

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

Telehealth access can be improved through interventions such as patient-level training, voice-activated commands, simpler designs, engaging informal caregivers, and finally improving interpreters' access to the telehealth portal.

'Disparities in telehealth use: How should the supportive care community respond?' (p.14), in *Supportive Care in Cancer*.

U.S.A.

A word about the word too many of us are afraid to say

CHICAGO SUN-TIMES | Online – 22 October 2021 – It's time to call hospice something else. According to the American Cancer Society, hospice is "a special kind of care that focuses on the quality of life for people and their caregivers who are experiencing an advanced life-limiting illness." That organization describes hospice as "compassionate care for people in the last phases of incurable disease so that they may live fully and comfortably as possible." But hospice, as well as palliative care, the specialized care for people with serious chronic diseases, has gotten a bad rap. Although hospice has been around since the 1980s, prevailing myths prevent families from accessing the help they need to provide their loved ones with quality care as they "rage against the dying of the light." For instance, a persistent myth is that hospice is a place and can only be provided in a hospital or nursing home setting. Not so. About 70% of hospice care takes place in the patient's home. And while half of hospice patients nationwide have a cancer diagnosis, the other half have other diagnoses, according to the American Hospice Foundation. Other myths include: Medicare won't pay for it. But Medicare

beneficiaries can use their Medicare hospice benefit anytime. Another common myth is once you are in hospice you can't get out alive. The truth is, patients are free to leave hospice and return to treatment if they choose. After all, miracles do happen. But death is certain. We don't know when it will come for us. But we know it is coming. Still, for many, the very mention of hospice is enough to destroy relationships. Maybe it is time to rebrand and educate the public about what hospice really is. <https://bit.ly/3C3vV9D>

Specialist Publications

'**Evolution of palliative care in the Department of Veterans Affairs: Lessons from an integrated healthcare model**' (p.8), in *Journal of Palliative Medicine*.

'**Provision of palliative care during the COVID-19 pandemic: A systematic review of ambulatory care organizations in the U.S.**' (p.9), in *Medicina*.

End-of-life care program at UCLA benefited dying patients and loved ones despite COVID restrictions

CALIFORNIA | University of California Los Angeles – 18 October 2021 – A program offered by UCLA Health’s intensive care units is providing meaningful and compassionate support for dying patients and their families, despite the challenges brought about by COVID-19. A study about the initiative



... is the first to show empirically that a palliative care program could be adapted – and even expanded – during the pandemic.¹ It also could serve as a case study for improving end-of-life care during an era when visiting restrictions and infection control have introduced extraordinary new challenges for healthcare providers. Researchers analyzed the number and types of wishes granted, before and during the pandemic, through UCLA Health’s 3 Wishes Program, which fulfills small but meaningful requests from dying patients and their families. The research found that, despite the challenges of the pandemic, an average of 24.8 patients per month participated in the program ... up from 17.6 patients per month during the same period a year earlier. Patients who died at the UCLA medical centers during the pandemic were less likely than those who died prior to the pandemic to have family with them and, the study found, more likely to have their postmortem wishes fulfilled for their families. <https://bit.ly/3IPWljY>

1. ‘End-of-life care during the coronavirus disease 2019 pandemic: The 3 Wishes Program,’ *Critical Care Explorations*, 2021;3(10):e549. **Full text:** <https://bit.ly/3voAUz1>

Noted in Media Watch 6 July 2020 (#673, p.5):

- *BMC PALLIATIVE CARE* | Online – 29 June 2020 – ‘**Expanding the 3 Wishes Project for compassionate end-of-life care: A qualitative evaluation of local adaptations.**’ The authors describe the adaptations and refinements to the 3 Wishes Project that enabled successful implementation and fostered viability in variable intensive care unit settings despite different contexts, needs and resources. Commitment to quality end-of-life (EoL) care was an essential motivator, inspiring frontline clinicians to initiate the program, creatively resource it, and maintain enthusiasm. As the program became more established, it transitioned from an “add on” to existing EoL programs to become “embedded into” the unit’s approach to EoL care. **Full text:** <https://bit.ly/31t1M48>

Noted in Media Watch 15 June 2020 (#670, p.10):

- *PALLIATIVE MEDICINE* | Online – 10 June 2020 – ‘**Building organizational compassion among teams delivering end-of-life care in the intensive care unit: The 3 Wishes Project.**’ Interviews and focus groups were used by the authors to collect data from family members of dying patients, clinicians, and institutional leaders. Examining the 3 Wishes Project through the lens of organizational compassion reveals the potential of this program to cultivate the capacity for people to collectively notice, feel and respond to suffering. The authors’ data document multidirectional demonstrations of compassion between clinicians and family members, forging the type of human connections that may foster resilience. **Abstract (w. references):** <https://bit.ly/37jzp9B>

Goals-of-care conversations a priority for seriously ill patients

MASSACHUSETTS | *Hospice News* – 18 October 2021 – Recent research from the Massachusetts Coalition for Serious Illness Care found that collaborative communication between clinicians and patients is key to improving health equity among seriously and terminally ill populations.¹ Of nearly 2,500 people surveyed nationwide during the course of last year, 87% indicated that it was important for their physicians to know their priorities. The research was part of a multi-phase project designed to drive improvements in communication and care for people and families facing serious illnesses. The study found that patients and families most wanted to be heard and included in their healthcare decisions, and that they prioritize a collaborative approach above a clinician’s expertise, according to the research. However, people with a serious illness reported that clinicians tended to know their priorities and health goals “less well” than those without. Nearly a quarter of patients with a serious illness indicated feeling afraid to voice concerns to clinicians or ask questions. <https://bit.ly/3ITKruY>

Cont.

1. 'New research finds collaboration and connection between clinicians, patients and families is key to improving serious illness care and health equity,' Massachusetts Coalition for Serious Illness Care, October 2021. <https://bit.ly/3ITLxXB>

Patients say telehealth is OK, but most prefer to see their doctor in person

NATIONAL PUBLIC RADIO | Online – 18 October 2021 – Telehealth is continuing to have its breakout moment – transforming the way we receive routine medical care during the pandemic, when visiting medical centers has carried with it the risk of coronavirus infection. Yet even today, with that infection risk easing for those who have been vaccinated, many patients nevertheless prefer that doctors, nurses and other health workers be able to examine and talk to them in person. That's one finding from a poll by National Public Radio, the Robert Wood Johnson Foundation and the T.H. Chan School of Public Health at Harvard that surveyed patients in August and September. Around 42% of respondents said someone in their household had used telehealth. Of those, 82% reported satisfaction, yet nearly two-thirds (64%) would have preferred to see their nurse or doctor in person. Telehealth's use by various physical and mental health specialties grew tremendously in 2020, as federal and state governments and insurance companies adopted emergency COVID-19 measures, relaxing restrictions on coverage, privacy controls and professional licensing, for example. Now, some of those rules regarding telehealth appointments are being reinstated. <https://n.pr/3aOA0IV>

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

International

Is there equitable access to palliative care for people in prisons

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Blog – 18 October 2021 – Like populations around the world, prison populations are ageing and in some countries this means that increasing numbers of people are growing old and facing the end of life in prison. They often experience multiple and complex health problems in the last months and years of life, which place enormous strain on prison systems and staff, and present many challenges in terms of environments and facilities, equipment, medications, social care and PC. The Association's Task Force on Mapping Palliative Care Provision for Prisoners in Europe was set up in May 2017 with the purpose of examining the provision of PC in prisons in a small number of European countries, to make comparisons and facilitate learning between countries. A second purpose of the task force was to create an international network to bring together health and social care practitioners, researchers and prison staff interested in PC in prison, to share knowledge and potentially form new collaborations. The network, which started with a small handful of people, now has around 80 members from 20 different countries. The task force has now completed the first part of the mapping work,¹ a survey of prison systems in seven European countries (Belgium, Czech Republic, England & Wales, France, Scotland and Slovakia) and Australia. <https://bit.ly/3pmuVdk>



1. 'Mapping palliative care provision in European prisons: An EAPC Task Force survey,' *BMJ Supportive Palliative Care*, published online 22 April 2021. [Noted in Media Watch 26 April 2021 (#714, p.7)] **Abstract:** <https://bit.ly/2QPihnZ>

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,' last updated 1 August 2021. **Downloaded at the Palliative Care Network website:** <http://bit.ly/2RdegnL>



Would this article be of interest to a colleague?

Paupers funerals at record high in Nottinghamshire as more people live and die alone

U.K. (England) | Nottingham Live – 17 October 2021 – The number of paupers funerals arranged by councils in Nottinghamshire jumped by 40% last year, with poverty and rising costs potentially behind the increase. Officially known as “public health funerals,” these ceremonies are arranged by councils for those who die in poverty or with no next of kin. Funerals take place often without flowers, sometimes without even a service, and the dead may be laid to rest in unmarked or “common” graves shared with others. There were 209 such funerals carried out across Nottinghamshire in 2020, up from 149 in 2019 and the highest number in at least five years. Nottingham arranged the highest number of funerals at 164, up by three-quarters in a year from 94, which was also the biggest increase locally. Experts said they feared that low income, the rising cost of funerals, and increasing numbers of people living and dying alone were behind a longer term trend in paupers funerals. <https://bit.ly/3aRwQ0J>

Noted in Media Watch 24 April 2017 (#509, p.6):

- U.K. (England, Scotland & Wales) | iNews TV – 16 April 2017 – **‘Paupers’ funerals rise by 50% in four years.** The number of people who have paupers’ funerals because they die penniless and without relatives to meet the cost is soaring across the U.K. Councils have reported a 50% rise in just four years in the amount of burials and cremations for which they have to pick up the bill. Most people who receive a “public health funeral” are cremated or buried in an unmarked grave. The leap in numbers was attributed to the soaring cost of funerals and people’s savings dwindling as they live longer. Since 2011, cash-strapped authorities have faced an £8.8 million bill for “public health funerals” – an average of more than £60,000 for each town hall. <https://bit.ly/3jb47c2>

Specialist Publications

How can social work practice facilitate a dignified dying experience for people with intellectual disabilities? A scoping review

AUSTRALIAN SOCIAL WORK | Online – 13 October 2021 – Due to improvements in healthcare and the standard of living advancing, the life expectancy of people with intellectual disabilities (ID) has increased, with a greater number of people with ID now included among the ageing population. The aim of this review was to understand how social work practice can facilitate a dignified dying experience for this group of people. Six academic databases were searched with thematic analysis of included articles. The review included empirical qualitative, quantitative, mixed method studies as well as literature reviews, conceptual articles, and also grey literature. Forty-five studies met the inclusion criteria, and four themes

were identified. The establishment of social work specific research is necessary for the profession to understand systemic barriers and how opportunities can be implemented for a more enhanced and equitable dying experience. **Abstract:** <https://bit.ly/3BS0lGr>

Research Matters

‘Advance care planning evaluation: A scoping review of best research practice’ (p.14), in *BMJ Supportive & Palliative Care*.

N.B. Search back issues of Media Watch for additional articles on the palliative and end-of-life care needs of people living with “intellectual” or “developmental” disabilities: <http://bit.ly/2ThijkC>

Specialist Publications

‘Four aspects of spiritual care: A phenomenological action research study on practicing and improving spiritual care at two Danish hospices’ (p.9), in *Palliative Care & Social Practice*.

‘Support needs and barriers to accessing support: Baseline results of a mixed-methods national survey of people bereaved during the COVID-19 pandemic’ (p.10), in *Palliative Medicine*.

Managing clinical uncertainty in older people towards the end of life: A systematic review of person-centred tools

BMC PALLIATIVE CARE | Online – 22 October 2021 – Older people with multi-morbidities commonly experience an uncertain illness trajectory. Clinical uncertainty is challenging to manage, with risk of poor outcomes. Person-centred care is essential to align care and treatment with patient priorities and wishes. Use of evidence-based tools may support person-centred management of clinical uncertainty. The authors have identified how tools can change care processes to improve outcomes. They have also identified the properties tools need to be implemented and sustained in clinical practice. These include tools that are person-centred, target multiple domains and provide an actionable treatment plan. Tools that are brief and easy to use and developed for the target population and are used nationally or internationally with strong psychometric properties were also identified as easier to implement and sustain. There are multiple internationally established tools such as the Resident Assessment Instrument and the Palliative Care Outcome Scale. It is important that the science builds upon established tools and the existing evidence, and that future areas of research link to the logic model. Key areas of research need to include high quality randomized controlled trials, using the logic model to inform key processes, causal mechanisms and intended outcomes and implementation requirements. Further development work to understand the causal mechanisms and linkages to outcomes in wider contexts including low- and middle-income countries is also indicated. **Full text:** <https://bit.ly/3vA42DC>



How nurses support family caregivers in the complex context of end-of-life home care: A qualitative study

BMC PALLIATIVE CARE | Online – 18 October 2021 – The aim of this study is to explore how nurses currently approach and support family caregivers (FCGs) in end-of-life home care and which factors influence their support of FCGs. The authors identified two underlying nursing perspectives on supporting FCGs: an instrumental perspective (seeing FCGs mostly as collaborative partners in care) and a relational perspective (seeing FCGs as both providing and needing support). All the interviewed nurses stated that they pay attention to FCGs' needs. The activities mentioned most often were: identification of support needs, practical education, support in decision-making about the patient's treatment, emotional support, and organising respite care, such as night care, to relieve the family caregiver. The provision of support is usually based on intuition and experience, rather than on a systematic approach. Besides, nurses reported different factors at the individual, organisational and societal levels that influenced their support of FCGs, such as their knowledge and experience, the way in which care is organised, and laws and regulations. There is a risk that nursing support does not meet FCGs' needs. **Full text:** <https://bit.ly/3FXOVsj>

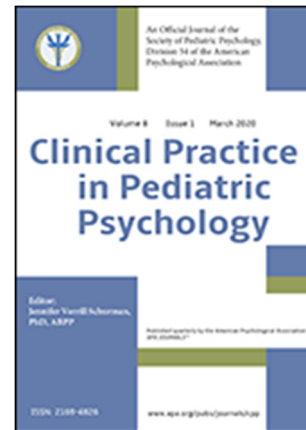
Palliative care practice for the end-stage cardiac disease population

CANADIAN JOURNAL OF CARDIOLOGY | Online – 1 October 2021 – End-stage cardiac disease processes lead to progressive, symptomatic and complex end-of-life care (EoLC). Associated with physical and emotional distress, advanced cardiac disease remains undertreated in the outpatient population that presents a unique symptom burden, increased caregiver demands, and variable disease trajectory, all leading to challenging prognostication. The palliative approach to care of cardiac life-limiting disease helps improve the quality of life for patients and their caregivers. Historically, the focus of palliative care (PC) has been malignant disease processes with clear transition points, rather than diseases with non-linear trajectories. Due to its varying clinical course and life-limiting progression, cardiac disease prognostication is difficult, thus challenging the norms of approaches to PC. Cardiologists, cardiac patients and their caregivers are confronted with the management of end-stage cardiac disease while respecting the wishes of patient and caregiver for quality palliative and EoLC. The University of Ottawa Heart Institute's (UOHI) innovative Cardiac Supportive & Palliative Care Program (CSPCP) provides specialized outpatient service for patients diagnosed with advanced cardiac disease. The program's goal is to initiate and bridge access to cardiac PC across Eastern Ontario. Implementing CSPCP has allowed patients to explore their goals-of-care and advance care plans with the UOHI CSPCP team, optimize end-stage cardiac symptom burden, initiate home care services and provide quality EoLC. **Abstract:** <https://bit.ly/3C1ZFDX>

Introduction to the special issue on palliative care, end-of-life, and bereavement: Integrating psychology into pediatric palliative care

CLINICAL PRACTICE IN PEDIATRIC PSYCHOLOGY, 2021;9(3): 219-228. While most pediatric palliative care (PPC) teams do not yet routinely include psychology, roles for pediatric psychologists in PPC are expanding. The goals of this special issue are to promote awareness of the breadth and depth of PPC, highlight the diverse and growing roles for psychologists as PPC clinicians, scientists, educators, and advocates, and showcase the latest interdisciplinary PPC research. The nine articles in this collection describe key PPC concepts and research approaches, the value of the interdisciplinary team in PPC, the impact of child illness and child loss on caregivers, needs of grieving families, ethical challenges in PPC and at end-of-life, and disparities among underrepresented and historically marginalized populations. The series of articles curated for this special issue illustrate the many contributions psychologists offer to the field of PPC. PPC-specific training and development of core competencies are necessary pathways to improve future integration of pediatric psychologists in pediatric care delivery, research, and advocacy.

Abstract: <https://bit.ly/3lQJ9AW>



Journal contents page:
<https://bit.ly/3n6tBZ5>

Noted in Media Watch 9 August 2021 (#729, p.5):

- *CLINICAL PRACTICE IN PEDIATRIC PSYCHOLOGY* | Online – Accessed 2 August 2021 – ‘**Psychologists in pediatric palliative care: Clinical care models within the U.S.**’ Pediatric psychologists are not currently recognized as core members of interdisciplinary pediatric palliative care teams, which aim to reduce physical, psychological, social, practical, and spiritual suffering for children with chronic illnesses. However, the authors’ findings suggest that pediatric psychologists provide important services to enhance the care of children with life-limiting conditions, including psychological assessment and treatment for patients and families, support for healthcare staff, supervision and mentorship of trainees, and skills in conducting research. **Abstract:** <https://bit.ly/2Vokbht>

Nurse burnout in hospice and palliative care: A scoping review

ILLNESS, CRISIS & LOSS | Online – 18 October 2021 – Burnout in hospice and palliative care (PC) nurses is a growing issue, especially in light of the COVID-19 pandemic. However, few studies have focused specifically on burnout in this population. Analysis of eight articles revealed three overarching categories: 1) Personal factors; 2) Organizational/workplace factors; and, 3) Nursing professional development factors. Each category was then divided into three cross-cutting subcategories: a) Contributory and noncontributory factors; b) Mitigating factors; and, c) Workplace issues. Recommendations for individuals include self-care as well as self-awareness of intrinsic characteristics that can predispose one to burnout. Within the workplace, leaders are challenged to support evidence-based practice and ongoing education. Role modeling positive communication skills, effective conflict mitigation, responsiveness, promotion of equity, and workplace commitment also help to create a culture of wellness. Nursing professional development may aid in resilience-building, and promotion of self-efficacy, self-confidence, and assertiveness. Although all identified recommendations were derived from the literature, no interventional studies have been conducted to test the effects of suggested interventions. Future research should include interventional studies as well as qualitative research to capture nuanced experiences of burnout in hospice and PC nurses. **Abstract (w. references):** <https://bit.ly/3n8Tms0>

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Related:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 October 2021 – ‘**Moral injury and moral resilience in healthcare workers during COVID-19 pandemic.**’ The 2019 COVID-19 pandemic placed unprecedented strains on the U.S. healthcare system, putting healthcare workers (HCWs) at increased risk for experiencing moral injury (MI). Moral resilience (MR), the ability to preserve or restore integrity, has been proposed as a resource to mitigate the detrimental effects of MI among HCWs. HCWs are experiencing MI during the pandemic. MR offers a promising individual resource to buffer the detrimental impact of MI. Further research is needed to understand how to cultivate MR, reduce ECI, and understand other systems level factors to prevent MI symptoms in U.S. HCWs. **Full text:** <https://bit.ly/2ZgEmQd>

Professionals’ expectations and preparedness to implement knowledge-based palliative care at nursing homes before an educational intervention: A focus group interview study

INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH, 2021;18(17):1-18. The provision of knowledge-based palliative care (PC) is rare in nursing homes. There are obstacles to practically performing this because it can be difficult to identify when the final stage of life begins for older persons. Educational interventions in PC in nursing homes are a challenge, and joint efforts are needed in an organisation, including preparedness. The aim of this study was to explore professionals’ expectations and preparedness to implement knowledge-based PC in nursing homes before an educational intervention. One major theme was identified: professionals were hopeful yet doubtful about the organisation’s readiness. The main categories of increased knowledge, consensus in the team, and a vision for the future illustrate the hopefulness, while insufficient resources and prioritisation illustrate the doubts about the organisation’s readiness. This study contributes valuable knowledge about professionals’ expectations and preparedness, which are essential for researchers to consider in the planning phase of an implementation study. The successful implementation of changes needs to involve strategies that circumvent the identified obstacles to organisations’ readiness. **Full text:** <https://bit.ly/3C9c9K3>

Moving and handling children after death: An inductive thematic analysis of the factors that influence decision-making by children’s hospice staff

JOURNAL OF HOSPICE AND PALLIATIVE NURSING | Inprint – Accessed 18 October 2021 – Hospices for children and adolescents in the U.K. provide care to the bodies of deceased children, in specially-designed chilled bedrooms called “cool rooms.” In an effort to develop resources to support hospice practitioners to provide this specialist area of care, this study aimed to identify the factors that influence decision-making when moving and handling children’s bodies after death in a hospice cool bedroom. An internet-based survey was sent to all practitioners employed by one children’s hospice. A total of 94.9% of eligible staff responded. Three core themes were identified that inform practitioners’ perception of appropriateness of moving and handling decisions: 1) Care of the body; 2) Stages of care; and, 3) Method of handling. The complexity of decision-making and variation in practice was identified. Practitioners relied on both analytical and initiative decision-making, with more experienced practitioners using an intuitive approach. Evidence-based policy and training influence the perception of appropriateness, and the decisions and behaviour of practitioners. The development of a policy and education framework would support practitioners in caring for children’s bodies after death, standardising expectations and measures of competence in relation to moving and handling tasks. **Abstract available at:** <https://bit.ly/3AYFtBC>

Noted in Media Watch 18 January 2021 (#700, p.12):

- *PALLIATIVE MEDICINE* | Online – 11 January 2021 – “**Cold bedrooms” and other cooling facilities in U.K. children’s hospices, how they are used and why they are offered: A mixed methods study.**’ Cooling facilities are a core element of U.K. children’s hospice provision. The views of directors of care that cooling facilities may support early grieving processes align with existing studies and grief theories. Further research is required to further understand the ways cooling facilities may affect early grieving processes, and how hospices’ cooling facility-related practices and care may impact on this. The second stage of this research, a multi-site qualitative investigation of bereaved parents’ experiences of using cooling facilities, addresses these evidence gaps. **Full text:** <http://bit.ly/39rLsmu>

Voluntarily stopping eating and drinking: Conceptual, personal, and policy questions

JOURNAL OF MEDICINE AND PHILOSOPHY | Online – 19 October 2021 – Although voluntarily stopping eating and drinking (VSED) as a way to hasten one's death is not yet a widely recognized practice in the U.S., it has received increasing attention in the medical and bioethics literature in recent years. After a brief review of the broader context of human death and dying, this article poses and examines 11 conceptual, personal, and public policy questions about VSED. The authors identify essential features of VSED and discusses whether VSED is a type of suicide. They identify reasons why people may or may not choose VSED, and it considers responses by family members and professional caregivers to people who have chosen VSED. The authors also consider how public policies may permit and regulate or restrict the practice of VSED. Examination of these questions is designed to increase understanding of VSED and to inform moral evaluation of this practice. **Abstract:** <https://bit.ly/3B3j31U>

Noted in Media Watch 13 July 2020 (#674, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 July 2020 – ‘**Experience of caregivers supporting a patient through voluntarily stopping eating and drinking.**’ Interviews with caregivers for individuals who had attempted voluntarily stopping eating and drinking (VSED) produced four themes: 1) Caregivers believe that VSED is the best death available to the patient; 2) Caregivers act as advocates and worry that the patient's goals will be challenged by healthcare professionals, the community, or legal authorities; 3) Through the VSED process itself, caregivers carry the responsibility for the patient's success as the patient becomes weaker and loses focus; and, 4) Because there is no social script to guide the VSED process, caregivers choose what roles to play during VSED... **Abstract:** <https://bit.ly/3fcdPXz>

Noted in Media Watch 26 March 2018 (#556, p.9):

- *FRONTIERS IN PHARMACOLOGY* | Online – 14 March 2018 – ‘**Ethical challenges for an understanding of suffering: Voluntary stopping of eating and drinking and the wish to hasten death in advanced patients.**’ The authors of this study analyzed the data reported in some studies in relation to primary care patients who died as a result of voluntarily stopping eating and drinking (VSED) and examined their results in light of the qualitative findings of patients that expressed a wish to die. In their view, VSED can be understood as a response to physical/psychological/spiritual suffering, as an expression of a loss of self, a desire to live but not in this way, a way of ending suffering, and as a kind of control over one's life. **Full text:** <http://bit.ly/2HBf4mW>

Evolution of palliative care in the Department of Veterans Affairs: Lessons from an integrated healthcare model

JOURNAL OF PALLIATIVE MEDICINE | Online – 19 October 2021 – Palliative care (PC) is beneficial, however, in many settings it is under-resourced and unable to consistently meet the needs of patients and their families. A lack of national health policy support for PC contributes to underutilization and the low value care experienced by many patients with serious illness at the end of life. Through a series of transformative healthcare structure and process improvements including developing robust initiatives and promoting institutional culture change, the U.S. Department of Veterans Affairs (VA) has significantly improved the quality of PC among veterans. VA's strategic simultaneous top-down and bottom-up approach to develop programs, policies, and initiatives provides important perspectives and deserves attention toward advancing PC in the broader U.S. healthcare system. Although opportunities for improvement exist, the comprehensive framework within VA should help inform the future of program development and serve as a model for integrated and accountable care organizations to emulate. **Abstract:** <https://bit.ly/3G5jGvB>



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.16.

Top ten tips palliative care clinicians should know about music therapy and art therapy

JOURNAL OF PALLIATIVE MEDICINE | Online – 19 October 2021 – Music therapists and art therapists are becoming increasingly available to palliative care (PC) teams and are advancing the diverse and unique clinical services available to effectively meet the holistic needs of patients with serious illnesses and their families. This article provides a concrete exploration of clinical music therapy and art therapy within PC and hospice paradigms, with discussion of therapists' training and expertise, therapeutic approaches within the setting of interprofessional team-based care, and discussion of evidence-based symptom management and outcomes supporting the inclusion of music and art therapies within medical education and clinical employment. **Abstract:** <https://bit.ly/3vvPOU8>

Provision of palliative care during the COVID-19 pandemic: A systematic review of ambulatory care organizations in the U.S.

MEDICINA | Online – 18 October 2021 – This comprehensive systematic review identified both facilitators and barriers related to the provision of palliative care (PC) in ambulatory care organizations located in the U.S. during the current COVID-19 pandemic. This study illustrates the unique challenges presented by the pandemic to patients requiring PC and to their providers. It also highlights unique steps and other potential processes/protocols to establish innovative manners of meeting the needs of this special population. It also identifies unique facilitators and barriers experienced by U.S. outpatient organizations that may also be beneficial for other healthcare industries. Many lessons learned highlighting best practices will come forth as a result of the pandemic. Specific to PC delivery, patient engagement, the benefit of advanced care planning, and the embracement of technology by both providers and patients are examples of successful constructs that are resulting in patient satisfaction and optimal health outcomes. Pandemic challenges related to PC identified in the research entail lack of resources such as telehealth equipment/training, insufficient bereavement/counseling resources for providers, and lack of access by certain patients. These challenges present areas for improvement in preparation for the next pandemic. **Full text:** <https://bit.ly/3ps8y6f>

Four aspects of spiritual care: A phenomenological action research study on practicing and improving spiritual care at two Danish hospices

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 22 October 2021 – In Denmark and internationally, there has been an increased focus on strengthening palliative care by enhancing spiritual care (SC). Dying patients, however, do not experience their spiritual needs being adequately met. The authors found four aspects of SC through which patients and staff seemed to perceive, feel, live, practice, and understand SC at hospice, and from where SC may be improved in hospice practice: 1) Relational; 2) Individualistic; 3) Embodied; and, 4) Verbal aspects of SC. Staff realized immanent limitations of individual aspects of SC but learned to trust that their relational abilities could improve SC. Embodied aspects seemed to open for verbal aspects of SC, but staff were reluctant to initiate verbal dialogue. They would bodily sense values about preserving patients' boundaries in ways that seemed to hinder verbal aspects of SC. During action-in-praxis, however, staff realized that they might have to initiate spiritual conversation in order to care for patients' spiritual needs. **Full text:** <https://bit.ly/3B0EXml>



[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>

Development and evaluation of an LGBT+ education programme for palliative care interdisciplinary teams

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 22 October 2021 – Despite national policy recommendations to enhance healthcare access for LGBT+ (lesbian, gay, bisexual, transgender, and those who do not identify as cisgender heterosexual) people, education on LGBT+ issues and needs is still lacking in health and social care curricula. Most of the available resources are focused on primary care, mental health, and sexual health, with little consideration to broader LGBT+ health issues and needs. The project described by the authors provides an example of how partnership working between different stakeholders can help respond to a real need within the health services to positively impact the care provided to marginalised populations. It shows how such initiatives can be adapted and replicated in different contexts to achieve a wider impact. Findings demonstrate that participants developed a better awareness of the additional issues that may face their LGBT+ patients and feel better equipped with the skills, knowledge, and tools to discuss personalised care and help LGBT+ people make informed choices in a palliative and end-of-life care (EoLC) context. **Full text:** <https://bit.ly/3psjC3d>

N.B. Search back issues of Media Watch for additional articles on the palliative and end-of-life care needs of the “LGBT+,” “LGBTQ” and “LGBTQ2S” communities at: <http://bit.ly/2ThijkC>

Support needs and barriers to accessing support: Baseline results of a mixed-methods national survey of people bereaved during the COVID-19 pandemic

PALLIATIVE MEDICINE | Online – 22 October 2021 – The results of this survey demonstrate high levels of need for emotional and therapeutic support, and the significant difficulties bereaved people face getting these needs met. Results elaborate upon pre-pandemic inadequacies in formal and informal support, while demonstrating new pandemic-specific challenges including more complex, crisis-specific needs, diminished opportunities for face-to-face and group support, acute social isolation and disruption to collective grieving and the wider societal consequences of the pandemic. Based on study findings the authors make three recommendations for improving the support available for bereaved people:



- 1) Increased provision and tailoring of services, including greater resourcing and expansion of national support as well as regional services in areas with long waiting lists. Safe ways to access face-to-face individual and group support as well as online and telephone support should be identified, with specific support available for groups with shared experiences and characteristics. This should include support which is culturally competent and crisis/context competent. Training in core competencies specific to COVID-19 and identifying and sharing best practice amongst bereavement and palliative care providers would facilitate this.
- 2) Strategies to improve awareness of bereavement support options, including providing information on grief and bereavement services proactively following a death and ensuring accessible public information is available online and in community settings. GPs and other primary care providers should be better resourced to signpost bereaved patients to appropriate support.
- 3) More help with loneliness and isolation, including flexible support bubble arrangements for the recently bereaved when restrictions are in place. Following compassionate communities approaches, informal community-based interventions should be expanded, whilst educational and society level initiatives are needed to improve how, as a society, we communicate and support people experiencing death, dying and bereavement.

Whilst most participants in this survey felt that they needed additional support, most had not tried to access help from bereavement services or from their GP. The main problems affecting the accessibility and quality of GP support were difficulties getting appointments or unsatisfactory telephone appointments, with inadequate signposting and referral to bereavement and mental health services... **Full text:** <https://bit.ly/3aXVdtY>

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Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 22 October 2021 – ‘**In-hospital bereavement services as an act of care and a challenge: An integrative review.**’ Only four articles defined bereavement care: two as services offered solely post loss and the other two as services offered pre and post loss. Although different bereavement services were delivered the time surrounding the death, the follow-up of bereaved relatives was less routinely offered. Relatives appreciated all bereavement services, which were rather informally and ad-hoc provided to them. Healthcare providers perceived bereavement care as important, but the provision was challenged by numerous factors... **Abstract (w. references):** <https://bit.ly/3B6j9FS>

ILIVE Project Volunteer study. Developing international consensus for a European core curriculum for hospital end-of-life-care volunteer services, to train volunteers to support patients in the last weeks of life: A Delphi study

PALLIATIVE MEDICINE | Online – 20 October 2021 – The European core curriculum created following this Delphi study is a potentially useful tool to underpin the training of volunteers, and the implementation of end-of-life-care (EoLC) volunteer services within the hospital setting. As well as identifying key topics for volunteer training, findings highlighted that any curriculum must include steps for embedding the EoLC volunteer service within the organisational infrastructure. This was seen as important to ensure that the service is recognised as a core part of the care provided to dying patients within the organisation, with established roles and responsibilities, as well as ensuring volunteers as part of the service have access to hierarchies of support. This was seen as particularly relevant for EoLC volunteers within the hospital, and reflects recent literature highlighting the unique challenges associated with this care setting. Recommendations for further research include further validation of this core curriculum with key stakeholders including volunteers, in-depth examination of the barriers and facilitators to the implementation of EoLC volunteer services and volunteer training in hospitals, alongside research into the experiences of key stakeholders. For example, EoLC volunteers, volunteer coordinators and hospital staff experiences of providing and facilitating volunteer support to dying patients, and most importantly, including the patient voice to understand how the volunteer service has affected their experience of care. **Full text:** <https://bit.ly/3pmNQEK>



N.B. iLIVE Project website: <https://bit.ly/3lXnjvu>

Related:

- *CANADIAN JOURNAL ON AGING* | Online – 20 October 2021 – ‘**(Dis)connecting through COVID-19: Experiences of older persons in the context of a volunteer-client relationship.**’ In this study, three themes were identified: 1) Pandemic emotions; 2) Negotiating social interactions; and, 3) Growing through the COVID-19 pandemic. These findings provide important insights into the experiences of hospice organizations and their volunteers and clients during the COVID 19 pandemic, further highlighting the importance of acknowledging both older persons’ vulnerability and their resilience, of building in compassionate community approaches to care, and of finding innovative ways to foster volunteer–client relationships during times when physical visiting is not possible. **Abstract:** <https://bit.ly/3vs1c3q>
- *INTERNATIONAL JOURNAL OF HEALTH POLICY & MANAGEMENT* | Online – Accessed 20 October 2021 – ‘**Prohibit, protect, or adapt? The changing role of volunteers in palliative and hospice care services during the COVID-19 pandemic: A multinational survey (Covpall).**’ The aim of this study was to understand volunteer deployment and activities within palliative care services and to identify what may affect any changes in volunteer service provision during the pandemic. Volunteer re-deployment plans are needed that take a more considered approach, using volunteers more flexibly to enhance care while ensuring safe working practices ... widening the volunteer base away from those who may be considered to be most vulnerable to COVID-19. **Abstract (w. references):** <https://bit.ly/3GOvWOB>

N.B. CovPall is a project that is trying to understand more about how palliative care 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>

“It feels it’s wasting whatever time I’ve got left”: A qualitative study of living with treatable but not curable cancer during the COVID-19 pandemic

PALLIATIVE MEDICINE | Online – 19 October 2021 – Strategies are currently being implemented to ensure the recovery of disrupted cancer services and the authors would urge that the psychosocial impact of the pandemic on patients and carers is recognised by those who commission and deliver cancer care and that services are also developed or adapted to address these needs. Numbers diagnosed with treatable but not curable cancer are predicted to increase in the future, in part linked to the COVID-19 pandemic and the delays in people being diagnosed due to late presentation of patients experiencing symptoms as well as healthcare service disruptions. This makes it even more imperative to focus on addressing the needs of this group, particularly within the context of the threat of a third wave of COVID-19 and continued pressure on health services. The findings of this study provide detailed insights on the nature of the challenges, uncertainty and lost opportunities as a result of the pandemic for both patients and carers living with cancer that is treatable but not curable, which has wider resonance for people living with other life-limiting conditions. **Full text:** <https://bit.ly/3pkBrB8>

Chaplain care in the intensive care unit at the end of life: A qualitative analysis

PALLIATIVE MEDICINE REPORTS | Online – 18 October 2021 – The authors data highlights the particularly valuable role that ICU chaplains can play in contributing to interdisciplinary care to critically patients and their families and those who care for them. Furthermore, this report may be helpful in alerting ICU providers to the work of chaplains in the ICU and their contributions to patient care, and in turn prompt both individual and institutional efforts at integrating chaplains more intentionally into the care of critically ill patients. Providers often have a limited or distorted understanding of the role of chaplains in clinical care, although there are efforts occurring in medical education that seek to inform trainees about the work of chaplains. As the scope and nature of ICU chaplaincy evolves to include more explicit notions of advocacy and patient navigation, it becomes even more imperative that clinicians are better informed of the work of chaplains to enable them to collaborate more effectively with chaplains. **Full text:** <https://bit.ly/3aRFf14>

Noted in Media Watch 12 April 2021 (#712, p.11):

- *JOURNAL OF PALLIATIVE CARE* | Online – 5 April 2021 – ‘**Harnessing the chaplain’s capacity to identify unmet palliative needs of vulnerable older adults in the emergency department.**’ A palliative chaplain-fellow conducted a retrospective chart review evaluating emergency department (ED) patients... An emergency medicine physician and chaplain-fellow screened 10% of these charts to provide a clinical assessment. One year post-study, charts were re-examined to identify which patients received a palliative care (PC) consultation or died, providing an objective metric for comparing predicted needs with services received. Establishing chaplain-led PC screenings as standard practice in the ED setting may improve end-of-life care for older patients. **Abstract (w. references):** <https://bit.ly/3msbE6D>

Noted in Media Watch 1 February 2021 (#702, p.4):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 28 January 2021 – ‘**The role and activities of board-certified chaplains in advance care planning.**’ A cross-sectional, web-based self-report survey was conducted with 585 board-certified chaplains recruited from three major professional chaplains’ organizations in the U.S. More participants worked in community hospital settings (42%) and academic medical centers (19.6%) than in any other setting. Over 90% viewed advance care planning as an important part of their work, 70% helped patients complete advance directives, and 90% helped patients discuss their preferences about end-of-life treatments. Many were not consistently included in team discussions regarding decision-making... **Abstract (w. references):** <http://bit.ly/3pobloC>

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Noted in Media Watch 4 January 2021 (#698, p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 30 December 2020 – ‘**Chaplain-physician interactions from the chaplain’s perspective: A mixed method analysis.**’ The value of healthcare chaplains to patient care is increasingly recognized. However, physicians’ understandings of the role of pastoral care have been reported to be poor, which have raised concerns about the quality of chaplain-physician interactions and their impact on patient care. This study provides contemporary data on the nature of chaplain-physician interactions as reported from the perspective of chaplains. Further, these findings highlight opportunities for interventions to enhance the chaplain-physician relationship. **Abstract (w. references):** <http://bit.ly/2Ju6uYl>

Adapting the collaborative care model to palliative care: Establishing mental health-serious illness care integration

PALLIATIVE & SUPPORTIVE CARE | Online – 21 October 2021 – Models of palliative care-specialist serious illness care integration have allowed a greater number of people to enjoy the benefits of palliative care (PC). Mental health integration is the next frontier in providing holistic care to individuals living with serious illnesses. Models of mental health-medical integration, such as the collaborative care model, are attractive means by which to achieve mental health integration because they have been used effectively to improve mental health service delivery in primary care and other medical settings; they have also been adapted to PC integration with oncology and other medical fields. The tripartite integration of specialty medical care, PC, and mental health is low-hanging fruit for the alleviation of suffering and improvement of quality of life. Thus, the authors call on research funders and healthcare institutions to support these efforts, as the building blocks are there; all we must do is start stacking. **Full text:** <https://bit.ly/3B2hJfN>

Noted in Media Watch 6 September 2021 (#733, p.12):

- *PALLIATIVE MEDICINE* | Online – 3 September 2021 – ‘**End-of-life care for people with severe mental illness: Mixed methods systematic review and thematic synthesis.**’ This rigorous, mixed methods, systematic review and thematic synthesis has brought together research from 10 countries, plus exemplar policy and guidance from the four nations of the U.K., in an important but neglected area. Beyond people with severe mental illness, findings have relevance for the end-of-life care (EoLC) of other disadvantaged groups for whom health inequalities persist. With regards to future work, EoLC for people with severe mental illness is a wide-open area for well-designed research, including intervention studies of which no examples were found meeting the inclusion criteria for this review. **Full text:** <https://bit.ly/3tfatuB>

Emergency medical services’ experience caring and communicating with patients and families with a life-limiting-illness

PREHOSPITAL EMERGENCY CARE | Online – 20 October 2021 – In their work with patients with life-limiting illness, participating emergency medical services (EMS) providers reported challenges for which their formal training had not prepared them: responding to grief and emotion expressed by families during traumatic events or death notification, and performing in the moment decision-making to determine the course of action after acute, unexpected, and traumatic events. Many participants reported becoming comfortable with grief counselling and death notification after acquiring some clinical experience. In the moment decision-making was eased when patients and families had had advance care planning (ACP) discussions, however many patients, especially those from vulnerable and underserved populations, lacked ACP. In the face of situations where the course of action was not immediately clear, EMS providers voiced two frames for their role in caring for patients with life-limiting illness: 1) Transportation only (“transport people”) versus a more “holistic” view, where EMS providers provided counseling; and, 2) Information about available resources. There is an opportunity to provide formal training to EMS providers around grief counseling as well as how they can assist patients and families in in the moment decision-making to support previously identified goals and align care with patient goals and preferences. **Abstract:** <https://bit.ly/30Lztzv>

Bioethics and palliative care in medical school: A curriculum proposal

REVSITA BIOÉTICA, 2021;29 (3):534-46. Population aging caused by increased life expectancy will result in an increasing demand for professionals specialized in palliative care (PC). Due to the growing number of patients in need of this care profile, medical schools must prioritize palliative education during undergraduate studies, since the teaching of bioethics and PC remains timid in the curricula of Brazilian medical schools. Discussing new curricula can therefore contribute to medical education in the field and allow for better training in palliative medicine for the future professional trajectory of medical students. A new curriculum proposal is presented, result of a research on the teaching of bioethics and PC in a medical school in the Federal District, Brazil. **Full Text:** <https://bit.ly/3poVWRf>

N.B. English language article.

Disparities in telehealth use: How should the supportive care community respond?

SUPPORTIVE CARE IN CANCER | Online – 19 October 2021 – The increase in telehealth entails great opportunities to increase patients' access to cancer professionals and to streamline the workflow of health care providers during and beyond the COVID-19 period. Furthermore, telehealth holds tremendous potential for transforming the follow-up care, with a reduced burden for in-person visits. However, important concerns relating to associated regulatory frameworks, digital poverty and exclusion, and the respect of patients' preferences need to be addressed concomitantly to its deployment. The authors present a clear multilevel strategy and development of best practices required to address these barriers. First, at the patient level, they recommend a comprehensive assessment for patient-level barriers, including readiness to use telehealth, access to broadband, disabilities that limit telehealth use, and limited digital literacy. Telehealth access can be improved through interventions such as patient-level training, voice-activated commands, simpler designs, engaging informal caregivers, and finally improving interpreters' access to the telehealth portal. Second, at the health system level, it is crucial to design clinical workflows with a health equity lens to not exacerbate existing disparities but to increase access to care. To be genuinely successful, patient education and training for digital and telehealth tools must be built within clinical workflows to address disparities in access. While this training is often time-consuming and resource-intensive, it is an investment in excellent cancer care that is likely to increase patient engagement. One potential option is to leverage lay health workers and navigators for this type of training. Third, telehealth systems were primarily designed for the business community and have not been optimized for team-based care including interpreters, volunteers, and administrative personnel. These systems should address these barriers, informed by patient experience, and incorporate feedback from end-users, including both clinicians and patients on an ongoing basis. **Full text:** <https://bit.ly/30Au0eM>



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

Research Matters

Advance care planning evaluation: A scoping review of best research practice

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 19 October 2021 – Various indicators have been used to evaluate advance care planning (ACP), including completion rates, type of care received, and satisfaction. Recent consensus suggests, though, that receiving care consistent with one's goals is the primary outcome of ACP and assessment should capture this metric. Goal concordant care is challenging to measure, and there is little clarity about how best to do so. The aim of this scoping review is to explore what methods have been used to measure goal concordant care in the evaluation of ACP. 135 original studies

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were included for review. Studies used retrospective chart review, questionnaire and interview, focusing on both patients and proxies. Studies considered both actual care received and hypothetical scenarios anticipating possible future care; some studies did both. While the reviewed studies demonstrate the possibility of working towards a solid methodology, there were significant weaknesses. Notably, studies often lacked enough reporting clarity to be reproducible and, relatedly, key concepts, such as end-of-life or preferred care, were left undefined. The recommendations that follow from these findings inform future research approaches, supporting the development of a strong evidence base to guide ACP implementation in practice.

Abstract: <https://bit.ly/3aUXiqv>

Noted in Media Watch 11 October 2021 (#738, p.7):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 8 October 2021 – ‘**What’s wrong with advance care planning?**’ Advance care planning (ACP) has emerged during the last 30 years as a potential response to the problem of low-value end-of-life care. The assumption that ACP will result in goal-concordant EoL care led to widespread public initiatives promoting its use, physician reimbursement for ACP discussions, and use as a quality measure by the U.S. Centers for Medicare & Medicaid Services, commercial payers, and others. However, the scientific data do not support this assumption. The clinical and research communities should learn from the evidence that does not support prior hypotheses and proceed with different approaches to improve care for seriously ill patients. **Full text:** <https://bit.ly/3FyPlje>

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

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

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