

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

To what extent is palliative care included in global guidelines that have been developed to support healthcare systems and providers to respond to infectious disease outbreaks?

'The under-representation of palliative care in global guidelines for responding to infectious disease outbreaks: A systematic narrative review' (p.7), in *International Health*.

Canada

Provisional death counts and excess mortality, January 2020 to August 2021

STATISTICS CANADA | Online – 8 November 2021 – COVID-19 continues to affect communities and families in Canada. Beyond deaths attributed to the disease itself, the pandemic could also have indirect consequences that increase or decrease the number of deaths as a result of various factors... To understand both the direct and indirect consequences of the pandemic, it is important to measure excess mortality, which occurs when there are more deaths than expected in a given period. It should be noted that, even without a pandemic, there is always some year-to-year variation in the number of people who die in a given week. This means that the number of expected deaths should fall within a certain range of values. There is evidence of excess mortality when weekly deaths are consistently higher than the expected number, but especially when they exceed the range of what is expected over several consecutive weeks. From March 2020 to the beginning of July 2021, there were an estimated 19,488 excess deaths in Canada, or 5.2%

more deaths than what would be expected were there no pandemic, after accounting for changes in the population, such as aging. Over this same period, 25,465 deaths were directly attributed to COVID-19. While COVID-19 claimed the lives of 6,255 Canadians from the end of January 2021 to the beginning of July 2021, significant excess mortality was not observed nationally during this time. <https://bit.ly/3BV9Zg2>

Specialist Publications

'What's suffering got to do with it? A qualitative study of suffering in the context of medical assistance in dying (MAiD)' (p.5), in *BMC Palliative Care*.

'Integration of a palliative approach in the care of older adults with dementia in primary care settings: A scoping review' (p.5), in *Canadian Journal on Aging*.

U.S.A.

Perspectives on providing end-of-life care for the nation's incarcerated

MARYLAND | National Public Radio (WYPR, Baltimore) – 8 November 2021 – According to the Maryland Center for Economic Policy, the state of Maryland spends about \$1 billion per year incarcerating roughly 20,000 people convicted of crimes. A third of them come from the city of Baltimore. In 2015, the state spent \$17 million locking up people from one neighborhood alone: Sandtown-Winchester in West Baltimore. For many of those who are given long sentences, their lives will end while they are behind bars. An essay in *The Baltimore Sun*, a couple of months ago, about palliative care for prisoners when they are diagnosed with terminal illnesses caught this station's attention,¹ ... The first guest on WYPR's Midday program is Dr. Raya Elfadel Kheirbek, Chief of the Division of Geriatrics and Palliative Medicine at the University of Maryland School of Medicine, author of *The Baltimore Sun* essay. She is joined by three activists working with an organization called the Humane Prison Hospice Project. <https://bit.ly/3H56B60>



Prison Hospice: Backgrounder Updated 1 November 2021

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

Photo: Lori Waselchuk, Philadelphia, PA

1. 'Dying prisoners deserve dignity and palliative care, if not compassionate release,' *The Baltimore Sun*, 28 September 2021. [Noted in Media Watch 4 October 2021 (#737, p.2)] <https://bit.ly/3igjico2>

International

Number of people dying at home is highest in 20 years

U.K. (England & Wales) | *The Telegraph* (London) – 10 November 2021 – The number of people dying at home is now the highest since the turn of the century as patients continue to struggle to access healthcare, official statistics suggest. Between January and June this year, 21,471 excess deaths occurred in private homes in England and Wales – almost 2,000 more compared to the same time last year. 85,910 people died at home during the first six months of the year, the highest figure in Office for National Statistics (ONS) data, which goes back to 2001, when 51,517 people died at home. Excess deaths are the number of deaths above the average when compared to the same period in the pre-pandemic years of 2015-2019. Across the entire pandemic, 62,792 excess deaths were registered in private homes in England and Wales from Jan 2020 to June 2021, the ONS figures showed. Professor Kevin McConway, emeritus professor of applied statistics at The Open University, said

the data suggest patients have been dying at home who would in previous years have died in a hospital, care home or hospice, and questions remain about the quality of the end-of-life care they received. <https://bit.ly/2YFbIIS>

Specialist Publications

'A collaborative palliative care response to the COVID-19 pandemic in residential aged care' (p.3), in *Australasian Journal on Ageing*.

'A novel care guide for personalised palliative care: A national initiative for improved quality of care' (p.4), in *BMC Palliative Care*.

'GPs involvement to improve care quality in care homes in the U.K.: A realist review' (p.9), at National Library of Medicine Journals.

Cont.

Noted in Media Watch 14 June 2021 (#721, p.2):

- U.K. | *The Guardian* (London) – 9 June 2021 – ‘**Benefits claimants suffering under end-of-life Department for Work & Pensions rule.**’ More than 100 terminally ill people are each month being rejected for benefits despite having less than six months to live, and many are spending their final weeks fighting in vain for social security support. The Marie Curie and the Motor Neurone Disease Association charities have called for an urgent review of Department for Work & Pensions rules after official data revealed in an 18-month period 1,860 people in the U.K. died within six months of their claim for disability benefits being turned down. The charities said the government had to scrap the restrictive “six-month rule” under which people must prove they have six months or less to live... <https://bit.ly/351sjWT>

Ending well: The urgent case for accessible palliative care

NEW ZEALAND | Maxim Institute (Auckland) – 2 November 2021 – Whether the cause is COVID-19 or something else, death is inevitable for all of us. A good death, however, is not. In spite of the care, expertise, and knowledge now available, bad deaths are unfortunately all too common for many New Zealanders. Palliative care (PC) is an important ingredient for good end-of-life care (EoLC) – even when the person has complex medical issues or has struggled with significant pain. It is an approach that “prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.” Studies have shown that PC can result in improved quality of life, an increased life expectancy and, due to lowered interactions with the hospital and admission process, can relieve financial costs on the healthcare system. One study found, for example, that “involvement from PC was associated with significantly lower hospital costs in the order of \$5,000-8,000 (Australian) for all patient groups, but most particularly for non-cancer diagnoses.” For too many New Zealanders, however, good palliative and EoLC is out of reach. As demographics change and New Zealand’s population ages the number of people struggling to access PC services is growing rapidly. In fact, studies project the need for New Zealand PC services to increase by half in the next 20 years, and almost double in the next 50 years. New Zealand’s health system is currently undergoing significant reform, through systemic changes as well as with the introduction of legalised assisted dying. With these changes underway it is essential that PC services are not forgotten, but get the necessary attention and support so that all New Zealanders have the best opportunity for a good death. This paper identifies five key areas where policy changes could improve access to PC services for New Zealanders. **Download at:** <https://bit.ly/3oiACXA>

Specialist Publications

“We couldn’t have managed without your team”

A collaborative palliative care response to the COVID-19 pandemic in residential aged care

AUSTRALASIAN JOURNAL ON AGEING | Online – 10 November 2021 – The global COVID-19 pandemic has challenged healthcare, aged care and palliative care (PC) provision in ways previously unimaginable. In Australia, this has been felt particularly amongst the country’s most vulnerable members of society, those residing in residential aged care. Currently representing the majority of COVID-19 deaths and healthcare worker infections, this vulnerable sector has borne the greatest impact. A collaborative response comprising a tertiary hospital PC outreach service, residential InReach geriatric service and a community PC service effectively delivered comprehensive and timely specialist care to residents infected with COVID-19. Daily videoconferencing rounds were efficient, minimised infection risk and facilitated family members attending virtually during patient assessments and care planning discussions. This model was both reactive and proactive and importantly scalable should further infective outbreaks occur in Australasian residential aged care facilities. This study illustrates an innovative model whereby residential aged care services can be supported by collaborative tertiary hospital specialist services and community PC services, providing comprehensive and timely specialist care. **Full text:** <https://bit.ly/3D9T8rb>



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“It was one of those complicated cases”

Health practitioners’ perspectives and practices of providing end-of-life care for people with profound intellectual and multiple disability

BMC PALLIATIVE CARE | Online – 12 November 2021 – This study provides valuable insights into a neglected field of research relating to end-of-life (EoL) decision-making and planning for people with profound intellectual and multiple disability (PIMD). The results show that, due to negative perceptions of a person with PIMD’s decision-making capacity, people with PIMD are likely to be assessed as unable to express choice and preference regarding EoL care and are offered limited opportunity to be involved in their own EoL care. Health practitioners have an important role in addressing EoL care needs and preferences, but feel uncertain about their competencies in providing care for people with PIMD during or at the end of their life. There is a clear need for additional and specialised support in EoL decision-making and planning for people with PIMD. The provision of such support is common practice in some parts of the world. For example, in The Netherlands specialised palliative and pastoral care for people with intellectual disabilities is acknowledged and respected as a medical specialty. Positive attitudes toward the capacity of people with PIMD to participate in decisions about their EoL care, coupled with an increase in the accessibility of this care in the form of specialist support, such as palliative care professionals and pastoral care teams, are important for achieving equality for people with PIMD at the EoL. **Full text:** <https://bit.ly/3HryUvR>

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>



A novel care guide for personalised palliative care: A national initiative for improved quality of care

BMC PALLIATIVE CARE | Online – 11 November 2021 – The Swedish Palliative Care Guide (S-PCG) has the potential to provide meaningful support in identifying palliative care (PC) needs; facilitates inter-professional assessment and care of these patients; and emphasizes the needs of the family throughout the palliative trajectory. It supports high-quality personalised PC, and when properly used may help patient and families express their too-often-neglected needs, support individual negotiation of goals of care, and subsequently promote relevant care. Choosing to implement S-PCG includes responsibility for its use in concordance with the principles of good PC. The next step entails scientific evaluation of the clinical impact and effect of S-PCG in different care settings – including implementation, patient and family outcomes, and experiences of patient, family and staff. **Full text:** <https://bit.ly/2YAsTer>

Specialist palliative care teams and characteristics related to referral rate: A national cross-sectional survey among hospitals in The Netherlands

BMC PALLIATIVE CARE | Online – 11 November 2021 – This cross-sectional survey shows that the palliative care (PC) programmes of almost all hospitals in The Netherlands consist of specialist palliative care teams (SPCTs) providing inpatient consultation services. Moreover, nearly two third of these SPCTs are interdisciplinary staffed, half of the programmes provide outpatient clinics and a substantial part has dedicated acute care beds and provides community-based PC. However, the median referral rate is limited to 0.56% of total annual hospital admissions and referral to these SPCTs occurs late in the disease trajectory. SPCTs with a high referral rate seem to be more mature than low referral rate SPCTs as the latter frequently have a shorter time of existence and limited staffing with a more basic level of education. In addition, high referral rate SPCTs appear to be better integrated as they are more often related to presence of dedicated outpatient clinics and subsequent earlier timing of referrals, more frequently participate in other departments’ multidisciplinary team meetings and in research, and more often provide education outside their own hospital. Overall, our three-yearly surveys show that the number of Dutch hospitals providing a SPCT with inpatient consultation services has grown steadily from 39% in 2013, 77% in 2015 to 94% in 2018. **Full text:** <https://bit.ly/3HcQZgV>

What's suffering got to do with it? A qualitative study of suffering in the context of medical assistance in dying (MAiD)

BMC PALLIATIVE CARE | Online – 11 November 2021 – Findings from this study have important clinical implications. First, they point to the essential knowledge and skills that healthcare providers should have to engage in conversations with those considering MAiD. Healthcare providers need to have phenomenological knowledge about what it is like to travel the dying trajectory within healthcare systems and clinical communication skills to elicit the suffering story. Only then will the moral and legal obligations of accepting patients' suffering stories and attempting to ameliorate that suffering be fulfilled. Second, these conversations take time. Time may be less of a factor if healthcare providers have longstanding relationships with clients, but in the Canadian system where MAiD is often delivered through specialized teams, this is not always the case. We cannot afford to have these conversations conducted within unrealistic time constraints that do not allow for a fair and faithful determination that this is the right procedure for this person at this time. Third, we need to take steps to ensure that decision-making around MAiD is not driven by institutional suffering that occurs as a result of a lack of good advance care planning. Finally, we need to develop further evidence and best practices about ameliorating the suffering that occurs around a MAiD process. Much work has been done to ensure that MAiD follows a person-centered approach. However, the moral and political contentiousness of MAiD has perhaps made us reluctant to reveal that it is not without its own characteristic sufferings. **Full text:** <https://bit.ly/3n57CTL>

Integration of a palliative approach in the care of older adults with dementia in primary care settings: A scoping review

CANADIAN JOURNAL ON AGING | Online – 8 November 2021 – No studies were found that looked at the integration of a palliative approach in persons with mild to moderate dementia. As such, the findings in this article relate to the integration of a palliative approach in advanced dementia, which appears to be most common. Primary care providers are reluctant to initiate advance care planning (ACP) discussions because of the barriers related to the unpredictable and protracted trajectory of dementia, leading to difficulty in prognostication and concerns about stripping hope and causing psychological distress, as well as lack of training and experience in caring for the persons with dementia. Primary care physicians worry about the ability to offer appropriate symptom management and psychosocial support to patients and caregivers. This is because of a lack of interdisciplinary approach, collaboration among specialties and sectors, and integration of health and social services. The authors operationalize a definition of a palliative approach in the context of dementia and used this definition to scope the existing literature in this area. There is variability in the literature regarding what constitutes an integrated palliative approach to care for older adults with dementia at various stages within their trajectory from the perspective of non-palliative specialists. Therefore, setting out the four main components of a palliative approach – ACP, pain and symptoms management, psychosocial and spiritual support, and the process of shared decision-making – was a necessary first step. **Full text:** <https://bit.ly/3oqeIBR>

N.B. Search back issues of Media Watch for additional articles on palliative and end-of-life care for people living with “dementia” at: <http://bit.ly/2ThijkC>

Barry R. Ashpole

MY INVOLVEMENT IN HOSPICE AND PALLIATIVE CARE DATES FROM 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://bit.ly/2RPJy9b>



“With every fiber of their being”

Perspectives of healthcare professionals caring for children with non-malignant life-limiting conditions

CHILD: CARE, HEALTH & DEVELOPMENT | Online – 9 November 2021 – The findings of this study highlighted the unfailing determination and dedication of healthcare professionals who provided care despite challenges with what seemed like “with every fiber of their being.” Three key themes marked such strength and commitment... “Being there” explicitly highlighted expert care that was individualized and responsive to the child and family’s unique needs. The provision of such care was often threatened and potentially compromised by the intricacies and challenges associated with children’s palliative care (PC) and service provision. “Being focused” captured the sense that the healthcare professionals remained entirely focused on providing expert care despite these challenges. “Being strong” epitomized the personal and professional impact on healthcare professionals who are working in this area and the manner in which they sustain themselves in “being focused” and in “being there.” The healthcare professionals demonstrated their unwavering commitment to deliver quality care required by children and families, however against a background of issues relating to organizational constraints. The findings have implications for education/service providers such as the need for specific PC education at both pre-registration level and continuing professional development. **Abstract:** <https://bit.ly/3ceeTdP>

Related:

- *CHILD: CARE, HEALTH & DEVELOPMENT* | Online – 11 November 2021 – ‘**Living with a child who has a life limiting condition: The functioning of well-siblings and parents.**’ Living with a child who has a life limiting condition (LLC) is likely to have a major impact on all family members. There is a need to have a clearer understanding of the nature and extent of this impact on parents and well-siblings. The current study aimed to investigate the psychosocial functioning of well-siblings and parents living with a child with a LLC. Although one cannot infer a causal direction from the current study, greater self-reported well-sibling and parental resilience were associated with aspects of better self-reported psychosocial functioning. **Abstract:** <https://bit.ly/3HcVLLr>

Unbefriended, uninvited: How end-of-life doulas can address ethical and procedural gaps for unrepresented patients and ensure equal access to the “good death”

CLINICAL ETHICS | Online – 11 November 2021 – In response to a global population with increasingly complex issues at the end of life (EoL), a movement in the U.S. has emerged incorporating doulas into EoL care. These EoL doulas are not just focused on the quality of life, but also the quality of death. Like birth doulas, who provide support for pregnant patients and their families, EoL doulas help alleviate physical and mental discomfort in those who are dying. The authors explore the role of EoL doulas in improving the care of unrepresented patients, who lack decision-making capacity and have no surrogates or documents to guide their healthcare decisions. They argue that EoL doulas may help this traditionally underserved population experience a “good death” by answering several ethical and procedural challenges. As quasi-independent, non-medical members of the healthcare team, they provide a balancing, advocating voice on behalf of the patient, and may also help reduce inappropriate treatment, delays in care, and the over-burdening of the public guardianship system. As such, attention should be given to formally defining their place within the healthcare infrastructure. **Abstract (w. references):** <https://bit.ly/3FbdQIO>

N.B. Search back issues of Media Watch for additional articles on EoL “doulas” at: <http://bit.ly/2ThijkC>



Media Watch: Access Online

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

Healthcare coach support to assist with advance care planning and symptom management: A randomized controlled trial

CONTEMPORARY CLINICAL TRIALS | Online – 5 November 2021 – The Health Care Coach Support intervention was developed to improve cancer care. The intervention assigns a lay or community health worker “health coach” to all patients newly diagnosed with advanced stages of cancer who aims to educate and activate patients in advance care planning discussions and symptom management with their clinicians. Patients are randomized in a 1:1 allocation to either the 12-month health coach intervention combined with usual oncology care or usual oncology care alone. The primary outcome is to evaluate whether the intervention reduces acute care use measured at 6-months follow-up more than usual care. Secondary outcomes include the effect on acute care, palliative care, and hospice at 12-months follow-up and one month prior to death for patients who die. Additional secondary outcomes include changes in patient satisfaction with decision and patient satisfaction with care from baseline (time of enrollment) to 3-, 6-, 9- and 12-months post-enrollment. This study addresses an important gap in supportive cancer care by testing whether a team-based approach using non-professional personnel can ensure delivery of these services. **Abstract:** <https://bit.ly/3BYxy7Q>

Pre-loss grief experiences of adults when someone important to them is at end-of-life: A qualitative systematic review

DEATH STUDIES | Online – 9 November 2021 – Limited understanding exists about the impact of pre-loss grief on bereavement. This systematic review aimed to synthesize qualitative research evidence reporting adults’ experiences of pre-loss grief within cancer care. Thirteen studies were selected, and three key themes identified. Findings indicate that relatives transitioned through lived experiences during end-stage cancer, and that meanings attached to these experiences influenced how they experienced pre-loss grief. Limited formal support was identified to navigate these experiences; however, context was seen as important, and skilled healthcare practitioners and physical environment were key to facilitating preparedness. **Abstract:** <https://bit.ly/3odJRYR>

Teaching death: Exploring the end of life in a novel undergraduate course

INNOVATION & EDUCATION | Online – 7 November 2021 – Western culture discourages discussion of death and dying, especially with healthy emerging adults. Yet, research shows that engaging this population in conversations about death and dying is empowering and important for young people’s decision-making around and understanding of the end of life. The authors show that students are indeed ill-informed on such issues, but that they desire to learn more. The authors describe and assess a pilot undergraduate course in palliative care addressing this need, and they demonstrate its success in engaging and educating students using pedagogical approaches built to develop a social and intellectual community of trust. **Full text:** <https://bit.ly/3knlcQG>

The under-representation of palliative care in global guidelines for responding to infectious disease outbreaks: A systematic narrative review

INTERNATIONAL HEALTH | Online – 9 November 2021 – Recent literature has described a “growing consciousness of need” for palliative care (PC) in humanitarian emergencies, including infectious disease outbreaks, an essential step towards the successful implementation of PC within healthcare responses to crises. This review reveals that although there is a growing appreciation for PC, there continues to be very limited inclusion of PC in guidelines and hence limited implementation in the setting of infectious disease outbreaks. Further development of guidelines and policies that detail the management and implementation of PC is crucial to deliver best-practice care to patients in the context of infectious disease outbreaks and to reduce the burden of unnecessary suffering in such times. **Full text:** <https://bit.ly/3C7aKCB>



N.B. Additional articles on the provision and delivery of PC during humanitarian crises or natural disasters noted in Media Watch 5 July 2021 (#724, p.11).

In-home care at the end of life: How much is needed?

JAMA NETWORK OPEN | Online – 8 November 2021 – As the need for care at the end of life (EoL) grows in the face of an aging population, understanding how best to configure and fund services for people approaching the EoL is increasingly important. It requires consideration of what outcomes we are aiming to achieve and for whom (the patient, their carer, and/or the health system), and whether those who are at the end of their life prioritize these factors similarly. In terms of models of care, the challenge is to determine the role, configuration, and optimal timing for in-home services, as well as the proportion of overall services that should be performed in the community. When home is the preferred place of death, in-home services are critical to ensure we can meet this preference while maintaining adequate symptom control and support for both the person themselves and their caregivers. Meta-analyses support increased odds of dying at home when adults with advanced illness receive home-based palliative care, with reduced symptom burden. **Full text:** <https://bit.ly/3kjLUJT>

Related:

- *JAMA NETWORK OPEN* | Online – 8 November 2021 – ‘**Association of the frequency of in-home care services utilization and the probability of in-home death.**’ The provision of end-of-life (EoL) care is an important policy issue associated with population aging around the world. Yet it is unclear whether the provision of in-home care services can allow patients the option of in-home death at EoL. The findings from this study indicated that frequent use of in-home care services at the EoL was associated with a higher probability of recipients’ death at home. One policy implication of these results is that in order to meet the EoL preferences of patients, it is not only necessary to promote the provision of medical services at home, but also to ensure an adequate supply of care workers. **Full text:** <https://bit.ly/3H5XHFd>

Developing successful palliative care teams in rural communities: A facilitated process

JOURNAL OF PALLIATIVE MEDICINE | Online – 11 November 2021 – Developing palliative care (PC) programs in rural settings is challenging due to limitations on training, staff, resources, and reimbursement. Employing established frameworks and processes can assist rural communities in developing quality PC programs. Even with limitations, results of a prospective, observational, quality improvement initiative implemented over 18-24 months demonstrate that a structured facilitated planning process can help rural communities develop and implement PC services, despite barriers. Additional resources and support are needed to continue to expand access to high-quality PC services in rural communities, including the continued need for flexibility in reimbursement structures that support an interdisciplinary community-based approach. Implementation and uptake of value-based care arrangements vary widely across rural areas. Rural participation in value-based care programs from multiple payers has the potential to align payment incentives that support implementation of PC services. Additional opportunities include potential for better utilization of telehealth to access specialty-level skills and to provide in-home monitoring and support. Recent telehealth reimbursement and policy changes stemming from the pandemic should help enable use of technology to support service development. **Full text:** <https://bit.ly/3onU98X>

Noted in Media Watch 3 May 2021 (#715, p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 28 April 2021 – ‘**Examining barriers and facilitators to palliative care access in rural areas: A scoping review.**’ Access to palliative care (PC) remains challenging for rural Americans... Given the demand and benefits of PC, a comprehensive view of PC access would inform policymakers in developing PC services in rural areas. The findings of this review highlight the need for funding support to increase provider competency, service availability and accessibility, and the public knowledge and awareness of PC in rural areas. A holistic and tailored PC model that standardizes care delivery, referral and coordination, including family caregiver support programs, can improve care access. **Abstract (w. references):** <https://bit.ly/2R0dsIp>

Place of death and phenomenon of going home to die in Chinese adults: A prospective cohort study

THE LANCET REGIONAL HEALTH | Online – 8 November 2021 – China is embracing an ageing population without sustainable end-of-life care services. However, changes in place of death and trends of going home to die (GHTD) from the hospital remains unknown. In this large population-based Chinese cohort, the authors found that home deaths accounted for a significant and constant proportion of all deaths that occurred throughout the study period. The GHTD phenomenon was common among decedents who received inpatient services before death and associated with health insurance (HI) schemes. There was a marked increase in the proportion of GHTD regardless of HI schemes. Urban and Rural Residents' Basic Medical Insurance beneficiaries were more likely to experience GHTD compared to Urban Employee Basic Medical Insurance counterparts. **Full text:** <https://bit.ly/3CaKurn>

[Publishing Matters](#)

'Stumbling and growing: A bibliometric study of academic publications of palliative care in mainland China for 2010-2020' (p.12), in *Journal of Palliative Care*.

Related:

- *BMC PUBLIC HEALTH* | Online – 8 November 2021 – **'Advance directives and end-of-life care preferences among adults in Wuhan, China: A cross-sectional study.'** Similar to previous studies that were conducted among older adults or older adults with chronic diseases, only a very small portion of those in this sample in Wuhan, Mainland China have heard of advance directives (ADs). Nonetheless, most of them indicated positive attitudes after learning about what comprises an AD. This finding is similar to the studies conducted in Hong Kong and Macao. The low awareness of ADs and the positive attitudes towards it suggests a need for enhancing the promotion of ADs and potentially considering legislation to support ADs in Mainland China. **Full text:** <https://bit.ly/3qjAYQj>

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

GPs' involvement to improve care quality in care homes in the U.K.: A realist review

NATIONAL LIBRARY OF MEDICINE JOURNALS | Online – Accessed 9 November 2021 – Close working between general practitioners (GPs) and care homes is crucial for good-quality care. In the U.K., GPs provide medical care to residents and control access to other health services. The authors aimed to summarise how GPs work with care homes to improve care. They used a realist review to summarise improvement initiatives. This method suited the complex nature of improvement initiatives in care homes and the variations in the way that GPs were involved. The authors searched for studies carried out in residential and nursing homes for older people in the U.K., and investigated any interventions involving GPs. They selected 30 articles about medication review and end-of-life care (EoLC) and developed two overarching theories. Theory 1 described where a GP played a supportive role while another professional, such as a pharmacist, led the initiative. Negotiation was required to match improvement initiatives to the variety of

Extract: GPs supporting end-of-life care

A care home improvement project about EoLC used an appreciative inquiry method to bring together the care team. The project had identified areas of uncertainty within teams when decisions had to be made about EoLC and this could lead to conveyance to hospital towards the end of life. A series of three workshops brought together the care home manager, GP and district nurse, from three care homes. Appreciative inquiry enabled issues to surface, including who should lead care decisions, communication and care routines. This approach engaged GPs in how changes were planned and elicited the commitment to deliver the agreed change. Discussions explored different perspectives that members of the team may bring to care of individual residents

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ways in which GPs worked. This could improve prescribing and EoLC. Theory 2 was about national or regional programmes, led by prominent GPs, that aim to improve EoLC in a way that is consistent with the working patterns of GPs. There was evidence that these resulted in clear specification of the role that GPs should play, but there was limited detail about the role GPs actually play in improvement. Only a small number of studies described GPs' role in improvement in care homes. GPs make valuable contributions to improvement, but they are often in supporting other professionals, who take the lead. Future research should explore the exact function of GPs in improving care for residents. **Full text:** <https://bit.ly/3CVEWSy>

Pathway project offers three new practices for end-of-life care, goals

NEPHROLOGY | Online – 7 November 2021 – The Pathway Project identified and presented 14 evidence-based best practices that could be incorporated into kidney care to dialysis organizations, then refined the final package to prioritize three best practices. These practices focused on seriously ill patients. The first best practice of the Pathway Project encourages nephrologists to screen patients by asking themselves the “surprise” question: “Would I be surprised if this patient died in the next 6 or 12 months?” Answering no would mean that the patient is seriously ill. The second best practice is to prioritize goals-of-care conversations with seriously ill patients. The third best practice is offering palliative care (PC) pathways that allow patients to transition to less frequent dialysis, hospice or dialysis discontinuation based on their goals of care. Ten hemodialysis centers [in the U.S.] voluntarily adopted and implemented these practices after two learning sessions. The serious illness screening was implemented and sustained, even after the beginning of the COVID-19. The third best practice, the PC pathway, was implemented the least, and no centers developed protocols to transition patients to hospice or dialysis withdrawal. **Full text:** <https://bit.ly/3C2m6b0>

Noted in Media Watch 9 November 2020 (#691, p.3):

- *ADVANCES IN CHRONIC KIDNEY DISEASE*, 2020;27(4):350-355. ‘**Palliative care in nephrology: The work and the workforce.**’ Kidney palliative care (PC), a growing subspecialty of clinical practice, education, and research in nephrology, is an essential aspect of care for patients across the continuum of advanced kidney disease (AKD) who have high symptom burden, multi-dimensional communication needs and limited life-expectancy. Training in PC can occur in a variety of ways, from didactic curricula and clinical experiences embedded in nephrology fellowship training to the pursuit of additional dedicated fellowship training in PC. This article discusses opportunities and challenges in building a skilled workforce that will address the palliative needs of patients living with AKD. **Full text:** <https://bit.ly/3kPTv0N>

N.B. Search back issues of Media Watch for additional articles on PC for patients living with “kidney” disease: <http://bit.ly/2ThijkC>

Patients receiving palliative care and their families’ experiences of participating in a patient-centered family meeting: A Qualitative sub-study of the Valuing Opinions, Individual Communication, and Experience Feasibility Trial

PALLIATIVE MEDICINE REPORTS | Online – 10 November 2021 – In this study, the patients and families interviewed about the meeting model reported beneficial and supportive experiences. The patient-set agenda enabled the patients to identify and discuss psychosocial, emotional, and relationship issues and concerns related to their current condition and end-of-life preparation. For some patients, these meetings were critical for beginning the difficult conversations with their family that they wished to have before their death, often to resolve outstanding concerns. To enhance the uptake and provide patients and families with an opportunity to participate in this meeting model, consideration can be given to offering this meeting earlier in the disease trajectory. When patients are physically compromised, an alternative is for the family, as proxy decision-makers for the patient, to meet with the interdisciplinary team to ensure that both patient’s and family’s needs and concerns are raised and discussed. The authors have previously noted that this meeting model is not feasible for all patients. This observation was based on the recognition that there were finite clinical resources and time required to provide them as standard care, and that not all patients would require or be suitable for this meeting model. It is important to establish with greater clarity any causal link between the Meeting and the patients’ and families’ experience. Further research is also required to identify which patients and families would receive either a benefit from this type of meeting or (potentially) consider this type of meeting a burden. **Full text:** <https://bit.ly/3wAihJg>

Prevalence and timing of specialist palliative care access among advanced cancer patients and association with hospital death

PROCEEDINGS OF SINGAPORE HEALTHCARE | Online – 4 November 2021 – Even though international guidelines recommend that all advanced cancer patients should receive specialist palliative care (SPC) from the time of diagnosis, published studies report a much lower percentage of 5-11% of patients who are referred to SPC services. The higher referral rate of 47.7% in this study sample may be attributed at least in part to the close working relationship between oncologists and SPC clinicians, with the SPC service being co-located within the cancer centre. Nonetheless, less than half of the advanced cancer patients in this study received SPC; furthermore, those who did receive SPC support very late in their illness trajectory. This highlights a gap in care that needs to be addressed urgently. One possible reason for inadequate and late access to SPC is that existing care models are resource-intensive and consequently have limited capacity to provide care for large number of cancer patients. Innovative models of care need to be developed, evaluated and implemented, in order to feasibly upscale services and extend the reach of SPC. For example, there could be novel ways of integration between oncologists and SPC providers to utilise limited resources more efficiently and deliver more coordinated palliative care (PC) support to advanced cancer patients. This may involve oncologists providing generalist PC for those without complex needs who may not require SPC. **Full text:** <https://bit.ly/3F3nU5N>

A mixed intra-hospital mobile team of geriatrics and palliative care: The Neuchâtel experience

REVUE MEDICALE SUISSE, 2021;17(757):1890-1893. The increasing life expectancy, the earlier detection of terminal illnesses, and the increasing complexity of care pathways led the authors to propose an innovative response within the Neuchâtel Hospital Network [in Swiss canton of Neuchâtel], in the form of a mixed intra-hospital mobile team, composed of doctors and nurses from geriatrics and palliative care. Through geriatric and palliative assessment, the authors highlight the patient's different medical problems. The Network's team, after two years of existence, has successfully met patients' needs as well as the hospital teams' needs. And yet, they encountered certain challenges. **Abstract:** <https://bit.ly/3mVrF6R>

N.B. French language article.

Related:

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 9 November 2021 – ‘**Interprofessional geriatric and palliative care intervention associated with fewer hospital days.**’ With increasing complexity of our aging inpatient population, the authors implemented an interprofessional geriatric and palliative care (PC) intervention on a hospitalist service. This study aimed to measure the intervention's impact on length of stay (LoS), 30-day readmission, and the daily intensity of inpatient services utilization. An interprofessional intervention of geriatric and PC consultation in collaboration with a hospitalist service may reduce LoS, especially for geriatric patients, without an increase in readmissions. This model may have broader implications for hospital care and should be further studied. **Abstract:** <https://bit.ly/3F3lUsZ>

N.B. Selected articles on the interface between geriatric and palliative medicine noted in Media Watch 9 August 2021 (#729, p.13).

[Publishing Matters](#)

Strengthening research integrity: The role and responsibilities of publishing

INTERNATIONAL SCIENCE COUNCIL | Online – Accessed 11 November 2021 – An essential purpose of scientific publishing is “to make the evidence on which a scientific truth claim is based, accessible to scrutiny by peer review and post-publication analysis so that method and logic can be validated or invalidated, conclusions scrutinized, and any observations or experiments replicated.” This process is the foundation of the “self-correction of science” that, in turn, is a bedrock of the integrity that underpins the public value of

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science and ultimately trust in science and the scientific method. Research integrity is weakened by practices that range from sloppy research methodology through poor data handling and analysis and unethical practices to plagiarism and deliberate fraud. The ultimate responsibility for such breaches lies with the researchers involved. However, the act of publishing and the processes involved can – indeed should – play an essential role in detecting their possible occurrence and thus acting as a significant deterrent. Unfortunately, there is increasing and compelling evidence that publishing is not fulfilling this role as well as it could. While significant changes in culture and expectations of both publishers and researchers are necessary, modest reforms are feasible and warranted. This paper, designed to spur discussion, suggests that focusing on two modest reforms while pursuing a more significant reform of scientific publishing would be beneficial. **Full text:** <https://bit.ly/31PdVTe>

Stumbling and growing: A bibliometric study of academic publications of palliative care in mainland China for 2010-2020

JOURNAL OF PALLIATIVE CARE | Online – 8 November 2021 – This study aimed to describe the development of palliative care-related publications in Mainland China in various aspects. A total of 3,682 publications were identified, 754 of them (20.5%) published in Chinese core journals or international journals. The annual publication number and impact factor rose rapidly after 2016 and dropped again in 2020. There is no specialized palliative care (PC) journal in Mainland China. The publication numbers differed significantly between East and Western China and were closely linked to the economy. The megacities Beijing and Shanghai comprised 2.6% of the total population of Mainland China, but produced 22.6% of the publications. PC in cancer patients was the most common topic. Practical keywords such as “pain management” and “living will” gained popularity recently. PC-related research and publication in Mainland China are growing in recent years. However, the early stage growth is unstable, with a conspicuous regional disparity. Policies should be designed, in an equitable manner, to encourage original research and publication of PC. **Abstract (w. references):** <https://bit.ly/3BTkTTD>

[Media Watch: Editorial Practice](#)

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Cont.

Something Missed or Overlooked?

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

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International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3CX3lr3>

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Canada



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

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

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

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