

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.

19 July 2021 Edition | Issue #726



Compilation of Media Watch 2008-2021 ©

Compiled & Annotated by Barry R. Ashpole

Medical students and non-palliative health personnel consider hospices and palliative care units as sad, dark, and quiet places.

'Insights from a community-based palliative care course: A qualitative study' (p.5), in *BMC Palliative Care*.

U.S.A.

Dying patients with rare diseases struggle to get experimental therapies

KAISER HEALTH NEWS | Online – 14 July 2021 – For patients ... with serious or immediately life-threatening conditions who do not qualify for clinical trials and have exhausted all treatment options, there may be another option: seeking approval from the Food & Drug Administration (FDA) for expanded, or compassionate use, of experimental therapies. Definitive numbers are hard to find, but studies from researchers, actions by drugmakers and insights from experts suggest that getting expanded access to unproven therapies for rare diseases is more difficult than for more common illnesses, such as cancer. Even with experimental treatments on the rise, patients with rare diseases frequently face an unwillingness by drug companies to provide them before clinical studies are completed. Developing drugs for these diseases is an especially fragile process because the patient populations are small and often diverse, having different genetics, symptoms

and other characteristics, which makes studying the drugs' effects difficult. Drugmakers believe of offering a drug before studies are finished could impair its development and jeopardize FDA approval. <https://bit.ly/3yXmSFj>

Specialist Publications

'**Dying in place: Factors associated with hospice use in assisted living and residential care communities in Oregon**' (p.7), in *Journal of Aging & Environment*.

'**Palliative care attitudes and experiences among resident physicians at historically Black colleges and universities**' (p.8), in *Journal of Pain & Symptom Management*.

N.B. Search back issues of Media Watch for articles on "right-to-try" laws at: <http://bit.ly/2ThijkC>



Share this issue of Media Watch with a colleague

International

Families caring for dying relatives at home need better support with medication management, says new study

U.K. | *Mirage News* – 13 July 2021 – Families who are caring for a relative who is seriously ill and dying at home need more support from healthcare professionals (HPs) in order to help manage their medication, according to a new study.¹ When somebody is seriously ill and dying at home, managing their medications can be a difficult and complex task. This is made more difficult given that the care often needs to be given when patients and their families are tired and emotional. Family members are often assumed to be willing and able to support patients with their medication. However, little is known about what these tasks involve or how families cope with them. In this study, a team of experts explored the views of patients and families managing medications in their homes. The research found: 1) More awareness is needed to understand the ways that managing medications add to the considerable burden of care and work that must be undertaken when someone is seriously ill and dying at home; 2) Family caregivers are increasingly expected to undertake complex and technical medication

tasks formerly carried out by HPs, but with little if any training, supervision or support (this trend has been exacerbated by COVID-19; and, 3) The work of managing medications is critical to enabling patients to remain at home at the end of life. The findings of the research have implications for practice and policy. <https://bit.ly/3ehfMDG>

Specialist Publications

'Priorities and opportunities for palliative and end of life care in U.K. health policies: A national documentary analysis' (p.4), in *BMC Palliative Care*.

'Transferring home to die from critical care units: A scoping review of international practices' (p.7), in *Journal of Critical Care*.

'Australian perspectives on spiritual care training in healthcare: A Delphi study' (p.9), in *Palliative & Supportive Care*.

1. 'The "work" of managing medications when someone is seriously ill and dying at home: A longitudinal qualitative case study of patient and family perspectives,' *Palliative Medicine*, published online 12 July 2021. **Abstract (w. references):** <https://bit.ly/3eieAjs>

Noted in Media Watch 18 May 2020 (#666, p.7):

- *BMC PALLIATIVE CARE* | Online – 11 May 2020 – **'An exploration of the experiences of professionals supporting patients approaching the end of life in medicines management at home. A qualitative study.'** Healthcare professionals reported a variety of ways in which they tried to support patients to take medications as prescribed. While this article presents some solutions and strategies reported by professional respondents it is clear from both professional and patient/family caregiver accounts in the wider study that rather few professionals provided this kind of support. Standard solutions offered included: rationalising the number of medications; providing different formulations; explaining what medications were for and how best to take them. **Full text:** <https://bit.ly/2xWPdBR>

Noted in Media Watch 18 February 2019 (#602, p.13):

- *MEDSCAPE* | Online – 13 February 2019 – **'Dying at home: The burden of medication management.'** The management of medications in patients with late stage disease is becoming a major area of concern. A recent literature review explored the experiences and perspectives of family caregivers in managing medications for a family member being cared for and dying at home.¹ The authors reviewed 15 studies in this area and synthesized the findings into five key themes that provide a framework to improve support for these caregivers: These concepts provide important perspectives on caregiver fears, such as over-medicating the patient, and challenges in understanding instructions, particularly with multiple medications. **Full text:** <https://wb.md/2X43MeD>

1. 'Managing medicines for patients dying at home: A review of family caregivers' experiences.,' *Journal of Pain & Symptom Management*, published online 11 September 2018. [Noted in Media Watch 17 September 2018 (#581, p.12)] **Full text:** <http://bit.ly/2tli8t8>

Specialist Publications

Prolonged grief and bereavement supports within a caregiver population who transition through a palliative care program in British Columbia, Canada

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 July 2021 – In this population of bereaved caregivers within the Fraser Health Authority, 4.7% (high-risk group) met the diagnostic criteria for prolonged grief disorder (PGD) 12-months after their loss. The rate of prolonged grief identified in this palliative care program is quite low. Studies that have similarly used the PG-13 [prolonged grief scale] to assess PGD, report rates between 1.8-15.1% at 12-13 months post-loss. The authors' findings fit within this range. Risk factors for PGD include being female, a spouse or parent of the deceased, having a life-threatening illness, lower income, lack of social support, cultural or language barriers, prior loss, pre-existing mood or anxiety disorders, substance abuse, previous psychological trauma, insecure attachment with the deceased, and the death being sudden or violent. One might have expected the rates of PGD to be higher in the study population given that the majority of caregivers were female, the spouse of the deceased, and had experienced the previous loss of a loved one. Furthermore, almost half had a mental or emotional issues or previous separation anxiety and nightmares, and 21% had financial concerns.

However, the low rates of PGD in this population may be due protective factors observed such as having a high level of education, being Caucasian (implies minimal cultural/language barriers), having religious beliefs, feeling well supported by others, and not struggling with substance use. In addition, the ease of accessibility to counseling and bereavement support groups available through the hospice societies in the Fraser Health region may contribute to a lower incidence of PGD. **Full text:** <https://bit.ly/3xFMPZP>

Research Matters

'The learning health system: An R&D department for local solutions' (p.9), in *Healthy Debate*.

Publishing Matters

'Educating authors and users of the literature to increase vigilance of predatory publishing' (p.10), in *Journal of Hospital Librarianship*.

Reimagining the inpatient palliative care consult: Lessons from COVID-19

AMERICAN JOURNAL OF MANAGED CARE | Online – 12 July 2021 – As the number of inpatients with advanced age and chronic conditions rises, so too does the need for inpatient palliative care (PC). Despite the strong evidence base for PC, less than 50% of all inpatient PC needs are met by inpatient consults. Over the past several months in epicenters of the COVID-19 pandemic, PC providers have responded to the increased need for PC services through innovative digital programs including telepalliative care programs. In this article, the authors explore how PC innovations during COVID-19 could transform the PC consult to address workforce shortages and expand access to PC services during and beyond the pandemic. They propose a 3-pronged strategy of bolstering inpatient telepalliative care services, expanding electronic consults, and increasing training and educational tools for providers to help meet the increased need for PC services in the future. **Full text:** <https://bit.ly/3wDjqXI>

Death and dying are not dirty words: Palliative care and the older person in the COVID-19 pandemic

PSYCHOGERIATRICS | Online – 14 July 2021 – COVID-19 has forced our hand. We need to think and talk about death and dying, particularly with our older patients, their families, and carers. This is an opportunity to inspire change, as one geriatrician has noted: “. . . the outsized impact of COVID-19 on elders has laid bare medicine's outdated, frequently ineffective or injurious approach to the care of patients who are the planet's fastest-growing age group and the generations most often requiring healthcare.” This ineffective or injurious approach has long been the bane of our clinical existence as old age psychiatrists caring for patients who are least likely to receive a “good death.” By a good death we mean a death that is self-determined according to personal preferences and needs. **Full text:** <https://bit.ly/36EQgUz>

Cont.

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

Priorities and opportunities for palliative and end-of-life care in U.K. health policies: A national documentary analysis

BMC PALLIATIVE CARE | Online – 14 July 2021 – National and international calls to strengthen palliative care (PC) through policy have had limited success. The brief references to PC identified in policies imply that a comprehensive, national level effort to improve palliative and end-of-life care is not a major priority for policymakers in the U.K. Even though PC is increasingly recognised as a human right, the role of PC can be poorly understood and recognised, which may hinder political support. Indeed, PC was notably absent from the WHO guidance on maintaining essential health services during the COVID-19 pandemic, even though it is arguably an essential component of the pandemic response. Framing PC as a way to deliver explicit health priorities may be more effective than direct approaches. Furthermore, aligning PC with mainstream health and social care priorities could help to reduce known inequalities in access to care such as by age, socioeconomic position and diagnosis. The authors of this study identify three clear policy priorities that may be opportunities to promote provision of PC in the U.K; calls to increase provision of PC should be framed with these levers in mind. For ongoing research studies, particularly those testing interventions, inclusion of outcomes relating

to the priorities identified will help promote impact following completion of studies. While the authors' results are based on U.K. data, their methods can be replicated in other world regions to identify locally relevant policy levers. **Full text:** <https://bit.ly/3kloMvf>

Is end-of-life care a priority for policy-makers? Qualitative documentary analysis of healthcare strategies

PALLIATIVE MEDICINE | Online – 17 July 2018 – Almost half of Health & Wellbeing Strategies in England included no mention of end-of-life care (EoLC), and very few included EoLC as a priority area. There was a lack of connection between identification of need, relevant targets and interventions for improvement. Even among the six strategies that prioritised EoLC, just three identified a need, a target and an intervention. There was sparse use of evidence, particularly in the context of interventions. Given that the core aim of Health & Wellbeing Strategies is to develop local “evidence-based priorities,” the sparse use of evidence in them is a concern. **Full text:** <http://bit.ly/2ZnGeBR>

N.B. *Palliative Medicine* article noted in Media Watch 23 July 2018 (#573, p.3):

Noted in Media Watch 14 December 2020 (#696, p.12):

- *PALLIATIVE MEDICINE* | Online – 9 December 2020 – ‘**Inclusion of palliative care in healthcare policy for older people: A directed documentary analysis in 13 of the most rapidly ageing countries worldwide.**’ It is unclear to what extent healthcare policy for older people includes elements of palliative care (PC) and thus supports its integration. The aim of this analysis was to develop a reference framework for identifying PC contents in policy documents, and to determine inclusion of PC in public policy documents on healthcare for older people. Analysis of public policy documents on healthcare for older people and using existing literature, the authors developed a reference framework and data extraction form assessing 10 criteria of PC inclusion. **Abstract (w. list of references):** <https://bit.ly/3lV2T36>



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>

Insights from a community-based palliative care course: A qualitative study

BMC PALLIATIVE CARE | Online – 13 July 2021 – Community-based learning in outpatient settings and classroom teaching are very different approaches to learning and their combination enriches the learning process from theory to practice and from everyday practice to teaching. A key pedagogical element is to enable students to apply what they have learned in the classroom and to reflect on their experience. The risk is that, if lectures are not followed up with experience and reflection, students miss the human aspects of the experience. It is necessary to integrate this kind of teaching in educational palliative care (PC) programs. Students' apprehension of the patient and their family beyond the medical relationship allowed them to better appreciate the holistic claim of PC. Bringing students directly from the hospital to the patients in their homes shows the benefits of an integrated healthcare system. Students realize the possibilities and limits of the different PC models of service provision. Healthcare educators should consider evaluating and changing their clinical teaching environment, and exploring community-based learning as the 'Patient Home Visits' model, adapting it to their own needs. This concept could, conceivably, be transferred to other medical faculties and subjects. Further analysis of the topics and additional recording of patient and faculty would be interesting for future projects. **Full text:** <https://bit.ly/36EdOZT>

Artificial intelligent-based clinical decision-making systems in palliative medicine: Ethical challenges

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 13 July 2021 – Despite the integration of artificial intelligence (AI)-based services into routine healthcare practice could have a positive effect of promoting early activation of advance care planning (ACP) by means of a timely identification of palliative care (PC) needs, from an ethical point of view, the provision of these automated techniques raises a number of critical issues that deserve further exploration. The authors reviewed literature with the objective of identifying and discussing the most important ethical challenges related to the implementation of AI-based data processing services in PC and ACP. AI-based mortality predictions can signal the need for patients to obtain access to personalised communication or PC consultation, but they should not be used as a unique parameter to activate early PC and initiate an ACP. A number of factors must be included in the ethical decision-making process related to initiation of ACP conversations, among which are autonomy and quality of life, the risk of worsening healthcare status, the commitment by caregivers, the patients' psychosocial and spiritual distress and their wishes to initiate end-of-life discussions. **Abstract:** <https://bit.ly/3i5H6Wv>

Noted in Media Watch 1 March 2021 (#706, p.7):

- *NEJM CATALYST*, 2021;2(3). '**Supporting acute advance care planning with precise, timely mortality risk predictions.**' Leaders at New York University Langone Health determined that a system more precise than "not being surprised" by a patient's death in six months would give confidence to attending physicians in recognizing patients at the end of life and prioritizing advance care planning conversations accordingly. Replacing the standard "surprise question" with a three-tiered, artificial intelligence – enabled, electronic health record – integrated system has helped physicians identify a narrower, higher-risk population of hospitalized adults with a positive predictive value of 61% for two-month mortality. **Summary:** <https://bit.ly/3seald7>

Noted in Media Watch 6 July 2020 (#673, p.2):

- *STAT* | Online – 1 July 2020 – '**An experiment in end-of-life care: Tapping artificial intelligent's cold calculus to nudge the most human of conversations.**' A handful of hospitals and clinics around the country are deploying cutting-edge artificial intelligence models in palliative care. The daily email that arrived in physician Samantha Wang's inbox ... contained a list of names and a warning: These patients are at high risk of dying within the next year. This list of names was generated by an algorithm that had reached its conclusions by scanning the patients' medical records. The email was meant as a nudge, to encourage Wang to broach a delicate conversation with her patient about his goals, values, and wishes for his care should his condition worsen. <https://bit.ly/38q2Auu>



Would the *BMJ Supportive & Palliative Care* be of interest to a colleague?

Race, ethnicity, and goal-concordance of end-of-life palliative care in pediatric oncology

CANCER | Online – 13 July 2021 – Racial and ethnic minority children with cancer disproportionately receive intensive care at the end of life (EoL). It is not known whether these differences are goal-concordant or disparities. The authors sought to explore patterns of pediatric palliative care (PC) and healthcare utilization in pediatric oncology patients receiving subspecialty PC at the EoL (last 6 months) and to examine goal-concordance of location of death in a subset of these patients. A total of 115 patients including 71 White, non-Hispanic patients and 44 non-White patients (including 12 Black patients and 21 Hispanic patients) were included in the analytic cohort. There were no significant differences in oncologic diagnosis, cause of death, or healthcare utilization in the last 6 months of life. White and non-White patients had similar pediatric PC utilization including time from initial consult to death and median number of pediatric PC encounters. Non-White patients were significantly more likely to die in the hospital compared to White patients. Analysis of a sub-cohort with documented preferences revealed that 91% of White patients and 93% of non-White patients died in their preferred location of death. Although non-White children with cancer were more likely to die in the hospital, this difference was goal-concordant in the authors' cohort. Subspecialty pediatric PC access may contribute to the achievement of goal-concordant EoL care. **Abstract:** <https://bit.ly/3yWM3rE>

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 13 July 2021 – ‘Healthcare professionals’ experiences of the barriers and facilitators to paediatric pain management in the community at end-of-life: A qualitative interview study.’ Inadequate pain management in community paediatric palliative care is common. Seven themes emerged: parents’ abilities, beliefs and wellbeing; working relationships between families and healthcare professionals (HPs), and between healthcare teams; HPs’ knowledge, education and experience; health services delivery; nature of pain treatment; and paediatric-specific factors. The concepts of partnership working between families and HPs, and within healthcare teams, and sharing expertise were prevalent. **Abstract (w. references):** <https://bit.ly/2VGpZDg>

The anticipation of an investigation: The effects of expecting investigations after a death from natural causes in prison custody

CRIMINOLOGY & CRIMINAL JUSTICE | Online – 29 June 2021 – The growing number of deaths from natural causes in prison custody adds urgency to the need to consider what influences the behaviour of prison staff towards dying prisoners. This article identifies the effects on prisoners, their families and prison staff of defining quality end-of-life care (EoLC) as that which meets the expected requirements of an anticipated post-death investigation. Using data collected in two English prisons via ethnographic methods, it explores the practical consequences, emotional effects and bureaucratisation of death arising from the anticipation of an investigation. Taking its lead from research participants, it focuses on the influence of anticipating an investigation by the Prison & Probation Ombudsman, but also the effects of expecting police and coronial investigations.

Analysing responses to anticipating an investigation reveals consequences for the care of prisoners, their families and prison staff, which are arguably unintended by the investigating bodies. **Full text:** <https://bit.ly/3AMIKGp>

Extract from *Criminology & Criminal Justice* article

Of primary interest here is how the anticipated post-death investigation influenced participants’ understandings of acceptable EoLC in prison and informed their actions when caring for a dying prisoner. The expectation of an investigation after a death provided staff and prisoners with one way of informally evaluating care.

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

Integration of palliative care in Parkinson's disease management

CURRENT MEDICAL RESEARCH & OPINION | Online – 13 July 2021 – Analysis of various existing literature has demonstrated promise in timely palliative care (PC) integration for patients with Parkinson's disease, which has shown improvement in the quality of life (QoL) of Parkinson's disease patients. It also strives to alleviate caregivers' stress and improve their QoL, although insufficient research exists to support this. PC in Parkinson's disease is a growing area of interest, evidently demonstrating the potential to expand among the current approaches. Understanding the connections between the themes surrounding PC is crucial for successful integration in Parkinson's disease management. It is determined that integration of PC in patients with Parkinson's disease help to not only improve patients' experiences but also their caregiver's experiences throughout the disease trajectory. Further research should be conducted to address how PC will focus on alleviating caregiver burden and establish specific prognostication tools for Parkinson's disease patients. **Abstract (w. figures & tables):** <https://bit.ly/3wAER2z>

N.B. Search back issues of Media Watch for additional articles on "Parkinson's" disease at: <http://bit.ly/2ThijkC>

Dying in place: Factors associated with hospice use in assisted living and residential care communities in Oregon

JOURNAL OF AGING & ENVIRONMENT | Online – 23 June 2021 – Hospice use among assisted living residents may support aging in place. A cross-sectional survey was used to characterize variation in the health and personal care needs of Oregon assisted living (AL) and residential care residents who did and did not receive hospice services. All AL communities licensed in Oregon as of fall 2019 were asked to answer questions about three randomly selected residents. A final sample of 998 residents was included in the analysis. Multiple variable logistic regression was used to examine associations between resident- and community-level characteristics and hospice use. While hospice services provide supplemental support for AL residents' end-of-life process, findings show that residents often receive continued assistance from AL staff as their condition deteriorates. **Abstract:** <https://bit.ly/3hxAjpG>

N.B. Selected articles on end-of-life care in assisted living communities in the U.S. noted in Media Watch 26 October 2020 (#689, p.5).

Transferring home to die from critical care units: A scoping review of international practices

JOURNAL OF CRITICAL CARE, 2021;65(10):205-215. Of the 28 papers meeting the authors' eligibility criteria 19 were published in the West and seven in China. Transferring home to die is an international phenomenon but varies in the way it is operationalised across countries. In the West transfer is a rare and complex event which is driven by personal preferences and wishes. In Eastern societies transfer practice is motivated by cultural expectations and traditions. Globally different criterion are applied to patients who can be transferred home to die. Reported key barriers to transfer included: lack of evidence guiding transfer practice, the critical care unit environment and culture; practical and logistical factors; and; family members expectations and reactions. Key facilitators of transfer were reported as: engagement with the multidisciplinary team; and, personal patient and family wishes. A key barrier to transfer is that this practice is under-researched and further research is needed to gain more insights. **Abstract:** <https://bit.ly/3wxpMz4>

Family dynamics and the transition to end-of-life caregiving: A brief review and conceptual framework

JOURNAL OF FAMILY THEORY & REVIEW | Online – 5 July 2021 – Family members are an integral part of providing care and comfort at the end of life (EoL). Yet, individuals providing EoL care for a family member are vulnerable to emotional and psychological stress, and often indicate they do not have the knowledge or skills needed for providing this type of care. In addition, family dynamics across the life course may influence family communication and support during the transition to EoL care. Despite these findings, few

Cont.

studies examine family caregiving in the context of the family system during this transition. This study presents a brief review of extant literature and a conceptual framework designed to foster research in family caregiving systems, specifically how family dynamics influence preparedness for the transition to EoL caregiving. The complexity of individual and family aging experiences should be recognized in future research to advance the study of family caregiving and promote family caregivers' health and well-being. **Abstract:** <https://bit.ly/3e7xCc3>

Palliative care attitudes and experiences among resident physicians at historically Black colleges and universities

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 13 July 2021 – Seriously ill Black patients receive lower quality palliative care (PC) than White patients. Equitable access requires PC skills training for all physicians. Historically Black colleges and universities (HBCUs) play a key role in educating Black physicians and have less access to PC resources. Internal medicine and family medicine residents at two HBCUs completed an online survey assessing attitudes towards PC and teaching and clinical experiences in PC. Residents reported receiving less teaching about providing PC than about managing sepsis. In the first survey exploring PC education at HBCUs, residents viewed PC as important but described the quality of their PC education as poor. This study highlights opportunities for improving PC education at HBCUs as a step toward addressing disparities in serious illness care. **Abstract (w. references):** <https://bit.ly/3ei88sx>

Palliative care professionals' inner life: Exploring the mediating role of self-compassion in the prediction of compassion satisfaction, compassion fatigue, burnout and wellbeing

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 12 July 2021 – Palliative care (PC) professionals are exposed to suffering on a daily basis. Working in such an environment frequently raises existential issues, psychological challenges, and emotional distress, that can detract from compassionate care. Identifying factors that help professionals cope with frequent exposure to issues related to mortality, such as compassion, could enhance PC providers' and patients' quality of life (QoL) and wellbeing. A cross-sectional online survey of PC professionals was conducted through the Spanish Society of Palliative Care. The model tested showed an adequate fit ... and the authors' hypotheses were supported. Self-care and awareness predicted coping with death and self-compassion, which in turn predicted professional QoL. Self-compassion had the greatest predictive power. Professional QoL showed a statistically significant and positive effect on personal wellbeing, explaining more than 50% of its variance. For PC professionals, the cultivation of self-compassion is equally needed as compassion for others. Professional QoL and compassionate care are related to professionals' wellbeing: when professionals take care of themselves, this will lead in a more compassionate care, but also in healthier, happier professionals. **Abstract (w. references):** <https://bit.ly/3hBT0Zp>

“Made me realize that life is worth living”: A qualitative study of patient perceptions of a primary palliative care intervention

JOURNAL OF PALLIATIVE MEDICINE | Online – 14 July 2021 – Primary palliative care (PC) is needed to meet the complex needs of patients with serious illness and their families. However, patient perceptions of primary PC are not well understood and can inform subsequent primary PC interventions and implementation. Participants in this study were asked about what was most and least helpful, how the intervention affected participant" lives, and what should be changed about the intervention. The six themes identified that primary care intervention: 1) Cared for my psychosocial needs; 2) Encouraged self-management; 3) Medication recommendations worked; 4) Facilitated goal attainment; 5) Team was beneficial; and, 6) Good visit timing. Participants experienced benefits from the primary PC intervention and attributed these benefits to individualized assessment and support, facilitation of skill building and self-management, and oversight from an interprofessional care team. **Abstract:** <https://bit.ly/3rigYMu>

Top ten tips palliative care clinicians should know about prognostication in oncology, dementia, frailty and pulmonary diseases

JOURNAL OF PALLIATIVE MEDICINE | Online – 14 July 2021 – Prognostication has been described as “medicine’s lost art.” Taken with diagnosis and treatment, prognostication is the third leg on which medical care rests. As research leads to additional beneficial treatments for vexing conditions like cancer, dementia, and lung disease, prognostication becomes even more difficult. This article, written by a group of palliative care clinicians with backgrounds in geriatrics, pulmonology, and oncology, aims to offer a useful framework for consideration of prognosis in these conditions. This article will serve as the first in a three-part series on prognostication in adults and children. **Abstract:** <https://bit.ly/36GczcM>

Australian perspectives on spiritual care training in healthcare: A Delphi study

PALLIATIVE & SUPPORTIVE CARE | Online – 13 July 2021 – This study revealed that spiritual care (SC) training for Australian healthcare professionals should emphasize the understanding of the role of spirituality and SC in healthcare, include a range of delivery methods, and focus upon the incorporation of spiritual screening. The most highly ranked components of SC training were “relationship between health and spirituality,” followed by “definitions of spirituality and SC.” Consensus was not achieved on the item “comparative religions study/alternative spiritual beliefs.” Preferred teaching methods include case studies, group discussion, role-plays and/or simulated learning, videos of personal stories, and self-directed learning. The most highly ranked clinical scenario to be addressed in SC training was “screening for spiritual concerns for any patient or resident.” When asked who should conduct an initial spiritual review with patients, consensus was achieved regarding all members of the healthcare team, with most nominating a chaplain or “whoever the patient feels comfortable with.” It was considered important for SC training to address one’s own spirituality and self-care. Consensus was not achieved on which SC assessment tools to incorporate in training. Further work is required to identify how SC screening should be conducted within an Australian healthcare setting. **Abstract (w. references):** <https://bit.ly/3wDogLB>

Research Matters

The learning health system: An R&D department for local solutions

HEALTHY DEBATE | Online – 14 July 2021 – For the most part, healthcare organizations don’t have R&D departments. Typically, researchers at health organizations apply for grants for a one-off study, but there’s not a steady stream of R&D funding, nor a strategic, leadership-driven approach to research. That’s a problem. As Noah Ivers, a family doctor and researcher at Women’s College Hospital [Toronto, Canada], puts it, “a corporation that is doing research and development doesn’t give a pocket of money for a short amount of time, and then tell the team to disband, and start again, which is basically how health systems research works right now.” A healthcare R&D department could invest in long-term data gathering and analysis and look at where a major healthcare organization is falling short. It could find solutions to address shortcomings and monitor progress over many years. Fortunately, examples of this are emerging. Taking an R&D approach means recognizing that research involves “sunk costs.” Research grants fund people to research one project for a fixed amount of time but an R&D approach of steady funding is needed too ... to get ideas off the ground, connect various research projects and continue improving upon projects even after grants run out. <https://bit.ly/36RDpPf>



Publishing Matters

Educating authors and users of the literature to increase vigilance of predatory publishing

JOURNAL OF HOSPITAL LIBRARIANSHIP | Online – 8 July 2021 – Educating authors and clinicians about predatory publishing and its consequences is vital to protect scholarship and evidence-based practice and is particularly important for those early in their health care careers. Librarians at Mayo Clinic in Rochester, Minnesota, have incorporated this important topic into ongoing literature searching training for internal medicine residents. This article summarizes the level of existing awareness of predatory publishing and the effectiveness of discussing it in small group educational sessions. It is crucial for all healthcare professionals to be informed about the serious threat to the integrity of scientific literature and the potential adverse impact on patient care. **Abstract:** <https://bit.ly/3xKjyNy>



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.

Distribution

MEDIA WATCH IS DISTRIBUTED AT NO COST to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

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.

[Search Back Issues of Media Watch @ http://bit.ly/2ThijkC](http://bit.ly/2ThijkC)



Palliative Care Network

Palliative Care for Everyone, Everywhere

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

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3xFdLsN>

[Scroll down to 'Media Watch: At-home Care']

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://bit.ly/2ThijkC>

PALLIATIVE CARE NETWORK: <http://bit.ly/2Ujdk2S>

PALLIMED: <http://bit.ly/2ResswM>

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at: <http://bit.ly/2MwRRAU>]

Asia



Asia Pacific
Hospice Palliative
Care Network

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

[Scroll down to 'Media Watch']

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/2RqTvYr>

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>

Barry R. Ashpole, Ontario CANADA

e-mail: BarryRAshpole@bell.net