

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

The hospice model is still based predominantly on care of people with a primary diagnosis of cancer; specialist services need to evolve to take account of multimorbidity, and the associated symptom burden and uncertainty, as end of life approaches.

'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' (p.7), in *BMJ Open*.

U.S.A.

Patients with poor health literacy less likely to elect hospice

HOSPICE NEWS | Online – 2 February 2021 – Patients who have low levels of health literacy (HL) are more likely to seek intensive curative treatment at the end-of-life (EoL), as opposed to choosing hospice care. In addition to disparities in hospice utilization associated with race or ethnicity, a patient's understanding of their condition and the available treatments may also be a contributing factor, according to a recent study.¹ HL is the degree to which individuals can obtain, process and understand basic health information and services needed to make appropriate health decisions, according to the Institute of Medicine. A health illiterate patient may have a strong overall ability to read or have an advanced education but have a limited understanding of information specific to healthcare. "Medicare beneficiaries who resided in low HL areas were likely to receive aggressive EoL care," the study indicated. "Tailored efforts to improve HL and facilitate patient-

provider communications in low HL areas could reduce EoL care intensity." Patients who lack an understanding of healthcare information or terminology, do not understand their own illnesses, or who misconstrue the nature of hospice or palliative care may lack the necessary tools to make an informed decision about their EoL wishes <http://bit.ly/3j9nall>

Specialist Publications

'Awareness of palliative care, hospice care, and advance directives in a racially and ethnically diverse sample of California adults' (p.5), in *American Journal of Hospice & Palliative Medicine*.

'Dying poor in the U.S. – disparities in end-of-life care' (p.5), in *Journal of the American Medical Association*.

1. 'Associations between health literacy and end-of-life care intensity among Medicare beneficiaries,' *American Journal of Hospice & Palliative Medicine*, published online 21 January 2021. **Abstract (w. list of references):** <http://bit.ly/3pGr4oA>

N.B. Additional articles on the impact of HL on hospice and palliative care outcomes noted in Media Watch 22 June 2020 (#671, pp.10-11).

International

Government urged to increase investment in palliative care

AUSTRALIA | Palliative Care Australia – 3 February 2021 – Palliative Care Australia (PCA) has called on the Commonwealth Government to invest a further \$365 million to meet the growing palliative care (PC) needs of people in the community, hospitals and residential aged care. The three key funding initiatives are contained in PCA's 'Pre-Budget Submission' and form a comprehensive suite of funding measures designed to address a system that is failing to meet the demand for PC in Australia.¹ PCA Chair, Professor Meera Agar, says the evidence is clear that investing in PC delivers not just better health outcomes, but significant economic value as well. "All Australians have a human right to quality PC – when and where they need it, and on that alone, the argument for prioritising this funding is a powerful one. But we also know that investment in PC makes sound economic sense and delivers strong returns on investment," Professor Agar said. The three key initiatives would see an increase in funding of \$240 million per year in integrated home and community-based PC services, an additional \$50 million in hospitals and \$75 million in residential aged care. The recommendations are informed by a KPMG report 'Investing to

Save: The Economics of Increased Investment in Palliative Care in Australia,² commissioned by PCA in 2020, which found increased funding in community-based settings, hospitals and residential aged-care would deliver a strong return on investment and provide governments with significant cost savings. <http://bit.ly/2MRgOvn>

Specialist Publications

“Flattening” one curve: What about “raising the line” on the other? COVID-19 and palliative care in low-income and middle-income countries (p.8), in *BMJ Supportive & Palliative Care*.

‘Palliative care competencies for geriatricians across Europe: A Delphi consensus study’ (p.9), in *European Geriatric Medicine*.

‘Lessons learned from countries that have introduced palliative care services into their national health system: A narrative review’ (p.11), in *Journal of Palliative Care*.

1. 'Pre-Budget Submission: Palliative Care – its more than you think,' Palliative Care Australia, February 2021. **Download/view at:** <http://bit.ly/2MwsIL5>
2. 'Investing to Save: The Economics of Increased Investment in Palliative Care in Australia,' KPMG Australia, May 2020. [Noted in Media Watch 1 June 2020 (#668, p.5)] **Download/view at:** <https://bit.ly/3d8DFL2>

Report shows 95% of callers satisfied with local out-of-hours palliative care provision

U.K. (England) | *Shropshire Live* (Shrewsbury) – 3 February 2021 – Healthwatch Shropshire and Healthwatch Telford & Wrekin have just published a report about how palliative care (PC) is provided outside of normal GP hours in Shropshire, Telford & Wrekin.¹ Since July 2018 all out-of-hours calls have been directed to NHS 111. In Shropshire, Telford & Wrekin this service is provided by West Midlands Ambulance Service. In early March 2020 due to the Covid-19 pandemic the number of calls to NHS 111 grew which led to some delays in calls from patients being answered. To offer additional support at this time ShropDoc introduced a dedicated Palliative Care Helpline. The aim of the Healthwatch Survey was to understand the experience of patients on a PC pathway, and those supporting them, in getting help when they needed it from NHS 111 and ShropDoc during the pandemic. Healthwatch Shropshire and Healthwatch Telford & Wrekin are the independent consumer champions for health and social care in Shropshire, Telford & Wrekin. They gather the views and experiences of patients, service users, carers, and the general public about services including hospitals, GPs, mental health services, community health services, pharmacists, opticians, residential care and children's services. They also have statutory powers that can be used to influence service provision by encouraging improvements. <http://bit.ly/36CI7AA>

1. 'Experiences of End of Life & Palliative Care Services in Shropshire,' Healthwatch Shropshire, January 2021. **Download/view at:** <http://bit.ly/2MNxi7C>

Marie Curie calls for national leadership as 10,000 more Scottish people every year may need palliative care by 2040

U.K. (Scotland) | *Renfrewshire News* – 2 February 2021 – New research has projected that up to 95% of all people who die in Scotland may need palliative care (PC) by 2040, with over 60,000 people projected to be dying with a terminal condition. The number of Scots dying from multiple diseases is also set to increase by 82% by 2040. Led by researchers at Marie Curie and the University of Edinburgh, the research projects an increase in the number of people dying from cancer and dementia, but a decrease in deaths from organ failure in the next 20 years. People aged 85 and over are projected to account for nearly half (47%) of those dying with PC needs by 2040. Following this research, Marie Curie, has published its manifesto for the 2021 Scottish Parliament

elections.¹ The charity is calling on all parties to make PC a priority for the next Scottish Government with a new national strategy and dedicated national leadership to enable Scotland to meet the growing changes in demography and ensure dying people get the best possible support and care they need. <http://bit.ly/2MqA56W>

[Specialist Publications](#)

'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' (p.7), in *BMJ Open*.

1. '2021 Scottish Parliament Manifesto Dying, death and bereavement: Getting it right for all of Scotland,' Marie Curie, February 2021. **Download/view manifesto at:** <http://bit.ly/2YFa1Y0>

Noted in Media Watch 6 April 2020 (#660, p.3):

- U.K. (Scotland) | *The Scotsman* (Edinburgh) – 3 April 2020 – **'Palliative care for all when the end is approaching is still the national goal'** In 2016 the Scottish Government set out an ambitious vision that by 2021 everyone who needs palliative care will have access to it.¹ We are starting to see a developing picture of what care and support for people living with a terminal illness will look like in Scotland by 2040.² The number of people dying in Scotland will increase by 7,000 a year to over 65,000 by 2040, with people living longer into their mid-80s.³ By 2040 45% of all deaths will be people over 85. Our dying population will become increasingly older, frailer and living with multi-health conditions, which will create a new level of complexity in the care they will need. <https://bit.ly/2yr9wqJ>
 1. 'Strategic Framework for Action on Palliative & End-of-Life Care: 2016-2021,' Scottish Government, December 2015. [Noted in Media Watch 21 December 2015 (#441, p.8)] **Download/view at:** <https://bit.ly/2JBChU1>
 2. 'The impact of population ageing on end-of-life care in Scotland: Projections of place of death and recommendations for future service provision,' *BMC Palliative Care*, published online 19 December 2019. [Noted in Media Watch 16 December 2019 (#644, p.8)] **Full text:** <http://bit.ly/2qKez24>
 3. 'End-of-life care in Scotland: Trends in the population in need of palliative care.' *International Journal of Population Data Science*, published online 11 June 2018. [Noted in Media Watch 2 July 2018 (#570, p.9)] **Abstract:** <https://bit.ly/2UWXYmJ>



[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/2RPy9b>

Royal College of Physicians publishes end-of-life care resource for hospital doctors

U.K. | Royal College of Physicians – 1 February 2021 – The College has produced a resource in collaboration with the Society of Acute Medicine to support hospital doctors in improving the care and choices provided to people at the end of their life. 'End-of-life care (EoLC) in the acute care settings' aims to help hospital doctors identify those patients who are in their last days or weeks of life and ensure that their patients' choices are heard and supported, in a holistic and sensitive way. It provides guidance on starting the often-difficult conversation about EoLC with patients and their families or carers, recognising that every patient will have different needs and priorities. This resource provides: guidance on how to identify people in the last year of their life; suggestions for starting a conversation about EoLC; the role of advance care planning and specialist palliative care; advice on clinical management and anticipatory prescribing for the dying patient; recommendations for professional development in EoLC; and, an addendum on care of the dying patient with COVID-19. Identifying that someone is approaching the end of their life is challenging, as is offering them and those close to them a conversation about treatment choices for the future and different options for care. As a result, people with long-term conditions can be admitted repeatedly to hospital, although this may not be what they would want if asked. The majority of patients who express a preference would prefer to die at home, but currently only 45% of people at the end of their life die in their usual place of residence. **Download/view at:** <http://bit.ly/3ol25jA>

When dying is a feminist issue: Report reveals why terminal illness, their own or loved ones, hits women hardest

U.K. (Scotland) | *The Sunday Post* (Glasgow) – 1 February 2021 – Research by ... Dignity in Dying, which has long sought a change in the law to give terminally ill people the right to end their own lives, suggests the impact of current legislation on women is huge – and that the *status quo* should be challenged.¹ The charity's research involved speaking to women who had either been given a terminal diagnosis or who were caring for or had cared for a terminally ill loved one. And their tales of experience, worrying about how their lives will end or watching people they love suffer, highlights the need for change. The group says 80% of women are in favour of changing current legislation. Recent figures show that more than half of Scotland's 759,000 adult carers are female. Many have had to nurse relatives with terminal illnesses towards the end of their lives and spoke about the pain and suffering they witnessed, and how they wished there was something they could have done to end the suffering, or ensure a peaceful, dignified death. 82% of National Health Service nurses are female, meaning more women are exposed to the effects of lack of end-of-life choice. <http://bit.ly/39BfFkf>

Extract from Dying in Dignity Scotland report

When Dignity in Dying Scotland released the report 'The Inescapable Truth...' detailing how 11 Scots a week suffer as they die,¹ the report was met with resistance from palliative care (PC) professionals who reported that relatives were mistaking normal EoL symptoms for more distressing symptoms, making bereaved relatives question what they had seen. While some PC professionals recognise that a minority of terminally ill people die in pain, many have argued, in response to calls to legalise assisted dying, that the answer is simply to improve EoL care. This argument has also been made in debates in Holyrood. Advocating for more PC as an alternative to assisted dying ignores the reality that for many people, no amount of PC is enough to relieve their suffering.

1. 'The Inescapable Truth About Dying in Scotland,' Dying in Dignity Scotland, 2019. **Download/view at:** <http://bit.ly/2LfogqW>

1. 'Dying in Scotland: A Feminist Issue,' Dying in Dignity Scotland, February 2021: <https://bit.ly/3oK2rGp>

Specialist Publications

Awareness of palliative care, hospice care, and advance directives in a racially and ethnically diverse sample of California adults

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 4 February 2021 – The findings of this study reveal that lack of awareness of hospice and palliative care (PC) and advance directives (ADs) among California adults is largely influenced by race and ethnicity. In addition, demographic and socio-economic variables, health status, access to primary care providers, and having informal care giving experience were all independently associated with awareness of ADs and palliative and hospice care. These effects are complex, which may be attributed to various historical, social, and cultural mechanisms at the individual, community, and organizational levels. A large number of factors should be addressed in order to increase knowledge and awareness of end-of-life and PC as well as completion of ADs and planning. The

results of this study may guide the design of multi-level community and theoretically-based awareness and training models that enhance awareness of PC, hospice care, and ADs among minority populations. **Full text:** <http://bit.ly/2MyfBJu>

Publishing Matters

‘Publishing at any cost: A cross-sectional study of the amount that medical researchers spend on open access publishing each year’ (p.12), in *BMJ Open*.

‘Tip: Four best practices for covering palliative care’ (p.12), posted on the Journalism.comm.uk website.

Related:

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 2 February 2021 – **‘Dying poor in the U.S. – disparities in end-of-life care.’** The COVID-19 pandemic has focused attention on stark disparities in the U.S., with higher rates of infections and deaths among lower-income populations and communities of color. Illness and death rates are not the only sources of health inequity in this country. There are also substantial differences in the care that patients with serious illnesses receive near the end of life (EoL) that are based on race or socioeconomic status. Although pandemic-related efforts to improve equity rightfully focus on preventing death, in this and numerous other contexts, policymakers and clinicians should also work to eliminate disparities in EoL care. **Full text:** <http://bit.ly/3oJI0cD>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 5 February 2021 – **‘Preferences for more aggressive end-of-life pharmacologic care among racial minorities in a large population-based cohort of cancer patients.’** Minority patients receive more aggressive and potentially suboptimal care at the end of life (EoL). The authors investigated preferences about pharmacologic interventions at the EoL and their potential variation by socio-demographic factors among recently diagnosed cancer patients. Black and Hispanic cancer patients were more likely to express preferences toward more aggressive EoL pharmacologic care. These findings were independent of other sociodemographic characteristics, health literacy and trust in the medical profession. **Full text:** <https://bit.ly/2Lrilla>

Noted in Media Watch 25 January 2021 (#701, p.2):

- *HOSPICE NEWS* | Online – 19 January 2021 – **‘Race, socioeconomics are largest barriers to hospice and palliative care.’** Recent research reflects mounting concerns about inequitable access to hospice and palliative care (PC) across the U.S. Researchers from the John Hopkins University School of Nursing in Baltimore examined March 2020 data from three national healthcare databases that outlined disparities in hospice and PC. Of the studies the researchers assessed, 70% described differences in access out-comes to hospice and PC by ethnicity, race or socioeconomic status.¹ According to the researchers “there is growing evidence of disparities in access to hospice and PC services to varying degrees by sociodemographic groups.” <http://bit.ly/39HdTNI>

1. ‘Sociodemographic disparities in access to hospice and palliative care: An integrative review,’ *American Journal of Hospice & Palliative Medicine*, published online 11 January 2021. [Noted in Media Watch 18 January 2021 (#700, p.9)] **Abstract (w. list of references):** <http://bit.ly/3oBiKG3>

Evaluating the use of video communication technology in a hospital specialist palliative care team during the COVID-19 pandemic

AMRC OPEN RESEARCH | Online – 29 January 2021 – The authors' findings are in line with other studies, which describe how technology was used to support in palliative care (PC) delivery during the pandemic. Other authors have described the potential of this technology to improve communication between healthcare professionals and support the delivery of virtual consultations of patients and their families. Furthermore, a pre-COVID study reports that PC staff generally had favourable attitudes toward video visits and telehealth for home consultations. Outside of hospital, researchers have also identified how online resources and virtual communities have helped to support PC professionals and the public during the pandemic. Furthermore, these technologies further complement existing initiatives to improve PC delivery through technological innovation. The authors identified barriers to using technology in PC, which have been reported by other authors. Previous studies have identified the user-centred challenges of using technology in healthcare organisations, where difficulties in the implementation of information technology systems make it difficult for staff to work efficiently. There are advantages and disadvantages of different technological platforms. For example, the features of Microsoft Teams and Zoom may not align with the clinical workflow of healthcare organisations. Furthermore, many users enjoy the simplicity of Zoom, whereas many healthcare organisation favour Microsoft Teams due to integration with other software. The authors' work is also consistent with previous studies which highlight the ethical challenges of using patient data with technological systems. They also highlight the risk of widening inequalities between patients (and organisations) who have limited access to this technology. **Full text:** <http://bit.ly/3oEkiP1>

Dignity of informal caregivers of migrant patients in the last phase of life: A qualitative study

BMC PALLIATIVE CARE | Online – 4 February 2021 – Prominent for the dignity of informal caregivers is their desire to ensure good care for the patient and preserve the patient's dignity. To many respondents, that meant providing the patient care themselves; to others it meant advocating for good care and patient dignity in contacts with healthcare professionals and with other relatives. Even though caregivers reported that the physical and emotional impact of caregiving was heavy, being a good caregiver and ensuring good care from health professionals were vital to their own dignity. Many caregivers saw caregiving as part of maintaining a good relationship with their loved one and pointed out that providing care came with additional valuable aspects such as good conversations. This study also highlighted the relational aspects of caregivers' dignity. Their dignity was often linked to the patient's dignity. Care that undermined the patient's dignity also undermined their own dignity. Moreover, a patient's behavior, or a caregiver's own behavior toward the patient or significant others, could influence the caregiver's own dignity. Caregivers' dignity was strengthened when their role and their knowledge about the patient was acknowledged and supported by healthcare professionals. **Full text:** <http://bit.ly/39N5NnK>

Using routine databases to evaluate Electronic Palliative Care Co-ordination Systems

BMJ EVIDENCE-BASED MEDICINE | Online – 29 January 2021 – In response to the government's drive to expand Electronic Palliative Care Co-ordination Systems (EPaCCS) across England by 2020, further evidence for this intervention needs to be established quickly. With palliative and end-of-life care research being an underfunded area, the availability and lower costs of routine databases make it an attractive resource to integrate into studies evaluating EPaCCS without jeopardising research quality. This article describes how routine databases can be used to address the current paucity of high-quality evidence; they can be used in a range of study designs, including randomised controlled trials and quasi-experimental designs, and may also be able to contribute quality of life or patient-reported outcome measures. **Abstract:** <http://bit.ly/2Yt03sZ>

Cont. next page



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Noted in Media Watch 12 October 2020 (#687, p.8):

- *BMJ OPEN* | Online – 5 October 2020 – ‘**Information sharing challenges in end-of-life care: A qualitative study of patient, family and professional perspectives on the potential of an electronic palliative care co-ordination system.**’ There are only a limited number of qualitative studies exploring attitudes towards and use of an electronic palliative care co-ordination system (EPaCCS). The findings of this study support those of a recent systematic review that identified the burden of inputting data and information technology (IT) systems as the main challenge to implementation of EPaCCS.¹ Introduction of an EPaCCS alone does not provide a solution to some of the current difficulties regarding interdisciplinary management of end-of-life patients in the community. **Full text:** <https://bit.ly/3liSaj7>

1. ‘Electronic palliative care coordination systems (EPaCCS): A systematic review,’ *BMJ Supportive & Palliative Care*, published online 8 May 2019. [Noted in Media Watch 20 May 2019 (#614, p.8). **Full text:** <http://bit.ly/2Jvp5kQ>

Noted in Media Watch 9 December 2019 (#643, p.8):

- *BMC PALLIATIVE CARE* | Online – 5 December 2019 – ‘**Paramedic information needs in end-of-life care: A qualitative interview study exploring access to a shared electronic record as a potential solution.**’ This study identifies a need – and a strong desire – for improved access to accurate and in-date advance care planning documentation for paramedics attending patients at the end of life. Access to an electronic palliative care coordination system (EPaCCS) offers a potential solution, however, several barriers need to be addressed for this to be successful in practice. Further research is needed to support the development and implementation of EPaCCS for paramedics, and to evaluate its usefulness in practice. **Full text:** <http://bit.ly/34Ydwua>

Noted in Media Watch 19 September 2016 (#480, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 September 2016 – ‘**Crash course in Electronic Palliative Care Coordination Systems (EPaCCS): 8 years of successes and failures in patient data sharing to learn from.**’ EPaCCS are England’s pre-eminent initiative in enabling advance care planning and improved communication and coordination at the end of life. They are electronic registers or tools and processes for sharing data to enable access to information about dying patients. Striking outcomes have been reported around EPaCCS, such as 77.8% of ‘Coordinate My Care’ patients dying in their preferred place. EPaCCS have, however, been extremely challenging to develop and implement, with many projects remaining continuously “under development” or folding. **Full text:** <http://bit.ly/2VmEMgE>

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 | Online – 3 February 2021 – The authors project that by 2040, the number of people requiring palliative care (PC) will increase by at least 14%; and, by 20% if they factor in multimorbidity. The number of people dying from multiple diseases associated with different disease groups is projected to increase from 27% of all deaths in 2017 to 43% by 2040. To address increased need and complexity, experts prioritised sustained investment in a national digital platform, roll-out of integrated electronic health and social care records; and, approaches that remain person-centred. By 2040 more people in Scotland are projected to die with PC needs, and the complexity of need will increase markedly. Service delivery models must adapt to serve growing demand and complexity associated with dying from multiple diseases from different disease groups. Sustained investment is needed in secure, accessible, integrated and person-centred health and social care digital systems, to improve care coordination and optimise PC for people across care settings. **Full text:** <http://bit.ly/39HdPyy>



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 beginning on p.13.

Neonatal and perinatal palliative care pathway: A tertiary neonatal unit approach

BMJ OPEN PAEDIATRICS | Online – 1 February 2021 – A lack of well-structured guideline or care pathway results in inadequate, inconsistent and fragmented palliative care (PC) for babies and their families. The impact on the families could be emotionally and psychologically distressing. Not all neonatal units have specialist PC clinicians or teams, and such units will benefit from a well-planned perinatal PC pathway. In this article, the authors discuss a tertiary neonatal unit perinatal care pathway which provides guidance from the point of diagnosis and establishment of eligibility of a baby for PC through to care after death and bereavement support for families. **Full text:** <http://bit.ly/2LhdM2S>

N.B. Search back issues of Media Watch for additional articles on neonatal and perinatal PC at: <http://bit.ly/2ThijkC>

“Flattening” one curve: What about “raising the line” on the other? COVID-19 and palliative care in low-income and middle-income countries

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 4 February 2021 – The death toll from the COVID-19 pandemic has exposed the public to the reality of death and dying, raising awareness of the fragility of one’s mortality. It has revealed to many care professionals and policymakers the need for integrated, comprehensive care provision across public health and medical services, including palliative and end-of-life care. With large disparities in the capacity of health systems globally prior to the pandemic, inequity in the response to COVID-19-related palliative care (PC) needs was inevitable across low-income, middle-income and high-income countries. The immediacy of the dialogue around COVID-19 response preparedness has largely muted calls around the need to enhance PC service provision in low-income and middle-income countries, and the longer term development necessary to inform future disease outbreaks specifically and the needs of the dying generally. PC was initially deprioritised in the contagion compared with efforts aimed at curbing the infection, medical management and vaccine development. However, escalating admissions to high-income countries intensive care units increased awareness of the prevalence of patient symptoms that can be highly distressing, including breathlessness, pain and delirium. **Full text:** <http://bit.ly/36KcFR4>

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 5 February 2021 – ‘**The challenges of caring for people dying from COVID-19: a multinational, observational study (CovPall).**’ Palliative care (PC) services responded actively but most felt ignored by national health systems during the COVID-19 pandemic, despite supporting patients who were dying or had severe symptoms, supporting their families/carers and supporting other professionals to deliver care. Services provided expertise in symptom management and holistic care while facing shortages of equipment, staff and medicines. The crucial role of PC during pandemics must be better recognised and integrated. This is particularly the case for charity managed services and those providing care in people’s homes. **Full text:** <https://bit.ly/3rnwKnY>

U.K. Access to Palliative Care & Treatment of Children Bill

Children’s medical treatment decision-making: Reform or review?

CLINICAL ETHICS | Online – 4 February 2021 – This article considers proposals to reform the law in response to recent high profile cases concerning the medical treatment of children, currently before Parliament in the Access to Palliative Care & Treatment of Children Bill 2019-2021. It considers the proposed procedural change, to introduce a requirement for mediation before court proceedings, and argues that dispute resolution processes should be a matter of good practice rather than enshrined in law. It argues that the proposed substantive change to determination of best interests would not result in different outcomes because the best interests analysis co-exist with the legal and professional duties of doctors to children in their care. It argues that if there is to be reform of the law it needs to follow from a comprehensive review of all the issues in which the minimum standards imposed by law fit together with good practice standards and not in response to individual cases. **Full text:** <http://bit.ly/3txApRQ>

Palliative care competencies for geriatricians across Europe: A Delphi consensus study

EUROPEAN GERIATRIC MEDICINE | Online – 1 February 2021 – The World Health Organization definition of palliative care (PC) includes the provision of quality of life for patients and their families through the prevention/relief of suffering by means of early identification, comprehensive assessment and treatment of pain and other physical, psychosocial and spiritual suffering. Achieving these goals requires an integrative approach throughout societal structures, including appropriate policies, adequate access to treatment and interventions such as drug availability, education of both healthcare workers and public and implementation of generalist PC services at all levels of society. While not denying the reality of death, PC thus offers a positive approach for living life to the full even for older patients. Early identification of patients in need of PC becomes crucial in particular for older patients with chronic conditions. The Delphi process described in this article enabled the development of a European specific core competency catalogue to improve competencies of geriatricians to enable them to guide their patients through the last period of life. The current version of the PC competency catalogue represents an important step in the development of effective PC education within the training of geriatricians, which is essential given the condition's increasing relevance to twenty-first century healthcare. This catalogue equips geriatricians with skills mandatory to deliver person centered care to older patients until the end of their life. **Full text:** <https://bit.ly/36wpzSo>

N.B. The final version of core PC competences recommended by the European Geriatric Medicine Society included 35 competencies: <https://bit.ly/3oLrw3u>

Early serious illness communication in hospitalized patients: A study of the implementation of the Speaking About Goals & Expectations (SAGE) program

HEALTHCARE, 2021;9(2). The Speaking About Goals & Expectations (SAGE) Program, adapted from the Serious Illness Care Program, is a multicomponent intervention designed to foster earlier and more comprehensive serious illness conversations for patients admitted to the hospital. The authors present a quality improvement study of the SAGE Program assessing older adults admitted to a general medicine service at the Brigham & Women's Hospital in Boston, Massachusetts. Their primary outcomes included the proportion of patients with at least one documented conversation, the timing between first conversation documented and death, the quality of conversations, and their interprofessional nature. The authors trained 37 clinicians and studied 133 patients split between the SAGE intervention and a comparison population. Intervention patients were more likely to have documented serious illness conversations; these conversations occurred earlier and included more key elements of conversation. This study demonstrated significant differences in the frequency and quality of serious illness conversations completed earlier in the illness course for hospitalized patients. **Full text:** <http://bit.ly/2MMLQnO>

Advance care planning vs. advance serious illness preparations and planning

HEALTHCARE, 2020;8(3):E218. Much of the current advance care planning/advance directives movement has people (not patients) doing end of life planning/medical decision-making under conditions of certainty, devoid of context, and without support of clinical input. The way forward is to better prepare people for future serious illness decision-making, so they (or their surrogates) can better articulate their authentic values and informed treatment preferences in the context of "in the moment" shared medical decision-making with doctors and to help seriously ill patients with capacity to better plan their future medical care with their treating clinicians on documents recognized by the healthcare system.

Full text: <https://bit.ly/30GUkAc>

N.B. This article was noted in Media Watch 3 August 2020 (#677, p.9).

Cont.

Related:

- *BMC GERIATRICS* | Online – 2 February 2021 – ‘**Evaluation of an initiative to improve advance care planning for a home-based primary care service.**’ There is evidence advance care planning (ACP) reduces hospital-based interventions, especially at the end of life. ACP for frail older adults is especially important as this population is more likely to use hospital services but less likely to benefit from resource intensive care. The goal of this study was to evaluate whether an approach to ACP developed for frail older adults, known as the Palliative & Therapeutic Harmonization or PATH, demonstrated an improvement in ACP. Results suggest partial success in implementing the PATH approach to ACP in home-based primary care. **Full text:** <http://bit.ly/3jblrwp>
- *INTELLECTUAL & DEVELOPMENTAL DISABILITIES*, 2021;59(1):39-54. ‘**Development, implementation, and evaluation of an advance care planning program for professionals in palliative care of people with intellectual disability.**’ The program is based on 10 competencies needed for advance care planning (ACP) and was developed in a process with people with intellectual disabilities (ID), relatives, and professionals. The program was implemented in six ID care organizations in The Netherlands and consisted of an information pack, a training course, and an implementation interview about implementing ACP. Professionals indicated their competencies had improved, particularly regarding communication and application of ACP as a standard element in palliative care practice. **Abstract:** <http://bit.ly/3jm6Y0x>
- *SOCIAL SCIENCE & MEDICINE* | Online – 2 February 2021 – ‘**Occupational differences in advance care planning: Are medical professionals more likely to plan?**’ Social and health services professionals [in the U.S.] are no more likely than other professionals to do advance care planning (ACP). The on-the-job experiences and expertise of medical professionals may motivate them to discuss their own end-of-life (EoL) preferences, which may render them more trustworthy sources of information for patients and clients. The Affordable Care Act provides reimbursement for medical professionals’ EoL consultations with Medicare beneficiary patients, yet practitioners uncomfortable with such conversations may fail to initiate them. **Abstract:** <http://bit.ly/3twq8Wo>

Witnesses and victims both: Healthcare workers and grief in the time of COVID-19

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 5 February 2021 – With the scope and unpredictability of the ongoing COVID-19 public health crisis, we must acknowledge a growing, global mental health crisis, including among healthcare workers (HCWs). While no one can predict definitively what it takes for HCWs to mourn, grieve, process, and heal in the time of COVID-19, it is imperative try to prevent when possible and mend when necessary the psychological injury being caused by the pandemic. Clearly, much research is needed into how to prevent and treat complicated grief in patients as well as in HCWs in the time of COVID-19. In addition, more research is needed to understand the ongoing indications and best practices for providing clinical care... Finally, as a major constituent of the cultural and political “system,” healthcare must figure out how to become trustworthy and anti-racist in the face of the systemic racism laid bare in the time of COVID-19. Examining privilege and power are necessary within healthcare and among its practitioners. Through recognition of the risks for complicated or prolonged grief, we have an opportunity to promote both individual and systemic resiliency and resources to address HCW personal and professional grief in the time of COVID-19. Ultimately, competent clinical care requires not just our expertise but our humanity and vulnerability as well. HCWs owe such a comprehensive commitment to our patients, their loved ones, our own loved ones, and to ourselves. **Full text:** <https://bit.ly/3rtXd3g>

Related:

- *JOURNAL OF APPLIED GERONTOLOGY* | Online – 1 February 2021 – ‘**Interventions to reduce the impact of client death on home care aides: Employers’ perspectives.**’ While research demonstrates that client death can cause grief and job insecurity for aides, we currently lack home care agencies’ perspectives on this issue and approaches to addressing it. This study uses key informant interviews with leaders from a diverse sample of eight New York City home care agencies to explore facilitators and barriers to agency action. The authors found that agencies engaged primarily in a range of informal, reactive practices related to client death, and relatively few targeted and proactive efforts to support aides around client death. **Abstract (w. list of references):** <http://bit.ly/3teqpwZ>

Cont.

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 3 February 2021 – ‘**A tale of two surveys: Life-affirming strategy of mortuary improves the quality of bereavement care after hospital death.**’ The mortuary plays an important, under-recognized role in end-of-life care (EoLC). A “life-affirming strategy” was introduced in the mortuary of a university hospital to enhance respect for the deceased and next-of-kin (NoK). The greatest improvement was achieved in “mortuary environment,” “attitude of mortuary staff” and “body viewing arrangement in the mortuary.” The perceived need for additional psychosocial support was significantly reduced. Results of this study demonstrate success of the life-affirming strategy in enhancing EoLC for bereaved families. **Abstract (w. list of references):** <http://bit.ly/3aCnXb5>
- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 2 February 2021 – ‘**Unexplored costs of bereavement grief in Japan: Patterns of increased use of medical, pharmaceutical, and financial services.**’ This Japan-wide survey researched bereaved who showed increased reliance on medical, pharmaceutical, and financial/legal services. Increased use was most evident in the 50’s age bracket, and for unemployed widows; it corresponded less with low annual income than with high income declining significantly after bereavement. Increased users showed higher psychological and physical symptoms of grief, and reported their decline in physical health seriously influencing their work and lives, suggesting “presenteeism” – reduced productivity for those continuing to work. **Full text:** <http://bit.ly/3tpKeBm>
- *PROFESSIONAL CASE MANAGEMENT*, 2021;26(2):53-61. ‘**Death and grieving for family caregivers of loved ones with life-limiting illnesses in the era of COVID-19: Considerations for case managers.**’ Family caregivers of a loved one with a life-limiting or terminal illness are often overwhelmed by, and underprepared for, their responsibilities. They often need help from family members and friends to provide comprehensive care. When death occurs, funerals and other death-related rituals bring family and communities together to honor the life and mourn the death of a loved one and provide needed support to family and caregivers. These collective rituals are often deeply rooted in culturally-bound values and can facilitate grief and help make sense about loss. **Abstract:** <https://bit.ly/39ThoBU>
- *WESTERN JOURNAL OF NURSING RESEARCH* | Online – 29 January 2021 – ‘**Caregivers’ loss of the dyadic experience after their care partners’ death.**’ Little is known about the experience of family caregivers when their care partner dies and their dyadic relationship comes to an end. This study qualitatively examined and characterized the loss of the dyadic experience for the caregiver after the death of their care partner. Data was accrued as part of a randomized clinical trial in 29 older hospice caregivers. Findings suggest that asking several open-ended questions about the dyadic relationship will enable assessment for any continuing impact of relational uncertainty and partner interference on bereaved caregivers. **Abstract (w. list of references):** <http://bit.ly/3pFg22S>

Lessons learned from countries that have introduced palliative care services into their national health system: A narrative review

JOURNAL OF PALLIATIVE CARE | Online – 2 February 2021 – Thirteen reports met the authors’ inclusion criteria. Education and appropriate policies were the most frequent strategies covered by all countries included. Under education information about training healthcare providers was needed for the effective introduction of a palliative care (PC) program. Reviewing standards of care required to deliver PC effectively, and financial support for PC service development were considered the central policies needed. Furthermore, partnerships and collaborations across the health systems as well as providing care based on patients’ needs were required for the provision of a PC program. It is of the essence to learn from countries demonstrating enhanced PC practices before the implementation of a new PC program in a given country. Such practices could be used as a guide and to address barriers that may hinder the development of PC at a national level. Best practices can be achieved by focusing on educational and policy-based strategies through identifying patients’ needs, assessing general public awareness, healthcare providers’ knowledge and training as well as incorporating stakeholders’ perspectives. **Abstract (w. list of references):** <http://bit.ly/39CbOU9>



Would the *Journal of Palliative Care* article be of interest to a colleague?

What do young adults know about palliative care? A cross-sectional survey

PUBLIC HEALTH | Online – 2 February 2021 – A public health approach to palliative care (PC) that reorientates care towards the public is advocated in global policy. The public are drivers in identifying care priorities and partners in finding solutions to care issues; however, a necessary prerequisite is that the public knows what PC is and what it can achieve. The aim of this study was to investigate what young adults, an important cohort of the public, know about PC and identify key predictors of knowledge. The findings of a cross-sectional online survey conducted by researchers at the Institute of Nursing & Health Research, Ulster University, suggest that despite high levels of awareness and familiarity with the term, significant numbers of respondents indicated a lack of knowledge of PC rather than inaccurate knowledge. This suggests the need for public health organisations to partner with PC sectors to develop and disseminate clear unequivocal messaging relating to the breadth of PC that both informs and engages young adults. <http://bit.ly/3cMaRea>



Publishing Matters

Publishing at any cost: A cross-sectional study of the amount that medical researchers spend on open access publishing each year

BMJ OPEN | Online – 1 February 2021 – Clinical medical researchers could have paid as much as US\$34,676 (£27,186) in total article processing charges (APCs) for their first and senior author research and review articles in 2019. This analysis used a large number of sources to identify author and journal data, including Scopus, author institutional profiles, Journal Citation Reports, publisher databases on APCs, the Directory of Open Access Journals and individual journal websites. Secondary and sensitivity analyses were conducted considering author (gender, affiliation, region and training), journal, and APC-related characteristics. Although the total APCs in this study are estimates, it is important to understand the potential cost of open-access publishing to researchers as journals with APCs become more common. In particular, future studies should evaluate the impact of APCs on individuals who may not have the funding or institutional resources to cover these costs. **Full text:** <http://bit.ly/2O3McY4>

Tip: Four best practices for covering palliative care

JOURNALISM.COMM.UK | | Online – 4 February 2021 – Although this area of medicine is frequently cited in the pandemic coverage, it is often misunderstood by journalists and audiences alike. Here is how to get your wording right. Palliative care (PC) has been sadly a focus of news coverage throughout the pandemic. Although it features in many powerful stories, this area of medicine is often misunderstood. Author and journalist Michelle Seaton interviewed a couple of specialists for an article published by *Journalist's Resource* that provides four tips to covering PC.¹ An important takeaway is not to confuse PC with hospice care or end-of-life care. "You can say, 'Actually, PC is delivered at the same time as curative and life-prolonging treatment in an effort to maximise the quality of life,'" it reads. <http://bit.ly/3tp22N0>

¹Covering stories about palliative care: Four tips for journalists,' *Journalist's Resources*, published online 14 December 2020. [Noted in Media Watch 21 December 2020 (#697, p.1)] <http://bit.ly/3mlmVE7>

Media Watch: Editorial Practice

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CSPCP
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