

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.

21 June 2021 Edition | Issue #722



Compilation of Media Watch 2008-2021 ©

Compiled & Annotated by Barry R. Ashpole

Illness trajectories and prognostication have been described for people with progressive chronic illnesses but none of these trajectories are able to pinpoint the right time from a patient and carer perspective to start palliative care

'An exploratory qualitative study of computer screening to support decision-making about use of palliative care registers in primary care: GP think aloud and patient and carer interviews' (p.10), in *Journal of Primary Care & Community Health*.

Canada

Why is access to medically assisted death a legislated right, but access to palliative care isn't?

THE CONVERSATION | Online – 14 June 2021 – Neurologic illness accounts for 18% of deaths in the Canada, but rarely has palliative care (PC) involvement. By contrast, cancer accounts for 20-30% of deaths, but typically receives 75% of PC. Part of the challenge is that PC services are often hospital-based, but most people who could benefit get their care in the community. Similarly, patients have recently refused PC in the belief that is the same as medical assistance in dying (MAiD). In 2017, MAiD accounted for 1.07% of deaths, increasing to 2% in 2019. In June 2016, the passed [Federal] legislation gave all eligible Canadians the right to request MAiD. Colleges of physicians and surgeons required physicians to refer people who request MAiD to services or arrange for a physician who would make the referral. Since then, every province and territory devoted resources to navigate requests and assessments for MAiD. Typically, provinces have a website for self-referral, easily found by Internet search and/or dedicated healthcare staff to help navigate the MAiD process or inform those who are MAiD-curious. By contrast, the referral process for PC is often convoluted. Many provincial web pages simply give a definition of PC – some confuse the issue by including the MAiD navigation site – but do not provide a central access point for physicians or nurses. Referral forms (where available) are complex, which creates another barrier to access. Many PC programs have an unofficial prognosis of three to six months' life expectancy for services, despite research demonstrating that early PC improves outcomes and, in fact, can prolong life. What is the disconnect? <https://bit.ly/3gziULA>

Noted in Media Watch 12 April 2021 (#712, p.1):

- CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS | Online – 31 March 2021 – '**Canadian Society of Palliative Care Physicians submission to College of Physicians & Surgeons of Ontario consultation on medical assistance in dying and professional obligations and human rights policies.**' Medical assistance in dying (MAiD) is a practice distinct from the provision of palliative care (PC). PC must remain distinct from MAiD to ensure clarity and to avoid the risk of confusion and the potential for people to refuse PC services. This does not preclude people who contemplate, request or opt for MAiD from receiving PC. This is vital for people in communities that have an underlying distrust of the healthcare system who decline PC because they may confuse it with MAiD. **Download at:** <https://bit.ly/3dERsdP>

U.S.A.

Hospices mobilize to better serve mentally ill patients

HOSPICE NEWS | Online – 17 June 2021 – Access and quality of hospice care for patients with serious mental illness are rising concerns among providers. Hospices are increasingly recognizing the need to better understand the unique challenges these patients face as they reach the end of life (EoL), with cries for further research growing louder. Education and awareness around mental health will be key for hospices to bridge gaps to patients with serious mental illness and their families, along with expanding their interdisciplinary care teams to include psychiatric care professionals. Research indicates significant disparities in EoL care exist for those living with severe and persistent mental illnesses (SPMI). Roughly 6% of the U.S. population have a SPMI that is chronic or recurrent, significantly impairs functioning or requires ongoing intensive psychiatric treatment, according to research from the journal *General Hospital Psychiatry*.¹ The unique and sometimes complex needs of patients with serious mental illness can stretch beyond the scope of traditional hospice care. Hospice and palliative care providers are working to improve access and quality of care for these patients. <https://bit.ly/2U709HA>

1. 'A staggered edge: End-of-life care in patients with severe mental illness,' *General Hospital Psychiatry*, published online 20 October 2016. [Noted in Media Watch 24 October 2016 (#484, p.9)]. **Full text:** <https://bit.ly/2TMYLtg>

Noted in Media Watch 26 April 2021 (#714, p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 20 April 2021 – '**Help me understand: Providing palliative care to individuals with serious mental illness.**' This review describes the benefits of providing palliative care (PC) to individuals with serious mental illness (SMI) with concrete suggestions for communication and use of recovery-oriented language in the treatment of individuals with SMI. Recommendations for working with individuals with SMI ... are provided, including strategies to effectively manage SMI exacerbations. Interdisciplinary PC teams are in a unique position to lend assistance to those with serious SMI given their expertise in serious illness communication, values-based care and psychosocial support. **Abstract (w. references):** <https://bit.ly/2QkASlz>

Noted in Media Watch 22 March 2021 (#709, p.13):

- *PROGRESS IN PALLIATIVE CARE* | Online – 19 March 2021 – '**Lean in, don't step back: The views and experiences of patients and carers with severe mental illness and incurable physical conditions on palliative and end-of-life care.**' People with severe mental illness (SMI) have a life expectancy of up to twenty years less than the general population and many live with incurable physical health conditions. Yet, they continue to experience barriers when trying to access palliative and end-of-life care. Little research has been carried out which includes the views and experiences of people with SMI, and this study presents first findings which include people with both SMI and an incurable condition and their carers. **Abstract:** <https://bit.ly/30XohwA>

Noted in Media Watch 24 August 2020 (#680, p.8):

- *JOURNAL OF PALLIATIVE CARE* | Online – 18 August 2020 – '**Working at the intersection of palliative end-of-life and mental healthcare: Provider perspectives.**' The most prominent issues pertained to assessment of patients and differential diagnosis of chronic and persistent mental illness, and preparedness of caregivers to deliver mental health interventions, given the isolation of palliative care from other agencies. Among the assets mentioned, informal relationships with frontline caregivers were seen as the main support structure, rather than the formal policies and procedures of the practice settings. Strategies to improve mental healthcare in palliative and end-of-life care centered on holistic roles and interventions benefiting the entire palliative population... **Abstract (w. references):** <https://bit.ly/31fr7hr>



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International

A good death? Rise in number of Scots dying at home during pandemic

U.K. (Scotland) | BBC Scotland – 18 June 2021 – Scotland has recorded a 41% rise in deaths in the community since the start of the COVID-19 pandemic, according to official statistics. Since March 2020, 26,730 people have died at home or outside a hospital or care setting – an increase of 7,826 on the five-year average. Cancer accounted for more than a third (2,994) of those excess deaths. Charities are calling for more support for people dying at home, and a new national strategy for palliative care. Only 518 deaths outside hospitals or care homes were a result of Covid. <https://bbc.in/2SdiKkS>

Report calls for registered nurses on duty in aged care at all times

AUSTRALIA (New South Wales) | *Australian Ageing Agenda* – 16 June 2021 – A New South Wales (NSW) government upper house cross-party committee has recommended the state mandate registered nurses in NSW aged care homes at all times at the appropriate level based on the number of residents. The Legislative Council select committee report also calls on the Commonwealth [i.e., the national government] to fund and implement appropriate mandatory staffing levels of registered nurses (RNs), personal care workers and allied health professionals, but adds the state should investigate mandating these levels if the Federal Government doesn't act quickly enough. The committee ... found all aged staff play a critical role in providing holistic

N.B. Link to the Legislative Council select committee report, 'Provisions of the Public Health Amendment (Registered Nurses in Nursing Homes) Bill 2020,' embedded in the *Australian Ageing Agenda* article.

Huge palliative retraining needed

NEW ZEALAND | *The Gisborne Herald* – 15 June 2021 – Projections show that in the 20 years between 2016 and 2036 there will be a 77% increase of New Zealanders aged over 65, and 132.4% increase of New Zealanders aged over 80. Such significant demographic shift is already starting to impact our infrastructure, economy, and healthcare system – and that impact is only going to get bigger. To survive with the values of our society intact, we need to be active in respecting our elders right through to the very end of life (EoL) – even, and especially, when it comes at a cost. One area this must include is the capacity of our hospice and palliative care services to support dying people well. Palliative medicine is going to become much more necessary, with a large older population and cancers and chronic illnesses becoming more common at the EoL. This EoL medical care focuses on quality of life by relieving pain and suffering, whether physical, social, psychological or spiritual. One of the big gaps in our ability to provide this kind of quality care is that we're currently not educating or training our medical staff so that every doctor and nurse feels equipped to walk alongside families and whanau right to the EoL. <https://bit.ly/3iJR7dY>

Specialist Publications

'Palliative care and COVID-19, the Australian context: A review of patients with COVID-19 referred to palliative care' (p.4), in *Australian Health Review*.

'Early palliative care associated with lower costs for adults with advanced cancer: Evidence from Hungary' (p.8), in *European Journal of Cancer Care*.

'Palliative care nursing development in the Middle East and Northeast Africa: Lessons from Oman' (p.9), in *Journal of Cancer Education*.

'Care for the dying in contemporary Russia: The hospice movement in a low-income context' (p.11), in *Mortality*.

care, a need for increased transparency and accountability for Commonwealth funding and a need to create a stable workforce through better wages, secure employment, training and career pathways. <https://bit.ly/3xrH4OG>

Extract from *Australian Ageing Agenda* report

The report calls for NSW Government to enhance laws to ensure the availability of RNs on site at all times to safely manage, procure and administer medications as required by residents, particularly with respect to end-of-life and palliative care.

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Noted in Media Watch 1 March 2021 (#706, p.11):

- **NURSING EDUCATION TODAY** | Online – 23 February 2021 – ‘**Preparing nurses for palliative and end-of-life care: A survey of New Zealand nursing schools.**’ Palliative and end-of-life (EoL) care is an essential skill nurses need to learn. This article provides comprehensive information about palliative and EoL care teaching in undergraduate nurse education in New Zealand. Teaching on this subject is not a mandatory requirement so there are inconsistencies in the teaching provided between educational institutions, and significant barriers to development. Mandatory competencies need to be introduced to ensure graduates have the knowledge, skills and attitudes required to provide optimal care for people near the EoL. **Abstract:** <http://bit.ly/3qRNTX6>

N.B. A compilation of articles on the palliative care workforce, highlighted in past issues of Media Watch, can be viewed on the European Association for Palliative Care blog at: <https://bit.ly/3vtarPs>. Search back issues of the weekly report for additional articles offering an international perspective on the issue (suggested search word “workforce”) at: <http://bit.ly/2ThijkC>

U.K. faces post-pandemic bereavement crisis and lasting legacy of grief

U.K. | *Mirage* – 15 June 2021 – New research highlights the difficulties and distress people experienced when trying to get support after the death of a loved one during the pandemic, with more than half of people (51%) experiencing high or severe vulnerability in their grief and those seeking support facing long waiting lists or being told they are ineligible.¹ The survey, carried out by Cardiff University’s Marie Curie Palliative Care Research Centre and the University of Bristol, found that of bereaved people demonstrating high or severe levels of vulnerability, three quarters (74%) were not accessing formal bereavement services or mental health support. The majority of people seeking help with their grief said they had struggled to access bereavement services. Of the 40% who tried to get support, just over half experienced difficulties such as long waiting lists, ineligibility or a lack of appropriate support. People also reported discomfort asking for help and were unsure how to access services. The study is funded by the Economic & Social Research Council as part of UK Research & Innovations’ rapid response to COVID-19. <https://bit.ly/3gDDCKf>

1. ‘End of life and bereavement experiences during the COVID-19 pandemic: Interim results from a national survey of bereaved people,’ *BMJ Supportive & Palliative Care*, published online 16 March 2021. **Abstract:** <https://bit.ly/2Szz13G>

Specialist Publications

Palliative care and COVID-19, the Australian context: A review of patients with COVID-19 referred to palliative care

AUSTRALIAN HEALTH REVIEW | Online – 7 June 2021 – Fifty patients, of the 55 reviewed, died in hospital and the median time from palliative care referral to death was 3 days... Five patients were discharged back to residential aged care facilities. Overall 80% of referrals were from the aged care team. The patients had similar demographics, symptoms, medication needs and outcomes to patients in similar settings overseas. The symptom management of patients with COVID-19 was generally straightforward. However, psychosocial needs of patients were predominant and contributed to complexity. This

study highlights the need for well-integrated relationships between the Palliative Care Consultancy Service and the diverse range of key treating teams involved in pandemic healthcare delivery. **Abstract:** <https://bit.ly/35hOnMQ>

Publishing Matters

‘**Gaming the system: The flaws in peer review**’ (p.12), in *Mind Matters*.

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Related:

- *AUSTRALIAN HEALTH REVIEW* | Online – 8 June 2021 – ‘**Who needs, receives and misses out on palliative and end-of-life care? A population-based study to identify needs and gaps in a regional health service.**’ The study population comprised 3,175 patients aged 15 years and over who died in hospital in 2016 and 2017. An estimated 74.8% of decedents needed palliative or other end-of-life care (EoLC) in the year prior to death. Approximately 13.3% did not receive any EoLC despite its potential benefit. The highest proportions with “unmet need” were decedents with chronic obstructive pulmonary disease (31.0%) and heart failure (26.3%). Estimates of need and access provide a sound basis for planning local palliative and EoLC services. **Abstract:** <https://bit.ly/35mcJol>

The impact of COVID-19 on out-of-hours adult hospice care: An online survey

BMC PALLIATIVE CARE (Research Square) | In Review – Accessed 14 June 2021 – Globally COVID-19 has had a profound impact on the provision of healthcare, including palliative care (PC). However, there is little evidence about the impact of COVID-19 on delivery of out-of-hours specialist PC services in the U.K. The aim of the study is to investigate the impact of the COVID-19 pandemic on the delivery of out-of-hours community-based PC services. A national online census survey of managers of adult hospices in the U.K. was undertaken. Survey findings suggest that due to increased demand for community PC services, hospices had to rapidly adapt and reconfigure services. Even though this response to the pandemic led to some service improvements, in the main, out-of-hours service reconfiguration resulted in challenges for hospices, including workforce issues, and availability of resources such as personal protective equipment. These challenges were exacerbated by lack of integration with wider healthcare services. More research is required to fully understand the implications of such changes on the quality of care provided. **Full text (click on pdf icon):** <https://bit.ly/3gmQMMQ>

Noted in Media Watch 30 November 2020 (#694, p.11):

- *PALLIATIVE MEDICINE* | Online – 21 November 2020 – ‘**Effectiveness and cost-effectiveness of out-of-hours palliative care: A systematic review.**’ While out-of-hours palliative care is a recognised priority for patients and policymakers, no evidence base exists on which services are beneficial for patients and worthy of healthcare funding. The lack of evidence underscores the need for future studies to incorporate measurement of the effectiveness and/or cost-effectiveness of out-of-hours services. In principle there are two ways that such evaluations might be initiated. Consistent with other areas of palliative and end-of-life care research, this agenda will have to be flexible and pragmatic in matching methodological approaches to specific problems. **Full text:** <https://bit.ly/3nNIU7P>

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

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



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>

Experiences of fathers of children with a life-limiting condition: A systematic review and qualitative synthesis

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 17 June 2021 – Children with a life-limiting condition often require extensive and complex care, much of which is provided by their parents at home. There is a growing body of research that aims to understand the experiences of these parents, but the majority of this research is from mothers' perspectives, meaning that fathers' experiences are not well understood. Findings from 30 studies were included, representing the experiences of 576 fathers of children with a range of diagnoses including cancer, cystic fibrosis, genetic and neurological conditions. Themes detailed fathers' experiences of uncertainty and shock around the time of their child's diagnosis, their accounts of a "new normal," difficulties in discussing their emotions, forming relationships with and seeking support from professionals and working fathers' role conflicts. They discussed the life-changing nature of their child's diagnosis, an event that affected all aspects of their lives from everyday activities, to their relationships, spirituality, values and ambitions. Fathers experience many difficulties in response to their child's

diagnosis and ongoing treatment. Their responses are not widely understood, and research that directly addresses their own well-being is warranted. **Abstract:** <https://bit.ly/3iUuy6m>

Decision-making and poor prognosis: When death is silenced by action

MEDICAL ANTHROPOLOGY | Online – 16 June 2021- In the hospital milieu, daily questions relate to highly invested areas such as quality of life and death issues, choices to continue or stop active treatment, and the legitimacy of those who take part in such decisions. Stemming from an ethnographic study carried out in a hematology-oncology transplant unit in a Montreal [Quebec, Canada] pediatric hospital, the authors discuss the decision-making process (or lack thereof) when a patient faces poor prognosis and the change of trajectory from a curative/disease directed to a palliative perspective. The intricate relationship between science, caregiver, and care receiver sustains action even when (near) death is the probable outcome. **Abstract:** <https://bit.ly/35ArjA>

Noted in Media Watch 8 March 2021 (#707, p.7):

- *PEDIATRICS* | Online – 1 March 2021 – '**Grief and bereavement in fathers after the death of a child: A systematic review.**' The grief experience of fathers appears to be unique and is likely influenced by the cultural, societal, and religious contexts within their respective lived experiences. Despite evolving gender roles across the past several decades, many fathers remain anchored to the belief that men should deal with loss through stoicism, a "stiff upper lip," self-isolation, and hard work. Yet the literature suggests that, for some fathers, these coping mechanisms may be inadequate for navigating their grief. Better understanding of paternal grief and bereavement has the potential to lead directly to clinical improvements in the care and support of fathers after the death of a child. **Full text:** <http://bit.ly/3b7T7IM>

Noted in Media Watch 21 December 2020 (#697, p.8):

- *PALLIATIVE MEDICINE* | Online – 18 December 2020 – '**A meta-ethnographic study of fathers' experiences of caring for a child with a life-limiting illness.**' To the authors' knowledge, this is the first meta-ethnography focusing on fathers' experiences of caring for their children with life-limiting conditions and the first attempt to develop a conceptual model. Although fathers' characteristics and settings varied greatly, this meta-ethnography conceptualised their experiences during their personal and family crises, generated by their children's life-limiting conditions. It provides a dramatic window into the salience of these experiences in various stages of children's illness and treatment. A limitation is the reliance on data presented in included studies, which may not fully reflect the original data. **Full text:** <http://bit.ly/37vqlA3>

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

Noted in Media Watch 20 January 2020 (#649, p.8):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 17 January 2020 – ‘Engaging fathers in pediatric palliative care research.’ Barriers to study participation included: recruiting healthcare providers’ appraisal of fathers’ lack of well-being, bereaved fathers’ self-reported poor coping and the inability to locate and contact fathers, particularly after a child’s death. Strategies for improving the engagement of fathers into research entailed: educating recruitment personnel, designing “father-focused” studies, communicating the value of the research to recruitment personnel and potential participants, and ensuring that child health records are accurate and include fathers’ contact information. **Abstract:** <http://bit.ly/2TD9THo>

Reducing hospital visit rates in hospice patients using telemedicine

COMPUTERS INFORMATICS NURSING | Online -16 June 2021 – The purpose of this project was to examine the impact of accessibility to a provider via telemedicine on emergency department (ED) visit rates in adults, 35 years and older, on home hospice and palliative care. Utilizing a quasi-experimental design, 44 adults 35 years and older were educated on Doxy.me telemedicine usage as an intervention. Measures included gender, diagnosis, age, the reason for contact, and outcome (intervention group only); the number of ED visits, the number of 911 calls, and the number of discharges/transfers (control and intervention) in the 8 weeks after the evidence-based telemedicine intervention. Among the intervention group, the number of ED visits and the number of 911 calls decreased from to one post-intervention. Paired-samples tests show there were statistically significant differences in the number of ED visits and 911 calls between the two points in time. A telemedicine hospice care application may benefit a palliative and hospice organization by enhancing patient clinical outcomes and decreasing ED visit rates. **Abstract:** <https://bit.ly/3qeakK6>

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

“We are all humans and deserve a decent way to go”: Examining professional’s experiences with providing end-of-life care in correctional institutions

CRIMINAL JUSTICE REVIEW | Online – 11 June 2021 – The aging prison population has increased dramatically over the past two decades. As this population increases, correctional institutions are faced with healthcare challenges. Specifically, providing adequate end-of-life (EOL) care for terminally ill inmates has been a concern. Despite issues relating to providing EOL care, little is known about medical and correctional staff’s attitudes toward the implementation of EOL care. The purpose of this study was to understand the challenges faced by correctional and medical professionals, focusing on job satisfaction, obstacles, and emotional effects of providing EOL care in correctional institutions. The author’s data included 17 semi-structured, face-to-face interviews with medical and correctional staff assigned to the EoL care unit in a southern state [in the U.S.]. Although the entire sample stated overall satisfaction with their job, participants noted several challenges and stressors, which included the lack of resources and difficulties in balancing care. Participants agreed that it was emotionally stressful to maintain appropriate relationships with the inmates, deal with patient manipulation,

and be surrounded by dying and death. Implications are discussed relative to the needs and experiences of service providers and how to more effectively treat EoL inmate patients. **Abstract (w. references):** <https://bit.ly/3cFK6Hj>



Prison Hospice: Backgrounder

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 can be downloaded at the Palliative Care Network website: <http://bit.ly/2RdegnL>

Photo: Lori Waselchuk, Philadelphia, PA

Early palliative care associated with lower costs for adults with advanced cancer: Evidence from Hungary

EUROPEAN JOURNAL OF CANCER CARE | Online – 9 June 2021 – This study demonstrated that early palliative care (PC) for end-stage cancer patients with a very limited prognosis can add value to healthcare by reducing unnecessary costs associated with hospital stays and useless examinations and treatments. Facilitating increased use of home care in Hungary is economically rational and policymakers should investigate how this form of care could be developed (also considering the burden placed on family members, informal caregivers). If the health system can provide enough resources to manage patients at home, it will most probably save money at the system level. Also, awareness of PC needs to be increased in order to achieve earlier patient involvement in this form of care. The cost of PC is currently not reimbursed by the National Health Insurance Fund, but is financed from the hospital's budget, which represents a serious barrier to the access to care on a long-term. In order to increase service availability at hospitals proper funding of PC needs to be established. Sharing best practices and estimating the costs of PC is an essential part of planning for wider implementation in other locations. Policymakers in Hungary and other countries with restricted financial resources and limited specialised palliative services should consider implementing or further developing integrated PC models for the benefit of patients and the healthcare system. **Full text:** <https://bit.ly/3zoO4hh>

Liberating hope in the context of pediatric care at the end of life

INTERNATIONAL JOURNAL OF PRACTICAL THEOLOGY | Online – 12 June 2021 – The spiritual care of dying children and their families requires both sensitivity and competence. Parents – and adults, in general – not only recognize an intrinsic value in children, but also see them as important symbols of hope and as promise for the future. Hence, hope may be challenged when a child is facing death. From the field of spiritual and practical theology, this research attempts to correlate the experience of children and families, and Christian sources on hope. Particular attention is given to the importance of bodies and space, desires and fears, as well as to the role of narratives in order to deepen the meaning of hope in situations that seem bereft of it. **Full text:** <https://bit.ly/3xITUy1>

Learning from history: Remembering the successes and failures of the AIDS crisis to fight COVID-19

INTERNATIONAL PUBLIC HEALTH JOURNAL, 2021;13(1):111-117. Though the COVID-19 pandemic and the AIDS (acquired immunodeficiency syndrome) crisis differ significantly, there is a great deal to be learned about the present by looking back to the early years of AIDS. Considering both the disastrous mistakes and the effective responses made during that time can help us better confront the coronavirus. The problematic response to AIDS demonstrates that a drive for individual accolades can impede scientific collaboration and delay progress when competition goes unchecked. Similarly, it shows us that tragic consequences can occur when political interests take precedence over a duty to protect the public. We can also learn from the successes fighting the AIDS pandemic: how compassion revolutionized end-of-life care, how altruism led to the emergence of support structures for patients, and how a common need to mourn led to the development

of new models of collective grieving. Learning from the mistakes and triumphs of one tragedy can improve our response to another. **Full text:** <https://bit.ly/3gMJOQh>

Extract from *International Public Health Journal* article

The early years of AIDS serve as a precautionary tale about how personal grievances and a drive for individual accolades can impede scientific collaboration and delay progress. Similarly, they show us the calamitous costs that come when leaders prioritize political expediency over public health. Just as we can learn from these failures, however, we can also learn from the triumphs: how compassionate healthcare providers changed our understanding of hospice, how ingenuity and altruism led to novel support structures, and how a grieving public created new methods of mourning.

Essential package of palliative care for women with cervical cancer: Responding to the suffering of a highly vulnerable population

JCO GLOBAL ONCOLOGY | Online – 11 June 2021 – Women with cervical cancer, especially those with advanced disease, appear to experience suffering that is more prevalent, complex, and severe than that caused by other cancers and serious illnesses, and approximately 85% live in low- and middle-income countries where palliative care (PC) is rarely accessible. To respond to the highly prevalent and extreme suffering in this vulnerable population, the authors convened a group of experienced experts in all aspects of care for women with cervical cancer, and from countries of all income levels, to create an essential package of PC for cervical cancer (EPPCCC). The EPPCCC consists of a set of interventions, medicines, simple equipment, social supports, and human resources, and is designed to be safe and effective for preventing and relieving all types of suffering associated with cervical cancer. It includes only inexpensive and readily available medicines and equipment, and its use requires only basic training. Thus, the EPPCCC can and should be made accessible everywhere, including for the rural poor. The authors provide guidance for integrating the EPPCCC into gynecologic and oncologic care at all levels of healthcare systems, and into primary care, in countries of all income levels. **Full text:** <https://bit.ly/3gAPAV4>

Noted in Media Watch 4 February 2019 (#600, p.14):

- *OBSTETRICS & GYNECOLOGY CLINICS OF NORTH AMERICA*, 2019;46(1):179-197. **'Palliative care in gynecologic oncology.'** The integration of palliative care (PC) and hospice into standard gynecologic oncology care is associated with cost-savings, longer survival, lower symptom burden, and better quality of life for patients and caregivers. Consequently, this comprehensive approach is formally recognized and endorsed by the Society of Gynecologic Oncology, the National Comprehensive Cancer Network, and the American Society of Clinical Oncology. This article reviews the background, benefits, barriers, and most practical delivery models of PC. It also discusses management of common symptoms experienced by gynecologic oncology patients. **First page view:** <http://bit.ly/2G4Q5Gd>

Noted in Media Watch 20 August 2018 (#577, p.9):

- *GYNECOLOGIC & OBSTETRIC INVESTIGATION* | Online – 10 August 2018 – **'Gynecologic oncologists' perceptions of palliative care and associated barriers: A survey of the Society of Gynecologic Oncology.'** A total of 174 (16%) gynecologic oncologists [i.e., members of the Society] completed the survey. The majority (75%) agreed or strongly agreed that palliative care (PC) should be integrated into cancer care at diagnosis of advanced or metastatic cancer. The most frequently perceived PC barriers included patients' unrealistic expectations (54%), limited access to specialty PC (25%), poor reimbursement (25%), time constraints (22%), and concern of reducing hope or trust (21%). **Abstract (w. references):** <http://bit.ly/2RUZR4L>

Palliative care nursing development in the Middle East and Northeast Africa: Lessons from Oman

JOURNAL OF CANCER EDUCATION | Online – 15 June 2021 – The Oman Cancer Association in the Sultanate of Oman, in collaboration with the Middle Eastern Cancer Consortium and the Oncology Nursing Society, led a palliative care (PC) initiative over the past decade to better integrate PC into the healthcare system. Components of this initiative include integrating PC into the healthcare curricula and providing PC education to over 400 nurses and other healthcare professionals within Oman. The four-part education series includes the following courses: 1) Foundations of Palliative Care; 2) Advanced Concepts in Palliative Care; 3) Palliative Care Leadership; and, 4) Palliative Care Research. Additional participants from 17 different countries in the Middle East and northern Africa also attended the training. Twenty of the trainees who were considered PC leaders in their countries then participated in a Train-the-Trainer course. This group trained



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the last cohort of healthcare professionals in Oman and then took learned concepts and strategies back to their respective countries in order to provide country-wide education and build PC capacity in the region. Outcomes include the development of PC units, quality improvement projects that improved care, and advocacy projects to increase opioid availability within some countries. The collaborative continues its work and connections through social media, email, and virtual collaboration. Other countries can use this model to permeate PC within their regions. **Full text:** <https://bit.ly/3iLBqms>

Perceptions of need for palliative care in recently hospitalized patients with systolic heart failure

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 10 June 2021 – The symptom burden associated with heart failure (HF) remains high despite improvements in therapy and calls for the integration of palliative care (PC) into traditional HF care. Little is also known about how patients with HF perceive PC and patient-level characteristics associated with the need for PC, which could influence the utilization of PC in HF management. The authors analyzed data from the Hopeful Heart Trial, which studied the efficacy of a collaborative care intervention for treating both systolic HF and depression. PC preferences were collected during routine study follow-up. Participants were on average 64-years-old, male, and reported severe HF symptoms and poor to below average quality of life (QoL). Most had unfavorable impressions of PC, but many still perceived a need for PC. Factors associated with perceived need for PC included depression, non-white race, more severe HF symptoms, and lower mental & physical health-related QoL. Targeted education may help dispel mistaken beliefs about PC more effectively in HF management. **Abstract (w. references):** <https://bit.ly/3vvpDy3>

Noted in Media Watch 14 September 2020 (#683, p.8):

- *EUROPEAN JOURNAL OF HEART FAILURE* | Online – 6 September 2020 – ‘**Integration of a palliative approach into heart failure care: A European Society of Cardiology Heart Failure Association position paper.**’ Integrating palliative care (PC) into evidence-based heart failure (HF) management remains challenging for many professionals, as it includes the identification of PC needs, symptom control, adjustment of drug and device therapy, advance care planning, family and informal caregiver support, and trying to ensure a “good death.” This new position paper aims to provide day-to-day practical clinical guidance on these topics, supporting the coordinated provision of palliation strategies as goals-of-care fluctuate along the HF disease trajectory. **Full text:** <https://bit.ly/2R4dcVr>
- *CIRCULATION: HEART FAILURE* | Online – 9 September 2020 – ‘**Referral criteria to palliative care for patients with heart failure: A systematic review.**’ Patients with heart failure (HF) have significant symptom burden, care needs, and often a progressive course to end-stage disease. Palliative care (PC) referrals may be helpful, but it is currently unclear when patients should be referred and by whom. The authors identified 18 categories of referral criteria, including 7 need-based criteria and 10 disease-based criteria. This systematic review highlighted the lack of consensus regarding referral criteria for the involvement of PC in patients with HF. Further research is needed to identify appropriate and timely triggers for PC referral. **Full text:** <https://bit.ly/3m7OxNY>

Palliative care in the U.K.

An exploratory qualitative study of computer screening to support decision-making about use of palliative care registers in primary care: GP think aloud and patient and carer interviews

JOURNAL OF PRIMARY CARE & COMMUNITY HEALTH | Online – 12 June 2021 – This is the first study to capture GP decision-making about the palliative care (PC) register in real-time. The study has also identified that, in the authors’ sample, 60% of patients/carers were unaware of the PC register and if they/their relative was on it. Moreover, patients and carers in the sample did not know or did not perceive as important, what type of care – palliative or end of life – they were receiving or the label being used to define their care. This is similar to a previous study which found patients and carers have limited understanding of the concept PC. Nonetheless, all patients and carers in the study were fully aware that they or their relative had non-curative disease and that treatment was no longer with curative intent. More important than the use of the

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label PC was how making sure that a person was not suffering or in pain and that their care needs were being met. The study highlights that decision-makers for the PC register and patients and carers face a conundrum – participants on the PC register interviewed in this study perceived that they were not currently in need of PC and therefore not suitable for the PC register because they felt relatively well and healthy and could manage with no or minimal care. **Full text:** <https://bit.ly/3gyg6hE>

Related:

- *JOURNAL OF HEALTH ORGANIZATION & MANAGEMENT* | Online – 22 June 2021 – ‘**System transformation in palliative and end-of-life care: Developing a model for excellence.**’ Although systems’ thinking perspectives can help address the challenges of large-scale transformation ... the potential for systems to benefit from this approach is limited by the complexity of the processes involved and the sheer number of issues to be addressed in practical terms by policymakers and change leaders. The authors report on how the palliative and end-of-life (EoL) care community in one region of England worked together to create a new model for integrated palliative and EoL care to ... reduce unnecessary hospital admissions of people nearing the EoL... **Abstract (w. references):** <https://bit.ly/2SadiPy>

Care for the dying in contemporary Russia: The hospice movement in a low-income context

MORTALITY | Online – 10 June 2021 – This article offers a brief social history of the hospice movement in Russia. The author explains why the hospice movement has become so relevant over the last five years in modern Russia; who the people are who lead this movement; how their ideas collide with “reality”; and, what consequences of this collision can already be observed. The author presents the Russian hospice movement as a dynamic social process which arises in the particular context of the political protests of 2011-2012. The article is based on the first results of ethnographic research conducted in several hospices in Siberia, as well as on data from in-depth interviews with hospice movement activists and archival materials. The author argues that the hospice movements in contemporary Russia serve a social function as grassroots mediation for social and economic care between local bureaucracy and patients. **Abstract:** <https://bit.ly/3xhC53d>

Noted in Media Watch 11 March 2019 (#605, p.4):

- RUSSIAN LEGAL INFORMATION AGENCY | Online – 6 March 2019 – ‘**Russia’s President Putin signs palliative care bill into law.**’ The law specifies the concept of palliative care that involves a package of measures including medical treatment, after care, and psychological actions aimed to improve the quality of terminally ill patients’ living and is oriented to the amelioration of pain. The law confirms the right of terminal patients to pain relief including drug preparations and medical devices. Such assistance is to be rendered on an outpatient basis and at hospitals by specially trained health workers. Palliative patients are also to receive social and psychosocial support as well as religious care... Volunteers, social workers and representatives of religious confessions would be involved in these services. <http://bit.ly/2H4q4YG>

Defining end of life in dementia: A systematic review

PALLIATIVE MEDICINE | Online – 17 June 2021 – This systematic review presents evidence that a definition for end of life (EoL) in dementia remains poorly defined, and unrepresentative of the general population with dementia. Research investigating palliative care that only includes cognitive or functional decline, may fail to recognise other significant signs and unmet needs relevant to dementia and EoL. The authors suggest that researchers and healthcare professionals in dementia care accept the complex nature of EoL in dementia between and within individuals. They advocate for a transition beyond defining EoL by disease-stage, and to consider signs beyond cognitive and functional decline. Identifying the appropriate signs and needs of individuals at the EoL with dementia will require further research, but this will be imperative to an improved understanding of EoL in dementia. This approach may provide an improved response to EoL care for people with dementia and their families. **Abstract (w. references):** <https://bit.ly/3q7quBf>

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

Adapting the serious illness conversation guide for use in the emergency department by social workers

PALLIATIVE & SUPPORTIVE CARE | Online – 18 June 2021 – Although important treatment decisions are made in the emergency department (ED), conversations about patients' goals and values and priorities often do not occur. There is a critical need to improve the frequency of these conversations, so that ED providers can align treatment plans with these goals, values, and priorities. The Serious Illness Conversation Guide has been used in other care settings and has been demonstrated to improve the frequency, quality, and timing of conversations, but it has not been used in the ED setting. Additionally, ED social workers, although integrated into hospital and home-based palliative care, have not been engaged in programs to advance serious illness conversations in the ED. This report presents an adapted Serious Illness Conversation Guide for use in the ED by social workers. This Guide may provide a tool that can be used to increase the frequency and quality of serious illness conversations in the ED. **Abstract (w. references):** <https://bit.ly/3wErgQd>

“Don't forget the children”: A qualitative study when a parent is at end of life from cancer

SUPPORTIVE CARE IN CANCER | Online – 18 June 2021 – There is a need for honest and clear communication from health and social care professionals (HSCPs) to parents surrounding the reality of a parent's poor prognosis, to enable a systematic approach of preparing the children for the death of their mum or dad. While parents often feel ill-equipped to prepare their children for the death of a parent from cancer and desire supportive guidance from healthcare teams, this is a challenging aspect of care for HSCPs to provide. Consequently, family-centred care is often inadequate in practice. There is a need for HSCPs to reassure parents that by involving the children early in the end-of-life experience, when the ill-parent is “well enough” to parent, enables them to be actively involved in supporting their child through one, if not the greatest life changing event. This enables the sharing of sadness, providing love and support that only a parent can. Earlier preparations are likely to prevent “crisis management” as death becomes imminent in the final weeks and days of life and promote better adjustment for the children in the future. **Full text:** <https://bit.ly/3gyDrAZ>

N.B. See literature review at ‘The Crossroads of Grief: Understanding Grief & Diversity,’ published by the Children & Youth Grief Network, Ontario Canada.’ In particular, ‘Children's Understanding of Death & Dying’ (p.5), ‘Parental Illness, Dying & Death’ (p.13), and ‘Death of a Parent (p.30) at: <http://bit.ly/2OB4Y6C>

Publishing Matters

Gaming the system: The flaws in peer review

MIND MATTERS | Online – 15 June 2021 – In theory, the peer review process is intended to ensure that research papers do not get published unless impartial experts in the field deem them worthy of publication. Peer review is well-intentioned, but flawed in many ways. First, the best researchers are incredibly busy and naturally more inclined to do their own research than to review someone else's work. Thus, peer review is often cursory or done by people who have ample time on their hands because they do relatively little research. Ill-informed and contradictory reviews are familiar to everyone who publishes in academic journals. From the journal's perspective, academic journals can be a cash cow since authors and reviewers are not paid anything and universities feel obligated to subscribe. In 2012, Harvard University reported that some journals were charging its library \$40,000 annually and that its total annual cost of journal subscriptions was an “untenable” \$3.5 million. In 2019, after lengthy negotiations, the University of California stopped its Elsevier subscriptions which were costing \$10 million annually. The escalating costs have led to an open-science movement in which journal articles are freely available online, with the publication costs borne by authors (and are typically paid for by their employer or with grant money). However, as the open-access model gained traction, unscrupulous publishers moved in to exploit authors fighting the publish-or-perish battle. **Full text:** <https://bit.ly/3cH5uf6>

Media Watch: Editorial Practice

EACH LISTING IN MEDIA WATCH represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

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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.

IPCRC.NET International Palliative
Care Resource Center

Search Back Issues of Media Watch @
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Media Watch: Access on Online

International



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

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Asia



Asia Pacific
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ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://bit.ly/2SWdYWP>

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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



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

[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health: <https://bit.ly/3g82uuS>

[Scroll down to 'General Resources' and 'Media Watch']

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>

HUNGARY | Magyar Hospice Alapítvány: <http://bit.ly/2RgTvYr>

U.K. | Omega, the National Association for End-of-Life Care: <http://bit.ly/2MxVir1>

South America

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

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