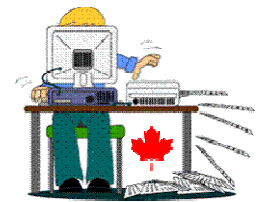


Media Watch...

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.

24 February 2020 Edition | Issue #654



Compilation of Media Watch 2008-2020 ©

Compiled & Annotated by Barry R. Ashpole

Visiting patients at home introduces you to their world in a way you never get to see in the hospital. The things that give life color and meaning for them are on full display.

'Think you want to die at home? You might want to think twice about that' (p.2), in *The Los Angeles Times*.

U.S.A.

Hospice deals remain hot amid heightened industry scrutiny

BLOOMBERG LAW | Online – 21 February 2020 – Government efforts to improve quality, fight fraud, and stop profiteering in the hospice industry are partly responsible for a record wave of mergers and acquisitions that hedge against a new Medicare payment system. From a handful of small non-profit organizations in the 1970s, hospice end-of-life care has grown into a thriving \$19 billion a year industry led mainly by for-profit, investor-owned companies. Medicare is the nation's largest payer for hospice care, covering more than 90% of patient stays in 2018 on behalf of more than 1.5 million beneficiaries. Use of the Medicare hospice benefit will grow as millions of aging baby boomers require end-of-life care in the coming years. In 2019, there were a record 42 hospice-related mergers and acquisitions, and the pace isn't likely to cool in 2020... <http://bit.ly/2HMMW9Tf>

Utah hospice center gives recently homeless people a place to spend last days

UTAH | KSL TV News (Salt Lake City) – 20 February 2020 – Homeless hospice caregivers have noticed a disturbing trend – community members who have never been homeless have been seeking their help for end-of-life care. Nearly 100 people died on the streets of Salt Lake City last year while experiencing homelessness. Some of them spent their last days of life in a hospice for the homeless called The Inn Between. Executive director Kim Correa said more and more people who have been employed throughout their lives are running out of resources and ending up in their care. <http://bit.ly/37OyQD5>

N.B. Additional articles on end-of-life care for the homeless in the U.S. noted in 4 November 2019 issue of Media Watch (#638, p.4).



Share this issue of Media Watch with a colleague

Dying patients' wishes ignored nearly 40% of time in study

BECKER'S HOSPITAL REVIEW | Online – 16 February 2020 – Nearly 40% of chronic illness patients nearing the end of life (EoL) who had physician orders limiting treatment received intensive care that was inconsistent with those orders, according to a new study.¹ Patients with chronic illness frequently use physician orders for life-sustaining treatment to document their wishes with regard to EoL care. For the study, researchers examined 1,818 chronic illness patients at a two-hospital academic health system... The patients were hospitalized for up to six months before they died. Of the 1,818 patients: 401 had physician orders for “comfort measures only”; 761 had orders for “limited additional interventions”; and, 656 had orders for full

treatment. Researchers found 31% patients with comfort-only orders, 46% of patients with limited-interventions orders and 62% with full-treatment orders were admitted to the intensive care unit. Among patients with comfort-only and limited-interventions order, 38% received ICU care not in line with their orders. <http://bit.ly/2uMJ0XE>

Specialist Publications

'Physician Orders for Life-Sustaining Treatment and limiting overtreatment at the end of life' (p.7), in *Journal of the American Medical Association*.

1. 'Association of Physician Orders for Life-Sustaining Treatment with ICU admissions among patients hospitalized near the end of life,' *Journal of the American Medical Association*, published online 16 February 2020. Full text: <http://bit.ly/2vBe6RX>

OP-Ed: Think you want to die at home? You might want to think twice about that

CALIFORNIA | *The Los Angeles Times* – 16 February 2020 – Nathan Gray, an assistant professor of medicine and palliative care at Duke University School of Medicine collaborated with an artist who draws comics on medical topics to “illustrate” Dr. Gray’s perspective on dying at home.

Many are trying to determine how we can save costs in medicine, but when we send people home to crisis, we're not necessarily saving costs; often we're simply shifting them from hospitals and insurers onto the backs of struggling families – families that will lose wages, spend their savings and risk their own health to provide care.



Download/view at: <https://lat.ms/2SSRjsG>

Related:

- *THE WASHINGTON POST* | Online – 16 February 2020 – **'Many Americans say they want to die at home. It's not always easy to make that happen.'** More Americans are dying at home than in the hospital or a nursing home.¹ This finding ... is encouraging because the vast majority of Americans say they prefer to die at home. So this reflects that many more people are being able to achieve that goal. But as more people die at home, it also means that much more responsibility falls on the shoulders of patients and their caregivers. Caregiver burden is a growing problem in America. As a doctor tending patients with heart failure, I am keenly aware of how hard managing care can be for both patients and family members. <https://wapo.st/2HpW5J5>

1. 'Changes in the Place of Death in the U.S.,' *The New England Journal of Medicine*, 2019;381(24): 2369-2370. [Noted in 16 December 2019 issue of Media Watch (#644, p.2)] Summary: <http://bit.ly/35fibfL>

Cont.

Noted in Media Watch 10 February 2020 (#652, p.9):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 1 February 2020 – ‘**The lived experiences of family caregivers of persons dying in home hospice: Support, advocacy, and information urgently needed.**’ Death in America is changing from hospital to home, which demands complex skills by family caregivers (FCGs). However, information from family members about the challenges of providing home hospice care until death is scant. To understand the challenges a family caregiver confronts when he/she decides to deliver hospice care and during the actual delivery of the hospice care, the authors used descriptive phenomenology methods to document the experience of 18 FCGs as they delivered home hospice care. **Abstract:** <http://bit.ly/2v64Pkp>

Noted in Media Watch 27 January 2020 (#650, p.2):

- NATIONAL PUBLIC RADIO | Online – 21 January 2020 – ‘**Patients want to die at home, but home hospice care can be tough on families.**’ According to a recent Kaiser Family Foundation poll, 7 in 10 Americans say they would prefer to die at home, when the time comes.¹ And that’s the direction the healthcare system is moving, too, hoping to avoid unnecessary and expensive treatment at the end of life. Still, when it comes to where we die, the U.S. has reached a tipping point. Home is now the most common place of death, according to new research,² and a majority of Medicare patients are now turning to hospice services to help make that possible.³ Fewer Americans these days are dying in a hospital, under the close supervision of doctors and nurses. <https://n.pr/37h5Oqa>
 1. ‘Kaiser/Economist survey highlights Americans’ views and experiences with end-of-life care, with comparisons to residents of Italy, Japan and Brazil,’ *Kaiser Health News*, published online 27 April 2017. [Noted in 1 May 2017 issue of Media Watch (#510, p.3)] <http://bit.ly/2v1pINJ>
 2. ‘Changes in the Place of Death in the U.S.,’ *The New England Journal of Medicine*, 2019;381(24): 2369-2370. [Noted in 16 December 2019 issue of Media Watch (#644, p.2)] **Summary:** <http://bit.ly/35fibfL>
 3. ‘Site of death, place of care, and healthcare transitions among U.S. Medicare beneficiaries, 2000-2015,’ *Journal of the American Medical Association*, published online 25 June 2018. [Noted in 2 July issue of Media Watch (#570, p.4)] **Full text:** <http://bit.ly/2TJJIPu>

Noted in Media Watch 5 November 2018 (#588, p.8):

- *JOURNAL OF HOUSING FOR THE ELDERLY* | Online – 25 October 2018 – ‘**The motivations and consequences of dying at home: Family caregiver perspectives.**’ Five family caregivers participated in semi-structured interviews about their experiences witnessing and supporting the end-of-life process of an older family member who died at home. Their stories paint a vivid picture about the motivations and consequences of the experience, including themes such as caregivers’ immense feelings of uncertainty regarding their caregiving abilities and decision-making, the significance of the home environment as a symbol of comfort and security, the influence of family and social networks, and “dying well” as a social justice issue. **Abstract:** <http://bit.ly/2UrFwVh>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Victoria) | ABC News (Melbourne) – 19 February 2020 – ‘**More than 130 Victorians apply to end their lives in first six months of state’s assisted dying laws.**’ More than 50 Victorians legally ended their own lives in the first six months of the state’s voluntary assisted dying laws – far more than the State Government expected. A new report into the laws, which were introduced in Victoria in June last year, revealed that of the 136 people who applied to end their life, 43 self-administered the medication while nine had their doctor administer the drugs. Nineteen applications for voluntary assisted dying were withdrawn because of administrative errors or the applicants died by other means. Voluntary Assisted Dying Review board chairwoman Betty King said the rest of the applications were rejected for a range of reasons, including applicants not being Australian citizens. Victoria was the first state in Australia to legalise voluntary assisted dying, and Western Australia passed its laws in December last year. <https://ab.co/2vKdjhE>

International

Most adults have never considered where they want to be cared for

IRELAND | *The Irish Times* (Dublin) – 17 February 2020 – Eighty per cent of adults have not thought or talked about where they would like to be cared for if they became seriously ill or frail, according to new research launched by Safeguarding Ireland. Just 5% have documented what their place of care preferences are. The research ... found that 21% of adults had personally considered where their preferred place of care would be if they were seriously ill or nearing death. Just 17% had discussed with a family member or other trusted person and only 5% had documented their preference. Around 70% are confused about decision-making and consent protocols when caring for a seriously ill or frail older person. Consideration of place of care was higher among older adults (65+), but still just 43% had considered it, 35% had discussed it and 9% had documented their wishes. When asked if a family member has authority to make decisions for someone who is frail but still has decision-making capacity without their consent,

30% said that yes the family member does have this authority, 28% did not know, and just 40% recognised that the decision continues to lie fully with the person as long as they have decision-making capacity. <http://bit.ly/2SB500L>

Specialist Publications

'Communicating about death and dying with adults with intellectual disabilities who are terminally ill or bereaved: A U.K.-wide survey of intellectual disability support staff' (p.8), in *Journal of Applied Research in Intellectual Disabilities*.

'The global nursing workforce: Realising universal palliative care' (p.11), in *The Lancet: Global Health*.

'Strengths of the French end-of-life law as well as its shortcomings in handling intractable disputes between physicians and families' (p.12), in *The New Bioethics*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | The Royal College of General Practitioners – 21 February 2020 – **'The Royal College of GPs remains opposed to change in the law on assisted dying.'** The College will continue to oppose a change in the law on assisted dying, following a consultation of its members. The decision was ratified by the College's governing council. 6,674 members from across the U.K. responded to an online survey – 13.47% of those consulted: 47% of respondents said that the College should oppose a change in the law on assisted dying; 40% of respondents said the College should support a change in the law on assisted dying, providing there is a regulatory framework and appropriate safeguarding processes in place; 11% of respondents said that the College should have a neutral position; and, 2% of respondents abstained from answering. <http://bit.ly/39RbbTT>

Noted in Media Watch 10 February 2020 (#652, p.14):

- *PULSE* | Online – 6 February 2020 – **'British Medical Association launches first-ever survey of doctors' views on assisted suicide.'** Currently, the association's position is to oppose all forms of physician-assisted suicide... Members will be asked: 1) Whether they believe the association should support, oppose, or take a neutral stance on a change in the law to permit doctors to prescribe drugs for eligible patients to end their own life; 2) About a stance to a change in the law to permit doctors to administer drugs with the intention of ending an eligible patient's life; and, 3) Their personal opinions, the reasons behind them, and about how the association should respond in the event of any future proposals to change the law. **Full text:** <http://bit.ly/39h9vmG>
- PORTUGAL | Reuters (Lisbon – 20 February 2020 – **'Pro-euthanasia bills get green light in Portugal, negotiations ahead.'** The decriminalization of euthanasia and assisted suicide is a step closer to becoming a reality in Portugal after lawmakers approved a set of bills, a move applauded by many but opposed by religious groups and conservatives. One by one, lawmakers in the 230-seat parliament were called to cast their votes on five proposals made by five political parties, including the ruling Socialists, to legalise the practices in certain cases and under strict rules. All five proposals were approved, with the Socialists receiving 127 votes in favour and the Left Bloc's bill getting the green light from 124 lawmakers. <https://reut.rs/2VansyP>

Specialist Publications

The influence of spirituality on decision-making in palliative care outpatients: A cross-sectional study

BMC PALLIATIVE CARE | Online – 21 February 2020 – Spiritual wellbeing significantly correlated with greater levels of physical, emotional and functional wellbeing and a better quality of life. Greater spiritual wellbeing was associated with less decisional conflict, decreased uncertainty, a feeling of being more informed and supported and greater satisfaction with one's decision. Most patients successfully implemented their decision and identified themselves as capable of early decision-making. Patients who were able to implement their decision presented lower decisional conflict and higher levels of spiritual wellbeing and quality of life. Within the 16 themes identified, spirituality was mostly described through family. Patients who had received spiritual care displayed better scores of spiritual wellbeing, quality of life and exhibited less decisional conflict. Patients considered spirituality during illness important and believed that the need to receive spiritual support and specialised care could enable decision-making when taking into consideration one's values and beliefs. **Full text (w. link to reviewers' comments):** <http://bit.ly/2VcoTNb>

End-of-life care in general practice: Clinic-based data collection

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 17 February 2020 – There are no processes that routinely assess end-of-life care (EoLC) in Australian general practice. This study aimed to develop a data collection process which could collect observational data on EoLC from Australian general practitioners (GPs) via a questionnaire and clinical data from general practice software. The developed data collection process consisted of three questionnaires: 1) Basic practice descriptors (32 items); 2) Clinical data query (32 items); and, 3) GP-completed questionnaire (21 items). Data extraction from general practice software was performed for 97 decedents of 10 GPs and gathered data on prescriptions, investigations and referral patterns. Reports on care of 272 decedents were provided by 63 GPs. The GP-completed questionnaire achieved a satisfactory level of validity and reliability. The data collection process developed and tested in this study is feasible and acceptable for Australian GPs, and comprehensively covers the major components of EoLC. Future studies could develop an automated data extraction tool to reduce the time and recall burden for GPs. These findings will help build a nationwide integrated information network for primary EoLC in Australia.



THE UNIVERSITY OF
**WESTERN
AUSTRALIA**

Abstract: <http://bit.ly/38FkciX>

N.B. Selected articles on the role of GPs in palliative care noted in November 2020 issue of the newsletter of the International Association for Hospice & Palliative Care (scroll down to 'Media Watch: GPs & Quality Care'): <http://bit.ly/2NqALqN>

Advance care planning and palliative care in adult congenital heart disease: The healthcare providers' perspective

CARDIOLOGY IN THE YOUNG | Online – 14 February 2020 – Advance care planning (ACP) and palliative care (PC) are gaining recognition as critical care components for adults with congenital heart disease (CHD), yet these often do not occur. Survey respondents reported low levels of personal PC knowledge, without variation by gender, years in practice, or prior PC training. Providers appeared more comfortable managing physical symptoms and discussing prognosis than addressing psychosocial needs. Providers recognised advance directives (ADs) as important, although the percentage who would initiate ACP ranged from 18-67% and referral to PC from 14-32%. Barriers and facilitators to discussing ACP with patients were identified. Over 20% indicated that ACP and end-of-life discussions are best initiated with the development of at least one life-threatening complication/hospitalisation. Providers noted high value in ADs yet were themselves less likely to initiate ACP or refer to PC. This raises the critical questions of when, how, and by whom discussion of these important matters should be initiated and how best to support adult CHD providers in these endeavours. **Abstract (w. list of references):** <http://bit.ly/2UZAhmK>

Cont.

Noted in Media Watch 16 December 2019 (#644, p.10):

- *CANADIAN JOURNAL OF CARDIOLOGY*, 2019;35(12):1723-1739. ‘**Heart failure in adult congenital heart disease: From advanced therapies to end-of-life care.**’ There is mounting recognition that some of the most urgent problems of adult congenital heart disease (ACHD) are the prevention, diagnosis, and management of heart failure (HF). Recent expert consensus and position statements not only emphasize a specific and pressing need to tackle HF in ACHD, but also highlight the difficulty of doing so given a current sparsity of data. Some of the challenges are addressed by this review. In the authors’ approach, advanced care planning and palliative care coexist with the consideration of advanced therapies. **Full text:** <http://bit.ly/356tUsF>

Resolving anticipatory grief and enhancing dignity at the end-of life: A systematic review of palliative interventions

DEATH STUDIES | Online – 19 February 2020 – Anticipatory grief is the experience of grief symptomatology prior to loss. This study is a systematic review of empirical interventions or interventional components that were observed to lessen or adaptively direct the experience of anticipatory grief for patients at the end of life and their family members. A search of 5 major databases found 13,718 articles, of which 10 high-quality randomized controlled trials were included for final review. Lebow’s “adaptational tasks of anticipatory mourning” was employed as a working model on the efficacy of the interventions. The interventions exhibited some positive outcomes, but none addressed anticipatory grief directly. Recommendations for future research are discussed. **Abstract:** <http://bit.ly/2uW0wZA>

Noted in Media Watch 23 September 2019 (#632, p.15):

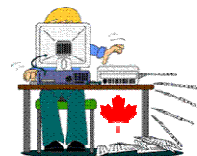
- *QUALITATIVE HEALTH RESEARCH* | Online – 16 September 2019 – ‘**Family caregivers’ anticipatory grief: A conceptual framework for understanding its multiple challenges.**’ Anticipatory grief (AG) lacks conceptual clarification. Findings from this study suggest that the AG experience is characterized by traumatic distress from being exposed to life-threatening conditions and the separation distress induced by loss anticipation and current relational losses, challenging the family caregivers (FCGs) to long-term emotional regulation effort demands. These results contribute to the conceptualization of AG and may inform intervention programs for the main challenges the FCGs face when adjusting to loss during EoL caregiving. **Abstract (w. list of references):** <http://bit.ly/2kualPw>

The grief and communication family support intervention: Intervention fidelity, participant experiences, and potential outcomes

DEATH STUDIES | Online – 19 February 2020 – This pilot study showed evidence that the Grief & Communication Family Support Intervention had high levels of fidelity, which enhances the internal validity of the intervention. Communication is considered to be a protective factor for parentally bereaved children’s psychological health. The length of the intervention, three sessions, appeared to be adequate and acceptable to participants. Furthermore, these three sessions led to reported improvements in communication and family relationships, which supports previous findings that brief interventions may be effective with parentally bereaved families. Participants reported that they learned new communications skills such as “I” messages, active listening, and openness in talking about feelings. In providing preliminary evidence for improving family communication and relationships in parentally bereaved families, the Grief & Communication Family Support Intervention may be a possible solution to the lack of bereavement and grief support interventions in Sweden. **Full text:** <http://bit.ly/2Pcfdl>

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>



Married just in time: Deathbed weddings, meaning and magic

INTERNATIONAL JOURNAL OF WHOLE PERSON CARE, 2020;7(1):5-6. Brave conversations in hospital, often facilitated by the palliative care team (PC), lead to a discovery of what really matters if time is short. Getting married turned out to be high on the agenda for many couples where one partner is facing mortality. There has been little exploration of romance and marriage in the context of advanced illness. Seven deathbed weddings in a tertiary cancer centre were analysed. These had taken place over a period of 2 years. Initial conversations, subsequent arrangements, the impact on the couple, and the subsequent reactions in bereavement were explored. Demographics, illness details, reasons for the marriage and logistics of the wedding were recorded. Bereaved spouses were subsequently interviewed about the meaning of the wedding. 6/7 weddings were identified as “goals” by the PC team. Momentous celebrations distracted patients, relatives and healthcare team from the daily tragedy they were immersed in. The focus became one of healing not curing. Teams were uplifted, symptoms improved. The stories reinforced the idea that self-esteem and need for connection are dominant forces even in the face of death. **Abstract:** <http://bit.ly/38ILyot>

Association between palliative care and death at home in adults with heart failure

JOURNAL OF THE AMERICAN HEART ASSOCIATION | Online – 19 February 2020 – This study of 74,986 community-dwelling adults who died with heart failure (HF) found that almost three quarters (75.4%) died in a hospital. Overall, 35,292 (47.1%) people received palliative care (PC) in the last 2 years of life, and PC was associated with a 2-fold increase in the odds of death at home compared with people who did not receive it. Among patients receiving PC, non-specialist PC physicians led its delivery 61.0% of the time. A generalist model of care was most often used (55.1% of patients), and PC was provided to 53.4% of patients in multiple locations. These findings support the authors’ hypothesis that PC in patients with HF is associated with death at home, a recognized indicator of high-quality end-of-life care (EoLC). Their findings have significant implications for the delivery of PC to people with non-cancer illnesses such as HF. The proportion of adults dying with HF who receive PC is half of that for those dying with cancer (88%). Prior research showed that 20% to 45% of patients died in an acute-care setting, a number that is substantially lower than the 75.4% of people in this study who died in a hospital with HF. These findings identify an opportunity to improve EoLC for patients with HF because most people report a preference for death at home. **Full text:** <http://bit.ly/2HGdKwa>

N.B. Additional articles on PC in HF noted in 13 January 2020 issue of Media Watch (#648, pp.9-10).

Physician Orders for Life-Sustaining Treatment and limiting overtreatment at the end of life

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 16 February 2020 – Lee and colleagues examine the association between Physician Orders for Life-Sustaining Treatment (POLST), which involve portable medical orders that document treatment limitations for out-of-hospital emergency care and for limiting overtreatment at the end of life (EoL).¹ The authors studied adults with chronic life-limiting illnesses who were hospitalized within the last 6 months of life and who had completed a POLST before their last inpatient admission. Among 1,818 patients enrolled, 656 (36%) had POLST orders for “full treatment” and 1,162 had orders for either “limited additional interventions” (42%) or “comfort measures only” (22%). Among the combined latter 2 groups, 472 (41%) were admitted to the intensive care unit (ICU), 436 (38%) received POLST-discordant intensive care, and 204 (18%) received POLST-discordant life-sustaining treatments, defined as mechanical ventilation, vasoactive infusions, new renal replacement therapy, or cardiopulmonary resuscitation. Patients with cancer or dementia were less likely to receive POLST-discordant intensive care, whereas patients hospitalized for traumatic injuries were more likely to receive POLST-discordant intensive care. These results are sobering. The authors conclude that patients with treatment-limiting POLSTs hospitalized near the EoL often receive care that seems inconsistent with their preferences. **Full text:** <http://bit.ly/322gcGB>

1. ‘Association of Physician Orders for Life-Sustaining Treatment with ICU admissions among patients hospitalized near the end of life,’ *Journal of the American Medical Association*, published online 16 February 2020. **Full text:** <http://bit.ly/2vBe6RX>

Communicating about death and dying with adults with intellectual disabilities who are terminally ill or bereaved: A U.K.-wide survey of intellectual disability support staff

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Online – 19 February 2020 – Illness and death are part of life for everyone, including people with intellectual disabilities. This study investigated the extent to which staff communicate about death with people with intellectual disability facing terminal illness or bereavement. 52.6% of people with intellectual disability who were terminally ill were told about their illness, and 18.1% were told they would die. Of those experiencing an anticipated bereavement, 32.4% of staff said no one talked about this with them beforehand. A quarter of staff had received training on end of life or bereavement. Staff require training and support in communicating death.

Abstract: <http://bit.ly/38KREVG>

N.B. See 'Current thinking on palliative and end-of-life care for patients living with intellectual and developmental disabilities,' European Association for Palliative Care blog: <http://bit.ly/300WMRT>

Bereaved families' perspectives of end-of-life care. Towards a bicultural *Whare Tapa Whā* older person's palliative care model

JOURNAL OF CROSS-CULTURAL GERONTOLOGY | Online – 20 February 2020 – The authors conducted a bicultural study with bereaved New Zealand Māori (indigenous) and non-indigenous family carers who, on behalf of their older family member, reflected on the end of life (EoL) circumstances and formal and informal care experienced by the older person. Interviews were undertaken with 58 people (19 Māori and 39 non-Māori), who cared for 52 family members who died aged over 80 years. A Kaupapa Māori thematic analysis of family/whānau perspectives identified examples of good holistic care as well as barriers to good care. These are presented in a proposed Whare Tapa Whā Older Person's Palliative Care model. Good healthcare was regarded by participants as that which was profoundly relationship-oriented and upheld the older person's mana (authority, status, spiritual power) across four

critical health domains: Whānau (social/family), Hinengaro (emotional/mental), Wairua (spiritual) and Tinana (physical) health domains. However, poor healthcare on one level impacted on all four domains affecting (reducing) mana (status). The "indigenous" model was applicable to both indigenous and non-indigenous experiences of EoL care for those in advanced age. Thus, Indigenous perspectives could potentially guide and inform EoL care for all. **Abstract (w. list of references):** <http://bit.ly/38YR8Tg>

Whare Tapa Whā

....is a well-known Māori model of health that has been used across a variety of sectors (i.e., health, education, justice). Te Whare Tapa Whā compares health to the four walls of a house where all four walls are necessary to ensure strength and symmetry.

N.B. Additional articles on Māori beliefs and practices in the context of end of life and end-of-life care noted in 27 January 2020 issue of Media Watch (#650, p.11).

Related:

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 20 February 2020 – '**Cross-cultural experiences of hospice and palliative care services: A thematic analysis.**' This study reviews the literature on the experiences of patients from non-Western and minority cultural backgrounds in hospice and palliative care (PC) services to inform clinical practice by Western providers. The key themes identified include: communication and flow of information, perceptions of hospice and PC, and compatibility with cultural beliefs. This review demonstrates similar themes across many non-Western and minority cultures interacting with hospice and PC services. These findings emphasize the importance of a cross-cultural approach in a PC and hospice setting. **Abstract (w. list of references):** <http://bit.ly/38WjLAE>



Would the articles above be of interest to a colleague?

After an end-of-life decision: Parents' reflections on living with an end-of-life decision for their child

JOURNAL OF PAEDIATRICS & CHILD HEALTH | Online – 19 February 2020 – Parents' role as end-of-life decision-makers for their child has become largely accepted Western healthcare practice. How parents subsequently view and live with the end-of-life decision (ELD) they made has not been extensively examined. To help extend understanding of this phenomenon and contribute to care, as a part of a study on end-of-life decision-making, bereaved parents were asked about the aftermath of their decision-making. Twenty-five bereaved parents participated. Results indicate that parents hold multi-faceted views about their decision-making experiences. An ELD was viewed as weighty in nature, with decisions judged against the circumstances that the child and parents found themselves in. Despite the weightiness, parents reflected positively on their decisions, regarding themselves as making the right decision. Consequently, parents' comments demonstrated being able to live with their decision. When expressed, regret related to needing an ELD, rather than the actual decision. The few parents who did not perceive themselves as their child's decision-maker subsequently articulated negative reactions. Enduring concerns held by some parents mostly related to non-decisional matters, such as the child's suffering or not knowing the cause of death. **Abstract:** <http://bit.ly/2SJYXql>



Noted in Media Watch 20 May 2019 (#614, p.9):

- *BMJ OPEN* | Online – 9 May 2019 – '**Parental experiences of end-of-life care decision-making for children with life-limiting conditions in the paediatric intensive care unit: A qualitative interview study.**' This study adds to the limited evidence base related to parental experiences of end-of-life care (EoLC) decision-making and provides findings that have international relevance, particularly related to place of care and introduction of EoLC discussions. The expertise and previous experience of parents is highly relevant and should be acknowledged. EoLC decision-making is a complex and nuanced process; the information needs and preferences of each family are individual and need to be understood by the professionals involved in their care. **Full text:** <http://bit.ly/2W0cKvs>

Theory-based development of an implementation intervention utilizing community health workers to increase palliative care use

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 21 February 2020 – Opportunities for the use of palliative care (PC) services are missed in African American communities, despite evidence demonstrating their benefits. Target behaviors identified were for patients to gain knowledge about benefits of PC, physicians to begin PC discussions earlier in treatment, and to improve patient-physician interpersonal communication. The intervention was designed to improve patient capability, physician capability, patient motivation, physician motivation, and increase patient opportunities to use PC services. Strategies to change patient and physician behaviors were all facilitated by community health workers and included: creation and dissemination of brochures about PC to patients, empowerment and activation of patients to initiate goals of care discussions, outreach to community churches, and expanding patient social support. **Abstract (w. link to references):** <http://bit.ly/2uloRYh>

Noted in Media Watch 17 December 2018 (#594, p.9):

- *JOURNAL OF PALLIATIVE CARE* | Online – 12 December 2018 – '**Engaging the African American church to improve communication about palliative care and hospice: Lessons from a multi-level approach.**' The authors' primary goal was to encourage churches to embrace palliative care and hospice (PCH) as acceptable alternatives for end-of-life care by creating venues to improve communications about PCH. This article compares their experience in five churches [in the Philadelphia region of Pennsylvania], revealing lessons learned and the challenges of engaging, implementing, and maintaining a multilevel approach in the churches, and the authors' strategies in response to those challenges. **Abstract (w. list of references):** <https://goo.gl/Y1ebhk>

Engaging specialist palliative care in the management of amyotrophic lateral sclerosis: A patient-, family-, and provider-based approach

JOURNAL OF PALLIATIVE CARE | Online – 17 February 2020 – Stakeholders' [i.e., study participants] general impressions of specialist palliative care (PC) are highly variable. Many expressed limited or inaccurate understandings of PC's definition and purpose. Perceptions of PC as hospice were common. Stakeholders generally supported the integration of specialist PC into amyotrophic lateral sclerosis (ALS) management, and many recognized the value of early integration of palliative services in both the community and the clinical setting. Key stakeholders readily identified a meaningful role for specialist PC in ALS management. Integration of specialist PC into existing systems of support would be facilitated by a more comprehensive understanding of the service among patients, family caregivers, and healthcare providers. **Abstract (w. list of references):** <http://bit.ly/3bGBi1E>

Noted in Media Watch 4 November 2019 (#638, p.17):

- *NEUROLOGY* | Online – 31 October 2019 – ‘**Dying of amyotrophic lateral sclerosis: Healthcare use and cost in the last year of life.**’ In this large population-based cohort of decedents living in Ontario, Canada, individuals living with amyotrophic lateral sclerosis (ALS) spent three times as many days in the intensive care unit, twice as many days using complex continuing care, received more community-based services, and incurred higher costs of care in the last year of life. A greater percentage of decedents with ALS received palliative home care and palliative physician home visits than decedents without ALS. Mean cost of care in the last year of life was greater for those with ALS (\$68,311.98 vs. \$55,773.48). **Abstract:** <http://bit.ly/34nRBMn>

N.B. Additional articles on PC for people living with ALS noted in 10 June 2019 issue of Media Watch (#617, p.12).

Surgery residents' experiences with seriously-ill and dying patients: An opportunity to improve palliative and end-of-life care

JOURNAL OF SURGICAL EDUCATION | Online – 14 February 2020 – General surgery residents across the state of Michigan. All residents in participating programs were invited to complete the survey in Phase I. Phase II consisted of a sub-set of the survey respondents who underwent semi-structured interviews. Among 119 survey respondents (response rate 70%), all had encountered a palliative care (PC) specialist, but only 58.8% had been taught when to consult or to refer to PC. Survey respondents reported on a multitude of barriers within the clinician, patient and family, and systemic domains. Interviews expanded on survey findings and 4 influential factors of PC delivery emerged: 1) Resident education and training; 2) Resident attitudes toward PC; 3) Knowledge of PC; and, 4) Training within a surgical culture. This study reveals how surgery resident training and experiences impact palliative and end-of-life (EoL) care for surgical patients at teaching institutions. Knowledge of how and when residents are providing primary PC and engaging with PC services will inform future knowledge and behavioral interventions for trainees who often provide care for patients nearing the EoL. **Abstract:** <http://bit.ly/2vG9IXk>

Noted in Media Watch 6 January 2020 (#647, p.8):

- *JAMA SURGERY* | Online – 2 January 2020 – ‘**Palliative care and end-of-life outcomes following high-risk surgery.**’ In this cross-sectional, multi-center study in the U.S., researchers using the Bereaved Family Survey, receipt of a palliative consultation was associated with better ratings of overall end-of-life care, communication, and support, as reported by families of patients who died within 90 days of high-risk surgery. Despite this, palliative care (PC) was not commonly used in a national cohort of patients undergoing high-risk operations; only one-third of decedents was exposed to PC. Expanding integration of perioperative PC may benefit patients undergoing high-risk operations and their families. **Abstract:** <http://bit.ly/36oVrGr>



Closing the Gap Between Knowledge & Technology
<http://bit.ly/2DANDFB>

The global nursing workforce: Realising universal palliative care

THE LANCET: GLOBAL HEALTH, 2020;8(3):E327-E328. The purpose herein is to identify how global healthcare systems can encourage the nursing workforce to implement the recommendations of The Lancet Commission and WHO guidance on palliative care (PC).^{1,2} Specifically, the skill set, experience, and perspectives of nurses are crucial to optimum PC policy development, strategic planning, service implementation, and research. The vision of WHO's Global Strategic Directions for Strengthening Nursing & Midwifery is "accessible, available, acceptable, quality and cost-effective nursing and midwifery care for all, based on population needs, in support of universal health coverage and the sustainable development goals." This vision indicates the indispensability of nursing to PC, especially in low-income and middle-income countries where this care is less accessible. WHO's declaration of the International Year of the Nurse & Midwife makes 2020 the ideal time to promote nursing contributions to PC policy, training, and services in low-income and middle-income countries. **Full text:** <http://bit.ly/32eE3D2>

1. 'Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,' *The Lancet*, October 2017. [Noted in 16 October 2017 issue of Media Watch (#534, p.14)] **Full text:** <http://bit.ly/2Ww8Cku>
2. 'Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers,' World Health Organization, 2018. **Download/view at:** <http://bit.ly/2Vbo7Ql>

Noted in Media Watch 10 February 2020 (#652, p.10):

- *PALLIATIVE MEDICINE* | Online – 2 February 2020 – '**Valuing palliative care nursing and extending the reach.**' It is estimated that 48 million people will die annually by 2060 with serious health-related suffering. Those affected are more likely to be: living in low- and middle-income countries (83%), older people, and people living with dementia. These statistics demand immediate global action to fully integrate palliative and end-of-life care into health systems, including a greater investment in ensuring the delivery of exemplary nursing care. As a result of these epidemiological and social changes, a large number of the world's 20 million nurses will be increasingly called upon to care for the millions of people in need of palliative care. **Full text:** <http://bit.ly/2UnJULl>

Noted in Media Watch 4 November 2019 (#638, p.17):

- *PALLIATIVE MEDICINE* | Online – 29 October 2019 – "'I'm going to push this door open. You can close it.": **A qualitative study of the brokering work of oncology clinic nurses in introducing early palliative care.**' Brokering PC represented the overarching concept of this study that linked other sub-categories: 1) Opening the door – creating the possibility of discussing early PC at a time when patients show signs of being receptive to this discussion; 2) Building trust – establishing relationships with patients as a starting point for open discussions about PC; 3) Tackling misconceptions – addressing patients' assumptions about PC as signifying death; and, 4) Advocating with oncologists – seeding the process of referral by bringing patients' concerns forward. **Abstract:** <http://bit.ly/2MYect7>

N.B. The author of this article discusses the background to this study on the European Association for Palliative Care blog at: <http://bit.ly/2T5aRdE>

"We come in as 'the nothing'": Researching non-intervention in palliative care

MEDICINE, ANTHROPOLOGY, THEORY | In Press – Accessed 16 February 2020 – This ethnographic study about palliative care in a U.K. medical setting and instances when medical staff do not do something that we have called "non-intervention," raised an obvious question: "How does one study something that is not happening?" In this think piece, the authors outline three ways in which they have tried to engage with this methodological question – from the initial grant application process to the point the authors are at now: first, a somewhat positivist approach, which allowed the authors to delineate the phenomenon of their study; second, a following technique, adopted to understand non-interventions as and when they are conceived of by their informants; and, a third approach to try and "trace enactments of non-doing" by

Cont.

mapping the range of different practices, and understanding how not doing invariably occurs alongside other forms of doing. The authors describe what these approaches have taught so far, and reflect on the limits of each. They do so in the hope to provide others with starting points for studying nothings, not-doings and absences. **Abstract:** <http://bit.ly/2vHzGEf>

Strengths of the French end-of-life law as well as its shortcomings in handling intractable disputes between physicians and families

THE NEW BIOETHICS | Online – 16 February 2020 – French end-of-life (EoL) law aims at protecting patients from unreasonable treatments, but has been used to force caregivers to prolong treatments deemed unreasonable. The authors describe six cases (5 intensive care unit patients including 2 children) where families disagreed with a decision to withdraw treatments and sued medical teams. An emergent inquiry was instigated by the families. In two cases, the court rejected the families' inquiries. In two cases, the families appealed the decision, and in both the first jurisdiction decision was confirmed, compelling caregivers to pursue treatments, even though they deemed them unreasonable. The authors discuss how this law may be perverted. Legal procedures may result in the units' disorganisation and give rise to caregivers' stress. Families' requests may be subtended by religious beliefs. French EoL law has benefits in theoretically constraining physicians to withhold or withdraw disproportionate therapies. These cases underline some caveats and the perverse effects of its literal reading. **Abstract:** <http://bit.ly/2vGU6xi>

N.B. Additional articles on patient rights and the doctor obligations under France's Claeys-Leonetti Law noted in 30 September 2019 issue of Media Watch (#633, p.12).

Dying with dementia: Caregiver observations of their family members' physical decline and behavioral or psychological changes during their last days

OMEGA – JOURNAL OF DEATH & DYING | Online – 20 February 2020 – Family caregivers (FCG) of older persons with dementia have significant challenges across many domains. These reported problems encountered over their caregiving time are for many reasons, but what makes the caretaking difficult is complicated by both the unknown nature of the dementia disease and the dying trajectory. While there are studies, primarily from healthcare professionals, of this dying process and the last few weeks of life for older persons with dementia, much less is known directly from the FCG's perspectives and experiences. This qualitative study of 30 caregivers of family members aged 65 years and older who died with dementia-related diagnoses used in-depth qualitative interviews conducted over a 12-month period and directed content analysis to understand the data. The study asked what physical, behavioral, and psychological changes they observed and experienced during their family members' last weeks of life. Three primary themes were identified around behavioral and psychological changes: 1) They become different people; 2) Did not recognize caregiver; and 3) Wandering and getting lost. Implications for families and professionals are reviewed and discussed. **Abstract (w. list of references):** <http://bit.ly/2VacSrA>

Challenging the status quo of physician attire in the palliative care setting

THE ONCOLOGIST | Online – 19 February 2020 – In this randomized controlled trial, doctors' attire did not affect the perceptions of patients with cancer of physician's level of compassion and professionalism, nor did it influence the patients' preference for their doctor or their trust and confidence in the doctor's ability to provide care. The significance of physician attire as a means of non-verbal communication has not been well characterized. It is an important element to consider, as patient preferences vary geographically, are influenced by cultural beliefs, and may vary based on particular care settings. Previous studies consisted of non-blinded surveys and found increasing confidence in physicians wearing a professional white coat. **Abstract:** <http://bit.ly/2HHYv5L>

Understanding usual care in randomised controlled trials of complex interventions: A multi-method approach

PALLIATIVE MEDICINE | Online – 21 February 2020 – The authors demonstrate that it is feasible and advantageous to use a multi-method approach to explore usual care in randomized controlled trials (RCTs) of complex interventions for patients nearing the end of life. They highlight embedded practices and knowledge, and variability in the usual care depending on healthcare professionals' skills, patient disease groups and contextual factors. This study makes a methodological contribution to the research field by providing a practical and feasible approach for describing usual care. While there has been a growth in the number of studies that have evaluated complex interventions, to date, there has been a lack of agreement on how usual care can be defined. The authors address this concern. To optimise the design of RCTs and improve evidence-based practice, future studies should adopt and develop the proposed multi-method approach in different settings. Within the context of limited funding opportunities for experimental studies, researchers conducting RCTs of complex interventions should aim to fully understand, and provide a definition of, the usual care. This would provide greater confidence in the study findings. Understanding usual care can strengthen the reliability of complex interventions tested in RCTs and accordingly set research funding and policy priorities. **Full text:** <http://bit.ly/2PjzT4>

"It's not what they were expecting": A systematic review and narrative synthesis of the role and experience of the hospital palliative care volunteer

PALLIATIVE MEDICINE | Online – 17 February 2020 – This review has identified that the role of hospital palliative care (PC) volunteers is uniquely different to other hospice and PC settings due to the short or once-off nature of interactions with terminally ill patients. The volume of research evidence in the included studies that describe volunteers' actions of "being with" terminally ill patients highlights not only the importance of this aspect of volunteer work but also exemplifies the aspects of volunteers' role they found most satisfying. Ideally, the patient-volunteer relationship would be determined as a result of a process of specifically matching volunteers to patients according to measures of personal compatibility and consideration of relational chemistry. But in the hospital setting, the rapid patient turnover associated with hospitals and limited time volunteers have with each patient and shift, means the opportunity to build relationships with patients, founded upon ongoing and close contact like in other PC settings is likely not possible. Even so, providing one-off or short-term support to a terminally ill patient is likely better than no support at all. The review identified a lack of clarity about the volunteer's role in inpatient hospital settings; and whether volunteers were part of, or complementary to the healthcare team. **Full text:** <http://bit.ly/2vFhE5E>

Noted in Media Watch 10 December 2018 (#593, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 7 December 2018 – '**The liminal space palliative care volunteers occupy and their roles within it: A qualitative study.**' Volunteers have an important place in palliative care (PC), positively influencing quality of care for seriously ill people and those close to them and providing a link to the community. However, it is not well understood where volunteers fit into PC provision or how to support them adequately. The authors describe volunteer roles across care settings through the perspective of those closely involved in the care of terminally ill people. Two volunteer roles were identified. The first was "being there" for the dying person. The second was the "liaison" role. **Abstract:** <http://bit.ly/2XEMioy>

Case series of introducing palliative care consultation in psychiatry

PALLIATIVE MEDICINE | Online – 17 February 2020 – The author analyzes the introduction of palliative care (PC) consultation in a large psychiatric hospital. PC consultation was established and details including patient age, department, diagnosis, main problem, solution and discharge were analysed during the first two years. Two consultations in the first year and 18 consultations in the second year were requested ... involving two domains: delirium associated with dementia or another condition (75%) and mental illness (e.g., alcoholic psycho-syndrome, psychosis, suicidal tendency, schizophrenia, depression), and cancer (25%). Recommendations of consultations were realized in 95%. Implementation of PC consulta-

Cont.

tion in psychiatry is one possible method of how to introduce PC in a field of medicine with lack of PC. Future research should focus on reasons for reservations about PC in psychiatry, include more patients with severe persistent mental illness and assess the value of PC consultation in resolving this problem. **Abstract (w. list of references):** <http://bit.ly/38BEWln>

Noted in Media Watch 20 January 2020 (#649, p.7):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 January 2020 – ‘**Mental healthcare and palliative care: Barriers.**’ Psychological symptoms are common among palliative care (PC) patients with advanced illness, and their effect on quality of life can be as significant as physical illness. The demand to address these issues in PC is evident, yet barriers exist to adequately meet patients’ psychological needs. This article provides an overview of mental health issues encountered in PC, highlights the ways psychologists and psychiatrists care for these issues, describes current approaches to mental health services in PC, and reviews barriers and facilitators to psychology and psychiatry services in PC, along with recommendations to overcome barriers. **Abstract:** <http://bit.ly/35YIN1e>

Noted in Media Watch 20 August 2018 (#577, p.4):

- *BJPSYCH ADVANCES* | Online – 10 August 2018 – ‘**Palliative care for older people: The psychiatrist’s role.**’ The authors encourage clinicians to reflect on the effects of terminal illnesses on the mental health of dying people and the current provision of palliative psychiatric care: 1) Appreciate that patient-centred care builds on providing individualised care for the dying person to meet their needs and wishes; 2) Understand the collaborative role of psychiatry in assessing the aetiology and appropriate response to patients presenting with problems of loss, grief, anxiety, depression, hopelessness, suicidal ideation, personality change and confusion; and, 3) Recognise that maintaining hope and living with hope is a way for terminally ill patients to endure and cope with their suffering. **Summary (w. list of references):** <http://bit.ly/2m7gf2U>

Noted in Media Watch 6 August 2018 (#575, p.9):

- *AMERICAN MEDICAL JOURNAL OF ETHICS*, 2018;20(8):E717-E723. ‘**Four communication skills from psychiatry useful in palliative care and how to teach them.**’ Expert communication in palliative care (PC) is not only vital for patients and families but also can be a challenge for clinicians of all levels. In considering the communication skills needed in PC, the authors note parallels with psychiatric training. PC has always been interdisciplinary in perspective and practice, as reflected not only in its team approach to care but also in its recruitment of physicians from diverse specialties, including psychiatry. The authors propose that these similarities exist due to the intimacy of the clinical relationship in PC and psychiatry, the affectively charged clinical situation in which care occurs, and the primary role of patient-clinician relationships in decision-making and treatment. **Full text:** <http://bit.ly/2m8nPKA>

Early integration of palliative care in a long-term care home: A telemedicine feasibility pilot study

PALLIATIVE & SUPPORTIVE CARE | Online – 18 February 2020 – This project focused on palliative telemedicine, specifically evaluating whether integration of early palliative care (PC) specialist consultation into a long-term care home LTCH would be feasible through the implementation of video-conferencing during routine interdisciplinary care conferences. Palliative telemedicine feasibility was evaluated using staff and family member surveys. The results support the feasibility of video-conferencing as a means of PC provision. Despite technical issues, most clinical staff and families were satisfied with the video-conference and were willing to use it again. Early integration of PC specialist services into an LTCH through video-conferencing also led to improved self-rated confidence in the palliative approach to care by clinical staff. **Abstract (w. list of references):** <http://bit.ly/37BVr5N>

N.B. Additional articles on hospice and PC in LTCFs noted in 10 February 2020 issue of Media Watch (#652, pp.12-13). See also the October 2019 issue of the International Association for Hospice & Palliative Care’s newsletter (scroll down to ‘Media Watch: Long-Term Care’) at: <http://bit.ly/2p0p68g>

Improving nurses' understanding of pediatric-focused advance directives

PEDIATRIC NURSING, 2020;46(1):11-39. Nurses caring for pediatric patients with life-limiting and life-threatening conditions are often faced with the challenge of providing care to patients receiving palliative and hospice care. In some instances, patients or caregivers (such as a parent or guardian) will have had advance care planning (ACP) discussions with their (PC) care team that are not directly shared with the interprofessional team, including nursing staff providing direct patient care. Despite caring for chronically ill patients, nurses are often unfamiliar with the ACP process, and are uncertain of their role in ACP, how to incorporate the patient's wishes into daily nursing care, and how to assist with patient and family decision-making surrounding advance directives (ADs). Although there is substantial literature available distinguishing the differences between PC and hospice care, as well as the need for early PC consultation intervention, less information and knowledge exist about what ADs are available in the pediatric patient population. This uncertainty coupled with a lack of knowledge in how to best navigate these difficult conversations may delay pertinent ACP conversations. By understanding pediatric and adolescent and young adult-focused ADs – specifically, Five Wishes®, Voicing My CHOICES™, and My Wishes – pediatric nurses will better understand their role in guiding and supporting patients and families, and as a result, be better prepared to assist with the ACP process. **Abstract:** <http://bit.ly/2SAuPxQ>

Related:

- *PEDIATRICS*, 2020;145(2):e20192241. 'Toward an understanding of advance care planning in children with medical complexity.' This study revealed four major themes and several associated sub-themes: 1) Holistic mind-set; 2) Discussion content [beliefs and values, hopes and goals, and quality of life]; 3) Communication enhancers [partnerships in shared decision-making, supportive setting, early and ongoing conversations, consistent language and practice, family readiness, provider expertise in advance care planning (ACP) discussions, and provider comfort in ACP discussions]; and, 4) The ACP definition. The results aided development of a family-centered framework to enhance the delivery of ACP... **Abstract:** <http://bit.ly/2V2LAU8>

N.B. Additional articles on children's involvement in ACP noted in 21 October 2019 (#636, p.6).

Healthcare utilization among children and young people with life-limiting conditions: Exploring palliative care

SCIENTIFIC REPORTS | Online – 14 February 2020 – The results of this study provided preliminary data contributing to the design of a government-funded paediatric palliative care (PPC) pilot program, into which patients with life-limiting conditions (LLCs) – both cancer and non-cancer – aged 24 and younger have been enrolled. The program has been designed to support the establishment of specialized paediatric palliative consulting teams in tertiary hospitals. It was launched in two hospitals in July 2018 and two more in January 2019. Each hospital is funded with 160,000 \$US per year, and patients do not need to make additional payments for palliative care (PC). As healthcare professionals in South Korea are unfamiliar with PPC, the authors used the Paediatric Palliative Screening Scale from Switzerland to assist them in deciding when is the best time to introduce PPC to patient and family. Furthermore, unmet needs should be assessed such as the need for community-based PPC, to expand the PPC program appropriately. Also, to improve accessibility, the PPC program is needed to be implemented in other specialized public medical centres for children, as well as tertiary hospitals that are not designated as specialized public medical centres for children, considering the distribution of residences of children and young people (CYP) with LLCs. PC has become an essential aspect of paediatrics, and the number of countries that provide PPC has increased. CYP who require PC need more consideration, and policy development should be based on their needs. Countries planning to set up a PPC system should first identify the characteristics, distribution, and needs of CYP with LLCs. The analysis of national health data can be an efficient way to assess such aspects and may help to establish socially and culturally appropriate PPC systems worldwide. **Full text:** <https://go.nature.com/2uNlx8z>

서울대학교
SEOUL NATIONAL UNIVERSITY

Cont.

Noted in Media Watch 17 February 2020 (#653, p.7):

- *BMC PALLIATIVE CARE* | Online – 10 February 2020 – ‘**Who needs and continues to need paediatric palliative care? An evaluation of utility and feasibility of the Paediatric Palliative Screening Scale (PaPaS).**’ The PaPaS promotes greater clarity and effective handover for everyone involved, particularly at care transitions. This can lead to important outcomes like alignment of expectations between stakeholders, and critically, optimal case management. Ultimately, the child and family living with life-shortening illness is flagged in a timely manner to receive PC based on needs rather than prognosis, in spite of challenges posed by disease diversity and uncertain trajectories, through a process of screening that is both robust and informational... **Full text:** <http://bit.ly/2UHdk0f>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *THE HASTINGS REPORT*, 2020;50(1):32-43. ‘**Medically assisted dying and suicide: How are they different, and how are they similar?**’ The practice of medically assisted dying has long been contentious, and the question of what to call it has become increasingly contentious as well. Particularly among U.S. proponents of legalizing the practice, there has been a growing push away from calling it “physician-assisted suicide,” with assertions that medically assisted dying is fundamentally different from suicide. Digging deeper into this claim about difference leads to an examination of the difference between two kinds of suffering – suffering from physical conditions and suffering from psychological conditions – and therefore leads also toward an examination of whether requests for medical assistance in dying by those suffering from psychological conditions and those suffering from physical conditions should be painted with the same brush. In this article, the author aims both to illuminate some of the considerations that ought to be included in discussions related to medically assisted dying and to shed light on what the indirect effects of such discussions can be. She considers some of the reasons commonly given for holding that suicide and medically assisted dying differ fundamentally and then whether the conclusion that medically assisted dying should not be called “suicide” follows from the premises. The author asks what else might justify the conclusion that the two acts ought to be called by different names, and she examines possible justifications for accepting this premise, as well as what justifications might exist for emphasizing how the acts are alike. Finally, the author argues that we should be cautious before concluding that medically assisted dying should not be called “suicide.” **Abstract:** <http://bit.ly/39Lfv7q>
- *PROFESSIONAL CASE MANAGEMENT*, 2020;25(2):77-84. ‘**Patient rights at the end of life: The ethics of aid-in-dying.**’ Case managers (CMs) are an instrumental and integral part of the end-of-life care team. They are held to the same standard of practice as clinical care providers when it comes to promoting the biomedical ethical points autonomy, beneficence, nonmaleficence, justice, and fidelity. Following these ethical principles is critical for CMs to consider when supporting the desires and preferences of terminally ill patients. CMs should be involved in all the patient-centered decision-making for a terminally ill patient’s desire for death with dignity and physician assisted death. It is critical for CMs to follow their organization’s defined code of professional conduct as well their specific professional organization and professional certifying body’s defined code of ethics and conduct despite their personal convictions. **Abstract:** <http://bit.ly/39O3YnA>

Media Watch: Editorial Practice

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

Cont.

Distribution

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

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

[Search Back Issues of Media Watch @ http://bit.ly/2ThijkC](http://bit.ly/2ThijkC)

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://bit.ly/3blzifk>

[Scroll down to 'Media Watch: Grief & Bereavement']

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

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

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

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

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: [HTTP://BIT.LY/2SWDYWP](http://bit.ly/2SWDYWP)

[Scroll down to 'e-Library' ('From Around the Region') and 'Media Watch Barry Ashpole']

Australia

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

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

Canada



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

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

Cont.

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

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTP://BIT.LY/300WMRT>

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

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

South America

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

Barry R. Ashpole, Ontario CANADA

e-mail: barryashpole@bell.net