It is essential in both designing and conducting high-quality quantitative research to be well-informed about patient- and caregiver-centered outcomes and the requisite assessments. Furthermore, for trial results to be applicable in more than a single patient population and comparable across trials, the development of patient-reported outcome measures validated and relevant to a range of diagnoses is critical and should be a considered a research priority. **Full text:** <https://bit.ly/3wP7DgP>



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.14.

Publishing Matters

Global scientific outputs of palliative care publications: A holistic approach with bibliometric analysis

ACTA MEDICA | Online – 20 June 2021 – This study aims to summarize the scientific outputs of the palliative care (PC) studies conducted between 1975-2019 through bibliometric analyses, identify the top effective journals, top-cited studies, the collaboration between countries, and trend topics. The authors performed a bibliometric analysis on PC. “Palliative care,” “terminal care,” “end-of-life care” and “hospice care” terms were used as the keywords in the title section of articles in Web of Science database. Spearman correlation coefficient was performed for the correlation analysis between the number of publications produced by the countries and economic indicators. There were 22,361 publications about PC. Of these publications, 10,309 were articles. The top three countries that produced more than 100 articles were the U.S., the U.K., and Canada. The top three journals that had the highest number of publications were *Journal of Palliative Medicine*, *Journal of Pain & Symptom Management*, and *Palliative Medicine*. There was a positive, highly significant relationship between the number of publications and Gross domestic product. This study is believed to be a beneficial guide about the global outputs of PC for the clinicians and scientists and present new research ideas to the researchers. **Full text:** <https://bit.ly/3j8DZiQ>

Should I include studies from “predatory” journals in a systematic review? Interim guidance for systematic reviewers

JBI EVIDENCE SYNTHESIS | Online – 23 June 2021 – A systematic review involves the identification, evaluation, and synthesis of the best-available evidence to provide an answer to a specific question. The “best-available evidence” is, in many cases, a peer-reviewed scientific article published in an academic journal that details the conduct and results of a scientific study. Any potential threat to the validity of these individual studies (and hence the resultant synthesis) must be evaluated and critiqued. In science, predatory journals (PJ) continue to rise. Studies published in PJ may be of lower quality and more likely to be impacted by fraud and error compared to studies published in traditional journals. This poses a threat to the validity of systematic reviews that include these studies and, therefore, the translation of evidence into guidance for policy and practice. Despite the challenges PJ present to systematic reviewers, there is currently little guidance regarding how they should be managed. In 2020, a sub-group of the JBI Scientific Committee was formed to investigate this issue. In this overview paper, the authors introduce PJ to systematic reviewers, outline the problems they present, their potential impact on systematic reviews, and some alternative strategies for consideration of studies from PJ in systematic reviews. Options for systematic reviewers could include: excluding all studies from suspected PJ, applying additional strategies to forensically examine the results of studies published in suspected PJ, stringent search limits, and applying analytical techniques (such as sub-group or sensitivity analyses) to investigate the impact of suspected PJ in a synthesis. **Abstract:** <https://bit.ly/2U6pDFf>

Editors-in-chief perceptions of patients as (co) authors on publications and the acceptability of International Committee of Medical Journal Editors’ authorship criteria: A cross-sectional survey

RESEARCH INVOLVEMENT & ENGAGEMENT | Online – 14 June 2021 – In academia, authorship on a research publication is a central means to obtain credit for one’s contribution to a research project. In order to guide authorship decision-making and facilitate transparent processes, the International Committee of Medical Journal Editors (ICMJE) has produced recommendations for authorship. These recommendations are widely adopted by hundreds of medical journals. However, there is no research on whether the ICMJE’s recommendations for authorship appropriately recognize the distinct contributions of patient partners to research. This survey study asked editors-in-chief about their perceptions of patient partners as authors and on the suitability of the ICMJE authorship criteria. The authors find that a 30.8% of medical journal editors-in-chief do not view the inclusion of patient partners as authors on manuscripts as appropriate. Editors-in-chief reported wide ranging views on whether the ICMJE criteria for authorship were appropriate for patient partners. The implication of this work is that there is a need for education and for consensus building within the biomedical community to establish processes that will facilitate patient partners equitable inclusion in research, including on research outputs like publications. **Full text:** <https://bit.ly/3vEPotn>

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/2RBj7VW>

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Australia

PALLIATIVE CARE RESEARCH NETWORK: <http://bit.ly/2E1e6LX>

[Click on e-News (November 2019); scroll down to 'Useful Resources in Palliative Care Research']

Canada



CSPCP SCMSP
Canadian Society of
Palliative Care Physicians
Société canadienne des
médecins de soins palliatifs

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

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ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <http://bit.ly/2TboKFX>

ONTARIO | Mississauga Halton Palliative Care Network: <https://bit.ly/3tby3b3>

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTPS://BIT.LY/3WVL5RW>

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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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