***Media Watch...** is intended as an advocacy, research and teaching tool. The 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.*

21 March 2022 Edition | Issue #755

Compiled & Annotated by Barry R. Ashpole

Just as critical poverty scholars and primary care researchers have argued for a fairer political-economic system, so palliative and end-of-life researchers need to not only "wake up" but also "stand up" and become more political.

'The equity turn in palliative and end-of-life care research: Lessons from the poverty literature' (p.11), in *Sociology Compass*.

Effecting change in the (serious) illness experience. *BRA*

News Media

Palliative care and the Temel study

U.S. | *The Jewish Link* – 16 March 2022 – A major issue is the timing of referral to palliative care (PC). Many if not most patients see it as an abandonment of active or aggressive care – in essence, giving up on them. Referral to PC is usually delayed to the last possible moment, when the patient is truly on death's door, bordering on comatose, when there can be few benefits from the referral and when better symptomatic and emotional relief could have been achieved significantly earlier. A truly remarkable milestone study on this issue was published in 2010...[1] As hypothesized, the group randomized to upfront PC had better quality of life... There was an additional, remarkable finding. The group receiving early PC lived a median of 11.6 months while the control group lived 8.9 months, an unexpected finding. https://bit.ly/3wc8quZ

1. 'Early palliative care for patients with metastatic non-small-cell lung cancer,' *New England Journal of Medicine*, 2010;363(8):733-742. [Noted in Media Watch 23 August 2010 (#163, p.8)] **Full text:** https://bit.ly/39ayxpU

Services must be better equipped to support terminally ill people

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 10 March 2022 – People living with a terminal condition … become increasingly dependent on social care as they approach the end of their lives, alongside primary care and palliative care services. Their care and support needs are often very complex at this stage of their condition, placing increased demand on services, much of which cannot be fully accommodated because of long-standing issues with workforce capacity, care coordination and integration between health and social care. These issues have been laid bare throughout the [COVID-19] pandemic, and will have left deep scars for many health and social care professionals, terminally ill patients, families and carers who have experienced them most acutely. https://bit.ly/3pSMUHA

Huge increase in people dying at home since COVID-19 pandemic began

U.K. | Wales Online – 1 March 2022 – More than 100,000 extra deaths have taken place in private homes in the U.K. since the COVID-19 pandemic began… Extra deaths, known as excess deaths, are the number of deaths that are above the average recorded in previous years. But although COVID-19 has been one of the main drivers of excess deaths in hospitals and care homes, the virus has accounted for only a minority of the extra deaths in homes. Compiled by the PA news agency with Hospice UK, analysis shows 87,196 excess deaths in private homes have been registered in England and Wales since the start of the pandemic, while 11,113 have been registered in Scotland. The latest available figures for Northern Ireland show 2,620 excess deaths took place in private homes from March 2020 to December 2021. https://bit.ly/3MJ9RXE

Noted in Media Watch 1 November 2022 (#741, p.4):

- 'Dying at home: Not enough community staff to support a good death…,' *Nursing Standard*, Royal College of Nursing, 27 October 2021. https://bit.ly/3EjlU8R

The palliative care solution

CANADA | *Le Droit* (Ontario, ON) – 28 February 2022 – Across Canada, governments are trying to find a solution to escalating healthcare costs and resource pressures. Ontario is working to find a solution to a healthcare system that was already under pressure even before the COVID pandemic. What can the province do to address rising costs and capacity shortages resulting in back-end healthcare? Hospices are only a small part of the solution: they provide patients with compassionate palliative care (PC), which is less expensive than that provided by hospitals, and helps free up hospital beds. Ontario's Auditor General has estimated that the daily cost of a PC bed is about one-third that of an acute care hospital bed.[1] However, despite this economic advantage, hospices struggle to survive. https://bit.ly/34A2AZ1

1. '2014 Report of the Office of the Auditor General of Ontario (Chapter 3: Ministry of Health & Long Term Care – Palliative Care, pp.258-288),' 9 December 2014. [Noted In Media Watch 15 December 2014 (#388, p.2)] https://bit.ly/3KxSLdi

N.B. French language article. Selected articles on access to PC in Canada noted in Media Watch 7 February 2022 (#752, pp.4-5)]

Government & Non-Government Organizations *et al*

Time to Reflect National Survey findings

IRELAND | Irish Hospice Foundation – 18 March 2022 – The Foundation's research shows that 68% of respondents lost a loved one during the pandemic, while 43% suffered multiple bereavements over the two years. The necessary restrictions during COVID-19 meant 30% of those bereaved were not able to attend the funeral of their person who had died, with 82% stating they had family and friends excluded from funerals. The findings of the survey are not all negative … with 56% of people saying it has prompted them to open up conversations on death and dying with family and friends, 67% have a greater awareness of how the death of a loved one can impact on those left behind... https://bit.ly/3KW6f2C

Cont. next page

Reader feedback on the focus and content of Media Watch is critically important to know that the report has value as an advocacy, research and/or teaching tool.

Related:

- ‘How long should it take to grieve? Psychiatry has come up with an answer,’ *The New York Times*, 18 March 2022. https://nyti.ms/364ocgY

- ‘COVID has changed how we live, how we die, and how we grieve,’ *The Conversation*, published online 17 March 2022. https://bit.ly/3Jq627J

Private Equity at Home: Wall Street’s Incursion into the Home Healthcare & Hospice Industries

U.S. | Private Equity Stakeholder Project – 18 March 2022 – The home healthcare and hospice industries are some of the fastest growing industries in the U.S. economy, making it especially attractive to private equity firms. As for-profit companies continue to dominate these spaces, profit incentives continue to jeopardize quality of care (QoC) for patients and quality of life for employees. Major investments in these industries … can help provide the resources necessary to improve the QoC in the industry by supporting home healthcare and hospice workers. However, policymakers should prioritize transparency and accountability in this space to make sure public funds are being spent as intended, and to guarantee that the financial incentives of private equity firms do not distort the QoC… https://bit.ly/3L0SjVo

N.B. Private Equity Stakeholder Project website: https://bit.ly/3JpMtfP

Universal Principles for Advance Care Planning

U.K. (England) | National Health Service England – 17 March 2022 – In 2021, a Care Quality Commission report included recommendations for a consistent national approach to advance care planning (ACP)[1] … to enable people, their families and/or representatives, clinicians, professionals and workers to share the same understanding and expectations of ACP. The Department of Health & Social Care set up a Ministerial Oversight Group to provide assurances that progress was being made towards implementing the recommendations of that report. The purpose of this document is to set out six high level principles for ACP in England. These universal principles should be used to drive improvements in inclusion, equality and diversity everywhere across the country. https://bit.ly/3KU5d7w

1. ‘Protect, respect, connect – decisions about living and dying well during COVID-19,’ Care Quality Commission, March 2021. [Noted in Media Watch 22 March 2021 (#709, pp.3-4)] http://bit.ly/3eMn6ly

Hospice UK launches report on the future of palliative care in Wales

U.K. (Wales) | Hospice UK – 15 March 2022 – Hospice UK is calling for Welsh community health and care commissioners to ensure 24-hour care is available across Wales, focusing on the needs of those who are receiving care, their families, carers and loved ones. Despite the demand for specialist palliative care (PC) at home increasing, vital out-of-hours support for people dying at home is still not widely available across Wales. ‘Future Vision Cymru: Seamless and Sustainable’ suggests current projections indicate the nation’s ageing population, with children and adults living longer and often with more complex needs, will contribute to an increase of 25% in PC needs by 2040. **Download report at:** https://bit.ly/3JquiGD

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

Media Watch: Access Online

Media Watch (or a link to the report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.13.

The Cost of Dying 2022 Report: Examining the true impact of bereavement in America

U.S. | The Empathy Foundation – 14 March 2022 – Families dealing with loss have unique needs, issues that are often insufficiently addressed by the systems meant to support them. COVID-19 has brought these needs into sharp focus, highlighting the full scope of what families must go through after a loved one dies, and the lack of support that is available to guide them through all the financial, legal, and emotional challenges they face. This report takes a comprehensive look at the cost of dying… Not only the emotional toll of grief, but the actual, practical burden of dealing with every logistical detail of funerals, paying debts, or administering estates, which requires everyday people to spend their time, effort, productivity, and mental energy, not to mention significant sums of money... **Download report at:** https://bit.ly/3J4ZJWV

Center to Advance Palliative Care releases key findings from first comprehensive literature review of healthcare for Black patients with serious illness

U.S. | Center to Advance Palliative Care – 8 March 2022 – Black patients and their families experience worse pain management, ineffective communication from providers, and an outsized burden on family caregivers.[1] The goal of the literature review is to clearly establish what is known about disparities, barriers, and successful interventions. The review included peer-reviewed journal articles from PubMed, Scopus, and recommendations from the Center's initiative's steering committee members. Since "serious illness" was the overarching theme, research on various diseases fell within that umbrella, including cancer, heart disease, dementia, end-stage renal disease, and HIV. https://bit.ly/37j1mST

1. 'Healthcare for Black Patients with Serious Illness: A literature review,' Center to Advance Palliative Care, March 2022. https://bit.ly/3KzEZaf

N.B. Search back issues of Media Watch for additional articles on "disparities" and also "racism" in the U.S. healthcare system in the context of palliative and end-of-life care at: http://bit.ly/2ThijkC

Specialist Publications

Rural palliative care

Talking together in rural palliative care: A qualitative study of interprofessional collaboration in Norway

BMC HEALTH SERVICES RESEARCH | Online – 7 March 2022 – Formal and informal opportunities for talking together are a matter of providing coordinated collaborative patient care... Although recent Norwegian policy documents indicate a need for palliative care (PC) pathways and a focus on improving fragmented services and uncoordinated transitions of care, these shortcomings are rarely discussed as safety issues. There is evidence connecting patient safety to well-functioning collaboration amongst health professionals, as communication failures account for the majority of adverse events in patients. Participants perceived delayed discharge letters and lack of direct contact between hospitals and primary care as a safety risk. GPs could feel they had lost track of their patients in need of PC. **Full text:** https://bit.ly/3sU8qhf

Research Matters

'A case study of researcher experiences in studying dying, death and grief in an interdisciplinary setting' (p.11), in *Mortality.*

Publishing Matters

'Editorial misconduct: The case of online predatory journals' (p.11), in *Heliyon.*

'Combatting Predatory Academic Journals & Conferences' (p.12), InterAcademy Partnership.

'Analysis of 567,758 randomized controlled trials published over 30 years reveals trends in phrases used to discuss results that do not reach statistical significance' (p.12), in *Plos Biology.*

Cont.

Related:

- '"Hard to say goodbye over iPad": Experiences of palliative care providers and lessons learned during the COVID-19 pandemic in rural communities of Indiana, U.S.,' *Journal of Hospice & Palliative Nursing*, published online 10 March 2022. **Abstract:** https://bit.ly/3MNU49Y

- 'Implementation of a palliative care program in a rural hospital: Report from the first year,' *Journal of Hospice & Palliative Nursing*, 2022;24(2):125-131. **Abstract:** https://bit.ly/35ZLpR0

Palliative care in oncology

Personal positioning of oncology patients in palliative care: A mixed-methods study

BMC PALLIATIVE CARE | Online – 11 March 2022 – The patients who participated in the qualitative part of this study were focused on the possibilities of living in the present time and extending life into the future, however indeterminate and short-term. The intensification and relative distancing of the present are correlates of distancing from the disease condition and the threat of death, and the meaning and value of life, accompanied by the hope of continued life through faith, standing out. This description shows an investigation based on phenomenological proposals that allowed a new and more precise explanation of how the elements are sustained and constituted the complex phenomenon of the human positioning of patients with advanced cancer... **Full text:** https://bit.ly/3JbC9Yv

Related:

- 'Palliative care is the umbrella, not the rain – a metaphor to guide conversations in advanced cancer,' *JAMA Oncology*, published online 17 March 2022. **Abstract:** https://bit.ly/34X5lyk

- 'Advance directives in oncology and haematology: A long way to go – a narrative review,' *Journal of Clinical Medicine*, 2022;11(5):1195. **Full text:** https://bit.ly/3HZtqr6

Pediatric palliative and end-of-life care

A realist evaluation of a home-based end-of-life care service for children and families: What works, for whom, how, in what circumstances and why?

BMC PALLIATIVE CARE | Online – 8 March 2022 – Provision of end-of-life care (EoLC) in the preferred setting of children, young people and their families is a priority within palliative care policy and practice. The Care 24 Lothian service is an effective and valued model for providing high quality EoLC and support which is family oriented and led. This realist evaluation provides valuable insights into the essential components of a home-based EoLC service for children and their families, which will be of particular interest to policy-makers, researchers and professionals across health, social care and the third sector. The programme theory can be tested in other areas with the aim of enhancing paediatric EoLC for families who wish for their child to be cared for and die at home. **Full text:** https://bit.ly/3pP89Ky

Achieving global pediatric palliative care equity: What we have yet to learn

JAMA NETWORK OPEN | Online – 8 March 2022 – Nearly two-thirds of countries lack access to pediatric PC despite a clear need. Children in low- and middle-income countries experience disproportionately high illness-related morbidity and mortality, an inequity highlighted in pediatric cancer. More than 80% of U.S. children with cancer will survive 5 years, compared with less than 30% of children with cancer living in low- and middle-income countries; this injustice is more striking when considering that more than 80% of global pediatric cancer cases occur in these countries. For children with cancer living in low- and middle-income countries, improving integration of pediatric PC is just as crucial as improving access to life-extending therapies to decrease family suffering and improve quality of life. **Full text:** https://bit.ly/3KTHa8P

Cont.

Related:

- 'Advancing global palliative care over two decades: Health system integration, access to essential medicines, and pediatrics,' *Journal of Pain & Symptom Management*, published online 6 March 2022. **Full text:** https://bit.ly/35tXNZF
- 'Role of social workers in family conferences for critically ill infants,' *Journal of Palliative Medicine*, published online 14 March 2022. **Abstract:** https://bit.ly/3KETAkH
- 'The pediatric palliative advanced practice registered nurses: Leading the future,' *Journal of Pediatric Health Care*, published online 3 March 2022. **Abstract (w. references):** https://bit.ly/3vL0mB2
- 'Development of a research-based classification of approaches to paediatric palliative medicine service provision within children's and young adults' hospices: A mixed methods study,' *Palliative Medicine*, published online 14 March 2022. **Full text:** https://bit.ly/3wa1j6o

Discussing prognosis and what matters most for people with serious illness

BRITISH MEDICAL JOURNAL | Online – 28 February 2022 – Technological advances in medical care give clinicians unprecedented capability to prolong life. However, this may not be appropriate for patients with serious illness. Serious illness refers to health conditions that carry a high risk of mortality, poor function and quality of life (QoL), and strain on caregivers. For people with serious illness, life prolonging treatments may not align with their preferences or help meet their goals, and may increase their suffering and that of their family members. People with serious illness commonly express goals beside simply living longer. Those who recognise that they are nearing the end of life generally prefer care focused on QoL and increased time spent at home. **Abstract:** https://bit.ly/3hY9gD9

Death education and photovoice at school: A workshop with Italian high school students

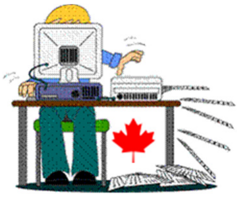
DEATH STUDIES | Online – 18 March 2022 – The study shows the effects of a death education workshop with Italian high school students. Students from 10 high schools throughout Italy participated: 212 in the experimental group and 204 in the control group. Four weekly, two-hour workshops about the themes of death, with theoretical lessons and an experiential artistic activity of photovoice. Results show that the students in the experimental group showed significantly increased self-efficacy levels and existential anxiety levels did not increase after death education intervention. Educating youth about death could give them the skills to improve the management of death-related events and cope with negative emotions. **Abstract:** https://bit.ly/36945hv

Noted in Media Watch 29 March 2021 (#710, p.8):

- '"Death education's "period of popularity": Lessons for contemporary P-12 schools in the U.S. during the COVID-19 pandemic,' *Death Studies*, published online 24 March 2021. **Abstract:** https://bit.ly/3d3TDHr

Noted in Media Watch 2 November 2020 (#690, p.10):

- 'Death education for children and young people in public schools,' *International Journal of Palliative Nursing*, published online 28 October 2020. **Abstracts:** https://bit.ly/37KQaN7



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

Community-based death preparation and education: A scoping review

DEATH STUDIES | Online – 11 March 2022 – The COVID-19 pandemic revealed a need for people and communities for death preparation. Few studies have examined community-level interventions for death preparation and education. This review scrutinized the relevant literature following PRISMA 2018 guidelines. Six databases were searched for articles published between 2010 and 2020. Cultural, socioeconomic, and individual values affected death preparation and that online courses and life-death education were effective preparation methods. Additional research is needed to identify the population-specific effectiveness of interventions. To fully investigate death preparation and education at the community level, theory-based studies employing quantitative and qualitative methods are also needed. **Abstract:** https://bit.ly/3KDIfSR

Research Matters

'Researching compassionate communities from an interdisciplinary perspective: The case of the Compassionate Communities Centre of Expertise' (p.11), in *Gerontologist*.

Related:

- 'Civic engagement in serious illness, death, and loss: A systematic mixed-methods review,' *Palliative Medicine*, published online 14 March 2022. **Abstract (w. references):** https://bit.ly/3MUaspy

End-of-life care for people with severe mental illness: The MENLOC evidence synthesis

HEALTH & SOCIAL CARE DELIVERY RESEARCH, 2022;10(4). People with severe mental illness … have significant comorbidities and experience higher mortality rates and reduced life expectancy than the general population. Policy across the U.K. includes a focus on improving end-of-life care (EoLC) where diagnosis is immaterial, and requires the introduction of palliative and supportive care earlier in the dying trajectory. In the context of calls for parity of esteem, referring to the expectation that care for people with mental health problems should be of the same quality as care for all other people, this project aimed to synthesise relevant research and other evidence relating to EoLC for people with severe mental illness. **Full text:** https://bit.ly/3Jna6Wk

Noted in Media Watch 7 March 2022 (#754, p.3):

- 'End-of-life care for people with severe mental illness: Mixed methods systematic review and thematic synthesis of published case studies (the MENLOC study),' BMJ Open, published online 22 February 2022. **Full text:** https://bit.ly/3sd7iVn

Mindful self-care, self-compassion, and resilience among palliative care providers during the COVID-19 pandemic

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 12 March 2022 – As the first known study to investigate mindful self-care, self-compassion and resilience among palliative care providers, this research has generated a number of key findings to advance knowledge in this area... Mindful self-care, self-compassion, and resilience are positively related to each other. These variables are also associated with greater satisfaction with professional life and perceived lessened impairment in physical and/or mental health stemming from decreased self-care activities due to routine changes related to professional performance in the COVID-19 pandemic. This is despite new self-care resources being developed and made widely accessible online to facilitate mindfulness meditation and promote resilience. **Full text:** https://bit.ly/3CKJETN

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Top ten tips palliative care clinicians should know about psychedelic-assisted therapy in the context of serious illness

JOURNAL OF PALLIATIVE MEDICINE | Online – 14 March 2022 – Serious illness-specific content to guide psychedelic-assisted therapy (PAT) applications in hospice and PC clinical settings has been limited. This article offers 10 evidence-informed tips for PC clinicians synthesized through consultation with interdisciplinary and international leading experts in the field with aims to: 1) Familiarize PC clinicians and teams with PAT; 2) Identify the unique challenges pertaining to this intervention given the current legalities and logistical barriers; 3) Discuss therapeutic competencies and considerations for current and future PAT use in PC; and, 4) Highlight critical approaches to optimize the safety and potential benefits of PAT among patients with serious illness and their caregivers. **Abstract:** https://bit.ly/3u1NGmS

> **N.B.** Selected articles on PAT in palliative and end-of-life care noted in Media Watch 24 January 2022 (#751, p.10).

To accompany, always: Psychological elements of palliative care for the dying patient

JOURNAL OF PALLIATIVE MEDICINE | Online – 8 March 2022 – Throughout this series [see sidebar] exploring the psychological elements of palliative care (PEPC), the authors suggested that the quality of care is enhanced when clinicians have a deeper understanding of patients' psychological experience of serious illness. This final installment of the series on PEPC has two aims. First, to integrate PEPC into a comfort-focused or hospice setting and, second, to demonstrate how the core psychological concepts previously explored in the series manifest during the dying process. These aspects include frame/formulation, attachment, attunement, transference/countertransference, the holding environment, and clinician wellness. **Abstract:** https://bit.ly/3t16Dqo

Journal of Palliative Medicine

Special series: Psychological elements of palliative care

This series defines elements of the therapeutic relationship in palliative care (PC). PC is not psychotherapy. Yet, it can adapt terms and concepts from traditional talk therapy to help clinicians better understand what's going on when they interact with patients. These concepts include frame and formulation, transference and countertransference, clinical attunement, attachment, and the holding environment. **Access series at:** https://bit.ly/3HVqGLv

Nurturing socio-culturally and medically appropriate palliative care delivery: Lessons learned by Israeli medical faculty

JOURNAL OF RELIGION & HEALTH | Online – 9 March 2022 – Israel is one of the few countries with a national policy and defined standards of palliative care (PC); its culture is highly diverse, more traditionally oriented in comparison with Western countries. Described are: 1) PC's current status, self-image, structural factors; 2) Its relation to cultural, political characteristics; and, 3) The chances, goals and obstacles of advancing PC in Israel. The following are discussed: 1) Definition of PC; 2) Multidisciplinary approach; 3) Special role of nurses; 4) Personal perceptions of death; 5) Understanding the role of medicine; 6) Specialty palliative medicine; 7) Religious, spiritual and cultural aspects; 8) Political and economic aspects; 9) Obstacles and weaknesses; and, 10) Prospects and goals of PC. **Full text:** https://bit.ly/3pTSt8L

> **N.B.** Search back issues of Media Watch for additional articles on palliative and end-of-life care in" Israel" at: http://bit.ly/2ThijkC

Unburdening expectation and operating between: Architecture in support of palliative care

MEDICAL HUMANITIES | Online – 16 March 2022 – The authors findings suggest that palliative care (PC) architects often respond to two briefs, one explicit and the other unspoken. Design responses in relation to the first include: formally expressing a differentiation in the philosophy of care (signaling difference), attention to quality, extending comfort and providing "moments." The second relates to the unburdening of PC facilities from their associative baggage and responding to the tension between the physical and imaginative inhabitation of space. In revealing the presence of this hidden brief, and the relationship between the two, this article invites a broader discussion regarding the capacity of architecture to support PC patients, their families and staff. **Abstract:** https://bit.ly/363uVaN

> **N.B.** Selected articles on the relationship between the architecture (i.e., the physical environment) of healthcare facilities and the quality of PC noted in Media Watch 24 January 2022 (#751, p.6).

Neuropalliative care

Clinical guidance in neuropalliative care: An American Academy of Neurology position statement

NEUROLOGY | Online – 8 March 2022 – In the minds of many physicians as well as the lay public, palliative care (PC) is often seen as synonymous with hospice, and therefore leads to missed opportunities for the provision of palliative services earlier in the disease process. The authors describe PC … and contrast it with specialty PC. They discuss essential elements of communication skills and prognostication and focus on ethical considerations in neuropalliative care as it relates to disorders of consciousness. This article replaces three other Academy position papers regarding supportive care for patients with unique disorders of consciousness: persistent vegetative state, those who are irreversibly paralyzed but retain cognition, and those who lack decisional capacity. **Full text:** https://bit.ly/35B4lWt

Related:

- 'A scoping review of the evidence for community-based dementia palliative care services and their related service activities,' *BMC Palliative Care*, published online 9 March 2022. **Full text:** https://bit.ly/3KuSjMZ
- 'Talking about the end of life: Communication patterns in amyotrophic lateral sclerosis – a scoping review,' *Palliative Care & Social Practice*, published online 15 March 2022. **Full text:** https://bit.ly/3i8pwBB

> **N.B.** Search back issues of Media Watch for additional articles on "neuropalliative" care at: http://bit.ly/2ThijkC. See also European Association for Palliative Care series on the evolving specialty of neuropalliative care at: https://bit.ly/3rge50A.

Death doulas as supportive companions in end-of-life care: A scoping review

PALLIATIVE MEDICINE | Online – 10 March 2022 – Death doulas take on diverse roles in end-of-life care (EoLC) … providing psychosocial, spiritual, practical support, companionship and resource navigation. The positive impacts of engaging a death doula include continuous presence, holistic service... The negative aspects include role inconsistencies and confusion among healthcare professionals (HCPs) and the public. Death doulas can augment existing EoLC services, providing holistic and personalised care services at home or hospital settings. Their roles are still evolving and remain mostly unregulated, with little evidence about their impact. There is a need for more studies to explore HCPs' views about this role and examine clinical outcomes among dying persons and their families. **Abstract (w. references):** https://bit.ly/3CHtmeo

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

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Unsolved problems and unwanted decision-making in the last year of life: A qualitative analysis of comments from bereaved caregivers

PALLIATIVE & SUPPORTIVE CARE | Online – 10 March 2022 – Patients in their last year of life, as well as their relatives, often feel that existent care structures of the healthcare system do not adequately address their individual needs and challenges. Particularly outside of hospice and palliative care services, study participants addressed the following, unsolved problems: 1) Poor communication with medical and nursing staff; 2) Insufficient professional support for informal caregivers; 3) Inadequate psycho-social support for patients; and, 4) Poor management of pain and other symptoms. Respondents often stated that their relative had to be cared for and die outside their own home, which the relative did not want. **Abstract (w. references):** https://bit.ly/3CtBjns

When does early palliative care influence aggressive care at the end of life?

SUPPORTIVE CARE IN CANCER | Online – 15 March 2022 – In this study, completed advance directives were associated with reduced chemotherapy in the last 30 days of life and reduced intensive care unit admissions. This may reflect goals-of-care and end-of-life (EoL) discussions and transition of care to comfort measures. Palliative care (PC) paradoxically when initiated within 90 days before death was associated with greater aggressive care at the EoL compared to no PC. This may be due to consultation late in the course of illness with a focus on crisis management in patients frequently utilizing the healthcare system. There is an associated reduction in the use of chemotherapy in the last 30 days of life if PC is consulted 90 days prior to death. **Abstract (w. references):** https://bit.ly/3I8iqaN

Home palliative and end-of-life care

Integrating home palliative care in oncology: A qualitative study to identify barriers and facilitators

SUPPORTIVE CARE IN CANCER | Online – 7 March 2022 – Barriers and facilitators were grouped into 3 themes: 1) Perspectives and ideas on integrating oncology and home palliative care (PC); 2) Barriers; and, 3) Facilitators. Barriers included lack of referral criteria for home PC services; financial elements related to home PC services; patients' lack of understanding of the illness trajectory; collusion in doctor-patient communication about imminent death; frequent visits to hospitals; variations in PC services; and, problems in providing treatment and care at home. Facilitators included relationships between oncologists and home PC physicians, and cancer hospital staff experience/knowledge of home PC. Some barriers were comparable with those to early integration of PC into oncology. **Abstract (w. references):** https://bit.ly/3HS1m91

Where Americans Die: Is there really "no place like home"?

NEW ENGLAND JOURNAL OF MEDICINE | Online – 12 March 2022 – The perception that a good death is one that occurs at home is ingrained in our cultural and social history. But palliative care clinicians have begun to question this idea. What is needed is high-quality end-of-life care that aligns with individual goals and needs. **Access article at:** https://bit.ly/37ksT6l

Related:

- 'Facebook online support groups for hospice family caregivers of advanced cancer patients: Protocol, facilitation skills and promising outcomes,' *Journal of Social Work in End-of-Life Care*, published online 12 March 2022. **Abstract:** https://bit.ly/3t5Sg4g
- 'Awareness, acceptance, avoidance: Home care aides' approaches to death and end-of-life care,' *Omega – Journal of Death & Dying*, published online 4 March 2022. **Abstract (w. references):** https://bit.ly/3sNnrkC
- 'Palliative care applied to the elderly at home,' *Revista de Pesquisa, Cuidado é Fundamental*, 2022;14(1): 1-9. **Full text:** https://bit.ly/3I4M54A

  N.B. English language article.

Research Matters

Researching compassionate communities from an interdisciplinary perspective: The case of the Compassionate Communities Centre of Expertise

GERONTOLOGIST | Online – 9 March 2022 – Compassionate communities (CC) are places and environments in which people, networks and institutions actively work together and are empowered to improve the circumstances, health, and well-being of those facing serious illness, death, dying and loss. The study of their development, implementation and evaluation requires an interdisciplinary research approach that has hitherto been lacking. Research groups at Vrije Universiteit Brussel united in the interdisciplinary Compassionate Communities Centre of Expertise (COCO) to investigate CC. This paper describes the first results of COCO; 1) An interdisciplinary mode of collaboration; 2) A shared conceptual understanding and definition of CC; and, 3) A shared research agenda on CC. **Abstract:** https://bit.ly/3I0eNUg

> **N.B.** Compassionate Communities Centre of Expertise website: https://bit.ly/3igFIX0. Selected articles on CC noted in Media Watch 20 December 2021 (#748, pp.6-7).

'Exploring Narratives of Death'

A case study of researcher experiences in studying dying, death and grief in an interdisciplinary setting

MORTALITY | Online – 9 March 2022 – The authors shed critical light on researcher experiences in an interdisciplinary collaboration on the topics of dying, death of grief, and examine what possibilities and challenges it prefaces for future interdisciplinary research in the field. An interdisciplinary study group … is examined over a period of one year through participant observation and semi-structured interviews. Researchers strongly advocate for more interdisciplinary agendas in death studies in order to develop greater intellectual advancement in the field and/or practical application of research in society. However, a lack of structural and temporal latitude in researchers' professional roles in the university could inhibit their ability to perform such research in the long term. **Full text:** https://bit.ly/3J0Bnxp

The equity turn in palliative and end-of-life care research: Lessons from the poverty literature

SOCIOLOGY COMPASS | Online – 15 March 2022 – Palliative and end-of-life care (EoLC) researchers are being issued "wake up" calls that they need to start adopting an equity framework and pay more attention to how the social determinants of health impact people at the end of their lives. Acknowledging systemic health inequities has become even more important during COVID-19. Learning needs to be incorporated from decades of work within critical poverty studies which critiques the very concept of poverty. The author highlights the most relevant of these critiques and advocates for the transfer and translation of these arguments into palliative and EoLC research by scholars working in the field. Just as poverty studies was critiqued in the 1990s for theoretical weakness and an uncritical empiricism… **Full text:** https://bit.ly/3wffVRZ

Publishing Matters

Editorial misconduct: The case of online predatory journals

HELIYON, 2022;8(3):E08999. Today, journals that exhibit non-standard behavior pose a threat to scholarly and scientific integrity. Their growth is skyrocketing, which indicates that there is a business niche that makes them profitable. Ostensibly their interest should be to disseminate knowledge, but in fact their aim is to benefit from unmindful researchers who find themselves under constant pressure to publish. There is thus a need for articles like this one, to bring attention to this worrisome situation and provide an opportunity to reflect on objectionable publishing practices. This, then, is the *raison d'être* for the objectives stated at the outset of this article, namely, putting the existing scientific literature to use to help spot journals of this kind and warn uninformed researchers about their editorial practices. **Full text:** https://bit.ly/3i7wcQp

Combatting Predatory Academic Journals & Conferences

INTERACADEMY PARTNERSHIP | Online – 11 March 2022 – The research sector has become increasingly vulnerable to overt commercial predation. As academic and publishing business models, research evaluation and peer-review systems continue to evolve, they are susceptible to exploitation and malpractice. Driven by profit and self-interest, the extent of this predation is on the rise. It risks polluting the global research enterprise, with serious implications for research quality and integrity; wasting research funding, derailing research careers, and compromising evidence-based policy decisions. Today sees the release of a new report from the InterAcademy Partnership. https://bit.ly/3pYIW1g

Analysis of 567,758 randomized controlled trials published over 30 years reveals trends in phrases used to discuss results that do not reach statistical significance

PLOS BIOLOGY | Online – 18 February 2022 – The power of language to modify the reader's perception of interpreting biomedical results cannot be underestimated. Misreporting and misinterpretation are pressing problems in randomized controlled trials (RCT) output. The authors' findings suggest specific phrasing to report nonsignificant findings remain fairly common in RCTs. RCTs are time- and energy-consuming endeavors, and an "almost significant" result, can, therefore, be a disappointing experience in terms of the interpretation and publication of the results… Description of the characteristics of the most prevalent phrases can help readers, peer reviewers, and editors to detect potential spin in manuscripts that overstate or incorrectly interpret their nonsignificant results. **Full text:** https://bit.ly/3tI06jE

Media Watch: Editorial Practice

EACH LISTING IN MEDIA WATCH represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The biweekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

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

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5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

IF YOU ARE AWARE OF A CURRENT REPORT, ARTICLE, ETC., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Media Watch: Access on Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://bit.ly/3HSZm09

[Scroll down to ‘Media Watch’]

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

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

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

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

Australia

PALLIATIVE CARE RESEARCH NETWORK: http://bit.ly/2E1e6LX

[Click on e-News (November 2019); scroll down to ‘Useful Resources in Palliative Care Research’]

Canada

BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION https://bit.ly/3two4xX

[Grief & Bereavement & Mental Health Summit 2021 ‘Resource Page.’ Scroll down to ‘Links: International Palliative Care Resource Center]

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

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

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

[Scroll down to ‘General Resources’ and ‘Media Watch’]

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

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

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): https://bit.ly/3wvL5RW

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

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