

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

Variation and inconsistencies in palliative care initiation and delivery have limited the applicability and role of research in informing evidence-based practice.

'Journey mapping as a novel approach to healthcare: A qualitative mixed methods study in palliative care' (p.5), in *BMC Health Services Research*.

Canada

These paramedics are helping give Canadians the choice to die at home

ONTARIO | CBC News (Toronto) – 30 August 2021 – Community paramedics could be part of the solution to a nation-wide shortage of palliative care (PC). PC ... is in short supply both in sparsely populated areas ... and larger urban centres. A Canadian Institute for Health Information report found that most Canadians with a terminal illness would choose to die at home if they could access PC, but only 15% are able to do so.¹ Different jurisdictions have come up with some creative ways to tackle the problem in recent years. Among them are programs that enable paramedics to provide care to PC care patients at home, as well as invaluable support to their families. In the sprawling Ottawa Valley – like other rural and remote areas that comprise much of the country – many patients, including frail seniors and people with cancer, don't have family doctors or nearby walk-in clinics. The emergency department is often the only place where they can get medical care. But the County of Renfrew Paramedic Service has started to fill

in some of those gaps for palliative patients at home ... working on teams that include the patient's family doctor, pharmacist and home-care workers. There are similar paramedic programs in other parts of Canada, including in parts of British Columbia, Alberta, Prince Edward Island, New Brunswick and Nova Scotia... This spring, Ontario's Ministry of Health announced a pilot program that gives paramedics in 33 municipalities the authority to administer some palliative medications, including opioids like morphine...² <https://bit.ly/3DtpUEj>

Specialist Publications

“‘Reflection and soul searching’”: Negotiating nursing identity at the fault lines of palliative care and medical assistance in dying’ (p.11), in *Social Science & Medicine*.

1. 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, September 2018. [Noted in Media Watch 24 September 2018 (#582, p.1)] **Download/view at:** <http://bit.ly/2MqmCYO>
2. 'Ontario paramedics to offer in-home palliative care to free up hospital capacity: Pilot to launch in 33 municipalities,' *The Brampton Guardian*, 26 April 2021. [Noted in Media Watch 3 May 2021 (#715, p.2)] <https://bit.ly/3dSgPKm>

U.S.A.

Hospices working to reach mentally ill, homeless

HOSPICE NEWS | Online – 31 August 2021 – Hospice providers are working to expand resources, services and programs for people who are homeless or experiencing housing insecurity. Homeless seniors are an overlooked and underserved population in the U.S. healthcare system, including hospice, facing an array of barriers preventing access. The high prevalence of mental illness among the homeless further complicates hospice providers' efforts to reach them. Adults 50 and older accounted for nearly half of the nation's overall homeless population in 2016, a rise from 11% in 1990 largely attributed to an aging baby boomer generation... People with a severe mental illness accounted for roughly 25% of the chronic homeless population in 2008... Many hospices have programs to care for the homeless.

These include offering care in hospice houses or at shelters in their communities. These are often non-profit hospices who use funds from philanthropic donations to finance the programs. <https://bit.ly/3ywo41H>

Specialist Publications

'Medical, ethical, and legal aspects of end-of-life dilemmas in the intensive care unit' (p.8), in *Cleveland Clinic Journal of Medicine*.

'The privilege of a good death: An intersectional perspective on dying a good death in America' (p.9), in *The Gerontologist*.

"My time to live": Through novel program, kidney patients get palliative care, dialysis 'til the end

KAISER HEALTH NEWS | Online – 30 August 2021 – Most dialysis patients face a harrowing choice between continuing dialysis or receiving hospice services. That's because the Medicare hospice benefit, which took effect in 1983, provides palliative care and support for terminally ill patients who have six months or less to live – and who agree to forgo curative or life-prolonging care. That rigid requirement could change in the future. The Centers for Medicare & Medicaid Services has approved an experimental model that will allow concurrent care for some patients starting next year. But, for now, Medicare will not simultaneously pay for dialysis and hospice care for patients with a terminal diagnosis of kidney failure. Hospices receive a daily per-patient rate from Medicare, typically \$200 or less, and must use it to cover all services related to the terminal diagnosis. Dialysis can easily cost \$250 a session, which means only the largest hospices, those with 500 or more patients, can absorb the costs of providing concurrent care. Only about 1% of the more than 4,500 hospices in the U.S. meet that mark. The result? About a quarter of dialysis patients receive hospice care, compared with about half of the general Medicare population. And their median time spent in hospice care is about five days compared with more than 17 days for the general population. This means that dialysis patients often receive aggressive medical treatment until the very end of life (EoL), missing out on the comfort of targeted EoL care. <https://bit.ly/3kEJt3Q>

Disparities and inequities in pediatric palliative/hospice care

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – 30 August 2021 – The current issue of the Organization's *Pediatric E-Journal* offers a collection of articles to stimulate discussion on the interdependent and yet distinct topics of disparities and inequities in pediatric palliative and hospice care. Highlights from this issue: advance care planning for transgender and non-binary youth; it's different with kids; a conversation about emotions and implicit bias; social determinants of grief and pediatric palliative care; and, ZOOM – an addition to racial trauma. **Download e-journal at:** <https://bit.ly/3mOf4CS>

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Noted in Media Watch 5 July 2021 (#724, p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 June 2021 – ‘**The Pediatric Palliative Improvement Network: A national healthcare learning collaborative.**’ Although multiple organizations have created consensus guidelines and metrics for pediatric palliative care (PPC), standardized implementation and measurement has been challenging. The Pediatric Palliative Improvement Network (PPIN) has become a sustainable organization which improves the quality of PPC through focus on national quality improvement methods training, successful collaborative projects, and the creation of a learning and peer support community with regular calls. The PPIN provides critical educational and organizational infrastructure to inform ongoing quality efforts in PPC... **Abstract (w. references):** <https://bit.ly/3y0MZuC>

N.B. See ‘Challenges and priorities for pediatric palliative care research in the U.S. and similar practice settings: Report from a Pediatric Palliative Care Research Network Workshop,’ *Journal of Pain & Symptom Management*, published online 21 August 2019. [Noted in Media Watch 26 August 2019 (#628, p.12)] **Full text:** <http://bit.ly/2MxvM8r>

- *PEDIATRICS* | Online – 28 June 2021 – ‘**Pediatric palliative care programs in U.S. hospitals.**’ The authors report on the operational features of inpatient pediatric palliative care (PC) programs across the U.S. There is considerable variability in pediatric PC program operations and structure in hospitals. This study affirms the need for updated program standards and guidelines, as well as research that describes how different care delivery models impact outcomes for patients, families, staff, and healthcare systems. Future studies that further define the clinical demand, workload, and sustainability challenges of pediatric PC programs are necessary to foster the provision of high-quality pediatric PC and maintain a vital clinical workforce. **Full text:** <https://bit.ly/3dnBgvd>

[International](#)

Rise in U.K. deaths at home during pandemic raises questions about support and treatment

U.K. | *The Financial Times* – 31 August 2021 – Swelling the numbers able to die in familiar surroundings, with loved ones at their side, has long been a goal of compassionate healthcare. But some fear that a sharp rise in the number of deaths at home during the 18 months of the pandemic is masking a bleaker story, raising questions about whether some have ended their lives without the right level of support or even died unnecessarily for lack of treatment. The rise in the number dying at home has been one of the most striking, but little remarked, phenomena of the pandemic. Data published last week showed that in the week ending 13 August, the number of deaths in private homes was 36.2% above the five-year average, amounting to 816 excess deaths.¹ Within care homes they were a far more modest 10.8% above the five-year average while those in hospitals were 6% above the five-year average. The rise in deaths at home has been evident since the early phase of the pandemic, according to Sarah Scobie, who is leading work at the Nuffield Trust think-tank to understand the reasons behind it. An analysis published by the Trust last September found that a third more people were dying at home than before the pandemic even as deaths in hospitals and care homes had returned to, or fallen below, the average com-

pared with the previous five years.² Researchers say many patients were reluctant to go into hospital at the height of the COVID-19 crisis, when visiting restrictions were so tight and there were fears of contracting the virus. However, charities and campaign groups are in no doubt that a shortage of resources is at least part of the story, with longstanding constraints on the taxpayer-funded health system now exacerbated by the pressure to clear a backlog of cases built up during the pandemic. <https://on.ft.com/3DMymyP>

[Specialist Publications](#)

‘**Development of the Dutch structure for integrated children’s palliative care**’ (p.8), in *Children*.

‘**2021 European Society of Cardiology guidelines for the diagnosis and treatment of acute and chronic heart failure...**’ (p.8), in *European Heart Journal*.

‘**Traumatized, angry, abandoned, but some empowered: A national survey of experiences of family caregivers bereaved by motor neurone disease**’ (p.6), in *Palliative Care & Social Practice*.

Cont.

1. 'Deaths registered weekly in England and Wales, provisional: Week ending 13 August 2021,' Office of National Statistics, 21 August 2021. <https://bit.ly/3gNHtFt>
2. 'Chart of the week: Home deaths account for as many excess deaths since start of the pandemic as deaths in care homes,' Nuffield Trust, September 2020. <https://bit.ly/2YbQNwd>

Specialist Publications

Challenges in pre-loss care to parents facing their child's end-of-life: A qualitative study from the clinicians perspective

ACADEMIC PEDIATRICS | Online – 27 August 2021 – Bereavement care for parents predominantly focuses on care after child loss. However, healthcare professionals (HCPs) feel responsible for supporting parents who are grieving losses in their child's end-of-life (EoL). Pre-loss care is tailored to the parents' needs, thus highly varying. To better understand the nature of pre-loss care, this study aimed to gain insight into the challenges HCPs encounter while providing care for parents during their child's EoL. From the HCPs' inner perspective, three dyadic dimensions in pre-loss care delivery were identified that create tension in HCPs: sustaining hope versus realistic prospects, obtaining emotional closeness versus emotional distance, and exploring emotions versus containing emotions. Throughout pre-loss care delivery, HCPs weighed which strategies to use based on their perception of parental needs, the situation, and their own competencies. HCPs remained with lingering uncertainties on whether the pre-loss care they provide constituted optimal care. As a result of the experienced tension, HCPs are at risk for prolonged distress and

possibly even compassion fatigue. In order to maintain a positive emotional balance in HCPs, education should focus on adapting positive coping strategies and provide hands-on training. Furthermore, on an institutional level a safe environment should be fostered and well-being could be enhanced through learning by sharing as a team.
Full text: <https://bit.ly/3BrMeMR>

Research Matters

'From lurking to engaging and finding meaning in pediatric palliative care research' (p.12), in *Cancer Care Research*.

'End of life care for people with severe mental illness: Mixed methods systematic review and thematic synthesis' (p.12), in *Palliative Medicine*.

'Palliative care for teenagers and young adults – the need for more evidence' (p.12), in *Palliative Medicine*.

Noted in Media Watch 3 April 2017 (#506, p.12):

- *PSYCHO-ONCOLOGY* | Online – 28 March 2017 – '**Pre-loss grief in family caregivers during end-of-life cancer care: A nationwide population-based cohort study.**' Severe grief symptoms in family caregivers during end-of-life (EoL) cancer trajectories are associated with complicated grief and depression after the loss. Nevertheless, severe grief symptoms during EoL caregiving in caregivers to cancer patients have been scarcely studied. In this Danish population-based prospective study of 3,635 caregivers to 9,512 patients severe pre-loss grief symptoms were significantly associated with distress, low preparedness, and little communication during caregiving. Severe pre-loss grief symptoms were reported by 432 caregivers (15.2%). **Abstract:** <https://bit.ly/3yr4YKw>



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.13.

Patients' preferred place of death: Patients are willing to consider their preferences, but someone has to ask them

AGE & AGING | Online – 28 August 2021 – The findings of this study, that patients can change their preferred place of death (PPD) over time, highlights the importance of discussing patients' preferences and following up on this to monitor any changes in their wishes. Proportions of deceased patients were similar for patients with and without a PPD, suggesting that some patients did not realise they were nearing the end-of-life (EoL) and died before they could consider their preferences. This highlights the importance of providing adequate information concerning diagnosis and prognosis and discussing EoL preferences at an early stage. The fact that patients who primarily claimed to have no preference but changed their mind over time indicates a willingness to consider the topic. Knowing that patients who have not been admitted to hospital before, patients with less chronic diseases and patients who live alone are less likely to have a PPD, healthcare professionals could make an extra effort to discuss EoL preferences with these patients, giving them the chance to think about and discuss their preferences and ultimately to die where they want to. **Full text:** <https://bit.ly/3n3GUeu>

Journey mapping as a novel approach to healthcare: A qualitative mixed methods study in palliative care

BMC HEALTH SERVICES RESEARCH | Online – 4 September 2021 – Journey mapping involves the creation of visual narrative timelines depicting the multidimensional relationship between a consumer and a service. The use of journey maps in medical research is a novel and innovative approach to understanding patient healthcare encounters. This study is one of the first to use a journey mapping tool in clinical practice to explore the healthcare journey and patient experience on a larger scale. The maps were used to depict a more fluid and continuous interpretation of the patient healthcare experience which enabled a more holistic and patient-centred analysis of palliative care (PC) provision. Furthermore, this is one of the first medical journey mapping studies to consider and propose potential pivot-points and opportunities for changes in the delivery of care. The use of journey maps can enhance the holistic patient healthcare experience and enable better patient-centred care not only in the PC setting, but also more broadly across healthcare from both a research and clinical practice perspective. **Full text:** <https://bit.ly/3yJN7OU>

Higher levels of unmet support needs in spouses are associated with poorer quality of life: A descriptive cross-sectional study in the context of palliative home care

BMC PALLIATIVE CARE | Online – 28 August 2021 – This study, performed in specialised palliative home care, shows associations between family caregiver's need for more support and their quality of life (QoL). Higher levels of support needs were significantly associated with poorer QoL for family caregivers. This gives additional weight to the importance of addressing the family caregivers' needs for support. In this research, Carer Support Needs Assessment Tool (CSNAT) was used as a research tool. For use in practice, the CSNAT is a communication tool that is integrated into a person-centered process of assessment and support. The response categories can facilitate communication with opportunities to express individual problems and concerns enabling more tailored support to address family caregivers' specific needs that can enable healthcare professionals to give individual support to them. With a deeper understanding of the complexities of supporting family caregivers in palliative care, healthcare professionals are better placed to increase family caregivers' QoL. **Full text:** <https://bit.ly/3sU0vih>

N.B. Additional articles on CSNAT noted in Media Watch 2 November 2020 (#690, p.6).

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Related:

- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 30 August 2021 – ‘**Traumatised, angry, abandoned, but some empowered: A national survey of experiences of family caregivers bereaved by motor neurone disease.**’ The low-risk group seemed to recognise the uncertainty of life and that meaning needed to be created by them. For the moderate-risk group, while motor neurone disease was a major disruption they could, with support, regroup and plan in different ways. The high-risk group did not have many resources, external or internal; they felt let down when professionals did not have answers and could not see or did not know how to change their ways of responding to this unwanted situation. **Full text:** <https://bit.ly/3DIIcCq>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 27 August 2021 – ‘**Caring for people who take care: What is already done?**’ This study reveals a scarcity of family-oriented programs and lack of certified mental health professionals as interventionists. Future studies and interventions should focus on the positive outcomes of the caregiving experience and must acknowledge the cultural differences when trying to replicate programs. Considering that there is no precise formula for dealing with terminal illness and grief, the authors submit that family-centered and systemic lenses are excellent approaches for support during this adjustment process. This study advocates for increased investment in the field, underscoring the importance of family caregivers’ mental health. **Abstract (w. references):** <https://bit.ly/3yqtADc>
- *PALLIATIVE MEDICINE* | Online – 3 September 2021 – ‘**Navigating the caregiving abyss: A metasynthesis of how family caregivers manage end-of-life care for older adults at home.**’ The findings of this study provide a conceptual framework to help guide the development of education, interventions, and health policy to meet the needs of family caregivers (CGs) in providing quality end-of-life care (EoLC). A total of 24 studies were identified. FCGs engaged in the process of “navigating a caregiving abyss” when providing and managing EoLC for older adults at home. The “caregiving abyss” consisted of four phases: 1) Managing multiple roles; 2) Encountering challenges; 3) Mobilizing resources; and, 4) Acknowledging death is near. **Abstract (w. references):** <https://bit.ly/38FrJQf>

Palliative care environments for patient, family and staff well-being: An ethnographic study of non-standard design

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 3 September 2021 – There is an increased expectation that contemporary hospital design will improve clinical outcomes and patient experiences and support staff well-being. In response, this study examined innovative approaches in the design of in-patient palliative care facilities. Three thematic areas of focus were derived from the analysis: 1) Planning solutions that support privacy plus connection; 2) Enhancing comfort through the use of non-standard materials, and managing the risks associated with those; and, 3) Shaking off tradition in hospital design. Myriad constraints resist innovation within the contemporary construction of hospital and hospice facilities. Drawing on a series of real-world examples, the authors findings point to the value of broad consultation and collaboration throughout the design process in achieving design solutions that go beyond standard practice for the benefit for patients, families and staff. **Abstract:** <https://bit.ly/3yKcqiO>

[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>



“Value” of advance care plans: Health economics revisited

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 1 September 2021 – Advance care planning (ACP) has become a much discussed concept in 21st century medicine and healthcare. ACP is a structured process in which skilled facilitators support patients’ ongoing deliberation of their healthcare preferences. A recent definition of an international panel consented in 2017 states that ACP “enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate.”¹ One important benefit of ACP is that it helps to determine a person’s goals and preferences for treatment and care in future situations where a person may have become incapacitated. In a manner of speaking, it thus extends healthcare decisions to a phase in life where people might not be able to state their own wishes anymore. Therefore, ACP has also come to play an important role in palliative care and end-of-life decision-making. Going beyond traditional advance directives, the concept takes into account that an individual’s situation, health status and treatment goals may change over time. Due to demographic ageing and an increasing older population in which chronic diseases and cognitive impairment have become epidemic, ACP is gaining importance. It has been discussed in the Anglo-American literature since the 1990s and has been implemented

in different countries and settings during the last years. There are numerous studies and several systematic reviews on the effectiveness of ACP. **Introduction:** <https://bit.ly/3zEuCMZ>

Preparedness for serious illnesses: Impact of ethnicity, mistrust, perceived discrimination, and health communication

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 3 September 2021 – This study draws attention to the need for healthcare systems and primary care providers to engage in effective discussions and education regarding serious illness preparedness with their patients, which can be beneficial for both individuals and family members and increase quality of care. The authors’ findings revealed that 19%, 24%, and 34% of non-Hispanic White, non-Hispanic Blacks, and Hispanic believed they were not prepared if their medical condition gets worse, respectively. Over 60% indicated that their healthcare providers never engaged them in discussions of their feelings of fear, stress, or sadness related to their illnesses. Results of bivariate analyses showed that race/ethnicity was associated with serious illness preparedness. However, multivariate analysis uncovered that serious illness preparedness was only lower in the presence of medical mistrust in healthcare providers, perceived discrimination, less communication with providers, and poorer quality of self-rated health. **Abstract (w. references):** <https://bit.ly/3kP6VM2>

1. ‘Definition and recommendations for advance care planning: An international consensus supported by the European Association for Palliative Care,’ *THE LANCET*, 2017;18(9):e543-e551. [Noted in Media Watch 11 September 2017 (#529, p.10)] **Summary:** <https://bit.ly/3gW5cTI>

Related:

- *BMC HEALTH SERVICES RESEARCH* | Online – 1 September 2021 – ‘**Efficacy of Normalisation of Advance Care Planning (NACP) for people with chronic diseases in hospital and community settings: A quasi-experimental study.**’ The challenges with advance care planning (ACP) lie in each step of the processes from initiation, discussion, documentation, and storage to execution. The intervention proposed addresses those challenges... This study provides evidence of the feasibility and efficacy of NACP service for people with chronic conditions and adds new evidence that suggests NACP facilitated by RNs was more effective in the community than the hospital setting. ACP takes time and appropriate training, but helps people die in a way consistent with their wishes. **Full text:** <https://bit.ly/3yzn50P>
- *MEDICAL LAW REVIEW* | Online – 30 August 2021 – ‘**Family involvement in the end-of-life decision-making process: Legal and bioethical analysis of empirical findings.**’ End-of-life (EoL) decision-making involves clinicians, patients, and relatives; yet, the law in Israel hardly recognises the role of relatives. This raises the question of the law’s impact in practice... This issue is examined on the basis of findings from a qualitative, interview-based study conducted in Israel among relatives of dying patients. There are areas in which clinicians and relatives do not adhere to the law in the EoL decision-making process. For example, they do not always ascertain the patient’s EoL preferences, which ignores a patient’s right to autonomy and their right to make informed decisions. **Abstract:** <https://bit.ly/38qBKRe>

Development of the Dutch structure for integrated children's palliative care

CHILDREN | Online – 27 August 2021 – This article describes the developments in The Netherlands over the past 15 years. The Foundation for Children's Palliative Expertise (PAL) was established as a nationwide initiative committed to improving palliative care (PC) for children countrywide. This led to the development of the first hospital-based children's PC team in 2012, which expanded to a total of seven teams adjacent to children's university hospitals. Regional networks for children's PC were developed in parallel to these teams from 2014 onwards. The networks are a collaboration of professionals from different disciplines and organisations, from hospital to homecare, and have covered the aspects of children's PC nationally from 2019 onwards. They are connected through the Dutch Knowledge Centre for children's PC. This centre was established in 2018 by the PAL Foundation in collaboration with the Dutch Association for Pediatrics. In 2013, the first evidence-based guideline ... provided access to knowledge for parents and healthcare providers, and in 2017, a format for an individual PC plan was established. Within the Knowledge Centre for children's PC, a physician's support centre for dilemma's regarding the end of life of children was set up. The efforts to children's PC embedded in the regular Dutch healthcare insurance are ongoing. **Full text (click on pdf icon):** <https://bit.ly/2Y1L1NE>

Medical, ethical, and legal aspects of end-of-life dilemmas in the intensive care unit

CLEVELAND CLINIC JOURNAL OF MEDICINE, 2021;88(9):516-527. Critical care is rife with medical, ethical, and legal dilemmas involving end-of-life care. The physician must be acutely aware of the ethical and jurisprudential considerations that should be balanced in navigating these sensitive situations. The cases presented here provide a small sampling of common issues that arise in clinical practice, although they clearly represent only the tip of the ethical and legal iceberg. Addressing these dilemmas requires careful analysis, an understanding of basic ethical and legal principles and perspectives, and reliable consultants to assist physicians and other clinicians in their time of need. A synthesis of medical, ethical, and legal concerns unique to each case is necessary to provide the most appropriate care to patients and families. **Full text:** <https://bit.ly/3jE1Cja>

2021 European Society of Cardiology guidelines for the diagnosis and treatment of acute and chronic heart failure...

EUROPEAN HEART JOURNAL | Online – 27 August 2021 – Guidelines summarize and evaluate available evidence with the aim of assisting health professionals in proposing the best management strategies for an individual patient with a given condition. Guidelines and their recommendations should facilitate decision-making of health professionals in their daily practice. However, the final decisions concerning an individual patient must be made by the responsible health professional in consultation with the patient and caregiver as appropriate. A great number of guidelines have been issued in recent years by the European Society of Cardiology (ESC), as well as by other societies and organizations. Because of their impact on clinical practice, quality criteria for the development of guidelines have been established in order to make all decisions transparent to the user. The recommendations for

formulating and issuing ESC Guidelines can be found on the ESC website.¹ The ESC Guidelines represent the official position of the ESC on a given topic and are regularly updated. **Full text:** <https://bit.ly/3DviQXA>

Extract from *European Heart Journal* article

Many patients with heart failure (HF) would derive benefit from the early integration of a palliative and supportive approach within the care provided by all members of the HF multidisciplinary team. Palliative and supportive care should be thought about for all patients with HF, regardless of stage of their illness. Patients in the advanced stages and those considered for mechanical circulatory support or heart transplantation should receive a palliative care consultation before such interventions as a matter of protocol.

1. ESC guidelines and scientific documents: <https://bit.ly/3sYmlRv>

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

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

The privilege of a good death: An intersectional perspective on dying a good death in America

THE GERONTOLOGIST | Online – 1 September 2021 – All individuals deserve an equitable opportunity to achieve a good death. Unfortunately, access to end-of-life care (EoL) care and services is largely unequal on the basis of race, gender, class, and other social identities. We need to understand how individuals with multiple marginalized identities face different access in attaining a good death and use this knowledge to bring equity to EoL care. The conceptual framework for this argument derives from intersectionality theory and the existing disparities in EoL care. This argument sheds light on the relationship between intersectionality and a good death, demonstrated by a case vignette, and suggests that the more marginalized social identities one has, the more difficult their access to a good death. Because it is particularly important to both recognize and actively combat these inequities, the author offers three practical strategies for EoL researchers and practitioners. For the sake of our increasingly diverse population, advancements in EoL care must be made to facilitate a good death for all. **Abstract:** <https://bit.ly/38w1dsM>

Related:

- *AUSTRALIAN JOURNAL OF ADVANCE NURSING* | Online – 26 August 2021 – ‘**Barriers to the provision of optimal care to dying patients in hospital: A cross-sectional study of nurses’ perceptions.**’ In this study of nurses working in a wide range of acute care settings across rural and metropolitan locations, substantial barriers to the provision of high-quality end-of-life care (EoLC) were perceived across all facets of healthcare provision. Important barriers included the continuation of potentially futile treatment, inadequacy of symptom control, and poor communication between doctors, patients and their families. Nurses perceive a range of patient, family, provider, and health system-related challenges to the provision of optimal EoLC in hospital. **Abstract:** <https://bit.ly/3kBC1Xj>

The C.A.R.E. model of employee bereavement support

JOURNAL OF OCCUPATIONAL HEALTH PSYCHOLOGY | Online – 2 September 2021 – Virtually every employee will experience bereavement and grief at some point in their careers, but organizations are often ill-prepared to support grieving employees. Little empirical work has been conducted on the experience of grief in the workplace, and this study answers calls for research on the subject. The authors interviewed bereaved employees who continued to work full-time. The results suggested four key themes that characterized effective bereavement support in the workplace and that together comprise the C.A.R.E. model of bereavement support: 1) Communication; 2) Accommodation; 3) Recognition of the loss; and, 4) Emotional support. The results provide insight into critical ways that employers, leaders, and coworkers can support grieving employees. **Abstract:** <https://bit.ly/38SAMh7>

Exploring the psychological aspects of palliative care: Lessons learned from an interdisciplinary seminar of experts

JOURNAL OF PALLIATIVE MEDICINE, 2021;24(9):1274-1279. Palliative care (PC) has been shown to help patients live well with serious illness, but the specific psychological factors that contribute to this benefit remain investigational. Although support of patient coping has emerged as a likely factor, it is unclear how PC helps patients to cope with serious illness. The therapeutic relationship has been proposed as a key element in beneficial patient outcomes, possibly undergirding effective patient and family coping. Understanding the distress of patients with psychological depth requires the input of varied clinicians and thinkers. The complex conceptual model developed draws upon the contributions of medicine, nursing, psychology, spiritual care, and social work disciplines. 'Healing Beyond the Cure: Exploring the Psychodynamic Aspects of Palliative Care' was held in May 2019 at Harvard University's Radcliffe Institute for Advanced Study. This special report describes the key psychological aspects of PC that we believe underlie optimal adaptive coping in PC patients. Outlined are key areas for further development in PC research, education, and clinical practice. The discussion held at this meeting became the basis for a planned series of articles on the psychological elements of PC that will be published in the *Journal of Palliative Medicine* on a monthly basis during the fall and winter of 2021-2022. **Abstract:** <https://bit.ly/3kNMQFJ>

Related:

- *MEDICINA* | Online – 1 September 2021 – '**Existential suffering in palliative care: An existential positive psychology perspective.**' The COVID-19 pandemic has exposed the inadequacies of the current healthcare system and needs a paradigm change to one that is holistic and community-based, illustrated by the healing wheel. Existential positive psychology represents a promising approach to meet the rising needs in palliative care. This framework has a two-fold emphasis on how to transcend and transform suffering as the foundation for wellbeing and how to cultivate spiritual and existential capabilities to achieve personal growth and flourishing. The authors propose that these objectives can be achieved simultaneously through dialectical palliative counselling... **Full text:** <https://bit.ly/38DIKLH>
- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 1 September 2021 – '**Psychological adjustment to spousal bereavement in older adults: A systematic review.**' A total of 15 articles involving 686 unique participants were identified. Five characteristics were discovered which can facilitate and inhibit psychological adjustment to spousal bereavement in older adults: 1) The pre-loss spousal relationship; 2) Social support; 3) Finding meaning; 4) Spirituality in loss, the surviving spouse's personality traits; and, 5) Death characteristics. These findings support that concepts of "meaning making" and social support should be incorporated into therapeutic work with bereaved spouses to help facilitate psychological adjustment. **Full text:** <https://bit.ly/2WO1p3F>

Noted in Media Watch 23 August 2021 (#731, p.11):

- *BMC HEALTH SERVICES RESEARCH* | Online – 18 August 2021 – '**Views of healthcare professionals on recruiting to a psychosocial randomised controlled trial: A qualitative study.**' Given the problems recruiting into randomised controlled trials, particularly within palliative care and trials of psychological interventions, it is important to explore why trials may under-recruit. The authors conducted interviews with healthcare professionals who had been involved in recruitment for a trial of a psychosocial intervention in an advanced cancer population. Their findings suggest that whilst healthcare professionals felt that research was important, they did not have the time to engage in recruitment, and that trials of medicinal products were often prioritised over trials of psychosocial interventions. **Full text:** <https://bit.ly/3D8myGK>



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Persuasive communication in medical decision-making during consultations with patients with limited health literacy in hospital-based palliative care

PATIENT EDUCATION & COUNSELING | Online – 25 August 2021 – Both patients in the palliative phase of their disease and patients with limited health literacy have an increased risk of being influenced by healthcare providers (HCPs) when making decisions. This study aimed to explore to what extent persuasive communication occurs during shared decision-making by providing an overview of persuasive communication behaviours relevant for medical decision-making and exemplifying these using real-life outpatient consultations. An exploratory qualitative design was applied: 1) Brief literature review; 2) Analysis of verbatim extracts from outpatient consultations and stimulated recall sessions with HCPs; and, 3) Stakeholder meetings. Twenty-four different persuasive communication behaviours were identified, which can be divided in seven categories: 1) Biased presentation of information; 2) Authoritative framing; 3) Probability framing; 4) Illusion of decisional control; 5) Normative framing; 6) Making assumptions; and, 7) Using emotions or feelings. Persuasive communication is multi-faceted in outpatient consultations. Although undesirable, it may prove useful in specific situations making it necessary to study the phenomenon more in depth and deepen our understanding of its mechanisms and impact. **Abstract:** <https://bit.ly/2WACCK1>

Noted in Media Watch 30 August 2021 (#732, p.13):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 26 August 2021 – ‘**A review of clinical trials of advance care planning interventions adapted for limited health literacy.**’ Only 11% of Americans have discussed advance care planning (ACP) with a healthcare provider. Individuals with limited health literacy (LHL) are even less likely to participate in ACP due to difficulty comprehending complex health information. The purpose of this review was to identify randomized controlled trials designed to address the effects of LHL on ACP, evaluate the quality of these studies, and summarize evaluation data to inform future studies. More high-quality intervention studies that address the effects of LHL on ACP in diverse populations and settings are needed. **Abstract (w. references):** <https://bit.ly/3sPhiD0>

N.B. Additional articles on health literacy noted in Media Watch 22 June 2020 (#671, pp.10-11).

“Reflection and soul searching”: Negotiating nursing identity at the fault lines of palliative care and medical assistance in dying

SOCIAL SCIENCE & MEDICINE | Online – 3 September 2021 – Authorities within the field of palliative care (PC) frequently espouse that assisted death is – and must remain – separate from PC. This fault line, between PC and assisted death, has important implications for how we enact end-of-life (EoL) care, particularly in jurisdictions where assisted death is legal. And yet little is known about how direct-care clinicians providing PC navigate this demarcation in everyday practice. This qualitative study reports on semi-structured interviews with 22 PC nurses from across Canada, where assisted death was legalized in 2016. Although a minority of participants did express categorical opinions around the (non) legitimacy of assisted death as an ethical EoL care option, most engaged in an ongoing and sometimes painful process of questioning and self-examination. Their ethical reflections were more nuanced than simply dismissing medical assistance in dying (MAiD) as incompatible with PC philosophy; yet this idea of incompatibility weighed heavily as they reasoned through their experiences and questioned their own perspectives. Nurses described grappling with the finality of assisted death, which contradicts their belief in the telos of PC; when adequately resourced, PC should be available to support people to live well before death. At the same time, commitment to important PC values such as the non-abandonment of dying people and respecting peoples’ individual EoL choices reveal the possibility of overlap between the ethos of assisted death and that of PC nursing. Drawing on scholarship in feminist ethics, this study sheds light on the moral identity work that assisted dying catalyzes amongst PC nurses. The authors highlight what is at stake for them as they navigate a delicate tension in responding ethically to patients whose suffering motivates an interest in assisted death, from within a wider professional collective that upholds a master narrative about the incompatibility of assisted death and PC. **Abstract:** <https://bit.ly/3kJXspa>

Research Matters

Personal insight

From lurking to engaging and finding meaning in pediatric palliative care research

CANCER CARE RESEARCH, 2021;1(3). As part of the pediatric intensive care unit (PICU) study team for the “How Parent Constructs Affect Parent and Family Wellbeing after a Child’s Death” ... (i.e., Good Parent study), I was responsible for both screening parent eligibility for the study, and conducting parent data collection. As a long-time childhood cancer nurse, I initially felt like a fish out of water. I was not a PICU nurse and I needed to learn the routines of the unit to identify and then recruit parent participants to the study. The study’s principal investigator developed thoughtful, complex enrollment procedures to mitigate potential harm to parents who were facing very difficult treatment decisions for their seriously ill children. There were 2 of us who were enrolling parents from the PICU and we alternated weeks of being “on call” for study enrollment. And week after week, we heard story after story of a parent’s worst nightmare, being part of treatment decision-making that could significantly change or end their child’s life.

Full text: <https://bit.ly/3kLKkQg>



End-of-life care for people with severe mental illness: Mixed methods systematic review and thematic synthesis

PALLIATIVE MEDICINE | Online – 3 September 2021 – 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 (EoL) care 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. Studies are needed examining the experiences of people and their carers with severe mental illness at the EoL, along with studies co-producing, introducing and evaluating new ways of providing and organising care. This programme of research should also include projects focusing on particularly disadvantaged groups, including people with severe mental illness at the EoL who are also homeless or who are in prison. Candidate interventions include advanced planning, advocacy and improved education for professionals along with the development of new or enhanced roles for practitioners and the introduction of models of integrated provision spanning the mental health, EoL and related care systems. **Full text:** <https://bit.ly/3tfatuB>

Palliative care for teenagers and young adults – the need for more evidence

PALLIATIVE MEDICINE | Online – 31 August 2021 – Teenagers and young adults ... have different healthcare needs than either children or adults due to their biological, psychological, and social developmental changes. These young people with life-limiting conditions are a heterogeneous group including those diagnosed with a life-limiting condition in childhood. Future research needs to focus on identifying key decision points within care pathways, and opportunities to work collaboratively with young people and their families. We also need to explore how to integrate palliative care earlier and how to support clinicians to have timely and compassionate conversations about end-of-life care with young people and their families. Getting it right for everyone is a challenge given the diverse nature and needs of younger people with life-limiting illness. One approach will not be appropriate for all, but it is clear that a collective research effort is needed with young people and their parents at the very heart of it. **Full text:** <https://bit.ly/3zzELLa>



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

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