

**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

## Caring for the terminally ill in prisons: An International Perspective on Palliative and Hospice Care in Prisons and Correctional Facilities (p.6)

### Canada

#### **Beyond cultural safety in palliative care: How to be an anti-racist palliative care clinician**

eHOSPICE | Online – 10 August 2021 – In palliative care (PC), we proclaim that the gold-standard of this interdisciplinary medical specialty is that the care provided is patient and family-centred. In collaborating with patients and families to elicit what is most important to them, we work to align patient values with medical care that might support their goals. As PC providers, we try to understand the context of patients' reasons for decisions even when we don't necessarily agree with them from a medical perspective, provide education to patients, families and our healthcare colleagues, and advocate on behalf of patients and families. But what if our approach to patient and family-centred care isn't as wholly inclusive as it should be? The field of PC is rooted in Western perspectives of death and dying and built on policies and practices that enforces euro-ethnocentrism. To better understand a patient and family's context, we must make space within ourselves and in our discussions with patients and families for the possibility of individual and inter-generational trauma that result from colonial policies that perpetuate institutional inequities and systemic, structural and interpersonal racism. To ignore this possibility runs the risk of inadvertently preserving the dynamics of oppressive interactions in the health system and in the helping professions. Furthermore, difficult patient-physician encounters in literature are framed within a colonial context with Western values and knowledge, similar to how medical professionalism is defined. This focus on one way of knowing perpetuates epistemic racism. <https://bit.ly/3CN1Tb5>

Noted in Media Watch 3 August 2020 (#677, p.3):

- **SOCIAL WORK HOSPICE & PALLIATIVE CARE NETWORK** | Online – Accessed 27 July 2020 – '**Social justice and palliative care policy.**' The Network's 'Statement on Racism and Structural Inequities in Hospice and Palliative Social Work' is suggesting the bold and necessary step of asking us to critically question how we, as hospice and palliative care social workers, are contributing to maintaining systems of inequity in the work we do. These are hard conversations to have, but needed to do the work necessary to correct racial and ethnic disparities inherent in end-of-life care. We need to examine our own personal biases and the systems of care that pay our salaries and contribute to poorer care provision for people who are not white. **Download/view Network's statement at:** <https://bit.ly/39z9jiS>

**N.B.** Search back issues of Media Watch for articles on ethnic and racial "disparities" and "inequities" in the provision and delivery of PC and end-of-life care: <http://bit.ly/2ThijkC>

## U.S.A.

### **Hospices feel strain of general inpatient care audits as inpatient care days dwindle**

*HOSPICE NEWS* | Online – 13 August 2021 – Hospice providers nationwide are reporting an increase in Medicare Administrative Contractor audits pertaining to claims for general inpatient care (GIP) stays that are longer than seven days. These audits can be expensive and time consuming processes for hospices; some of whom say they fear that this practice will inhibit patient access to that level of care. The U.S. Centers for Medicare & Medicaid Services (CMS) requires hospice providers to offer all four levels of care: routine home care, general inpatient care, inpatient respite care and continuous home care. Hospice utilization among Medicare decedents rose to exceed 50% for the first time during 2018, according to CMS. As utilization climbs, so does the amount of dollars CMS spends on hospice

care, spurring the agency and other regulators to step up enforcement in an effort to control costs. Medicare hospice expenditures rise by about \$1 billion annually. Documentation errors and omissions, live discharges and lengths of stay beyond six months are frequent red flags that could cause regulators to come knocking at a hospice's door. <https://bit.ly/2UfYnnZ>

#### **Specialist Publications**

**'A systematic review of palliative care content in the Doctor of Pharmacy curriculum'** (p.4), in *American Journal of Pharmaceutical Education*.

## International

### **Culturally-friendly settings can improve end-of-life for migrants**

AUSTRALIA | *Australian Ageing Agenda* – 11 August 2021 – Residential aged care providers should aim to make care settings more like a migrant resident's home to improve their end-of-life (EoL) experience... Dr. Katrin Gerber, a research fellow at National Ageing Research Institute's Melbourne Ageing Research Collaboration said making cultural changes in an aged care setting was important: "We know that people from culturally and linguistically diverse backgrounds have different preferences for place of care and place of death." Dying is hard enough. Now imagine doing this in the multi-cultural context of a different country while having to navigate a potentially unfamiliar healthcare system in a different language... Migrants often want to receive EoL care surrounded by their family, but they also long for the country of their birth, said Dr. Gerber, who has undertaken research on the EoL experiences of older migrants.<sup>1</sup> <https://bit.ly/3ISiZ16>

#### **Specialist Publications**

**'A national position statement on adult end-of-life care in critical care'** (p.4), in *Australian Critical Care*.

**'Palliative care providers' use of digital health and perspectives on technological innovation: A national study'** (p.5), in *BMC Palliative Care*.

**'Adaptation of the Australian Palliative Care Phase concept to the German palliative care context: A mixed-methods approach using cognitive interviews and cross-sectional data'** (p.5), in *BMC Palliative Care*.

**'Hospitalisation in the last month of life and in-hospital death of nursing home residents: A cross-sectional analysis of six European countries'** (p.7), in *BMJ Open*.

**'Dissemination, use, and impact of a community-based, conversational advance care planning intervention: Ripple effects of the Swedish DöBra cards'** (p.9), in *Palliative Care & Social Practice*.

1. 'End-of-life care for older first-generation migrants: A scoping review,' *BMJ Supportive & Palliative Care*, published online 9 December 2020. [Noted in Media Watch 14 December 2020 (#696, p.10)] **Abstract:** <https://bit.ly/3qJbMQU>

**N.B.** Search back issues of Media Watch for additional articles on EoL care for migrants, a public health issue in many countries, at: <http://bit.ly/2ThijkC>

## The Future of Hospice Care in Scotland – a new report from Hospice UK

U.K. (Scotland) | Hospice UK – 10 August 2021 – Scotland is witnessing a growing need for palliative care (PC) alongside a rising number of people dying at home. The pandemic accelerated these trends, but even as the death toll from COVID-19 recedes, the strain of these seismic changes will remain for years to come. It is evident there has never been a greater need for better hospice and end-of-life (EoL) care, yet despite an estimated 75-95% of people who die in Scotland each year needing PC, one in four are still missing out. Throughout the pandemic, hospices stepped up to provide vital support to the National Health Service and work collaboratively with community health and social care services to reach people in need, illustrating the vital role the sector can play to support those at the EoL. This blueprint of joined-up working, with hospices as equal partners in the system, must be the way forward. With the new Scottish Government now in place,

and a promise from Scottish leaders for a new PC strategy, Hospice UK is working with decision-makers and care providers alike to ensure everyone gets the right care in the right place and at the right time, particularly in the community. Hospice U.K.'s new report ... sets out how hospices are responding to meet Scotland's growing need for PC and emphasises the support that needs to be in place to underpin and enable the sector to be a catalyst for change. **Download Hospice UK report at:** <https://bit.ly/3s9dV9x>

### Specialist Publications

'Deaths in critical care and hospice – prevalence, trends, influences: A national decedent cohort study' (p.5), in *BMJ Supportive & Palliative Care*.

Noted in Media Watch 1 Match 2021 (#706, p.4):

- U.K. (Scotland) | *The Scotsman* (Glasgow) – 23 February 2021 – '**End-of-life care must be improved.**' We have seen a substantial shift in people dying at home instead of hospital over the last year; over 4,000 more deaths at home in Scotland in 2020 than in previous years, which has largely been driven by the need to free up hospital beds for COVID-19 patients. Marie Curie and University of Edinburgh research recently projected that by 2040 two thirds of Scots could die at home, in a care home or a hospice. This is similar to what was seen in 2020, thus we know what increased demand for support in the community and in care homes could look like in later years. By 2040, 95% of all people in Scotland who die may need a palliative care support...<sup>1</sup> <http://bit.ly/2NpbJes>

- 'How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery,' *BMJ Open*, published online 3 February 2021. [Noted in Media Watch 8 February 2021 (#703, p.7)] **Full text:** <http://bit.ly/39HdPvy>

**N.B.** Search back issues of Media Watch for additional articles on hospice and PC in "Scotland" at: <http://bit.ly/2ThijkC>



### 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>



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## Specialist Publications

### **Sexuality and intimacy needs within a hospitalized palliative care population: Results from a qualitative study**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 10 August 2021 – Palliative care clinicians are well trained to address physical, psychosocial and spiritual needs of patients who have a serious illness. However, one area that is often overlooked is intimacy and sexuality. Twenty-one interviews were analyzed and several themes emerged. Participants described the effect of physical and mental/emotional changes on their relationships. Family relationships, romantic relationships, and sexuality were prominent in patients' experiences of intimacy and how it changed as the illness progressed. Relationships were often noted to strengthen during the course of illness, while sexual activity was frequently reported to be negatively impacted. Patients consistently reported little provider communication on the impact of illness on intimacy beyond instructions about what sexual activities they could or could not engage in. This study

underlines the significant impact of serious, progressive illness on relationships, sexuality, and physical and emotional intimacy. It highlights that these topics continue to be priorities for patients with serious illness, and that medical teams frequently fail to address them at all. Future research should further explore these issues across diverse patient populations. **Abstract (w. references):** <https://bit.ly/3IVLCdU>

#### Research Matters

'Global palliative care research (2002-2020): Bibliometric review and mapping analysis' (p.11), in *BMJ Supportive & Palliative Care*.

'Recommendations for virtual qualitative health research during a pandemic' (p.12), in *Qualitative Health Research*.

**N.B.** Additional articles on intimacy and sexuality in palliative care noted in Media Watch 14 September 2020 (#683, p.10).

### **A systematic review of palliative care content in the Doctor of Pharmacy curriculum**

*AMERICAN JOURNAL OF PHARMACEUTICAL EDUCATION*, 2021;85(6):8468. A literature search retrieved 971 reports, from which 26 studies met all of study criteria. Educational interventions concerning palliative care (PC) included didactic courses, flipped classrooms, advanced pharmacy practice experiences (APPEs), workshops, and seminars. Total direct hours of education in PC ranged from 1-200. Seven (27%) focused experiences were reported as required, while nine (35%) were reported as elective. The majority of studies measured pharmacy students' confidence, attitudes, or perceptions as the main outcome, and of those most studies reported an improvement. Five studies reported on interprofessional experiences in PC conducted in the U.S., and four studies reported on similar experiences conducted outside the U.S.. When reported, most experiences were developed for students to complete prior to beginning their APPE year. All of the included studies used a non-randomized design. This review suggests a PC experience for pharmacy students should be interprofessional, occur during the year prior to APPEs, and measure skills-based outcomes. **Full text:** <https://bit.ly/3IWmnYE>

### **A national position statement on adult end-of-life care in critical care**

*AUSTRALIAN CRITICAL CARE* | Online – 10 August 2021 – Patient death in critical care is not uncommon. Rather, the provision of end-of-life care (EoLC) is a core feature of critical care nursing, yet not all nurses feel adequately prepared for their role in the provision of EoLC. For this reason, the Australian College of Critical Care Nurses (ACCCN) supported the development of a position statement to provide nurses with clear practice recommendations to guide the provision of EoLC, which reflect the most relevant evidence and information associated with EoLC for adult patients in Australian critical care settings. A systematic literature search was conducted between June and July, 2020... Preference was given to the most recent

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Australian or Australasian research evidence, where available. Once the practice recommendations were drafted in accordance with the research evidence, a clinical expert review panel was established. The panel comprised clinically active ACCCN members with at least 12 months of clinical experience. The clinical expert review panel participated in an eDelphi process to provide face validity for practice recommendations and a subsequent online meeting to suggest additional refinements and ensure the final practice recommendations were meaningful and practical for critical care nursing practice in Australia. ACCCN Board members also provided independent review of the position statement. **Full text:** <https://bit.ly/3iDWLxV>

#### **Related:**

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 11 August 2021 – ‘**Deaths in critical care and hospice – prevalence, trends, influences: A national decedent cohort study.**’ End-of-life and bereavement care support services differ in critical care (CC) and inpatient hospice settings. There are limited population-level data comparing deaths in these two locations. There were 710,829 deaths in Scotland from 2005-2017; 5.1% occurred in CC units and 6.1% in hospices. As a proportion of acute hospital deaths, CC deaths increased from 8.0% to 11.2%. Approximately 1 in 8 deaths in those aged under 40 years occurred in CC. Factors independently associated with hospice death included living in less deprived areas, cancer as the cause of death... **Abstract:** <https://bit.ly/3jGVIBY>

#### **Adaptation of the Australian Palliative Care Phase concept to the German palliative care context: A mixed-methods approach using cognitive interviews and cross-sectional data**

*BMC PALLIATIVE CARE* | Online – 14 August 2021 – The authors have developed a culturally adapted version of the Australian concept of palliative care (PC) phase and determined the inter-rater reliability of the revised German definitions. In Australia, the PC phase concept is very well established in specialist PC and is used nationwide. However, in order for it to be used in other countries and their healthcare systems, it needs to be adapted to the prevailing conditions. The results of cognitive interviewing showed that the formal translation of the phases was not fitting adequately to wording and procedures in the German specialist PC setting, e.g., the description of the bereavement phase or the need to use terms consistently. Moreover, some terms were not self-explanatory for the professionals and the single page of phase definitions was insufficient to convey a comprehensive understanding of the concept. These problems in understanding the concept became particularly apparent in respect of the phases “deteriorating” and “unstable.” Interviewees focused solely on patients’ condition rather than on the suitability of the care plan and whether the symptom/problems had been anticipated or not. The observed uncertainties with single terms as well as with the overall concept emphasized the need to complement the phase definition with further information in an additional manual. Overall, the results confirmed the need to adapt the formal translation of PC phases to the cultural context of the German specialist PC setting and consider setting specific wording/language as well as educational needs of professionals. **Full text:** <https://bit.ly/3siFQEn>

#### **Palliative care providers’ use of digital health and perspectives on technological innovation: A national study**

*BMC PALLIATIVE CARE* | Online – 7 August 2021 – This national study explored Australian palliative care (PC) providers’ current use of digital health and their perspectives on technological innovation. Given that implementation of digital health interventions represents a cultural transformation of traditional healthcare, understanding the confidence and attitudes of healthcare professionals regarding the use of digital health technologies is a growing priority. This research advances knowledge in that area, with scant research previously conducted in the context of PC providers. In the present study, there was a large uptake of digital health by multi-disciplinary PC providers who were, on average, moderately confident in their ability to use digital health and held positive beliefs that PC could be enhanced through digital health. They were generally supportive of ongoing innovation through digitally-enabled models of care. This supports earlier research that found rural nurses were able to accept, use, and report benefits of telehealth in paediatric hospice care, whilst cautioning about the importance of maintaining human connection. Digitally enabled models of care presents both benefits and challenges for providers of PC. **Full text:** <https://bit.ly/2VxY6gM>

**N.B.** Search back issues of Media Watch for additional articles on technology in PC. Suggested search words: “digital,” “telemedicine,” “telepalliative,” “virtual” reality at: <http://bit.ly/2ThijkC>

## “Tool kit” for World Hospice & Palliative Care Day addresses end-of-life care in the prison environment

Key messages for the 9 October 2021 event identified by the Humane Prison Hospice Project include:

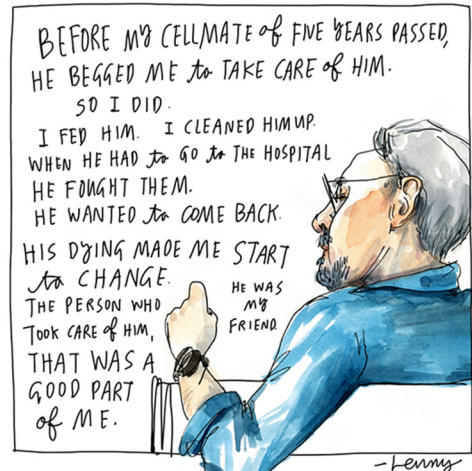
Governments that provide palliative care (PC) to prisoners are fulfilling their obligation to respect their right to health, setting a precedent of acknowledging and responding to our shared humanity.

Prison populations in many counties are rapidly aging; by 2030, older prisoners, many of whom have PC needs, are expected to account for one-third of the incarcerated population in the U.S.

Incarceration shortens life expectancy and hastens physiological aging, compounding existing health issues and heightening the risk that prisoners will develop PC needs.

Considering how prisoners die “inside” is imperative and requires appropriate investments and training.

Prison PC, when compassionate release is unavailable, allows prisoners to “die at home,” cared for by other prisoners with whom the patient has formed a familial bond. These trained prisoner volunteers can provide cost-effective and transformative PC while working with compassionate clinical staff.



Worldwide Hospice Palliative Care Alliance:  
<https://bit.ly/3lmKhMM>



Humane Prison Hospice Project:  
<http://bit.ly/2VLRkTK>

**Footnote on the illustration:** “Lenny” is one of the ‘Brother’s Keepers’ at San Quentin State Prison in the U.S. who participated in the Humane Prison Hospice Project training program to become peer support counselors and compassionate end-of-life caregivers. His words were captured by graphic journalist Wendy MacNaughton and was originally published in *The California Sunday Magazine* (see <https://bit.ly/2WXBqjb>).



### European Association for Palliative Care Task Force on End-of-Life Care in Prisons

The Task Force’s two main aims are to undertake scoping work in at least five countries to map the current provision of palliative care (PC) for prisoners,<sup>1</sup> and to develop an international network of professionals interested in PC for prisoners from as many European countries as possible, as well as other countries outside of Europe. **Task Force website:** <https://bit.ly/2WLZSLv>

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



### Prison Hospice: Backgrounder Updated 1 August 2021

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

Photo: Lori Waselchuk, Philadelphia, PA

## Hospitalisation in the last month of life and in-hospital death of nursing home residents: A cross-sectional analysis of six European countries

*BMJ OPEN* | Online – 12 August 2021 – In the European countries participating in the Palliative Care for older people in Europe (PACE) project, between 12% and 26% of nursing home residents were hospitalised in the last month of life and up to 19% died in-hospital. This indicates that although the participating countries vary in hospitalisation and in-hospital death, a minority of the residents were hospitalised in the last month of life. For those who died in-hospital, the main reason for hospital admission was an acute change in health status, those with a higher functional status being more likely to be hospitalised or to die in-hospital. The likelihood of hospitalisation in the last month of life and of in-hospital death increased if no conversation about the preferred course of care was held with a relative. Having no advance directive regarding hospitalisations increased the likelihood of hospitalisation in the last month of life but not of in-hospital death. Close monitoring of acute changes in a resident's health status – reinforced by staff training and support – and adequate equipment to manage these changes are critical in the nursing home setting to avoid unnecessary hospitalisations. In addition, strategies to increase discussion about individual preferences and advance care planning need to be developed and adapted locally. The authors findings can be used by policymakers – at government and nursing home level – to follow-up on the effects of their policies.

**Full text:** <https://bit.ly/3m7YoFY>

## COVID grief has cracked us open: How clinicians respond could reshape attitudes to bereavement

*BRITISH MEDICAL JOURNAL* | Online – 10 August 2021 – People working in healthcare experience grief professionally as well as personally and societally. Attitudinal shifts are needed ... to improve access to formal and informal support and make grief a less lonely experience. Doctors' openness and willingness to show vulnerability could help. Grief and death have something crucial in common: an incidence of 100%. The ache of grief is natural and unavoidable as we face the losses of everyday life – separation, serious illness, injury – and the pain of close bereavement, whether sudden or expected. Death and grief can come upon us at any time, regardless of whether our day job is saving lives. The COVID-19 pandemic starkly shows grief's ubiquity: some four million people have died globally, leaving over 35 million people bereaved. The horror of loss is writ large each day in newspapers worldwide and on social media. The grief entailed in practising medicine has never been so clear, pictured in the faces of exhausted nurses and doctors, the marks from their masks deep and red. The pandemic has raised barriers for grieving people seeking support and laid bare the necessity of better bereavement services – as well as highlighting the need for us all to make space for grief, other people's and our own. Clinicians have an important role to play in helping bereaved people; they are also particularly exposed to grief, and openly acknowledging this could help shift societal attitudes. **Full text:** <https://bit.ly/3xH1umy>

### Should we incorporate the work of Elisabeth Kübler-Ross in our current teaching and practice and, if so, how?

*OMEGA – JOURNAL OF DEATH & DYING*, 2021;8394:706-728. This article acknowledges the historical importance of the work of Elisabeth Kübler-Ross and her five stages model. Because her name and this model appear in many textbooks, professional educational programs, and popular culture, should we incorporate these subjects in responsible ways in our current teaching and practice? The answer proposed here is that we should incorporate these subjects, but only if (a) we focus on her recommendations on behalf of active listening and learning from persons diagnosed with a terminal illness, (b) we limit ourselves to her descriptions of the individual reactions and responses experienced by her interviewees, (c) we acknowledge criticisms of the five stages model as a framework for understanding coping with life-threatening illness and dying, (d) we draw instead on alternative theories of coping with dying, and (e) we recognize dangers in applying this model to issues involving loss, grief, and bereavement and do not do so. **Abstract (w. references):** <http://bit.ly/2yvkico>

**N.B.** Search back issues of Media Watch for additional articles on "Kübler-Ross" at: <http://bit.ly/2ThijkC>

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#### Related:

- *INTENSIVE & CRITICAL CARE NURSING* | Online – 6 August 2021 – ‘**Intensive care unit diaries to help bereaved family members in their grieving process: A systematic review.**’ The analysis of the selected studies show that the use of the ICU diary is perceived as positive, in fact it may help patient’s family members to understand and make sense of what has happened, to cope with their loss and it may have an important role in their bereavement process. Some relatives of the patients deceased in the ICU experienced diaries as comforting and helping them to realise how severely ill their loved ones were. They pointed out the importance of photographs attached to the ICU diary which may increase its relevance and positive impact on the family members’ bereavement process. **Full text:** <https://bit.ly/3xluHgR>

#### **Parent-led strategies supporting personal well-being when caring for a child with a life-limiting condition: A scoping review**

*JOURNAL OF CHILD HEALTH CARE* | Online – 9 August 2021 – The objectives of this review were to identify strategies initiated by parents of children with life-limiting conditions to support their own well-being at home and to describe the impact of these strategies on parental well-being. A systematic scoping review was performed ... identifying 15 relevant studies that fit the inclusion and exclusion criteria. There were no studies that specifically assessed how parents support their own well-being; however, the 15 identified studies did provide pertinent data secondary to the primary aims of each study. This resulted in the identification of 14 parent-initiated strategies which were grouped thematically into four categories: 1) Social experience and peer support; 2) Information and management techniques; 3) Reframed perspectives; and, 4) Prioritising own needs. Overall, there was some evidence of parents initiating specific, individualised and useful strategies to supporting their well-being. **Abstract (w. references):** <https://bit.ly/3lQgw7n>

#### Related:

- *SUPPORTIVE CARE IN CANCER* | Online – 7 August 2021 – ‘**Consensus-based recommendations for psychosocial support measures for parents and adult children at the end of life: Results of a Delphi study in Germany.**’ Within families, parents are increasingly faced with the challenge of caring for an adult child with terminal illness; likewise, adult children are continuing to cope with the limited life span of their aging parents. In the context of terminal illness, both the family setting and the interaction between patients and relatives have a vital impact on the quality of life (QoL) of patients and the burden experienced by their relatives. Furthermore, the QoL of patients and caregivers is associated with the availability of psychosocial support... **Full text:** <https://bit.ly/3Cts8TH>

#### **Social determinants of health and slippery slopes in assisted dying debates: Lessons from Canada**

*JOURNAL OF MEDICAL ETHICS* | Online – 4 August 2021 – The question of whether problems with the social determinants of health that might impact decision-making justify denying eligibility for assisted dying has recently come to the fore in debates about the legalisation of assisted dying. For example, it was central to critiques of the 2021 amendments made to Canada’s assisted dying law. The question of whether changes to a country’s assisted dying legislation lead to descents down slippery slopes has also come to the fore – as it does any time a jurisdiction changes its laws. We explore these two questions through the lens of Canada’s experience both to inform Canada’s ongoing discussions and because other countries will confront the same questions if they contemplate changing their assisted dying law. Canada’s Medical Assistance in Dying (MAiD) law has evolved through a journey from the courts to Parliament, back to the courts, and then back to Parliament. Along this journey the eligibility criteria, the procedural safeguards, and the monitoring regime have changed. In this article, the authors focus on the eligibility criteria. First, we explain the evolution of the law and what the eligibility criteria were at the various stops along the way. We then explore the ethical justifications for Canada’s new criteria by looking at two elements of the often-corrosive debate. First, we ask whether problems with the social determinants of health that might impact decision-making justify denying eligibility for assisted dying of decisionally capable people with mental illnesses and people with disabilities as their sole underlying medical conditions. Second, we ask whether Canada’s journey supports slippery slope arguments against permitting assisted dying. **Full text:** <https://bit.ly/3s1RbrZ>



## Incorporating the patient and caregiver voice in palliative care quality measure development

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 10 August 2021 – Despite rapid growth in outpatient palliative care (PC), there is a lack an understanding of patient and caregiver experiences of care received in this context. As part of a national effort to develop PC quality metrics for use in accountability programs, the authors sought to develop survey items assessing patients' experiences of outpatient PC, incorporating the patient's voice. The authors conducted 25 one-hour telephone cognitive interviews using a convenience sample of outpatient PC patients and caregivers to cognitively test survey items. Guided by a semi-structured protocol, they assessed the comprehensibility, ambiguity, and adaptability of survey instructions and specific items/response options. In general, question wording and response options did not present challenges to understanding content. Respondents ascribed a variety of meanings to the concepts, validating that the measures capture a range of experiences. However, the referenced timeframe of three months was more difficult to answer for some questions than others. Based on the findings from the cognitive testing, the survey items are being tested as part of a national study to understand the quality of care for patients. These measures may be used in the future by Medicare [in the U.S.] to help outpatient PC programs improve their care. **Abstract (w. references):** <https://bit.ly/2VKqEnm>

### Related:

- *EUROPEAN GERIATRIC MEDICINE* | Online – 12 August 2021 – '**Discordance and concordance on perception of quality care at end of life between older patients, caregivers and clinicians: A scoping review.**' Consumers and healthcare professionals agree on several important aspects of treatments at the end-of-life (EoL) care, particularly related to respecting patient autonomy and the role of family. However, consumers and healthcare professionals have discordant views about the role of healthcare provider and the purpose of treatment withdrawal at the EoL. This conflict ... potentially hinders the value of advance care directives and impacts on trust in the health system to deliver care that meets patient expectations, whether or not well informed. **Full text:** <https://bit.ly/3g31xTR>
- *SCANDANAVIAN JOURNAL OF CARING SCIENCES* | Online – 12 August 2021 – '**Family caregivers' experiences of end-of-life care in the acute hospital setting: A qualitative study.**' Effective communication is the cornerstone of quality of care and the fundamental part for establishing a positive and fruitful relationship and sense of security. In this study, the severity of the symptoms and the impact it had on the patient deeply affected the families' own well-being during end-of-life (EoL) care, calling for increased attention to this aspect of care. Furthermore, findings confirm the importance of acknowledging and appreciating the meaning of respect and dignity at the EoL as seen from family carers' perspective. **Full text:** <https://bit.ly/2VQJFVn>

## Dissemination, use, and impact of a community-based, conversational advance care planning intervention: Ripple effects of the Swedish DöBra cards

*PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 10 August 2021 – Despite increasing interest in community-based advance care planning (ACP) interventions, few studies investigate the societal impact of such initiatives. The DöBra cards, a Swedish adaptation of the GoWish cards, were first used for ACP conversations in a participatory action research project and later, due to popular demand, made available for purchase by the general public. Key factors influencing dissemination of the DöBra cards included "champions" with a mandate within their context or organization, policy documents including use of the cards, media coverage, and presentations of the cards in various settings. The DöBra cards were adapted for use individually and in groups in different private, professional, and organizational settings. Perceived benefits of the cards included acting as an icebreaker in initiating end-of-life (EoL) conversations and having preformulated statements to reflect upon. Other positive experiences included discussions on different interpretations of card statements, thus opening new perspectives regarding EoL. The DöBra cards functioned both as a means to raise EoL issues in different contexts, and as an end in themselves, for example, by facilitating ACP conversations for those with serious disease. Impact also included personal development and strengthening of private and professional relationships, with potential to affect EoL care. **Full text:** <https://bit.ly/3yHoZx4>

Cont.

Noted in Media Watch 18 May 2020 (#666, p.11):

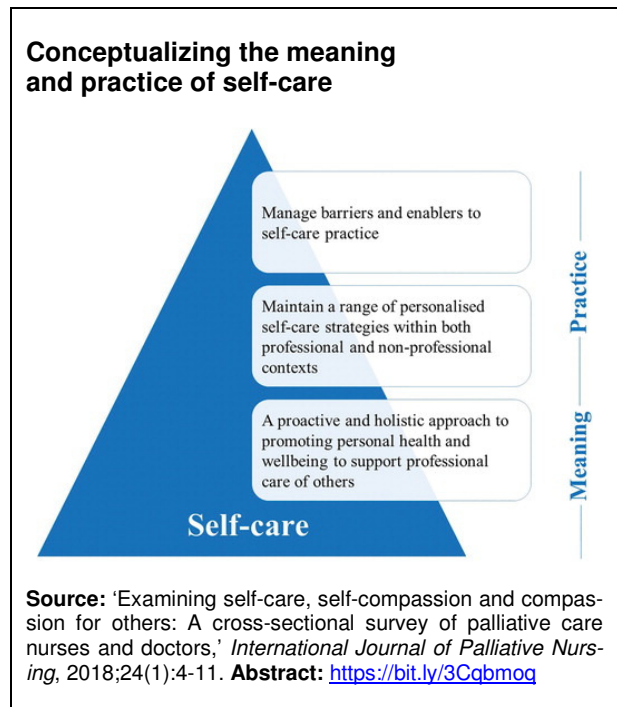
- **HEALTH & SOCIAL CARE IN THE COMMUNITY** | Online – 15 May 2020 – ‘**Death, loss and community-perspectives from children, their parents and older adults on intergenerational community-based arts initiatives in Sweden.**’ Studio DöBra is a community-based initiative in which children and older adults engage with topics related to dying, death and loss through shared arts activities. In an ageing society, Sweden’s end-of-life (EoL) care is increasingly professionalised and specialised, but there is little community involvement. One goal of Studio DöBra is, therefore, to support community engagement with EoL-related topics. Studio DöBra participants act as individuals with agency in creating spaces to connect across generations and engage with EoL topics. **Full text:** <https://bit.ly/2WafCir>

### The challenges of ethical deliberation in palliative care settings: A descriptive study

*PALLIATIVE & SUPPORTIVE CARE* | Online – 11 August 2021 – Inadequate deliberation processes about ethical problems occurring in palliative care (PC) settings may negatively impact both patients and healthcare professionals. Better knowledge of the PC professionals’ practices regarding such processes could help identify specific education needs to improve the quality of PC in the context of complex ethical situations. Thirty-six healthcare professionals took part in the simulated ethical deliberations and in the deliberative dialogue activities, and 13 were met in an individual interview. The study results revealed suboptimal interprofessional collaboration and ethical deliberation competencies, particularly regarding awareness of the ethical issue under consideration, clarification of conflicting values, reasonable decision-making, and implementation planning. Participants also reported facing serious organizational constraints that challenged ethical deliberation processes. This study confirmed the need for professional education in interprofessional collaboration and ethical deliberation so that PC professionals can adequately face current and future ethical challenges. It also enabled the identification of educational priorities in this regard. **Abstract (w. references):** <https://bit.ly/3jPAwEi>

### Theoretical foundations for self-care practice

*PROGRESS IN PALLIATIVE CARE*, 2021;29(4): 183-185. Common sense would suggest that self-care is a necessity rather than a luxury, whether you are a recipient or provider of healthcare. But in reality, effective self-care practice may not be so common for healthcare professionals. Much has been said in recent times about the importance of and need for self-care. From organizational and systemic issues to personal narrative accounts, the primary focus of self-care discourse has largely (and rightly) been concerned with collective practicalities in the clinical practice milieu, as well as related barriers and enablers to individual self-care practice. With lessons from the COVID-19 pandemic far from fully learned, this ongoing discourse is perhaps among the most important of our time, if a healthy and sustainable healthcare workforce will exist to ensure the future viability of healthcare provision and quality outcomes for patients and communities. It is timely, then, to consider the theoretical basis that underpins self-care. What theoretical foundations exist to support and enable self-care practice? **Full text:** <https://bit.ly/2VB5yb5>



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

## Telling it like it was: Dignity therapy and moral reckoning in palliative care

*THEORETICAL MEDICINE & BIOETHICS* | Online – 11 August 2021 – This article offers a conceptual analysis of self-respect and self-esteem that informs the ethics of psychotherapy in palliative care. It is focused on Harvey Chochinov's Dignity Therapy (DT), an internationally recognized treatment offered to dying patients who express a need to bolster their sense of self-worth. Although DT aims to help such patients affirm their value through summarized life stories that are shared with their survivors, it is not grounded in a robust theory of self-respect. There is reason to be skeptical about deathbed narratives, and DT can unintentionally encourage distorted representations at odds with the self-respect it aims to affirm. DT can also encourage distortions of self-esteem that are in conflict with self-respect. Although Chochinov does not address it, the distinction between self-respect and self-esteem is relevant to deathbed accounts. Robin Dillon's feminist revisioning of self-respect can inform the practice of DT by encouraging honest life stories through a reckoning with one's moral complexity, especially in moral generativity cases where patients seek forgiveness, relate atonement, or present their lives as examples to be followed. Her concept of self-esteem allows for therapeutic benefits that are less demanding, but no less significant, than those derived from a moral reckoning. Appropriate affirmations of self-esteem can provide much-needed solace when self-respect is damaged beyond adequate repair. Dillon's account of self-respect and self-esteem enables a richer understanding of the kinds of personal evaluation and disclosure that DT accommodates. As such, their place in DT needs more critical evaluation than it has received. **Abstract (w. notes, references):** <https://bit.ly/3jTUeim>

Noted in Media Watch 8 March 2021 (#707, p.10):

- *JOURNAL OF PATIENT EXPERIENCE* | Online – 25 February 2021 – '**Dignity therapy for end-of-life care patients: A literature review.**' Results revealed the feasibility, acceptability, satisfaction, and effectiveness of dignity therapy (DT) for life-limiting cases/conditions of patients in different age groups. They also highlighted the importance of the therapy setting and the need to apply this in the cultural context. The meaning of DT to patients and their family care members also emerged. Findings showed most patients displayed the need to leave a legacy and from this their core values surfaced. This review highlights the contribution of DT to the holistic care of patients who hope to leave a legacy. **Full text:** <http://bit.ly/3b9Tin4>

## Research Matters

### Global palliative care research (2002-2020): Bibliometric review and mapping analysis

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 9 August 2021 – This review portrays a primary step towards global mapping and classifying palliative care (PC)-related research in the globe. There is a need to expand PC-related research more on non-cancer diseases to overcome their increasing complexity of care with population growth. More international research and cross-institutional cooperation are required, particularly also focusing on low-income and middle-income economy countries and their specific research agendas. Setting up research agendas and priorities from funding bodies and organisations may also enhance cooperation among researchers. Also, it is likely that research capacity building can enhance both research quality and the volume of collaborative research, and this may be an important way to improve quality, quantity and impact of research, as shown in work in the U.K. **Full text:** <https://bit.ly/3jKn6JS>



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## Recommendations for virtual qualitative health research during a pandemic

*QUALITATIVE HEALTH RESEARCH* | Online – 12 August 2021 – Qualitative health research (QHR) has been uniquely affected by the COVID-19 pandemic. Various public health directives will likely remain in place until this pandemic is fully controlled, creating long-lasting impacts on the design and conduct of QHR. Virtual qualitative research (VQR) provides an alternative to traditional interviews or focus groups and can help researchers adhere to public health directives. In this commentary, the authors respond to methodological needs created by the COVID-19 pandemic. Specifically, they explore unique elements of, and recommendations for, the design and conduct of obtrusive VQR (online interviews, online focus groups, and email interviews) and demonstrate crucial ethical, recruitment, analytical, and interpretive considerations. Researchers are currently faced with an ethical imperative to advance VQR methods and ensure that rigorous QHR continues during this pandemic and beyond. This article provides a starting point for researchers to explore the potential of VQR. **Abstract (w. references):** <https://bit.ly/3iKqXHM>

### 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.

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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.
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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.



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<http://bit.ly/2DANDFB>

## Media Watch: Access on Online

### International



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

[Scroll down to 'Media Watch: Lessons Learned from COVID-19']

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



CSPCP SCMSP  
Canadian Society of  
Palliative Care Physicians  
Société canadienne des  
médecins de soins palliatifs

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

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

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

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

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <http://bit.ly/2TboKFX>

ONTARIO | Mississauga Halton Palliative Care Network: <https://bit.ly/3tby3b3>

### Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTPS://BIT.LY/3WVL5RW>

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

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

### South America

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

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