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.*

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Compiled & Annotated by Barry R. Ashpole

> **Family members recounted a myriad of situations where the nature, frequency, timing and availability of information, together with the effectiveness of staffs' communication skills appeared to influence the quality of the care experience.**
>
> 'Family experiences of in-hospital end-of-life care for adults: A systematic review of qualitative evidence' (p.9), in *Journal of Clinical Nursing*.

Important notice: The next issue of Media Watch will be published 25th April 2022.

News Media

"Large-scale fraud" and lax oversight plague California's hospice industry, audit finds

U.S. (California) | *The Los Angeles Times* – 29 March 2022 – A rapid boom in the number of hospices and other factors strongly point to a large-scale organized effort to defraud federal end-of-life care programs in Los Angeles County, putting vulnerable dying patients at risk of harm, according to a long-awaited state...[1] Auditors blamed lax oversight for the problems, noting that the California Department of Public Health became aware of possible fraud by some for-profit hospices seeking licenses yet still approved them, essentially enabling "hospice agency operators who are possibly fraudulent to continue functioning, placing patients at serious risk of not receiving appropriate care." The audit's findings mirror those of a 2020 *Los Angeles Times* investigation that uncovered widespread fraud and quality-of-care deficiencies in the state's booming but loosely regulated hospice industry.[2,3,4] https://lat.ms/36Uh6vo

Specialist Publications

'The hospice algorithm: Capitalizing on death and dying' (p.8), in *Home Health Care Management & Practice*.

1. 'California Hospice Licensure and Oversight,' Auditor of the State of California, 29 March 2022. https://bit.ly/38eF4lN
2. 'End-of-life care has boomed in California. So has fraud targeting older Americans,' *The Los Angeles Times*, 9 November 2020. https://lat.ms/3m0gsOH
3. 'Dying Californians suffer harm and neglect from an industry meant to comfort them,' *The Los Angeles Times*, 9 November 2020. https://lat.ms/2KaWfbF

Cont.

4. ‘What you need to know if you or a loved one requires end-of-life care,’ *The Los Angeles Times*, 9 November, 2020. https://lat.ms/37NvCSr

N.B. *The Los Angeles Times* articles were noted in Media Watch 14 December 2020 (#696, pp.2-3).

In difficult cases, “families cannot manage death at home”

U.S. | *The New York Times* – 26 March 2022 – Where do people most want to be when they die? At home, they tell researchers... That wish has become more achievable. In 2017 home surpassed the hospital as the most common place of death – 30.7% of deaths occurred at home, compared with 29.8% at the hospital.[1] “It’s probably the first time that’s happened in the U.S. in modern times,” said Dr. Haider Warraich, a cardiologist at the Veterans Affairs Boston Healthcare System and an author of a study. Technically, the proportion was even higher, since some people who died in nursing facilities (20.8%) were long-term residents and the nursing home effectively was their home. Dr. Warraich credited the change to the rise of hospice car… But not always. https://nyti.ms/3wF4R0E

1. ‘Changes in the place of death in the U.S.,’ *New England Journal of Medicine*, 2019;381(24):2369-2370. [Noted in Media Watch 16 December 2019 (#644, p.2)] **Access article at:** http://bit.ly/35fjbfL

For end-stage dementia, Medicare can make hospice harder to access

U.S. | *The Washington Post* – 26 March 2022 – Medicare’s hospice regulations are not working as intended for many people with dementia, says Elizabeth Luth, a sociologist at Rutgers University who studies end-of-life care. According to her study of 3,837 hospice patients with dementia, about 5%, are pulled from hospice when their condition seems to have stabilized.[1] Plus, the number of Americans over 65 with dementia is projected to more than double to 13.8 million by 2060. Many will need hospice care. “It’s worth asking the question, ‘Should we reevaluate?’” Luth says. The Centers for Medicare & Medicaid Services has been introducing new payment structures, pilot programs and quality metrics to address weaknesses in the hospice admission criteria. https://wapo.st/36u2Rxv

Specialist Publications

‘Palliative care for older people with dementia: We need a paradigm shift in our approach’ (p.4), in *Age & Ageing*.

1. ‘Survival in hospice patients with dementia: The effect of home hospice and nurse visits,’ *Journal of the American Geriatrics Society*, 2021;69(6):1529-1538. **Abstract:** https://bit.ly/3uP93IL

Related:

- ‘Number of seniors who die with dementia rises 30% since early 2000s,’ United Press International, 1 April 2022. https://bit.ly/3K1lW8I

Compassion and tech merge, helping Israelis navigate Jewish law at end of life

ISRAEL | *The Times of Israel* (Jerusalem) – 22 March 2022 – Through One Hundred Twenty is a year-old project of Tzohar, an Israel-based organization founded by religious-Zionist Orthodox rabbis to bridge gaps between religious and secular Jews by encouraging a more informed, accessible and compassionate understanding of Jewish tradition and identity. Tzohar rabbis take a non-judgmental and non-coercive approach, which they use to assist Israeli Jews with numerous lifecycle events connected to Jewish practice and tradition. By Israeli law, the ultimate decision-making power regarding the treatment of terminally ill patients rests in the hands of physicians and medical institutions. In recent decades, the importance of also considering the wishes of the patient and their family has been recognized. https://bit.ly/3txHPXB

N.B. Through One Hundred Twenty website: https://bit.ly/3NdERPA

Share this issue of Media Watch with a colleague.

Dying patients living longer than expected lose National Health Service funds

U.K. (England & Wales) | BBC News (London) – Accessed 23 March 2022 – More than 1,300 patients a year are having National Health Service (NHS) funding for their palliative care (PC) withdrawn after living longer than expected, BBC analysis shows. Terminally-ill or rapidly-declining patients are given fast-track support, allowing them to live outside hospital. The fast-track continuing healthcare scheme pays for all an individual's PC needs and is not means-tested. From 2018 to 2021, a total of 9,037 people had this funding reviewed in England and Wales, with 47% of them losing all support. The NHS said patient eligibility was assessed in line with government rules. A further 15% of patients had their continuing healthcare support replaced with the more limited NHS-funded nursing care. https://bbc.in/3tH8Gk9

Noted in Media Watch 24 January 2022 (#751, p.6):

- 'Fast-track hospital end-of-life discharge pathway: Is it actually fast? National clinical audit,' *BMJ Supportive & Palliative Care*, published online 12 January 2022. **Abstract:** https://bit.ly/3KashPO

Noted in Media Watch 26 July 2021 (#727, p.2):

- 'Findings from the evaluation of the Special Rules for Terminal Illness process,' U.K. Government, posted 20 July 21. **Download at:** https://bit.ly/3iwsIXD

Government & Non-Government Organizations *et al*

A briefing for MPs from Together for Short Lives on the amendments relating to children's palliative care

U.K. (England) | Together for Short Lives – 30 March 2022 – MPs should make sure access to palliative care (PC) for seriously children, young people and their families is a key focus during a House of Commons debate on amendments to the Heath & Care Bill made by peers in the House of Lords. These include a series of amendments which would, if passed by MPs, specifically require local National Health Service bodies in England to commission services or facilities for PC, including specialist PC, and, require the health and social care (H&SC) secretary to publish and lay before Parliament a report describing the government's policy on information-sharing by or with authorities with H&SC functions, for purposes relating to children's H&SC or the safeguarding or promotion of the welfare of children. https://bit.ly/3qPRAPc

Charlie's Law – my answer to the parent-doctor conflict

U.K. | *The Conservative Woman* – 28 March 2022 – This month has seen a significant development for desperate parents faced with their child dying. The House of Lords has voted in favour of an amendment to the Health & Care Bill, titled 'Dispute resolution in children's palliative care.' All too often tension arises as anxious parents search for other possible treatments and clinicians feel this is futile. This is aggravated by the power differential in the relationship between the specialist doctor and the parents with scant medical knowledge, which can result in parents feeling intimidated or ignored. Disputes develop and can become so serious that the disagreement between parents and doctors escalates to court, even when the alternative treatment proposal comes from a reputable centre. https://bit.ly/3JPpP0m

Noted in Media Watch 9 November 2020 (#691, p.10):

- 'Resolving disagreement: A multi-jurisdictional comparative analysis of disputes about children's medical care,' *Medical Law Review*, published online 4 November 2020. **Abstract:** https://bit.ly/2HY0Blv

N.B. Selected articles on the Charlie Gard court case, which ultimately triggered the amendment to the U.K. Health & Care Bill, and related issues, noted in Media Watch 29 June 2020 (#672, p.4).

Embedding a Palliative Approach to Care in Long Term Care Facilities

CANADA | Canadian Society of Palliative Care Physicians – Accessed 24 March 2022 – The vast majority of residents are admitted to long-term care (LTC) with advanced life-limiting illnesses... Consequently, residents of LTC facilities have a significant burden of morbidity and mortality. The annual mortality rate in LTC is estimated at 27%, with a median life expectancy of about two years.[1] Access to high quality, evidence-based palliative care (PC) should be guaranteed for all residents in LTC – and yet, the Canadian Institute of Health Information finds that only 6% of all LTC residents are recorded as having received PC in the last year of life.[2] **Download at:** https://bit.ly/3LfsFMm

Specialist Publications

'Dignity in care at the end of life in a nursing home: An ethnographic study' (p.5), in *BMC Geriatrics*.

1. 'What are staff perceptions about their current use of emergency departments for long-term care residents at end of life?,' *Clinical Nursing Research*,' 2017;28(6):692-707. **Full text:** https://bit.ly/3lBi5hi
2. 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, September 2018. [Noted in Media Watch 24 September 2018 (#582, p.1)] **Download/view at:** http://bit.ly/2MqmCYO

N.B. Selected articles on palliative and end-of-life care in LTC facilities in Canada noted in Media Watch 21 February 2022 (#753, p.3).

Specialist Publications

Palliative care for older people with dementia: We need a paradigm shift in our approach

AGE & AGEING | Online – 25 March 2022 – There is as yet limited evidence for truly integrated services, with current descriptions more of interdisciplinary partnerships, such as a dementia nurse specialist joining a community specialist palliative care (PC) team, or a PC nurse joining community primary care teams. We need to consider PC as a normal, integral part of dementia care, appropriate from the time of diagnosis. This paradigm shift would facilitate timely emotional and spiritual support to people and their families and allow opportunities for meaningful care planning, rather than late, proxy-derived decision-making. Integrated working across teams, be these situated in age-related services, memory services, primary care or specialist PC, makes sense. Optimal models are currently lacking. **Full text:** https://bit.ly/3uulfON

Related:

- 'Practice of end-of-life care for patients with advanced dementia by hospital physicians and nurses: Comparison between medical and surgical wards,' *Dementia*, published online 28 March 2022. **Full text:** https://bit.ly/3uCgYsD
- 'What will happen to my mom? A grounded theory on nurses' support of relatives' end-of-life decision-making process for residents living with dementia in long-term care homes,' *Dementia*, published online 25 March 2022. **Full text:** https://bit.ly/3JMwCbb
- 'Evaluating the use of participatory action research to implement evidence-based guidance on dementia palliative care in long-term care settings: A creative hermeneutic analysis,' *International Journal of Older People Nursing*, published online 31 March 2022. **Full text:** https://bit.ly/3qVVkOQ
- 'Which has more influence on a family's assessment of the quality of dying of their long-term care resident with dementia: Frequency of symptoms or quality of communication with healthcare team?' *Palliative & Supportive Care*, published online 29 March 2022. **Abstract (w. references):** https://bit.ly/3wMoa83

N.B. Search back issues of Media Watch for additional articles on EoL care for people living with dementia at: http://bit.ly/2ThijkC

Spanish chronic obstructive pulmonary disease guideline (GesEPOC) update: Comorbidities, self-management and palliative care

ARCHIVOS DE BRONCONEUMOLOGÍA | Online – 19 February 2022 – Palliative care (PC) is one of the pillars in the comprehensive treatment of the chronic obstructive pulmonary disease (COPD) patient, seeking to prevent or treat the symptoms of a disease, the side effects of treatment, and the physical, psychological and social problems of patients and their caregivers. Therefore, the main objective of this PC is not to prolong life expectancy, but to improve its quality. This chapter of GesEPOC 2021 presents an update on the most important comorbidities, self-management strategies, and PC in COPD... COPD requires a more comprehensive and individualized vision, prioritizing problems and selecting therapeutic objectives adapted to the personal circumstances of each patient. **Full text:** https://bit.ly/3tt2aNI

Related:

- 'Clinician perspectives on how to hold earlier discussions about palliative and end-of-life care with chronic obstructive pulmonary disease patients: A qualitative study,' *Journal of Hospice & Palliative Nursing*, published online 24 March 2022. **Abstract:** https://bit.ly/3JHlXPa

N.B. English language article. Search back issues of Media Watch for additional articles on PC for patients living with "COPD" at: http://bit.ly/2ThijkC

Dignity in care at the end of life in a nursing home: An ethnographic study

BMC GERIATRICS | Online – 21 March 2022 – Residents suffered from illness-related concerns that inhibited their possibilities to live a dignified life... Their failing bodies were the most significant threat to their dignity, as loss of abilities was constantly progressing. Together with a fear of becoming more dependent, this caused feelings of angst and loneliness. The most dignity-conserving repertoire came from within themselves. Their self-knowledge had provided them with tools to distinguish what was still possible from what they just had to accept. Their dignity was violated by long waiting times, lack of integrity in care, and deteriorating routines, but also by distanced and sometimes harsh encounters with assistant nurses. **Full text (click on pdf icon):** https://bit.ly/3qCuN9m

Participatory development of CURA, a clinical ethics support instrument for palliative care

BMC MEDICAL ETHICS | Online – 23 March 2022 – The authors used a participatory development design to develop a low threshold ethics support instrument for palliative care, called CURA. Working in collaboration with end users and other stakeholders helped to meet the needs of end users, to refine the instrument and to overcome limitations of existing clinical ethics instruments. The authors developed the instrument in three phases: 1) Identifying needs, in which was assessed the scope of moral issues, available ethics support and needs of end users; 2) Development, in which was developed the instrument in iterative co-creation with stakeholders; and, 3) Dissemination, in which was paved the way for future dissemination and implementation of CURA. **Full text:** https://bit.ly/3qwGbTU

Supportive & Palliative Care Indicators tool (SPICT™) in a Danish healthcare context: Translation, cross-cultural adaptation, and content validation

BMC PALLIATIVE CARE | Online – 24 March 2022 – Early identification of patients who require palliative and supportive care at the general palliative care level is challenging. A translation and cross-cultural adaptation and content validation of the SPICT™-DK in general practice, home care, home nursing, and the hospital were completed. Results show that some clinical and professional words and terms had to be discussed and adjusted to a Danish healthcare context. This indicates that cultural and linguistic differences do exist among different countries about communication in general and in different healthcare settings. Thus discussions and considerations in every step of the study were essential for translating and validating SPICT™ into a Danish healthcare context. **Full text:** https://bit.ly/3Ne1YtD

Cont.

Related:

- ‘Screening tools to identify patients with unmet palliative care needs in the emergency department: A systematic review,’ *Academic Emergency Medicine*, published online 28 March 2022. **Abstract:** https://bit.ly/3NMo1I6

- ‘NECPAL tool aids early identification of palliative care needs,’ *Journal of Palliative Medicine*, published online 28 March 2022. **Abstract:** https://bit.ly/3tQEdA0

Cases that burn us out

Burnout and emotions experienced in challenging situations: A qualitative study of experienced palliative care clinicians

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 24 March 2022 – Burnout is common among palliative care clinicians, occurring as a result of emotions experienced in caring for challenging patients or families. Awareness of these scenarios helps clinicians and teams appropriately manage their own emotions and prevent burnout. The following clinical situations were reported as particularly challenging, potentially leading to burnout: 1) Abusive patients and families; 2) “Bad deaths”; 3) Death of young patients; 4) Complex cases; and, 5) Having multiple deaths or difficult cases at any one time. Emotions encountered in the course of care of these cases included: 1) Feeling overwhelmed; 2) Having a sense of helplessness and failure; as well as. 3) A sense of injustice. **Abstract:** https://bit.ly/3urwVBU

Related:

- ‘“God hey, now I’ve been through something”: Moral resilience of coordinators in voluntary palliative terminal care,’ *Journal of Hospice & Palliative Nursing*, published online 24 March 2022. **Abstract:** https://bit.ly/3LgI2Ep

- ‘Vulnerability of inexperience: A qualitative exploration of physician grief and coping after impactful pediatric patient deaths,’ *Journal of Palliative Medicine*, published online 25 March 2022. **Abstract:** https://bit.ly/3Notkx1

COVID-19 deaths in care homes: Primary care management study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 22 March 2022 – Although Do Not Attempt Cardiopulmonary Resuscitation is in place for most individuals, holistic planning for end of life (EoL) is only present for a minority. The authors identify issues regarding applicability of advance care planning (ACP) as a result of changes in ways of working and nature of COVID-19. Important next steps are that these are addressed and integrated into wider changes implemented during COVID-19. A clear framework is required to support care home staff during COVID-19 outbreaks, focusing on clinical assessment and care planning. This evaluation highlights gaps between ACP and clinical plans for management of deterioration, and the weaknesses in the current approach to EoL planning in care homes. **Full text:** https://bit.ly/3wzwJTJ

Related:

- ‘Consequences of COVID-19: Limitations to the quality of palliative care and social work intervention,’ *Journal of Social Work in End-of-Life & Palliative Care*, published online 25 March 2022. **First page view:** https://bit.ly/3JJB7Du

- ‘Death and other losses in the COVID-19 pandemic in long-term care facilities for older adults in the perception of occupational therapists: A qualitative study,’ *Omega – Journal of Death & Dying*, published online 31 March 2022. **Abstract (w. references):** https://bit.ly/3u8aF17

- ‘It’s like standing in front of a prison fence – dying during the SARS-CoV2 pandemic: A qualitative study of bereaved relatives’ experiences,’ *Palliative Medicine*, published online 29 March 2022. **Abstract (w. references):** https://bit.ly/3qMIKl5

Decision-making in end-of-life and palliative care

Patient and family caregiver concordance and discordance: A systematic review and narrative synthesis

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 22 March 2022 – Studies focused primarily on end-of-life care and on patient and family caregiver (FCG) preferences for patient care. Discordance between patients and FCGs in palliative care (PC) can manifest in relational conflict and can result from a lack of awareness of and communication about each other's preferences for care. Patients' advancing illness and impending death together with open dialogue about future care including advance care planning can foster consensus between patients and FCGs. Patients and FCGs in PC can accommodate each other's preferences for care. Further research is needed to fully understand how patients and FCGs move towards consensus in the context of advancing illness. **Abstract:** https://bit.ly/3quF-HOi

12 tips for talking about death

THE MEDICAL REPUBLIC | Online – 24 March 2022 – In the context of life-limiting illness, there is often significant discordance about what the treating clinician knows and what the patient understands about their condition with serious consequences. Communication of accurate, relevant and timely information is essential for clarifying healthcare decisions and promoting the practice of shared decision-making. Communication is a core non-technical skill but is often considered a "soft skill," diminishing its very important role in the provision of safe, high-quality person-centred care. Many clinicians lack confidence discussing topics such as prognosis, advance care planning and end-of-life care and that clinicians do not always disclose bad news in an effective manner. **Full text:** https://bit.ly/3qOWyvq

Noted in Media Watch 16 August 2021 (#730, p.9):

- 'Discordance and concordance on perception of quality care at end of life between older patients, caregivers and clinicians: A scoping review,' *European Geriatric Medicine*, published online 12 August 2021. **Full text:** https://bit.ly/3g31xTR

N.B. Search back issues of Media Watch for additional articles on patient and family caregiver "concordance"/"discordance" in palliative and end-of-life care decision-making at: http://bit.ly/2ThijkC

Related:

- 'Advance care plans in U.K. care home residents: A service evaluation using a stepped wedge design,' *Age & Ageing*, published online 29 March 2022. **Full text:** https://bit.ly/3JT7JuF
- 'Australian general practice experiences of implementing a structured approach to initiating advance care planning and palliative care: A qualitative study,' *BMJ Open*, published online 28 March 2022. **Full text:** https://bit.ly/3tOsWjK
- 'Family-centered advance care planning: What matters most for parents of children with rare diseases,' *Children*, published online 21 March 2022. **Full text:** https://bit.ly/3NkVby2
- '"Who is going to take care of these grandkids if I go?": End-of-life planning by caregivers in grandparent-headed households,' *Death Studies*, published online 25 March 2022. **Abstract:** https://bit.ly/3qxBXLN
- 'Advancing goals and values, not advance care planning,' *Journal of the American Geriatric Society*, published online 24 March 2022. **Access article at:** https://bit.ly/3ix6SUp
- 'How well are serious illness conversations documented and what are patient and physician perceptions of these conversations?' *Journal of Palliative Medicine*, published online 28 March 2022. **Abstract (w. references):** https://bit.ly/3wDypf4
- 'Views and experiences of young people, their parents/carers and healthcare professionals of the advance care planning process: A summary of the findings from a qualitative study,' *Palliative Medicine*, published online 31 March 2022. **Full text:** https://bit.ly/379Awg1

Cont.

- 'Do not resuscitate orders in the time of COVID-19: Exploring media representations and implications for public and professional understandings,' *Progress in Palliative Care*, published online 31 March 2022. **Full text:** https://bit.ly/3JUuU7L

Opinion

Pushing back on the arguments of *The Lancet* Commission on the Value of Death

BRITISH MEDICAL JOURNAL | Online – 24 March 2022 – Introducing '*The Lancet* Commission on the Value of Death: Bringing death back into life'**[1]** at the Royal Society of Medicine, I blithely said that nobody seemed to disagree with our starting point that we have an unhealthy relationship with death and dying. But during the meeting people did disagree with some of what we concluded and recommended in our report. The Commission sees value in death. Without death, we argue, every birth would be a tragedy – and as the planetary crisis results from both too much consumption and too many people we are close to that point now. It's death that gives beauty – and for many, including me, meaning and a narrative – to life. That we all die reminds us of our common humanity – and of our shared frailty. **Full text:** https://bit.ly/3IFsZlY

1. 'Report of *The Lancet* Commission on the Value of Death: Bringing death back into life,' *The Lancet*, published online 31 January 2022. [Noted in Media Watch 7 February 2022 (#752, p.1)] **Access full text at:** https://bit.ly/3IOhSHU

Integrating palliative care into the modern cardiac intensive care unit: A review

EUROPEAN HEART JOURNAL: ACUTE CARDIOVASCULAR CARE | Online – 1 April 2022 – Palliative care (PC) has been shown to improve the quality of life and symptom burden in patients at various stages of illness, however, the integration of PC in the cardiac intensive care unit (CICU) has not been well-studied. The authors outline the fundamental principles of high-quality PC in the ICU, focused on timeliness, goal-concordant decision-making, and family-centred care. They differentiate between primary PC, which is delivered by the primary CICU team, and secondary PC, which is provided by the consulting PC team, and delineate their responsibilities and domains. The authors propose clinical triggers that might spur serious illness communication and reappraisal of patient preferences. **Full text:** https://bit.ly/3u0UDG4

Is there a need for cultural adaptation of the Last Aid Course?:
A mixed-methods study across the Danish-German border

HEALTHCARE | Online – 31 March 2022 – Last Aid courses (LAC) have been established in 20 countries in Europe, Australia, and America to improve the public discourse about death and dying and to empower people to contribute to end-of-life care (EoLC) in the community. The results of this study show that almost all participants appreciate the LAC as an option to talk and learn about death and EoLC. The informants find individual differences more important than cultural differences in EoLC, but describe differences connected to regulations and organization of services across the border. Suggestions for adaptation and improvement of the LAC include the topics of organization and support across the border, religions, and cultures, and supporting people in grief. **Full text:** https://bit.ly/36LVOAo

The hospice algorithm: Capitalizing on death and dying

HOME HEALTH CARE MANAGEMENT & PRACTICE | Online – 18 March 2022 – There is a paucity of information on hospice nurses' perceptions of the impact of the U.S. Hospice Medicare Benefit financial structure on care planning and delivery decisions (CP&DD). Six themes emerged in this study: 1) Finances are the guiding principle in CPⅅ 2) Appropriate patient selection allows hospices to maximize profit by maximizing length of stay (LoS) and minimizing service utilization; 3) Balancing patient care needs, cost, and LoS is a challenge; 4) Live discharge decisions save money, but can compromise care; 5) The interdisciplinary team is where most major decisions are made regarding patient care and finances; and, 6) Money drives patient care decisions... **Abstract (w. references):** https://bit.ly/3tuUr1m

Large-scale evaluation of a computer-based learning program to increase prison staff knowledge on geriatric and end-of-life care

INTERNATIONAL JOURNAL OF PRISONER HEALTH | Online – 29 March 2022 – There are almost 2.3 million U.S. persons incarcerated. Geriatric and end-of-life care in corrections is not as equitable as care in the free world. Technological delivery of geriatric training to staff through computer-based learning offers a novel approach to improve care and reduce disparities among those who are most vulnerable during confinement. Participants in this evaluation improved their knowledge after receiving the training. Correctional settings face increasing pressures to better address the healthcare and management needs of aged, chronically ill and dying incarcerated persons. This e-learning holds promise to contribute to better preparation of corrections staff to effectively care for these populations. **Abstract:** https://bit.ly/3DcxgMP

Prison Hospice: Backgrounder
Updated 1 February 2022

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

Family experiences of in-hospital end-of-life care for adults: A systematic review of qualitative evidence

JOURNAL OF CLINICAL NURSING | Online – 24 March 2022 – Despite the current orthodoxy for end-of-life care (EoLC) in a non-institutional setting, and home as the preferred place of death, it is likely the that hospital will remain the place of care and death for some people, whether in respect of personal choice, demand, unpredictable deterioration or following a fatal life-threatening illness or event. In view of this fact, enabling and improving peoples' experience of EoLC must remain part of the vision and mission of hospital organisations. This systematic review of qualitative evidence provided an aggregated perspective of what counts as a positive experience of care, as perceived by experiencing families. Relational aspects of care dominated the synthesised findings... **Full text:** https://bit.ly/3tGNcnp

Related:

- 'An audit of perioperative end-of-life care practices and documentation relating to patients who died in a surgical unit in three Victorian hospitals,' *Anaesthesia & Intensive Care*, published online 18 March 2022. **Abstract (w. references):** https://bit.ly/36AvNn0

A decade of studying drivers of disparities in end-of-life care for Black Americans: Using the National Institute of Minority Health & Health Disparities framework for health disparities research to map the path ahead

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 1 April 2022 – The sociocultural environment, physical/built environment, behavioral and biological domains remain understudied areas of potential causal mechanisms for racial disparities in end-of-life care. In the healthcare system domain, social influences including healthcare policy and law are understudied. In the sociocultural domain, the majority of the studies still focused on the individual level of influence, missing key areas of research in interpersonal discrimination and local and societal structural discrimination. Studies that focus on individual factors should be better screened to ensure that they are of high quality and avoid stigmatizing Black communities. **Abstract (w. references):** https://bit.ly/3uKkXU2

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

Interpersonal conflict between clinicians in the delivery of palliative and end-of-life care for critically ill patients: A secondary qualitative analysis

JOURNAL OF PALLIATIVE MEDICINE | Online – 1 April 2022 – The authors characterize three properties of interpersonal conflict: disagreement, interference, and negative emotion. In the context of delivering palliative and end-of-life care (EoLC) for critically ill patients, "disagreement" centered around whether patients were appropriate for palliative care (PC), which care plans should be prioritized, and how care should be delivered. "Interference" involved preventing PC consultation or goals-of-care discussions and hindering patient care. "Negative emotion" included occurrences of silencing or scolding, rudeness, anger, regret, ethical conflict, and grief. The authors findings provide an in-depth understanding of interpersonal conflict within palliative and EoLC for critically ill patients. **Abstract:** https://bit.ly/3wZ05Lq

Top ten tips palliative care clinicians should know about working with medical interpreters

JOURNAL OF PALLIATIVE MEDICINE | Online – 18 March 2022 – Rather than using an interpreter as a language tool, this article encourages palliative care (PC) clinicians to cultivate a partnership with the interpreter as a team member. They describe 10 tips for effective partnering with interpreters: the importance of including the interpreters in pre-encounter huddles and post-encounter debriefs, agreeing on strategies for interpreting "untranslatable" words and managing the encounters, using the "teach back" method to ensure understanding, acknowledging interpreters as cultural mediators, understanding the potential emotional impact of family meetings on interpreters, and enhancing follow-up with the PC team by providing contact information for PC staff to patients. **Abstract:** https://bit.ly/3LajFZ1

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

Developing an end-of-life care pathway for people with learning disabilities through partnership working

LEARNING DISABILITY | Online – 18 March 2022 – There is ample evidence of inconsistencies in end-of-life care (EoLC) service provision for people with learning disabilities. In 2013, in response to the findings of the first report of the Confidential Inquiry into Premature Deaths of People with Learning Disabilities … there is a need to support learning disability staff to provide good-quality EoLC to service users.[1,2] Findings from a literature review and a retrospective audit informed the development of an EoLC pathway for people with learning disabilities. The pathway is now in use by community learning disability teams across the county. The authors explain the background and rationale for the pathway and describe its development and implementation. **Abstract:** https://bit.ly/3qkDGEg

1. 'The Confidential Inquiry into Premature Deaths of People with Intellectual Disabilities in the U.K: Final Report,' University of Bristol, 2013. https://bit.ly/36gXXDW

2. 'The Confidential Inquiry into Premature Deaths of People with Intellectual Disabilities in the U.K.: A population-based study,' *The Lancet*, published online 11 December 2013. **Full text:** https://bit.ly/369RavW

N.B. 'Abstract Watch' on the European Association for Palliative Care blog highlights selected articles, noted in past issues of Media Watch, on a range of issues specific to palliative and EoLC. A past posting, for example, focuses on current thinking on palliative and EoLC for patients living with intellectual or developmental disabilities **Access at:** http://bit.ly/300WMRt

Area-Based Compassionate Communities: A systematic integrative review of existing initiatives worldwide

PALLIATIVE MEDICINE | Online – 30 March 2022 – Twenty articles were drawn from the peer reviewed search, three from grey literature and two from author-provided documentation. Notwithstanding the substantial variation in what is reported, all Area-Based Compassionate Community initiatives focus on multiple action areas of the Ottawa Charter for Health Promotion.[1] Variability in their contextual and developmental characteristics is high. Only a minority of initiatives have been evaluated and although conclusions are generally positive, what is evaluated often does not match their aims. Attaining support from policy makers can help in obtaining funding early in the project. Strengthening people's social networks was a recurring community engagement strategy. **Abstract (w. references):** https://bit.ly/3K2lF5B

1. 'Ottawa Charter for Health Promotion,' World Health Organization, 1986. https://bit.ly/3LC0qaT

N.B. See 'Compassionate communities: A global expansion,' a discussion of the *Palliative Medicine* article on the European Association for Palliative Care blog at: https://bit.ly/3uRqXJJ

Pediatric palliative care

Location of end-of-life care of children with cancer: A systematic review of parent experiences

PEDIATRIC BLOOD & CANCER | Online – 16 March 2022 – Important insights are gained through reflecting on the experiences of parents whose children have died, and these can help guide healthcare services and inform service development. Planning for the location of end-of-life (EoL) care requires clear and honest communication between healthcare providers and parents, which includes information about what supports are available in the home, hospice, or hospital. Early referral and implementation of palliative care … may assist families to prioritize goals and provide additional interprofessional expertise to achieve optimal quality of life for the child and their family. This may contribute to improved communication regarding EoL decision-making, including planning for the location of EoL care. **Full text:** https://bit.ly/3IxYDSo

Publishing Matters

'Nearly half of pediatric trials do not publish or report results, study finds' (p.12), in *Healio*.

Related:

- 'Unraveling Early and Periodic Screening, Diagnosis and Treatment and pediatric hospice care: An exploratory policy analysis,' *American Journal of Hospice & Palliative Medicine*, published online 31 March 2022. **Abstract (w. references):** https://bit.ly/3Lw0mcI
- 'Vulnerability of inexperience: A qualitative exploration of physician grief and coping after impactful pediatric patient deaths,' *Journal of Palliative Medicine*, published online 25 March 2022. **Abstract:** https://bit.ly/3Notkx1

Palliative care in The Netherlands

Development of a national quality framework for palliative care in a mixed generalist and specialist care model: A whole-sector approach and a modified Delphi technique

PLOS ONE | Online – 23 March 2022 – In a predominantly biomedical healthcare model focused on cure, providing optimal, person-centred palliative care (PC) is challenging. The general public, patients, and healthcare professionals are often unaware of PC's benefits. Poor interdisciplinary teamwork and limited communication combined with a lack of early identification of patients with PC needs contribute to suboptimal PC provision. The authors hypothesised that a whole-sector approach and a modified Delphi technique would be suitable to reach this aim. Analogous to the international AGREE guideline criteria and employing a whole-sector approach, an expert panel … answered the main question: "What are the elements defining high-quality PC in The Netherlands?" **Full text:** https://bit.ly/3D5S9Jz

Research Matters

Identification of digital health priorities for palliative care research: Modified Delphi study

JMIR AGING, 2022;5(1):e32075. This study identified 16 priority areas, which involved many applications of technologies, including care for patients and caregivers, self-management and reporting of diseases, education and training, communication, care coordination, and research methodology. The authors summarized the priority areas into eight topics: 1) Big data; 2) Mobile devices; 3) Telehealth and telemedicine; 4) Virtual reality; 5) Artificial intelligence; 6) Smart home; 7) Biotechnology; and, 8) Digital legacy. Human-centered design and robust governance systems should be considered in future research. It is important that the risks of using these technologies in palliative care are properly addressed to ensure that these tools are used meaningfully, wisely, and safely... **Full text:** https://bit.ly/3twR8qs

Palliative care volunteering: Pressing challenges in research

PALLIATIVE MEDICINE | Online – 31 March 2022 – Volunteers' position on the border between informal and formal, between professional and friend, can create ambiguity, stress and uncertainty in hospice and palliative care (PC) services, as not all healthcare professionals involved in the care for someone near the end of life are always familiar with volunteers. Nursing professionals, unfamiliar with volunteers may view volunteers with caution… These concerns may partially stem from more critical or cynical interpretations of economic evaluations of volunteering or governments discourse surrounding the socialization of care – the idea communities and informal caregivers should shoulder a larger share of PC provision to meet increasing demand for PC and increasing structural health constraints. **Access article at:** https://bit.ly/3wWVTfo

Publishing Matters

Nearly half of pediatric trials do not publish or report results, study finds

HEALIO | Online – 22 March 2022 – Nearly half of pediatric clinical trials initiated over a more than 12-year period did not report or publish their results, according to a new study.[1] Researchers conducted a cross-sectional analysis of 13,259 clinical trials that enrolled participants aged 18 years or younger from October 2007 to March 2020. The landscape of pediatric clinical trials, including drivers of completion and timely dissemination of results, is not well understood. The study aimed to characterize the prevalence of and factors associated with early discontinuation, results reporting, and publication of pediatric clinical trials. 11.1% of the trials were stopped early, with recruitment failure noted as a predominant reason for discontinuation. Around half reached completion, reported results or received publication. https://bit.ly/3qvcNO2

1. 'Early discontinuation, results reporting, and publication of pediatric clinical trials,' *Pediatrics*, published online 22 March 2022. **Abstract:** https://bit.ly/3NfQjdB

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

Media Watch: Editorial Practice

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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.

Search Back Issues of Media Watch @ http://bit.ly/2ThijkC

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

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