

Media Watch... is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

Patients, families and carers rate effective communication and shared decision-making as having primary importance, ahead of other end-of-life domains such as expert, respectful and compassionate care, and trust and confidence in clinicians.

'Care of the adult cancer patient at the end of life: European Society for Medical Oncology Clinical Practice Guidelines' (p.7), in *Cancer Horizons*.

Canada

Palliative care competency framework: A curriculum guide for educators and reference manual for people providing palliative care

CANADIAN PARTNERSHIP AGAINST CANCER | Online – Accessed 22 August 2021 – The framework establishes a minimum national standard for palliative care (PC) in Canada, and it seeks to direct consistent implementation and measurement of PC competencies in practice. It serves as a guiding document for jurisdictions that lack an explicit set of PC competencies, and also as high-level guidance for provinces that have built their own competency frameworks. The framework is written with several readers in mind: 1) Individuals, managers, and human resources personnel will use it to fill skills gaps and guide hiring practices; 2) Educators will use it to identify minimum standards for PC competencies, weave the development of essential skills into existing curricula, or build new curricula to teach the competencies; and, 3) National accreditation and regulatory agencies will use it as a guide for establishing minimum national standards in PC. **Download at:** <https://bit.ly/3zc1kFi>

U.S.A.

Advancing the Economics of Palliative Care: The Value to Individuals and Families, Organizations, and Society

CALIFORNIA | University of Southern California Schaeffer Center for Health Policy & Economics – Accessed 28 August 2021 – Current research assessing the economic outcomes of palliative care (PC) is limited, and policymakers, payers, patients and clinicians need more information to appropriately and systematically implement PC in the U.S. Filling this research gap can help identify optimal ways to deliver and pay for PC across settings as well as strategies to encourage PC referrals and uptake. Moreover, projecting

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future needs for PC through modeling and other analytic techniques can inform care provision, future research and, ultimately, policy decisions. In 2020, the USC Schaeffer Center for Health Policy & Economics established an advisory panel to identify and consider how to address the gaps in research at the interface of economics and PC. The panel includes clinicians, economists and select participants from health system, payer and policy domains. This background paper, authored by the panel chairs, aims to set the stage for developing a consensus-based research agenda that advances PC in the U.S. and makes a case for funders to support this research. **Download at:** <https://bit.ly/3gFqnJO>

Specialist Publications

'Palliative care training for geriatric psychiatry fellows: A national survey project' (p.3), in *American Journal of Geriatric Psychiatry*.

'Latino families' decisions to accept hospice care' (p.4), in *American Journal of Hospice & Palliative Medicine*.

'Analyzing the unique needs of international palliative care learners attending a U.S.-based palliative care education and practice course' (p.9), in *Journal of Palliative Medicine*.

Are you unvaccinated? It's time to make an end-of-life plan

NEWSWEEK | Online – 25 August 2021 – In the U.S., only 56% of people have had a conversation with their loved ones about end-of-life wishes.¹ Only 27% have documented their EoL wishes in the form of an advance directive (AD), and less than 20% discussed those wishes with their healthcare provider. In the early days of the pandemic, one health system saw a 4.9-fold increase in online completion of ADs. Given our experience with the pandemic, we can anticipate some of the choices you can expect to make. In the absence of an AD, an established healthcare proxy or available next of kin, the default approach is aggressive, invasive treatment in the intensive care unit. This typically includes placing a thick, hard, plastic tube down your windpipe, inserting needles into your blood vessels, and using machines to maintain your regular bodily functions. If your heart stops beating, you will receive chest compressions where ribs often crack under the pressure, which is often very painful, and if you survive, it can be traumatic. We are all entitled to choices. If you're not interested in vaccination to protect yourself from an infection – or to protect immunocompromised people, older adults and children who have not yet had the chance to receive a vaccine – then please take time to ponder your wishes should you become hospitalized. <https://bit.ly/3sMV1FU>

1. 'Kaiser/*Economist* survey highlights Americans' views and experiences with end-of-life care, with comparisons to residents of Italy, Japan and Brazil,' *Kaiser Health News*, published online 27 April 2017. [Noted in Media Watch 1 May 2021 (#510, p.3)] <http://bit.ly/2v1pINJ>

Illinois to release some incapacitated or terminally ill prisoners

ILLINOIS | **WTVO** (Chicago) – 21 August 2021 – Illinois Governor JB Pritzker signed legislation which would allow for the release of incapacitated or terminally ill prisoners from incarceration. HB 3665 allows for the discretionary early release of those who are medically incapacitated or terminally ill who are serving time in the Illinois Department of Corrections. Currently, the Prisoner Review Board (PRB) determines conditions of parole and notifies victims and families when an inmate will be released from custody. The board also makes recommendations for clemency petitions to the Governor. This legislation gives the PRB the authority to grant or deny a prisoner early release based on their medical incapacity or terminal illness. In cases of medical incapacity, individuals may not be terminally ill, but in a state that renders them no longer a threat to the community. HB 3665 not only provides better, more compassionate care to Illinois' seriously ill population, but helps improve the overall prison healthcare system. The law becomes effective 1 January 2022. <https://bit.ly/3zitWwX>

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Noted in Media Watch 17 February 2020 (#653, p.6):

- *AMERICAN JOURNAL OF PUBLIC HEALTH*, 2020;110(1):S25-S26. ‘Strategies to optimize the use of compassionate release from U.S. prisons.’ As many incarcerated older adults experience multiple physical and mental health conditions at higher rates than do non-incarcerated persons, prison yards are now peppered with walkers, wheelchairs, and other durable medical equipment. Incarcerated older adults are vulnerable to predation and often live in environments not designed to meet their physical needs. As a result, older adults generate high costs for overcrowded correctional systems, many of which are ill suited to provide the complex medical care needed for patients of advanced age or approaching end of life. **Full text:** <http://bit.ly/2ScUqNe>

N.B. End-of-life care in prisons 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 is available by way of a ‘Backgrounder.’ The Backgrounder was last updated 1 August 2021; additional articles on compassionate release in the U.S. are noted on pp.3-4. **Downloaded at Palliative Care Network website:** <http://bit.ly/2RdegnL>

Specialist Publications

Palliative care training for geriatric psychiatry fellows: A national survey project

AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY | Online – 21 August 2021 – Palliative care (PC) is an essential part of the standard of care for individuals with serious medical illnesses. Integration of PC and mental health is important for elderly patients with medical and psychiatric comorbidities. Geriatric psychiatrists are natural stewards of PC-mental health integration, however this is contingent on PC training. Currently, PC care training in geriatric psychiatry fellowship programs is uncharacterized. The authors surveyed geriatric psychiatry fellowship program directors in the U.S. to assess current PC training practices. 46% (28/61) of program directors responded to a web-based anonymous survey: 71% (20/28) of programs provide didactics on PC; 77% (20/26) of programs provide clinical experiences in PC; and 63% (15/24) have formalized interactions between geriatric psychiatry and PC fellows. PC training for geriatric psychiatry

fellows is robust but unstandardized. Operationalizing PC training for geriatric psychiatrists may improve mental health integration into serious illness care. **Abstract:** <https://bit.ly/3B5WUjZ>

Research Matters

‘A review of clinical trials of advance care planning interventions adapted for limited health literacy’ (p.13), in *Palliative & Supportive Care*.

Publishing Matters

‘A credit-like rating system to determine the legitimacy of scientific journals and publishers’ (p.13), in *Scientometrics*.

Noted in Media Watch 23 August 2021 (#731, p.8):

- *FOCUS* | Online – 18 August 2021 – ‘Palliative care: Critical concepts for the geropsychiatrist.’ Psychiatrists can make a significant contribution to improving quality end-of-life care (EoLC) for their patients, beyond managing their psychiatric and psychological conditions. Geriatric psychiatrists can build expertise in enhancing EoLC when caring for older adults with serious illnesses and their families, given the biopsychosociospiritual approach that significantly overlaps with palliative and hospice care approaches. It is essential for psychiatrists to understand the core principles and practices of palliative and hospice care, learn basic symptom management skills, and hone the ability to have crucial conversations regarding prognosis and advance care planning. **Abstract:** <https://bit.ly/3D7r7AQ>



Would the *American Journal of Geriatric Psychiatry* article be of interest to a colleague?

Latino families' decisions to accept hospice care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 25 August 2021 – The under representation of Latinos in hospice care is well-documented. A gap remains, however, in the literature's description of the factors that shape Latino families' decisions to enroll in hospice care. The need for such understanding is dire considering the shifts in population and the research evidence that Latinos experience worse end-of-life (EoL) outcomes compared to non-Latino whites. This study contributes to such understanding by exploring Latino older adults' experiences with healthcare broadly and reasons for choosing hospice care specifically, including how they learned about hospice and their understanding of the service at the time of enrollment. Findings show that hospice represents a way to access services, and not necessarily a philosophy of care that Latinos understand or seek at EoL. Healthcare providers such as hospital and hospice social workers must engage in efforts to enhance advance care planning discussions and hospice education with the Latino community. **Abstract (w. references):** <https://bit.ly/2UOQuGw>

Noted in Media Watch 5 April 2021 (#711, p.4):

- *GLOBAL QUALITATIVE NURSING RESEARCH* | Online – 23 March 2021 – **'Four kinds of hard: An understanding of cancer and death among Latino community leaders.'** As the Latino population in the U.S. continues to age, it is even more imperative to address effective delivery of palliative care (PC) and understand the cultural perspectives on cancer and death that influence end-of-life decisions. This project elicited the cultural perspectives of Latino leaders who affirmed the need for, and feasibility of, trained community members to initiate conversations about advance care planning and symptom management among Latino families with cancer. Community leaders can provide valuable direction for the development of PC services for underserved groups... **Full text:** <https://bit.ly/3csFvIQ>

Large differences in the organization of palliative care in nursing homes in six European countries: Findings from the PACE cross-sectional study

BMC PALLIATIVE CARE | Online – 25 August 2021 – Using previously defined quality indicators for the organization of palliative care (PC), this study identified several areas of improvement for the organization of PC in nursing homes in six European countries. Dedicated PC functions, specialist PC teams, and a dedicated contact person who maintained regular contact with the resident and relatives were often not structurally embedded in the organization of nursing home care in most countries, in particular in Finland and Poland. There was little structural availability of specialist advice for professionals delivering PC in Finland, Italy and Poland. The availability of opioids was low in nursing homes in Poland. Almost all structural indicators for quality of PC differed significantly between countries. Differences between nursing home types were limited to the availability of specialist PC advice, the regular assessment of relatives' care experiences and the availability of certain specialized equipment. **Full text:** <https://bit.ly/3DjEoXk>



Equal but inequitable

Response of specialist palliative care and hospice services to people from ethnic minority groups with COVID-19: An observational study (CovPall)

BMJ SUPPORTIVE & PALLIATIVE CARE | Inprint – Accessed 24 August 2021 – Policies introduced during the COVID-19 pandemic may have adversely impacted those from certain ethnic minority groups, making these at-risk populations even more vulnerable. Furthermore, the traditional palliative care (PC) focus on individual care may be insufficient to provide equitable care. During the para-COVID period, systemic steps, including equality impact assessments, are urgently needed to identify, label and address inequities to ensure favourable experience and outcomes at the end of life for all patients and their families. Within the U.K., all public authorities and organisations have a legal duty to consider how their policies or decisions affect those from ethnic minority groups. An equality impact assessment is a legal requirement designed to

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help organisations ensure that their policies, practices and decision-making processes are fair and do not unfairly disadvantage protected groups[. Where policies are found to unfairly disadvantage a protected group, safeguards and mitigation measures should be introduced. This may include flexibility in policies to take account of patients' communication and religious needs and the introduction of video-conferencing via tablets to facilitate communication for family, professional translation services and religious support. Whilst policies introduced rapidly during the first wave of the COVID-19 pandemic may have been justified by the legitimate aim of protecting the general public, all services now need to urgently assess the impact of these and future policies on patients and families from ethnic minority groups. This should include specifically targeting issues around language and distress caused by "one size fits all" policies. Formal safeguards and mitigation against the negative impact of these policies on these groups, beyond a sole focus on individualised care, is urgently needed. Whilst our work is focussed on PC services, our recommendations are relevant and timely for all healthcare specialities and settings. Whilst this data is U.K. based, recommendations would potentially be applicable internationally. **Download full text at:** <https://bit.ly/2UOf180>

N.B. CovPall is a project that is trying to understand more about how PC services and hospices are responding to the COVID-19 pandemic, the problems that services and patients and families/those affected by COVID-19 are facing, and how to best respond. **CovPall website:** <https://bit.ly/2ANoNDr>

Related:

- *AUSTRALIAN HEALTH REVIEW* | Online – 27 August 2021 – '**Palliative care and COVID-19 in the Australian context: A review of patients with COVID-19 referred to palliative care.**' Palliative care (PC) has played a key role in the response to the COVID-19 pandemic in Australia. There is limited research describing the Australian PC experience with the COVID-19 pandemic. Patients with COVID-19 referred to a hospital-based PC consultancy service in Australia had similar demographic characteristics, symptoms, medication needs and outcomes to patients with COVID-19 referred to other PC services in the U.K. and the U.S. There were significant psychosocial issues affecting patients, families and staff in the context of the pandemic. **Abstract (w. references):** <https://bit.ly/3ym61LM>
- *NEJM CATALYST INNOVATIONS IN CARE DELIVERY*, 2021;2(9). '**Systemwide advance care planning during the COVID-19 pandemic: The impact on patient outcomes and cost.**' WellSpan Health, an integrated system of eight hospitals and more than 170 outpatient locations, adopted a systemwide approach to implement team-based advance care planning (ACP) processes. A remote response team helped high-risk patients with COVID-19 with ACP. The authors analyzed ICU use and costs for 356 patients who died of COVID-19 after being admitted to WellSpan hospitals. Systematic ACP, leading to proactive decision-making for treatment preferences by patients and their family members, reduce unwanted medical interventions and cost of care. **Full text:** <https://bit.ly/3B75oHv>

We all want to die in peace. So why don't we?

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 19 August 2021 – Approximately 70% of Americans would prefer to die at home and avoid hospitalization or intensive care during the terminal phase of illness. Given the wish to die at home, it should follow the majority of Americans achieves their wish. However, recent data indicate ~60% of people die away from home... This article sets out to understand what makes it so difficult to attain what we aspire for in death and provide a starting point for change. The authors reviewed and analysed literature on elements which drive patients to continue treatment even though prospects are grim. Six elements which combine into a system driving non-peaceful death were identified (western culture, healthcare system, pharmaceutical industry, professionals, family and loves ones, patients themselves), complemented with three additional factors entrenched in us as humans which make the system particularly difficult to overcome (rational decision-making, option framing, inability to change). Dying in peace is easier said than done because the cards are stacked against us and we seem to remain unaware of the breadth and depth at which continuing treatment is ingrained in our system. **Abstract:** <https://bit.ly/3j57nWY>

Virtual reality in hospice: Improved patient well-being

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 19 August 2021 – Virtual reality (VR) technology as a therapeutic intervention has been gaining attention in healthcare settings in recent years. Studies suggest that using the technology can help alleviate symptoms such as pain and anxiety and induce positive emotions for people in hospital. Managing symptoms and promoting emotional and psychological well-being are core palliative care goals of relieving suffering of people with life-limiting illness. Accordingly, VR may be highly beneficial for use in hospice care yet remains underdeveloped in such settings. This qualitative study aimed to trial the technology and consider what benefits may emerge for hospice in patients. A one-off VR session was offered to patients at a hospice in Scotland. Nineteen hospice patients successfully tried an immersive VR experience. VR sessions were acceptable for people within the hospice environment. The majority of participants enjoyed the experience. Many expressed joy and delight at the process. VR holds possibilities for relieving symptoms such as pain and anxiety frequently experienced by people in hospices. Furthermore, the technology offers the capacity to reconnect with a previous sense of self and to allow respite through the capacity to transcend current reality and connect with another meaningful reality. This exploratory study offers a starting point for larger studies to investigate the utility of VR for hospice patients. **Abstract:** <https://bit.ly/3AZebv5>

Noted in Media Watch 16 August 2021 (#730, p.12):

- *QUALITATIVE HEALTH RESEARCH* | Online – 12 August 2021 – ‘**Recommendations for virtual qualitative health research during a pandemic.**’ The authors respond to methodological needs created by COVID-19. Specifically, they explore unique elements of, and recommendations for, the design and conduct of obtrusive Virtual qualitative research (VQR) – online interviews, online focus groups, and email interviews – and demonstrate crucial ethical, recruitment, analytical, and interpretive considerations. Researchers are currently faced with an ethical imperative to advance VQR methods and ensure that rigorous QHR continues during this pandemic and beyond. This article provides a starting point for researchers to explore the potential of VQR. **Abstract (w. references):** <https://bit.ly/3iKqXHM>

Noted in Media Watch 9 August 2021 (#729, p.4):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 6 August 2021 – ‘**Harnessing new and existing virtual platforms to meet the demand for increased inpatient palliative care services during the COVID-19 pandemic: A 5-key themes literature review of the characteristics and barriers of these evolving technologies.**’ Overall, telepalliative care does appear to have the capacity to meet the increased demand for safe and accessible inpatient palliative care (PC) during a pandemic. While virtual inpatient PC is not perfect and some challenges exist, this service allows patients to have meaningful interactions with their extended care team and family while isolated in hospital or in hospice, and feel more supported as they approach end of life. **Full text:** <https://bit.ly/3jvvi4E>

A national survey of ambulance paramedics on the identification of patients with end-of-life care needs

BRITISH PARAMEDIC JOURNAL, 2021;5(4):60-61. Developing the proactive identification of patients with end-of-life care (EoLC) needs within ambulance paramedic clinical practice may improve access to care for patients not benefitting from EoLC services at present. To inform development of this role, this study aimed to assess whether ambulance paramedics currently identify EoLC patients, are aware of identification guidance and believe this role is appropriate for their practice. Ambulance paramedics frequently encounter patients that they perceive are not receiving appropriate EoLC provision, and participants in this study overwhelmingly supported a role in highlighting this to primary care providers. Though many paramedics are already making referrals for these patients, the majority are performed without knowledge of validated EoLC assessment guidance. Provision of EoLC assessment training might therefore be expected to improve the timeliness and sensitivity of referrals, potentially addressing current inequalities in access to EoLC. The communication difficulties currently encountered when making a referral might be addressed by the provision of dedicated EoLC referral pathways. **Abstract:** <https://bit.ly/3kfk3M>

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

Care of the adult cancer patient at the end of life: European Society for Medical Oncology Clinical Practice Guidelines

CANCER HORIZONS | Online – 17 August 2021 – In palliative care (PC), the term “end of life” (EoL) is commonly used but inconsistently defined. This European Society for Medical Oncology Clinical Practice Guideline refers to EoL as care for people with advanced disease once they have reached a point of rapid physical decline, typically the last few weeks or months before an inevitable death as a natural result of a disease. This guideline considers the last weeks and days of life for the adult patient with advanced cancer. At EoL, the goal-of-care is focused towards comfort, offering a tailored and individualised management of quality of life (QoL) and approaching death of the patient. Thus, early integration of supportive care and PC in oncology is essential. Comfort care is holistic and person-centred, focusing on the interrelationship between physical, psychosocial and spiritual issues. This warrants the cessation of cancer-modifying treatments and disproportionate interventions, focusing on symptom relief and “whole person” or “total care.” It is well documented that PC teams improve symptom control, satisfaction and psychological support for patients and families in hospitals, hospices and community settings, particularly at EoL. In the absence of multi-professional PC teams, and to enhance better collaboration, oncologists need skills to intervene beyond oncological therapies. Communication with the patient and their family becomes a priority to ascertain the therapeutic choices available. Furthermore, the care setting at EoL needs careful evaluation so that monitoring of overall well-being enables the best QoL and a dignified death. EoL provides specific challenges in clinical management of oncology patients, which can be addressed through a multi-professional and collaborative approach. Oncologists have a responsibility to ensure the smooth transition of the patient and family from living to dying and to coordinate the necessary resources for effective and timely intervention. **Full text:** <https://bit.ly/3sAZueE>

Participatory design of an electronic medical record for paediatric palliative care: A think-aloud study with nurses and physicians

CHILDREN | Online – 12 August 2021 – Electronic medical records (EMRs) offer a promising approach to mapping and documenting the complex information gathered in paediatric palliative care (PPC). However, if they are not well developed, poorly implemented EMRs have unintended consequences that may cause harm to patients. One approach to preventing such harm is the involvement of users in the participatory design to ensure user acceptance and patient safety. Therefore, the aim of this study was to evaluate the acceptance of a novel patient chart module (PCM) as part of an EMR from the perspective of potential users in PPC and to involve these professionals in the design process. The results can be summarized in terms of general observations, performance expectancy, effort expectancy and facilitating conditions, all of which are likely to have a positive influence on acceptance of the PCM from the user perspective in the context of PPC. The involvement of users in the development of EMRs is important for meeting the requirements in PPC. Further software adaptations are necessary to implement these requirements. **Full text:** <https://bit.ly/3zdZns4>

Family and healthcare professionals managing medicines for patients with serious and terminal illness at home: A qualitative study

HEALTH SERVICES DELIVERY & RESEARCH | Online – Accessed 24 August 2021 – As patients’ health deteriorated, family caregivers (FCG) assumed the role of a care coordinator, undertaking the everyday work of organising and collecting prescriptions and storing and administering medicines around other care tasks and daily routines. Participants described the difficulties of navigating a complex and fragmented system and the need to remain vigilant about medicines prescribed, especially when changes were made by different professionals. Access to support, resilience and coping capacity are mediated through the resources available to patients, through the relationships that they have with people in their personal and professional networks, and, beyond that, through the wider connections – or disconnections – that these links have with others. Healthcare professionals often lacked understanding of the practical and emotional challenges involved. All participants experienced difficulties in communication and organisation within a

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healthcare system that they felt was complicated and poorly coordinated. Having a key health professional to support and guide patients and family caregivers (FCGs) through the system was important to a good experience of care. The study identified two key and inter-related areas in which patient and family caregiver experience of managing medicines at home in end-of-life (EoL) care could be improved: 1) Reducing work and responsibility for medicines management; and, 2) Improving co-ordination and communication in healthcare. It is important to be mindful of the need for transparency and open discussion about the extent to which patients and FCGs can and should be co-opted as proto-professionals in the technically and emotionally demanding tasks of managing medicines at the EoL. **Full text:** <https://bit.ly/3sJPYQ0>

N.B. Selected articles on managing medications for patients with serious and terminal illness at home noted in Media Watch 19 July 2021 (#726, p.2).

Related:

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 24 August 2021 – ‘**Factors influencing adult carer support planning for unpaid caregiving at the end of life in Scotland: Qualitative insights from triangulated interviews and focus groups.**’ This study highlights the importance of identifying carers early to ensure they have the support they need. The authors advocate for the need to move towards the presumption that a patient has an unpaid carer supporting them at home and ensure they are aware of their entitlements and how to access them. Assessment of support needs should start early and finish late in the carer’s journey, with the process having a longer trajectory than currently recognised, into bereavement. **Full text:** <https://bit.ly/3yld0Ey>

Negative media portrayal of palliative care: A content analysis of print media prior to the passage of voluntary assisted dying legislation in Victoria

INTERNAL MEDICINE JOURNAL | Online – 22 August 2021 – Key misunderstandings of palliative care (PC) exist in the community, with media being reported as a key source underpinning knowledge. This retrospective media analysis of consecutive articles sought to examine the portrayal of PC in the Australian print media, focussing on the 2 years (2016-2018) coverage preceding the voluntary assisted dying legislation in Victoria, Australia. Summative content analyses revealed coverage of PC was frequently (74%) in the context of a discussion of euthanasia. Only small numbers of articles described the activities of PC, and even fewer its potential beneficial impact, while a quarter (26%) described PC was inadequate to relieve suffering. These findings suggest that current coverage of PC in the media may contribute to negative public views and misconceptions. An opportunity exists to enhance media coverage, and in turn, improve the public understanding of care in serious illness. **Abstract:** <https://bit.ly/3B2xXpw>

Nordic specialist course in palliative medicine: Evaluation and impact on the development of palliative medicine in the Nordic countries

JOURNAL OF PALLIATIVE MEDICINE | Online – 20 August 2021 – This article describes the successful experience of establishing and running a common palliative medicine (PM) specialist training course between five Nordic countries (i.e., Denmark, Finland, Iceland, Norway, and Sweden). The survey results and registry data demonstrate a profound impact of the course on the participants’ career within PM, as well as implications for the development of PM in the Nordic countries. Almost all of the 225 participants in the first seven Nordic Specialist Course in Palliative Medicine fulfilled the requirements for the course diploma (98%). The participants’ evaluation of the course has been good. Moreover, besides the formal evaluation, participants have stressed the social and networking aspects of the education. Exchanging knowledge and experiences and building a network are seen as additional professional gains in their new medical field. The networking aspects, the international faculty, and the reputation for high quality have made the course stay attractive, also when Sweden and Finland in later years have organized national courses to obtain formal approval in PM. **Full text:** <https://bit.ly/3D5ZEzG>

N.B. Nordic Specialist Course in Palliative Medicine website: <https://bit.ly/3CZLgZP>

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Related:

- *HEALTHCARE* | Online – 27 August 2021 – ‘**A survey of attitudes and beliefs about care, compassion and communities networks in palliative care: A preliminary study for the development of a compassionate university.**’ The development of this survey, which contains a high reflective component on care, compassion and the way we behave with our own environment at the end of life (EoL), has allowed students to approach the knowledge of the subject in a way closer and compassionate, mobilized by action and not considered as a theoretical subject. Thanks to the results of this study, a Compassionate University project is being developed at the University that sensitizes, trains and mobilizes students and professionals to develop care networks around people at the EoL. **Full text:** <https://bit.ly/2Wv2FJo>
- *JOURNAL OF INTERPROFESSIONAL CARE* | Online – 26 August 2021 – ‘‘**Opening eyes to real inter-professional education’’: Results of a national faculty development initiative focused on inter-professional education in oncology palliative care.**’ This study evaluated participants’ feedback related to their experience in the Interprofessional Education Exchange (iPEX) program, a initiative for faculty development in interprofessional oncology PC education. Reflections submitted by those completing the training were analysed. The most appreciated aspects were the opportunity for exchange of ideas and programs and the time allowed during the workshop for each team to work on developing their unique plan for IPE in oncology PC at their home institution. **Abstract:** <https://bit.ly/2XONWJt>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 23 August 2021 – ‘**Analyzing the unique needs of international palliative care learners attending a U.S.-based palliative care education and practice course.**’ The authors analyzed feedback from international participants in a PC training course, ‘Palliative Care Education & Practice,’ to identify elements of the course that would meet the needs of international learners. Barriers to palliative care (PC) practice change included lack of awareness of PC among local providers, challenges navigating institutional leaders, and a lack of trained providers. Participants requested an increased focus on topics such as resiliency, leadership, and pediatric PC. PC courses should consider offering a specific track for international participants... **Abstract:** <https://bit.ly/3ggqUBjq>

COMPLETE (Communication Plan Early Through End of Life): Development of a research program to diminish suffering for children at end of life

JOURNAL OF PEDIATRIC NURSING | Online – 24 August 2021 – Despite the many advances in medical and nursing care, children with cancer still experience significant physical and emotional suffering over the course of their illness, especially at the end of life (EoL). Children endure significant rates of high-intensity medical interventions (e.g., intubation, intensive care unit admission) at the EoL despite many parents, adolescents, and young adult patients identifying home as their preferred location of death. Hospice care has the potential to ease suffering at the EoL and facilitate home deaths, and yet, most children still die in acute care settings without hospice care. Numerous barriers prevent timely enrollment in hospice among children with cancer who are in the EoL period. This report describes the development and testing of a palliative care/EoL communication intervention designed to overcome some of these barriers and improve EoL outcomes (i.e., earlier hospice enrollment, less use of high-intensity medical interventions, reduced pain and suffering) among children with cancer and their parents (i.e., less emotional distress and uncertainty, improved hope and healthcare satisfaction). **Abstract (w. references):** <https://bit.ly/38iWHNX>

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[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>

Related:

- *JAMA NETWORK OPEN*, 2021;4(8):e2122536. **‘How to make communication among oncologists, children with cancer, and their caregivers therapeutic.’** Therapeutic alliance refers to the “nature and strength of an affective bond between patient or family and the clinician in collaboration toward shared goals.” It is about the quality of clinician-patient relationships, including the mutual affect and respect necessary for trusting, constructive, compassionate, and goal-concordant care. Therapeutic alliance is something all clinicians should strive to achieve. However, there are few empirical descriptions of how to do so, and none explicitly focused on pediatric populations. *Kaye et al* begin to bridge that gap...¹ **Full text:** <https://bit.ly/3syJxWVy>
 1. ‘Facilitators associated with building and sustaining therapeutic alliance in advanced pediatric cancer,’ *JAMA Network Open*, 2021;4(8):e2120925. **Full text:** <https://bit.ly/2WbXaz7>
- *JAMA NETWORK OPEN*, 2021;4(8):e2121888. **‘Patient, family, and clinician perspectives on end-of-life care quality domains and candidate indicators for adolescents and young adults with cancer.’** Despite recommendations from the U.S. National Academy of Medicine for inclusion of stakeholder voices in the development of quality indicators, inclusion of patient and caregiver perspectives remains an underused aspect of quality indicator development. In addition to revealing important quality domains for adolescent and young adults, some of the domains identified in this qualitative study may have relevance to older adults as well. These domains may have not been previously identified owing to more limited use of patient perspectives in quality measure development. **Full text:** <https://bit.ly/2WYI7Vt>
- *JOURNAL OF PEDIATRIC NURSING* | Online – 16 August 2021 – **‘Implementing compassion in pediatric healthcare: A qualitative study of Canadian patients’, parents’, and healthcare providers’ perspectives.’** This study identifies how compassion can be operationalized within pediatric healthcare. Participants generated an operational model of compassion indicating how compassion could be implemented across the organization and larger healthcare system. The data revealed four themes and associated sub-themes: 1) Teach and train; 2) Recognize and reward; 3) Measure and report; and, 4) Embed compassion across the healthcare system. Improving compassion in pediatric healthcare needs to extend beyond the efforts of individual health professionals. **Abstract (w. references):** <https://bit.ly/3kijuPo>

Access and attitudes toward palliative care among movement disorders clinicians

MOVEMENT DISORDERS | Online – 25 August 2021 – Neuropalliative care is an emerging field for those with neurodegenerative illnesses, but access to neuropalliative care remains limited. Members of the Task Force on Palliative Care for the International Parkinson & Movement Disorder Society sought to determine Society members’ attitudes and access to palliative care (PC). Completed surveys indicating country of the respondent overwhelmingly represented middle- and high-income countries. Government-funded homecare was available to 54% of respondents based on patient need, 25% limited access, and 21% during hospitalization or an acute defined event. Eighty-nine percent worked in multidisciplinary teams. The majority endorsed trigger-based referrals to PC, while 24.5% indicated any time after diagnosis was appropriate. Although 66% referred patients to PC, 34% did not refer patients. Barriers were identified by 68% of respondents, the most significant being available workforce, financial support for PC, and perceived knowledge of PC physicians specific to movement disorders. Of 499 respondents indicating their training in PC or desire to learn these skills, 55% indicated a desire to gain more skills. The majority of respondents endorsed a role for PC in movement disorders. Many have palliative training or collaborate with PC physicians. Although significant barriers exist to access PC, the desire to gain more skills and education on PC is an opportunity for professional development within the Society. **Abstract:** <https://bit.ly/2UTwsuy>

N.B. Task Force on Palliative Care for the International Parkinson & Movement Disorder Society website: <https://bit.ly/3sN78mm>

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Related:

- *FRONTIERS IN NEUROLOGY* | Online – Accessed 24 August 2021 – ‘**Communication about end of life for patients living with amyotrophic lateral sclerosis: A scoping review of the empirical evidence.**’ This review demonstrates a small increase in empirical articles discussing end-of-life (EoL) communication with people living with amyotrophic lateral sclerosis. Most reviewed articles were published in clinical neurology journals. Overall, communication about the EoL remains a peripheral part of more broadly focused investigations. This review found that generic communication skills, such as expressing empathy, were important; however, information substance and sufficiency was central to high quality, effective health communication. **Full text:** <https://bit.ly/3j8tcVj>

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

Parenting through grief: A cross-sectional study of recently bereaved adults with minor children

PALLIATIVE MEDICINE | Online – 22 August 2021 – Bereaved adults with minor children are at increased risk of developing depressive disorders. For parentally bereaved children, the surviving parent’s emotional health is both influential and predictive of the children’s psychological outcomes. Among bereaved adults raising minor children, women experience more depressive symptoms in bereavement than men. For bereaved adults raising minor children, the unanticipated death of a co-parent was associated with greater grief distress but not symptoms of depression. Lower parenting efficacy and higher parenting concerns in early bereavement were closely associated with poorer adjustment to bereavement in parents. Assessing parenting concerns in the early bereavement period could enhance the provision of family-centered end-of-life care for dying parents. Across the globe, the devastating toll of the COVID-19 pandemic creates a pressing need to support the mental health of newly bereaved adults with minor children. **Full text:** <https://bit.ly/3mnyX3p>

The experiences of health professionals, patients, and families with truth disclosure when breaking bad news in palliative care: A qualitative meta-synthesis

PALLIATIVE & SUPPORTIVE CARE | Online – 25 August 2021 – Disclosing the truth when breaking bad news continues to be difficult for health professionals (HPs), yet it is essential for patients when making informed decisions about their treatment and end-of-life care. This literature review aimed to explore and examine how HPs, patients, and families experience truth disclosure during the delivery of bad news in the inpatient/outpatient palliative care setting. Eight papers were included in the meta-synthesis and were represented by five Western countries. Following the synthesis process, two concepts were identified: “Enablers in breaking bad news” and “Truth avoidance/disclosure.” Several elements formed the concept of Enablers for breaking bad news, such as the therapeutic relationship, reading cues, acknowledgment, language/delivery, time/place, and qualities. A conceptual model was developed to illustrate the findings of the synthesis. The conceptual model demonstrates a unique way to look at communication dynamics around truth disclosure and avoidance when breaking bad news. Informed decision-making requires an understanding of the whole truth, and therefore truth disclosure is an essential part of breaking bad news. **Abstract (w. references):** <https://bit.ly/3jg89An>

Noted in Media Watch 29 March 2021 (#710, p.6):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 24 March 2021 – ‘**Breaking bad news: Tackling cultural dilemmas.**’ The authors use analysis of the existing literature to develop a communication tool for practitioners facing requests for diagnostic non-disclosure. Their approach builds on existing strategies, in providing a mnemonic communication tool, permitting more than one outcome, and focusing on the need for mutual understanding and cooperation. Existing work on this dilemma highlights the need to appreciate the family’s standpoint, affirm their benevolent intentions and correct misperceptions. To this end, the authors have developed a mnemonic tool, ‘ARCHES.’ to be used in situations where the family has requested diagnostic non-disclosure. **Abstract:** <https://bit.ly/3d7xTdH>

Increasing our understanding of non-physical suffering within palliative care: A scoping review

PALLIATIVE & SUPPORTIVE CARE | Online – 25 August 2021 – Non-physical suffering is emotional, psychological, existential, spiritual, and/or social in nature. While palliative care (PC) is a discipline dedicated to the prevention and relief of suffering – both physical and non-physical – little is known about existing research specific to non-physical suffering within the context of PC. This scoping review helps to fill this gap. Losses, worries, and fears comprise patients' primary sources of non-physical suffering. Patients face numerous barriers in expressing their non-physical suffering to healthcare providers. The idea that patients can choose how they perceive their circumstances, thereby minimizing their non-physical suffering, is pervasive in the research. The nature of non-physical suffering experienced by family caregivers and PC clinicians is revealed in the review. The unique and sensitive interplay between non-physical suffering and both palliative sedation and requests for hastened death is also evident. Overall, seven themes can be identified: 1) Patients' experiences of non-physical suffering; 2) Patient coping mechanisms; 3) Efforts to measure non-physical suffering; 4) Palliative sedation; 5) Requests for hastened death; 6) Family suffering; and, 7) Clinician suffering. This is the first scoping review to map PC's research specific to suffering that is social, emotional, spiritual, psychological, and/or existential in nature. Its findings expand our understanding of the nature of non-physical suffering experienced by patients, families, and PC clinicians. The review's findings have significant implications for front-line practice and future research. **Abstract (w. references):** <https://bit.ly/3jbNi0V>

Noted in Media Watch 10 September 2018 (#580, p.11):

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 5 September 2018 – '**Navigating the intangible: Working with non-physical suffering on the front lines of palliative care.**' Results of this study revealed that palliative care clinicians face several challenges in their efforts to navigate patients' non-physical suffering in their day-to-day work, including: 1) The intangible nature of non-physical suffering; 2) Systemic barriers (e.g., lack of time and adequate resources); 3) Clinician helplessness or suffering; and, 4) A lack of education, training, and support for clinicians specific to their work with patients' non-physical suffering. Study outcomes have the potential to improve frontline clinical care with patients and support and education for clinicians. **Abstract (w. references):** <https://bit.ly/38lbF61>

Evaluating the European Association for Palliative Care Madrid Charter on volunteering in hospice and palliative care: Reflections on impact

PROGRESS IN PALLIATIVE CARE | Online – 22 August 2021 – The Madrid Charter on volunteering was launched in 2017 to advocate for the support, recognition, promotion and development of volunteering in hospice and palliative care (HPC). However, charters are rarely evaluated, and impact often assumed *a priori*. The authors aimed to assess the awareness, reach and impact of the Charter and evaluate its potential as an advocacy tool in HPC. An online survey questionnaire ... was sent to a convenience sample of all 55 Association-member organizations, other regional and national ... volunteering organizations. Forty-six responses were received from 11 countries. The Charter mainly spread through word of mouth (72%). Sixty-four per cent of respondents had heard of the Charter; of these 80% had signed it but only 30% had used it. Directors used the Charter in policy documents (70%). Volunteer coordinators had used it in various ways (57%). Most general coordinators (83%) found no use for the Charter. Feedback from participants indicated a lack of practical applications. The Charter was considered useful for policy negotiation but lacking practical applications to support HPC volunteering in the short term. Charters may be tools for long-term change, rather than immediate change in practice. A multipronged approach may be required where Charters are complemented by practical instruments. **Abstract:** <https://bit.ly/3mExlTI>



Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.15.

Environmental considerations for effective telehealth encounters: A narrative review and implications for best practice

TELEMEDICINE JOURNAL & E-HEALTH | Online – 24 August 2021 – The COVID-19 pandemic has led to expansions in the use of telehealth technology to provide patient care, yet clinicians lack evidence-based guidance on how to most effectively use video communication to enhance patient experience and outcomes. A narrative review was conducted to describe environmental factors derived from research in social psychology and human-computer interaction that may guide effective video-based clinician-patient telehealth communication. Factors such as non-verbal cues, spatial proximity, professionalism cues, and ambient features play an important role in patient experience. The authors present a visual typology of telehealth backgrounds to inform clinical practice and guide future research. A growing body of empirical evidence indicates that environmental cues may play an essential role in establishing psychological safety, improving patient experience, and supporting clinical efficacy in these virtual experiences. The expanded use of telehealth visits suggests the need for further research on the relative effects of these environmental factors on patient experience and outcomes. **Abstract:** <https://bit.ly/3kpbAUF>

N.B. Search back issues of Media Watch for additional articles on “telehealth” in the context of palliative and end-of-life care at: <http://bit.ly/2ThijkC>

Research Matters

A review of clinical trials of advance care planning interventions adapted for limited health literacy

PALLIATIVE & SUPPORTIVE CARE | Online – 26 August 2021 – Only 11% of Americans have discussed advance care planning (ACP) with a healthcare provider. Individuals with limited health literacy are even less likely to participate in ACP due to difficulty comprehending complex health information. The purpose of this review was to identify randomized controlled trials designed to address the effects of limited health literacy on ACP, evaluate the quality of these studies, and summarize evaluation data to inform future studies. A search yielded 253 studies and five studies were included in the final review. Studies were conducted in mostly White patients in outpatient clinics in the U.S. Researchers wrote text at lower reading levels, added images to materials, and created videos to enhance communication. Health literacy interventions increased participant knowledge, preference for comfort care, engagement, and care documentation; however, several methodological issues were identified, including baseline differences in treatment and control groups, issues with blinding, lack of valid and reliable outcome measures, and inappropriate statistical analyses. More high-quality intervention studies that address the effects of limited health literacy on ACP in diverse populations and settings are needed. **Abstract (w. references):** <https://bit.ly/3sPhiD0>

Publishing Matters

A credit-like rating system to determine the legitimacy of scientific journals and publishers

SCIENTOMETRICS | Online – 18 August 2021 – The predatory nature of a journal is in constant debate because it depends on multiple factors, which keep evolving. The classification of a journal as being predatory, or not, is no longer exclusively associated with its open access status, by inclusion or exclusion on perceived reputable academic indexes and/or on whitelists or blacklists. Inclusion in the latter may itself be determined by a host of criteria, may be riddled with type I errors (e.g., erroneous inclusion of a truly predatory journal in a whitelist) and/or type II errors (e.g., erroneous exclusion of a truly valid scholarly journal in a whitelist). While extreme cases of predatory publishing behavior may be clear cut, with true predatory journals displaying ample predatory properties, journals in non-binary grey zones of predatory criteria are difficult to classify. They may have some legitimate properties, but also some illegitimate ones. In such cases, it might be too extreme to refer to such entities as “predatory.” Simply referring to them as “potentially

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predatory” or “borderline predatory” also does little justice to discern a predatory entity from an unscholarly, low-quality, unprofessional, or exploitative one. Faced with the limitations caused by this gradient of predatory dimensionality, this article introduces a novel credit-like rating system, based in part on well-known financial credit ratings companies used to assess investment risk and creditworthiness, to assess journal or publisher quality. Cognizant of the weaknesses and criticisms of these rating systems, the authors suggest their use as a new way to view the scholarly nature of a journal or publisher. When used as a tool to supplement, replace, or reinforce current sets of criteria used for whitelists and blacklists, this system may provide a fresh perspective to gain a better understanding of predatory publishing behavior. The authors’ tool does not propose to offer a definitive solution to this problem. **Full text:** <https://bit.ly/381ssLd>

[Media Watch: Editorial Practice](#)

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Media Watch: Access on Online

International



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Barry R. Ashpole, Ontario CANADA

e-mail: BarryRAshpole@bell.net