

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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It is essential that those dying from COVID-19 ... receive high-quality relief of suffering, which is mandated by the human right to health and a recognised component of essential universal health coverage. Without access to the essential palliative care package, countries will not meet the sustainable development goals, and inequity of access to quality end-of-life care is likely to increase.

'Modelling palliative and end-of-life resource requirements during COVID-19: Implications for quality care' (p.5), in *BMJ Open*.

U.S.A.

Cost savings, rising awareness boosting palliative care growth

HOSPICE NEWS | Online – 25 May 2021 – The track record of palliative care (PC) providers helping patients avoid hospitalizations and readmissions is a significant driver of their growth. Rising awareness of the nature and availability of PC is also promoting utilization of these services... More stakeholders are beginning to realize the cost-saving potential of PC. Community-based PC can reduce total healthcare costs by 36%, a Turn-Key Health indicated indicated.¹ These services can also reduce hospital admissions by 48%, resulting in 28% cost savings per patient day. Home-based PC could reduce societal healthcare costs by \$103 billion within the next 20 years, the non-profit economic research group Florida TaxWatch said in a 2019 report.² About 50% of community-based PC providers are hospices, according to the Center to Advance Palliative Care. Historically, PC providers to a large

degree have used a moral argument to market their services. PC was simply the right thing to do. In today's environment, demonstration of cost savings is coming to the fore as providers work to educate referral partners and payers about the value they can bring... <https://bit.ly/3wxpngi>

Specialist Publications

'Despite big buildup, few benefit from Medicare's advance care planning coverage' (p.6), in *Journal of the American Medical Association*.

'POLST is more than a code status order form: Suggestions for appropriate POLST use in long-term care' (p.6), in *Journal of the American Medical Directors Association*.

1. 'Unlock the Value of Community-Based Palliative Care to Close Clinical and Non-Clinical Care Gaps,' Turn-Key Health Whitepaper. **Download at:** <https://bit.ly/3oPJF1O>
2. 'Palliative Care in Florida: Challenges and options for Florida's future,' TaxWatch, March 2019. [Noted in Media Watch 8 April 2019 (#609, p.2)] **Download at:** <http://bit.ly/2OT8liu>

International

Significant increase in palliative care services provided at home

AUSTRALIA | *News GP* (Royal Australian College of General Practitioners) – 26 May 2021 – One in 10 palliative care (PC) related services in Australia is provided at home, a new report from the Australian Institute of Health & Welfare has found.¹ According to the report, home visits for PC specialist services increased by an annual average of 18% between 2015-2016 and 2019-2020, with a total of 2,240 patients receiving home visits in 2019-2020. However, most PC services continue to be received in a hospital or surgery, with such services increasing by 12% over the same five-year period. While it has historically been assumed that PC will only commence once all treatment aimed at “curing” people has finished or when a person is dying, it is now well accepted that there is benefit in providing PC in association with disease-modifying therapies that aim to prolong life. It is also recognised that many people with life-limiting illnesses are not “cured” but continue to live with these illnesses for many years. <https://bit.ly/3wzWbW1>

1. ‘Palliative care in Australia,’ Australian Institute of Health & Welfare, Government of Australia, May 2021. **Download at:** <http://bit.ly/2QekeFX>

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

- AUSTRALIA | 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 report at:** <http://bit.ly/37KQMkV>

Hospice UK report examines equality in the hospice and end-of-life sector

U.K. | Hospice UK – 26 May 2021 – Hospice UK has launched a new report looking at the inequalities in access to end-of-life (EoL) care some people experience. ‘Equality in Hospice & End-of-Life Care’ outlines what needs to be done ... to ensure that everyone – no matter who they are, where they are or why they are ill – receives the best possible care at the end of their life. Everyone has the right to high quality care and support at the EoL. But many people are still not enabled to access the help they need in their final days and months. Inequalities of access and standards of care are particularly felt by those who have already encountered unfairness and discrimination throughout their lives. Palliative and EoL care services, commissioners and partners must do more and do so quickly. The hospice sector rightly prides itself on leading the way in designing and delivering high quality and innovative care. However, high quality does not equate to universal reach which is why many hospices are putting addressing inequalities at the heart

Specialist Publications

‘Palliative care and hospice care from the perspective of the *maqasid al-shari’ah*’ (p.4), in *Al-Risalah: Journal of Islamic Revealed Knowledge & Human Sciences*.

‘Hidden lives and deaths: The last months of life of people with intellectual disabilities living in long-term, generic care settings in the U.K.’ (p.7), in *Journal of Applied Research in Intellectual Disabilities*.

‘Spiritual care training needs in hospice palliative care settings in South Africa: Chorused national, provincial and local voices’ (p.8), in *Journal for the Study of Spirituality*.

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of their strategies. This drive within our sector reflects a wider movement in society, in the U.K. and at a global level. Hospices and other EoL care providers equally have a responsibility to ensure that everyone who needs it can access the care they want and need in a way that reflects who they are. The onus must be on the sector to listen, reflect, innovate and advance so that people from all communities are included, along with their families and carers. **Download report at:** <https://bit.ly/3bXkTb3>

Her Majesty's Prisons Stafford leads the way in national first

U.K. (England) | In Your Area – 24 May 2021 – Prisoners across 12 West Midlands prisons will have access to rehabilitation and palliative care as the first service of its kind in the country launches. The programme ... will see a specialist eight-bed ward established at Her Majesty's Prisons (HMP) Stafford. Patients from across the region's 12 prisons will also have access to a multi-disciplinary specialist care service led by a team of doctors, senior nurses, occupational therapists and physiotherapists, to help them recover from falls, strokes or other medical issues that require rehabilitation. As well as assessing patients and creating care plans, the HMP Stafford-based team will also give additional training to the prisons' healthcare teams to help them effectively deliver the additional care. The Specialist Care Unit plan has come about as National Health Service England wants to reduce the number of prisoners who need to leave prison for treatment, as this puts additional strain on both prison and hospital services. It is also hoped that the programme will reduce the number of lengthy bed-watch episodes that can take up prison officers' time. The care is also designed to improve the patient's mobility and abilities, allowing them to live independently on their own prison wing. <https://bit.ly/3fJzLuG>

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

National palliative care community survey snapshot

AUSTRALIA | Palliative Care Australia (PCA) – 24 May 2021 – A multimedia campaign developed by PCA, with the support of the Australian government, seeks to challenge perceptions that palliative care (PC) is a "last resort" and empower individuals to engage with their healthcare professionals early in their diagnosis in the hope to live as well as possible for as long as possible. It is conservatively estimated that in addition to the 40,000 Australians receiving PC, there are at least a further 40,000 Australians who would also benefit from PC treatment. Three quarters of Australians say they would ask for PC for themselves or a family member when first diagnosed with a terminal illness. However, there is strong evidence that Australians do not fully understand the full breadth of PC and its benefits, which then presents as a barrier to accessing timely care. Fewer than four out of ten Australians correctly understand that PC can be requested when a person is first diagnosed with a terminal, chronic or degenerative illness. And only three out of ten Australians surveyed correctly understand that general practitioners are among those who can provide PC. Almost 90% of Australians surveyed agree that people should plan for end-of-life (EoL) and think it is important to start thinking and talking about their wishes and preferences for care if they were to become seriously or terminally ill. However ... half of all survey respondents have done nothing regarding their EoL wishes, finding the subject of death and planning for the EoL too difficult to talk about and think talking about their preference for EoL with their family will upset them. <https://bit.ly/3oRlwXO>



Barry R. Ashpole

MY INVOLVEMENT IN HOSPICE AND PALLIATIVE CARE DATES FROM 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness

– both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://bit.ly/2RPJy9b>

Specialist Publications

Palliative care and hospice care from the perspective of the *maqasid al-sharī'ah*

AL-RISALAH: JOURNAL OF ISLAMIC REVEALED KNOWLEDGE & HUMAN SCIENCES, 2021;5(2):167-185. It is crucial that Muslim healthcare professionals understand the Islamic perspective of life, health, illness, and death issues to provide a holistic care to their patients, especially those who are terminally or critically ill. Terminally ill patients would inevitably require specialized treatment such as palliative care (PC) or hospice care, depending on their conditions to improve their remaining quality of life (QoL). PC is an established approach for patients diagnosed with terminal illnesses such as cancer, where the goal is comfort care while hospice involves caring to those with a terminal illness that has become advanced, progressive, and incurable. In both, the goal-of-care is “comfort care.” The authors examined the approach used by healthcare providers in providing PC and hospice care from the perspective of *maqasid shari'ah*... Islam emphasizes that Muslims should aspire for good death or *husnul khatimah* as the desirable end of life (EoL) on this temporary abode. The multidisciplinary concept of care that involves experts from various disciplines to address the physical, mental, psychosocial, and spiritual needs of patients and improve the QoL is acceptable in Islam and regarded as commendable act in Islam as

patients, viewed as individuals require assistance to face the reality of reaching the inevitable end of their lives from the caretakers, family members and healthcare team. As the terminal condition worsen and the inevitable EoL is deemed imminent, very often doctors need to make ethical decisions with consultation of patient's surrogate decision-maker, such as withholding, withdrawing of life support, do not attempt resuscitation and advanced medical directives. Resolving ethical dilemmas requires understanding and application of ethical principles both contemporary and Islamic ethics of the *maqasid al-sharī'ah* before sound decisions could be made. **Full text (click on pdf icon):** <https://bit.ly/3fM52Nl>

Research Matters

'Economic evaluation of palliative care interventions: A review of the evolution of methods from 2011 to 2019' (p.11), in *American Journal of Hospice & Palliative Medicine*.

'A randomized controlled trial of structured palliative care versus standard supportive care for patients enrolled in Phase 1 clinical trials' (p10), in *Cancer Medicine*.

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 27 May 2021 – **'Comparison of clinical characteristics and end-of-life care between COVID-19 and non-COVID-19 Muslim patients during the 2020 pandemic.'** Muslim COVID-19 patients have prolonged mechanical ventilation and ICU stay than non-COVID patients. Code status of over half of the patients in both groups was changed to do not attempt resuscitation (DNAR)... The practice of withholding or withdrawal of therapy at end of life (EoL) is still not that prevalent. Upstream palliative care and chaplaincy services, beyond facilitating goals-of-care and advanced care planning discussions, may help with supporting Muslim patients, their families, and the healthcare teams caring for them. **Full text:** <https://bit.ly/3hZiCUB>

N.B. Search back issues of Media Watch for additional articles on the “Muslim” perspective on EoL and EoL care at: <http://bit.ly/2ThijkC>

Challenges and opportunities of providing pediatric funeral services: A national survey of funeral professionals

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 26 May 2021 – Funeral professionals offer a unique opportunity to support, educate, and advocate for grieving families after the death of a child. From the initial point of contact to the burial, funeral professionals shape the final moments and memories of a family and a community. And yet, little is known about the needs of funeral professionals to

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provide high quality services when a child dies. Active National Funeral Directors Association members were surveyed on their experience and needs in providing pediatric funeral services. The survey contained 41 questions about experience, skills, and knowledge in providing pediatric funerals. The respondents conducted 43 pediatric funeral services in a 5-year period (approx. 8 services/year). The top 5 self-identified training needs included grieving parents, grieving siblings, memorials, comforting the community, and outreach. Themes from the open-ended questions were: 1) Maintaining professionalism. 2) Managing emotions and experiences; 3) Assessing family dynamics; 4) Managing professional skills; and, 5) Building collaborative networks. **Abstract (w. references):** <https://bit.ly/3fSvzJg>

Multi-disciplinary supportive end-of-life care in long-term care: An integrative approach to improving end of life

BMC GERIATRICS | Online – 22 May 2021 – This study identified three key recommendations. The first is to establish knowledge and training expectations and resources for long-term care (LTC) staff and physicians, which focuses on a palliative approach, mentorship, communication and collaboration in LTC. The second is to build connections between all those involved in providing end-of-life care (EoL) care, including family members. The third is to create policies and provide funds needed to meet comfort care needs at EoL. Considering the identified priorities, the authors developed a 5-point strategy to providing supportive EoL care within LTC. Three lists of interventions required to optimize supportive EoL care in Canadian LTC facilities include: clinical practice change, communication and culture change, and organizational policy change. Clinician educators can use the authors' findings to support the provision of palliative education and skills training, as well as mentorships. Administrators should explore opportunities to reconfigure LTC culture through communication changes, as well as the physical environment through facility design modifications. The authors have also shown the benefits of multi-method research that integrates qualitative interviews, quantitative surveys, and multi-stakeholder participatory methods in the development of evidence-based strategies to improve care within LTC. Residents and family caregivers should also be engaged in research and change efforts targeted at optimizing EoL care provision within LTC. **Full text:** <https://bit.ly/3fcD6mO>

N.B. Search back issues of Media Watch for additional articles on EoL care in “long-term care” at: <http://bit.ly/2ThijkC>

Modelling palliative and end-of-life resource requirements during COVID-19: Implications for quality care

BMJ OPEN | Online – 25 May 2021 – Our cultural bias towards healthcare heroics risks overlooking the essential contribution of palliative and end-of-life care (EoLC) to a pandemic. Armed with the structure to outline palliative care (PC) pandemic planning, this study allows realistic modelling of the essential ingredients to prepare, plan and deliver a PC pandemic response tailored to local work patterns and resource. Without anticipating the resource constraints, equitable care is compromised. This pandemic is a reminder of the vital need for collaborative, flexible working and quality data collection to inform preparation and planning to prevent deaths with physical and psychosocial distress. There is limited evidence on cost-effectiveness of PC overall, with research complicated by the heterogeneity of specialist PC services in the U.K. During the pandemic, the authors have found no evaluation comparing the financial cost of care for those affected who do and do not receive PC, and this is an area that requires greater research and understanding. Emphasising EoLC does not negate the importance of life-saving or even life-sustaining care but acknowledges the moral imperative to provide care for everyone in a pandemic, even where a cure is not possible. The model presented here provides evidence of the predicted resource essential to provide quality PC during a pandemic. **Full text:** <https://bit.ly/3bRwrMH>

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Related:

- *PALLIATIVE MEDICINE* | Online – 27 May 2021 – ‘**The COVID-19 pandemic: A tipping point for advance care planning? Experiences of GPs.**’ Six themes were identified: 1) Urge of advance care planning (ACP); 2) the GP’s perceived role in it; 3) Preparations for it; 4) Proactively discussing it; 5) Essentials for good communication; and, 6) ACP in the near future. Calls for proactively discussing ACP in the media and in COVID-guidelines caused awareness of its importance. GPs envisaged an important role for themselves in initiating it, especially with patients at risk to deteriorate or die from COVID-19. Timing ACP appeared difficult... Digital way of communication was considered problematic due to missing nonverbal communication and difficulties in involving relatives. **Abstract (w. references):** <https://bit.ly/34nZu6J>
- *PALLIATIVE MEDICINE* | Online – 26 May 2021 – ‘**Understanding and addressing challenges for advance care planning in the COVID-19 pandemic: An analysis of the U.K. CovPall survey data from specialist palliative care services.**’ This study describes the challenges that U.K. specialist palliative care services experienced regarding advance care planning during COVID-19 and changes made to support timely conversations. Challenges are demonstrated through six themes: 1) Complex decision-making in the face of a new infectious disease; 2) Maintaining a personalised approach; 3) COVID-19-specific communication difficulties; 4) Workload and pressure; 5) Sharing information; and, 6) National context of fear and uncertainty. **Abstract (w. references):** <https://bit.ly/3fmXmll>

POLST is more than a code status order form: Suggestions for appropriate POLST use in long-term care

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 21 May 2021 – POLST (Physician Orders for Life-Sustaining Treatment) is a medical order form used to document preferences about cardiopulmonary resuscitation (CPR), medical interventions such as hospitalization, care in the intensive care unit, and/or ventilation, as well as artificial nutrition. Programs based on the POLST paradigm are used in virtually every state [in the U.S.] under names that include POST (Physician Orders for Scope of Treatment), MOLST (Medical Orders for Life-Sustaining Treatment), and MOST (Medical Orders for Scope of Treatment), and these forms are used in the care of hundreds of thousands of geriatric patients every year. Although POLST is intended for persons who are at risk of a life-threatening clinical event due to a serious life-limiting medical condition, some nursing homes and residential care settings use POLST to document CPR preferences for all residents, resulting in potentially inappropriate use with patients who are ineligible because they are too healthy. This article focuses on reasons that POLST is used as a default code status order form, the risks associated with this practice, and recommendations for nursing homes to implement appropriate use of POLST. **Full text:** <https://bit.ly/2SuigX2>

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

Related:

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 26 May 2021 – ‘**Despite big buildup, few benefit from Medicare’s advance care planning Coverage.**’ In 2016 Medicare launched a much-anticipated advance care planning (ACP) benefit that pays physicians to counsel patients about living wills, advance directives, and end-of-life care options. During the ACP process clinicians can help patients determine the type of care they would want in a medical crisis or at the end of life and reassure them that their preferences will be observed. Numerous medical and patient advocacy organizations backed the Medicare initiative, asserting that compensation for physicians would encourage proactive end-of-life care discussions. However, the benefit isn’t being widely used. **Full text:** <https://bit.ly/3bY3rmG>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 28 May 2021 – ‘**End-of-life planning depends on socio-economic and racial background: Evidence from the U.S. Health & Retirement Study.**’ Americans express a strong preference for participating in decisions regarding medical care, yet are often unable to participate in decision-making regarding end-of-life (EoL) care. EoL planning depends on several patient characteristics and circumstances, with socio-economic and racial/ethnic background having the largest effects. The probability of having a living rises sharply late in life, as we would expect, and is further modified by the patient’s proximity to death. The dying process, exerts a stronger influence on EoL planning than does the aging. **Abstract (w. references):** <https://bit.ly/3vK0mwR>

Hidden lives and deaths: The last months of life of people with intellectual disabilities living in long-term, generic care settings in the U.K.

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Online – 24 May 2021 – This article offers a description of mortality and the need for end-of-life care (EoLC) among adults living in generic care settings, a population that is important but difficult to locate. Although it is not possible, in the U.K. at least, to determine the size of this population, the age structure and rates of death reported for the sample described here suggest that generic settings are important, if unrecognised last places of care for many older adults with intellectual disabilities (ID). This is not reflected in the current literature concerning EoLC and people with ID. The mortality rates reported in each of the two types of generic care settings studied here were considerably higher than those reported for adults in intellectual disability settings. The “surprise question” was used to estimate potential need for EoLC in the study sample. The authors’ findings, that almost one in four adults in this sample had a potential need for EoLC, would be unlikely to be matched in a population of adults in intellectual disability care settings who are younger and have a lower risk of death in the immediate future; and, where death is often not anticipated for long. Current concerns about issues of access and quality of EoLC in relation to people with intellectual disabilities (ID) ... must be extended to include people with ID living in generic care settings. The role of generic care homes as important providers of EoLC and need for continuing service development in this regard is increasingly recognised. However, we cannot assume, without further research, that people with ID will benefit from any overall uplift in service quality in this sector. The need for more research here is clear. **Full text:** <https://bit.ly/3yEh4Bq>

N.B. Search back issues of Media Watch for additional articles on EoLC for people living with intellectual “disabilities” at: <http://bit.ly/2ThijkC>

Recommendations to improve palliative care provision for marginalized populations: Summary of a roundtable discussion

JOURNAL OF PALLIATIVE MEDICINE | Online – 21 May 2021 – Palliative care (PC) is increasingly recognized as fundamental to health and human dignity. However, a growing body of evidence highlights the variations in access to PC based on personal characteristics, belonging to a certain group, and socioeconomic background. Discriminatory attitudes and behaviors and lack of legal reform protecting the rights of marginalized populations are still common, particularly across Lebanon and the Middle East and North Africa region. This article presents a summary of a roundtable discussion organized by the Lebanese Medical Association for Sexual Health in collaboration with the Lebanese Center for Palliative Care-Balsam, focusing on improving PC provision for the following populations: prisoners; lesbian, gay, bisexual, and transgender people; refugees; migrant domestic workers; and, people with substance use disorder. It also offers recommendations based on the key themes identified from the discussion, in the hope that they will guide the development of guidelines and policy to advance equity in PC provision for marginalized populations. **Abstract:** <https://bit.ly/3bQ1ybA>

Why are dying individuals stigmatized and socially avoided? Psychological explanations

JOURNAL OF SOCIAL WORK IN END OF LIFE & PALLIATIVE CARE | Online – 26 May 2021 – Extant research on the topic of death and dying in modern society frequently includes the observation that death is now rendered invisible, and dying individuals are stigmatized and socially avoided. The current research speculated that lack of contact with a dying individual may promote negative perceptions of the dying, and this may in turn lead to further avoidance of them. Three studies were conducted: The first examined how frequently the current U.S. participants had social contact with a dying individual; the second investigated what perceptions they have of the dying, and the third study tested for potential causal links between negative perceptions of the dying and social avoidance of them. The results indicated: only a small number of the U.S. participants ever had frequent social contact with a dying individual outside their family; they, nevertheless, shared several common negative perceptions of the dying; and those negative perceptions exerted different effects on one’s avoidant attitude toward a dying individual-only making males more avoidant, especially in a physically close social relationship. Two concepts, medicalization and masculinism, were suggested as possible explanations for why dying individuals are stigmatized and avoided in modern society. **Abstract:** <https://bit.ly/3fqdKCa>

Spiritual care training needs in hospice palliative care settings in South Africa: Chorused national, provincial and local voices

JOURNAL FOR THE STUDY OF SPIRITUALITY | Online – 21 May 2021 – Globally, spiritual care is recognized as an important component of palliative care (PC). In the Global North spiritual care training is gaining momentum and being prioritized, but not so in the Global South. This study seeks to establish what the national spiritual care training needs are in hospice PC settings with formalized spiritual care services in a middle-income country in the Global South. This was a three-part study: 1) A quantitative national online survey of hospices in South Africa establishing what their spiritual care training needs were; 2) A qualitative study consisting of focus group discussions with hospices in the Western Cape Province, South Africa, who have formalized spiritual care services, with the aim of understanding their spiritual care practices and workforce needs; and, 3) A qualitative study drawing on the experiences of a cohort of spiritual care workers from an established hospice in Cape Town to understand their training needs in spiritual care and explore their workforce issues. Results revealed a chorused need for the development of a national training curriculum in spiritual care for hospices providing PC in South Africa and a chorused recognition that spiritual care services are nuanced and require both formalization and flexibility for spiritual care workers to be led by patient needs. Two elements – finance and human capital – were identified as key barriers to developing a spiritual care curriculum. **Abstract:** <https://bit.ly/34a4s6U>

Advance care planning interventions for older people with early-stage dementia: A scoping review

NORDIC JOURNAL OF NURSING RESEARCH | Online – 20 May 2021 – Advanced care planning (ACP) in dementia care can be a valuable way to alleviate suffering for both people with dementia and family caregivers (FCGs). ACP for dementia patients provides an opportunity for relationship-centered triad care that includes the person with dementia, the family caregiver, and professional care staff. Staff competence is of great significance in ACP for all patient groups; even more so in dementia care where the diminishing cognition, reduced decision capacity, and extraordinary vulnerability associated with the illness provide significant ethical challenges. The ACP process should be organized as a continuous collaboration between care professionals, people with dementia and their family caregiver. The ethical challenges, the complexity of ACP program or intervention implementations in early-stage dementia care, and the development of process and outcome evaluation measures need further study. The results of this scoping review provide a starting point for healthcare organizations, such as memory clinics, to develop a structure for ACP discussions with people with dementia and their FCGs. **Full text:** <https://bit.ly/2QNhDHI>

Related:

- *PLOS ONE* | Online – 27 May 2021 – ‘**Developing an applied model for making decisions towards the end of life about care for someone with dementia.**’ The authors consider the contextual factors that influence the decision-making process, including personal preferences, advance care planning and Lasting Power of Attorney, capacity and health and wellbeing of the person with dementia, and support from others and clarity of roles. This process consists of 7 inter-linked stages: 1) Identifying the decision maker or team; 2) Sharing and exchanging information; 3) Clarifying values and preferences; 4) Managing and considering emotions; 5) Considering the feasibility of options; 6) Balancing preferred choice and the actual choice; and, 7) Implementation and reflecting on outcomes. **Full text:** <https://bit.ly/3uuMeb0>

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



Media Watch: Access Online: Updated 05.24.2021

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.12.

Nationwide evaluation of palliative care (Q-PAC study) provided by specialized palliative care teams using quality indicators: Large variations in quality of care

PALLIATIVE MEDICINE | Online – 29 May 2021 – Although a number of quality indicators for palliative care (PC) have been implemented worldwide, evidence regarding the performance of PC teams is scarce. The aim of this study was to evaluate the quality of PC using quality indicators, to describe the variation in quality between PC teams, and to suggest quality benchmarks for these teams. Between 2014 and 2017, five quality measurements with questionnaires were conducted in 982 patients receiving PC, 4,701 care providers and 1,039 family members of deceased patients. 7,622 assessments were received. Large risk-adjusted variations between the different PC teams were identified in regularly updating patient files, having multidisciplinary consultations about care objectives, discussing end-of-life care decisions with patients, relieving shortness of breath, regularly assessing pain and symptoms by means of validated scales, initiating PC at least 2 weeks before death, and weekly contact with the general practitioner in the last 3 months of life. The large risk-adjusted variation found across the quality indicator scores suggest that repeated and standardized quality improvement evaluations can allow teams to benchmark themselves to each other to identify areas of their PC delivery that need improvement. **Abstract (w. references):** <https://bit.ly/3c0nKzK>

What does effective end-of-life care at home for children look like? A qualitative interview study exploring the perspectives of bereaved parents

PALLIATIVE MEDICINE | In print – 20 May 2021 – What home-based, end-of-life care (EoLC) should entail or what best practice might look like is not widely reported, particularly from the perspective of parents who have experienced the death of a child at home. Parents reported effective aspects of EoLC provided at home to include: 1) Ability to facilitate changes in preferred place of death; 2) Trusted relationships with care providers who really know the child and family; 3) Provision of child and family-centred care; 4) Specialist care and support provided by the service as and when needed; and, 5) Quality and compassionate death and bereavement care. Whilst parents typically did not use the term “anticipatory care planning” in their interviews, they spoke of the initial and ongoing conversations with staff which underpinned and informed EoLC. Parents with lived experiences of caring for a dying child at home offer valuable input to future policy and practice of effective home-based, EoLC of children including the essential role of anticipatory care planning and recommendations for

shared learning, improving access, and dispelling hospice myths. **Abstract:** <https://bit.ly/3bRrhka>

Development of the Readiness for Home-Based Palliative Care Scale for primary family caregivers

HEALTHCARE | Online – 19 May 2021 – In Chinese or Eastern society, most end-of-life patients still choose to die at home. However, primary family caregivers (FCGs) usually do not prepare themselves to face the death of patients. Therefore, a measurement of the readiness for home-based palliative care (PC) for primary FCGs is needed. This study recruited 103 participants from five branches of one municipal hospital system [in Taiwan]. The reliability and validity of the Readiness for Home-Based Palliative Care Scale (RHBPCS) was evaluated using expert validity examination, confirmatory factor analysis, and item analysis. RHBPCS had strong goodness-of-fit and good reliability and validity. In summary, the RHBPCS is suggested for assessing the readiness for home-based PC of primary FCGs. **Full text:** <https://bit.ly/2QNhDHI>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 25 May 2021 – ‘**Patterns of healthcare services during pediatric concurrent hospice care: A national study.**’ The authors examined the healthcare services [in the U.S.], unique clusters of healthcare services, and characteristics of the children in the clusters. The 6,243 children in the study generated approximately 500,000 non-hospice, healthcare service claims while enrolled in hospice care. The authors identified three unique classes of healthcare services use: low (61.1%), moderate (18.1%), and high (20.8%) intensity. The children in the three classes exhibited unique demographic profiles. The findings suggest that concurrent hospice care is not a 1-size-fit all solution for children. **Abstract (w. references):** <https://bit.ly/3i5gsin>

Cultural considerations in palliative care provision: A scoping review of Canadian literature

PALLIATIVE MEDICINE REPORTS | Online – 20 May 2021 – It is clear from this review that culture plays a large role in assuring effective and holistic palliative care (PC) for a number of Canadian populations. It has been shown that what constitutes a norm for one community does not directly translate to another. There is a demonstrated need for cultural competency and sensitivity on the parts of Canadian healthcare providers, particularly those working in urban areas where cultural differences are more likely to be observed. By being reflexive about what we mean by “culture” in a PC context, lending attention to common cultural norms related to views of life, illness and death, spiritual and psychosocial needs, involvement of family and community in care, as well as holding an awareness of visibility (or invisibility) of cultural minorities, healthcare providers can create culturally accessible palliative programs. The continued study of values and preferences that are central to defining good care in the context of one's experience of culture will contribute to a more holistic health system equipped to care for all residents of Canada, not only those identifying with the cultural majority. **Full text:** <https://bit.ly/2Snp7S7>

Compassion in pediatric oncology: A patient, parent and healthcare provider empirical model

PSYCHO-ONCOLOGY | Online – 22 May 2021 – Compassion has long been considered a cornerstone of quality pediatric healthcare by patients, parents, healthcare providers and systems leaders. However, little dedicated research on the nature, components and delivery of compassion in pediatric settings has been conducted. This study aimed to define and develop a patient, parent, and healthcare provider informed empirical model of compassion in pediatric oncology in order to begin to delineate the key qualities, skills and behaviours of compassion within pediatric healthcare. Four domains and 13 related themes were identified, generating the Pediatric Compassion Model, that depicts the dimensions of compassion and their relationship to one another. A collective definition of compassion was generated – a beneficent response that seeks to address the suffering and needs of a person and their family through relational understanding, shared humanity, and action. Future research on compassion in pediatric oncology and healthcare should focus on barriers and facilitators of compassion, measure development, and intervention research aimed at equipping healthcare providers and system leaders with tools and training aimed at improving it. **Abstract:** <https://bit.ly/3flxPm0>

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 28 May 2021 – “**Still caring for the family**”: **Condolence expression training for pediatric residents.** Ten percent of pediatric residents surveyed reported having training on condolence expression. Almost all residents considered condolence expression to be beneficial for bereaved families and most for clinicians, too, yet most had never formally expressed condolences in their roles as physicians: 83.1% had never written a condolence letter, 85% had never made a condolence phone call, and 90.5% had never attended a memorial event. Commonly reported barriers to condolence expression included lack of experience and training, as well as concern about upsetting families. **Abstract (w. references):** <https://bit.ly/3p30Rks>

Research Matters

A randomized controlled trial of structured palliative care versus standard supportive care for patients enrolled in Phase 1 clinical trials

CANCER MEDICINE | Online – 25 May 2021 – The primary purpose of Phase 1 trials remains to assess toxicity rather than the efficacy of investigational agents. Patients who participate in these trials typically have advanced disease and have exhausted standard therapies, making them eligible for either investigational studies or hospice care. Most Phase 1 participants also have significant baseline symptom burden or sequelae from their disease and prior therapies, and Phase 1 trials may increase symptoms and decrease quality of life (QoL). Simultaneously, the benefits of palliative care (PC) in patients with advanced cancer

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have been increasingly recognized, with improved clinical outcomes, and it is recommended that PC be incorporated for all patients with advanced disease. The authors' data confirm that patients and caregivers have significant psychosocial needs in addition to physical symptoms and caregiving burden at the time of enrollment that warrants PC involvement. They demonstrated that PC provided simultaneously to Phase I trial enrollment is feasible, did not seem to add extra burden to patients or their caregivers, and potentially influenced duration on the study and positively affected QoL. **Full text:** <https://bit.ly/34xJEXj>

Economic evaluation of palliative care interventions: A review of the evolution of methods from 2011 to 2019

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 24 May 2021 – Economic evaluation of palliative care (PC) is challenging but also a necessity given the disproportional share of healthcare expenditure for patients at the end-of-life (EoL). While the use of quality adjusted life years (QALYs) in measuring outcomes in PC has been debated in the past, recent guidelines for pharmacoeconomic evaluations calls for the use of cost-utility analysis. For that reason, a literature review was completed to examine whether methods of PC economic evaluations have evolved since the deficiency in cost-utility analysis was last reported in 2011. Despite the small increase in cost-utility studies since 2011, the methods of PC economic evaluations have not evolved significantly. Aligned with the guidelines for the economic evaluation of healthcare programs in several countries (e.g., Canada, U.K. and the U.S.), researchers are encouraged to compare PC interventions in terms of costs and QALYs from a payer (e.g., Ministry of Health) or a societal (e.g., also taking into account productivity losses or out of pocket expenditures) perspective. To truly evaluate value for money and improve decision-making, it is also very

important that researchers take into account in their analyses the different types of uncertainty inherent to the economic evaluation according to best practices (e.g., sampling uncertainty for trial-based economic evaluations, parameter uncertainty when conducting model-based economic evaluations). Researchers should follow reporting guidelines for economic evaluations of healthcare programs. **Full text:** <https://bit.ly/3hQBWiG>

Extract from *American Journal of Hospice & Palliative Medicine* article

In Ontario (one of Canada's most populous provinces) 51.9% of all decedents receive some form of PC in the last year of life. While families bear substantial caregiving and out-of-pocket costs, a lot of these EoL costs are absorbed by the Canadian healthcare system. As a result, the sustainability of publicly funded healthcare interventions, especially for terminally ill patients, has been under question. Fortunately, there is evidence that indicates that PC services can significantly reduce the healthcare costs of EoL care through reduced hospital admission, length of stay, visits to intensive care unit and inappropriate diagnostics or interventions.



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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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