The tendency to avoid discussions about terminal prognoses and to create unrealistic expectations of fighting death is seriously harming patients, families and healthcare professionals, and the delivery of high-quality and equitable care.

‘Dealing with death in cancer care: Should the oncologist be an amicus mortis?’ (p.16), in Supportive Care in Cancer.

Canada

Home care agencies seek key role in ... health reforms

ONTARIO | CBC News (Toronto) – 12 November 2019 – As the provincial government prepares to launch its health system reforms, Ontario’s home care sector is pitching itself as a key part of the solution to the province’s overburdened hospitals. Home Care Ontario is urging the province to expand the types of healthcare that its workers can provide to patients at home, helping to ease the so-called “hallway medicine” problem. That’s one of the key recommendations in a new policy paper from Home Care Ontario, aimed at the government’s soon-to-be-created Ontario Health Teams (OHTs). The teams will bring together hospitals, home care agencies and long-term care (LTC) facilities in geographic areas. Each team will receive a combined pot of funding to provide the range of health services its population needs. The paper says the government’s restructuring of the health system and the creation of the OHTs can make it easier for people to be cared for at home and can shift the burden of care away from hospitals when patients truly don’t need to be hospitalized.


Extract from Home Care Ontario white paper

Many patients with a terminal diagnoses express the wish to die at home, but in the end are transferred to acute care because the family does not have access to enough home care services and supports to manage the final stages of life. With eShift, the nurse providing home care is electronically connected to a Directing Registered Nurse (DRN) who is an expert in palliative care. By consulting the DRN and adjusting the treatment plan to keep the patient and their family comfortable and informed, the likelihood of an unplanned and unnecessary hospital admission falls dramatically. With eShift involvement, less than 2% of patients were admitted to hospital in the final weeks of their lives.

Specialist Publications

‘Hospice use and one-year survivorship of residents in long-term care facilities in Canada: A cohort study’ (p.6), in BMC Palliative Care.


Granting dying patients’ wishes may help families feel better about end-of-life ICU care

THE NATIONAL POST | Online – 11 November 2019 – Families of dying patients may feel better about end-of-life care (EoLC) in the ICU if they are granted simple wishes... Researchers interviewed families and caregivers of 730 terminally ill patients about their experiences with the 3 Wishes Project (3WP), a program designed to create meaningful patient- and family-centered memories as part of compassionate EoLC. “3WP facilitates compassionate care by recognizing the inherent dignity of dying patients and encouraging connections among patients, clinicians, and family members,” Dr. Deborah Cook of McMaster University in Hamilton, Ontario, and colleagues report. The goal of the study was to see how feasible it might be to implement the 3WP program at multiple facilities, how much families and clinicians appreciated the experiences, and how much it might cost to grant wishes to dying patients and their families on a regular basis. http://bit.ly/2Qb6tK5


U.S.A.

Dozens of for-profit hospices fail to visit dying people in their final days, Government Accountability Office says

NEWSWEEK | Online – 16 November 2019 – Dozens of for-profit hospice providers failed to visit dying patients in their last few days, according to a recent report by the U.S. Government Accountability Office (GAO). The investigation focused on providers paid by the Centers for Medicare & Medicaid Services (CMS) in 2017. While for-profit and non-profit hospices had similar scores on pain assessment and other quality measures, more than 450 private groups discharged patients before they died. This is not the first troubling report on the Medicare-paid hospice system. Earlier this year, the Office of Inspector General (OIG) found that 18% of all hospices in a nationwide survey had serious deficiencies, like failing to vet staff. In the recent report, eighty for-profits failed to send registered nurses, physicians or nurse practitioners to visit discharged patients even once in the last 72 hours of their lives, while only three non-profits did the same. Both for-profit and non-profit hospices gave these end-of-care visits to most patients, but the dozens that didn't left at least 800 dying people and their families without guidance. A smaller number of for-profit hospice units (55) did not provide any visits from medical social workers, chaplains or spiritual counselors, licensed practical nurses or hospice aides in the entire week preceding more than 600 patients' deaths. http://bit.ly/2Xlwubk

Specialist Publications
‘Integration of an advance care planning model in home health: Favorable outcomes in end-of-life discussions, Practitioner Orders for Life-Sustaining Treatment rates, and 60-day hospital readmissions’ (p.8), in Home Healthcare Now.

‘Quality measurement of serious illness communication: Recommendations for health systems based on findings from a symposium of national experts’ (p.11), in Journal of Palliative Medicine.


Designing End-of-Life Care Settings to Enhance Quality of Life

CORNELL UNIVERSITY REPORT | Online – Accessed 13 November 2019 – This report presents straightforward design guidance for settings in which end-of-life (EoL) care is delivered. Focused on accommodating the unique and unfamiliar changes experienced during the EoL journey, the research reflected here examined four primary design elements of the built environment that profoundly influence EoL care settings. The material in this document can be used to inform conversations among designers, users, and stakeholders to support creation of custom design solutions that support residents, families, and caregivers. Download/view at: http://bit.ly/2NIcxs2

Hospice and palliative care survey reveals attitudes about medical marijuana, religion and end-of-life care

FLORIDA | MorseLife Hospice & Palliative Care (West Palm Beach) – 13 November 2019 – MorseLife has released the results of a new online survey of 2,008 adults age 18+ conducted on its behalf by The Harris Poll in September 2019. The top three insights include overwhelming support of medical marijuana, opinions on religion when dealing with a life-limiting illness and overall understanding of hospice care.

Download/view at: https://bwnews.pr/354llOW

Cont. next page
HEALTH ENVIRONMENTS RESEARCH & DESIGN | Online – 11 January 2019 – ‘Palliative design meets palliative medicine: A strategic approach to the design, construction, and operation of healthcare facilities to improve quality of life and reduce suffering for patients, families, and caregivers.’ A built environment designed to be appropriate for palliative care can make a profound difference for people with life-limiting illnesses. The built environment affects a patient’s quality of life, the management of physical and psychological symptoms, and the quality of social interactions with loved ones and caregivers. This article is informed by the emerging trends in the research and practice in the disciplines of architecture, design, medicine, and nursing. Abstract: http://bit.ly/2Qkbsfl

N.B. Selected articles on the relationship between the architecture of healthcare facilities and the quality of EoL care noted in 16 July 2018 issue of Media Watch (#572, pp.1-2).

As Vietnam Veterans age, hospices aim to meet their needs

THE NEW YORK TIMES | Online – 11 November 2019 – In addition to high rates of disability and psychological issues, some vets facing the end of life are confronting long-suppressed memories of the traumas of war. Mr. [Timothy] Hellrung is one of the roughly 28,000 veterans who spent their final days this year in a Veterans Affairs’ (VA) hospice care program that provides a unique way of honoring their dignity at the end of their lives. The Department of Veterans Affairs’ hospice program for this population is designed to specifically address the complexities they face as memories of the traumas of war surface – in many cases, for the first time. Each veteran receives care from a multidisciplinary team, including social workers, physicians, nurses and spiritual leaders addressing not only physical but emotional, social and spiritual needs. Veterans tend to be more chronically ill compared to the general population, with high rates of disability, intricate psychiatric issues, post-traumatic stress disorder and depression. Hospice care is available to everyone under Medicare with a life expectancy of six months or less. But for veterans to receive the services through the VA, they have to register, something only a third of the 22 million veterans in the US have done. The VA hospice care program is offered at 170 VA hospitals, and the agency has more than 1,000 outpatient facilities that can make referrals, connecting veterans with other hospice providers. Veterans may be eligible for a broad array of benefits that Medicare doesn’t offer, such as compensation for burial costs and a survivors’ pension. https://nyti.ms/2CyD18W

N.B. Selected articles on palliative and end-of-life care for World War II, Korea, and Vietnam veterans noted in 10 September 2018 issue of Media Watch (#580, p.4).
International

Rest homes struggling to care for patients “admitted to die,” study finds

NEW ZEALAND | Stuff.co.nz (Auckland) – 14 November 2019 – Stretched hospitals and hospices are sending elderly, terminally ill patients to die in rest homes – but staff are struggling to cope… A Otago University, Wellington, study revealed the burden aged care facilities face when caring for patients discharged from hospitals and hospices to die. In the past those patients would have been cared for in public hospitals and hospices but those facilities were under increasing pressure to free up beds for acute or urgent care, the study said. Hospitals were considered inappropriate and costly for those dying over weeks to months of incurable illness, and hospice capacity is increasingly strained. The study … recommended the Ministry of Health fund some aged care facilities to provide specialist end-of-life care. [Link]


Londoners urged to choose their end-of-life care in “death plan”

U.K. (England) | The Evening Standard (London) – 14 November 2019 – Londoners are being urged to complete a “death plan” that outlines how and where they should be treated by the National Health Service (NHS) if they become seriously ill. It enables them to choose to die at home rather than in hospital and can prevent paramedics from attempting resuscitation after a cardiac arrest. The doctor leading the roll-out of the scheme said it could prevent people turning to foreign clinics such as Dignitas as they knew their death would be handled as they wished by the NHS. More than 81,000 Londoners with long-term health conditions already have a Co-ordinate My Care (CMC) plan, including patients with cystic fibrosis, sickle cell disease and dementia. It will give medics instant details of a patient’s health, previous treatment and wishes for end-of-life care. The scheme has been open to all adult Londoners since May, enabling them to fill in their plan, known as myCMC, online. It is then sent to their GP, approved and added to the NHS database after the patient has discussed their choices. It can be viewed by the patient on their smartphone and updated. [Link]

Noted in Media Watch 20 May 2019 (#614, p.4):

- U.K. (England) | BT News (London) – 13 May 2019 – ‘Online plan to let dying people share their wishes backed by Health Secretary.’ The Health Secretary is backing a new online National Health Service scheme where people who are dying can share their wishes around treatment and care. Matt Hancock welcomed the move towards giving chronically ill patients and those nearing death more control of what happens in an emergency, such as whether they would want to be resuscitated or if they wish to die at home. The online plan, myCMC (my Co-ordinate My Care), enables details to be shared between care providers such as 111 [a medical helpline], out-of-hours GPs, and the ambulance service. [Link]
Cancer patients with the six deadliest forms of the disease are being “neglected” due to lack of research funding, according to new report

U.K. (England) | The Daily Mail (London) – 10 November 2019 – Patients with the six deadliest forms of cancer are being “neglected” due to a chronic lack of research funding, a report has revealed. Survival rates for pancreatic, liver, brain, lung, oesophageal and stomach cancer stand at just 14% [see sidebar]. For breast cancer, the figure is 87%. While the deadliest forms of the disease account for half of all common cancer deaths, they receive just 7% of research spending on cancer in the U.K. This creates a “vicious cycle” that means there are few treatment options or clinical trials available for those with the least survivable cancers on the National Health Service. https://dailym.ai/2qEpgmC

Articles noted in past issues of Media Watch on palliative and end-of-life care for patients living with...

Pancreatic cancer – 18 February 2019 (#602, p.2);
Oesophageal cancer – 29 July 2019 (#624, p.7);
Lung cancer – 2 September 2019 (#629, p.8);
Brain cancer – 21 October 2019 (#636, p.14); and,


Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND | TVNZ News (Auckland) – 13 November 2019 – 'Parliament passes euthanasia bill in night of emotionally charged speeches; now it's up to voters.' Euthanasia legalisation has passed its final hurdle in Parliament – moving the decision out of the hands of parliamentarians and into the public. A referendum will now be held at next year’s election, after MPs voted 69-51 in favour of the third reading of the End of Life Choice Bill. If passed, a person would be eligible for euthanasia if they suffer from a terminal illness and are likely to die within six months, if they are in an advanced state of irreversible physical decline and are also experiencing unbearable suffering that cannot be relieved. They also need to be competent to make an informed decision. A person cannot be eligible for euthanasia for the only reason being of an old age, having a disability or having a mental illness or disorder. http://bit.ly/33VhJi5

Specialist Publications

Hospice use and one-year survivorship of residents in long-term care facilities in Canada: A cohort study

BMC PALLIATIVE CARE | Online – 12 November 2019 – The actual use of hospice care among long-term care facilities (LTCF) residents is very poor in Canada. Residents who received hospice care and died within 1 year of assessment exhibited more severe and complex clinical needs than those who did not receive hospice care and those who were alive 1 year following the assessment. Residents who received hospice care and were alive 1 year following the assessment exhibited more severe acute clinical needs (i.e., pain, high pressure risk, and health instability) and had less chronic clinical needs (i.e., cognitive impairment, depression, and low social engagement) than those who did not receive hospice care but died within 1 year. This study indicates several possible barriers to hospice use in the LTCF population including ageism, rurality, and a diagnosis of dementia. All these factors come together to explain and inform health care utilization. Immediate action is needed to address inequality in care at the end of life for the LTCF population and provide improved access to high quality hospice care in LTCFs in Canada. Full text: http://bit.ly/2KoDIGg

N.B. A selection of articles on palliative and end-of-life care in LTC, from past issues of Media Watch, noted in October issue of the International Association for Hospice & Palliative Care's newsletter [scroll down to ‘Media Watch: Long-Term Care’] at: http://bit.ly/2p0p68g
Paramedics and serious illness: Communication training

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 15 November 2019 – The need to empower ambulance service staff at the point of delivery of end-of-life care (EoLC) is crucial. The authors describe the delivery, outcomes and potential impact of the Serious Illness Conversation project delivered to Welsh Ambulance Service Trust (WAST) staff. Over an 18-month period, 368 WAST staff attended face-to-face teaching, which included serious illness conversation communication skills, symptom control and “shared decision making.” WAST staff view themselves in several important roles, acting as “facilitators” to patient-centred, seamless care, providing support, liaison between services and practical help in patient care at the end of life. The difficult questions and situations pertaining to EoLC were related to discussions on death and dying and managing expectation. The predominant barriers identified related to communication. Quantitative outcomes on the six communication domains indicate statistically significant improvement in self-assessed confidence. The overall impact to the wider ambulance service suggests a trend towards better use of resources. **Abstract:** [http://bit.ly/2QrAdCz](http://bit.ly/2QrAdCz)

**N.B.** Articles on paramedics and palliative and end-of-life care noted in past issues of Media Watch: in Canada 2 September 2019, #629, p.1; in Australia 11 February 2019, #601, p.12; and, in the U.K. 20 August 2018, #577, p.7.

End-of-life care for frail older people

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 15 November 2019 – Frailty is the tendency to crises or episodes of rapid deterioration. These are often functional or non-specific in nature, such as falls or delirium, and recovery is usually expected. Health-related problems can be defined in terms of distress and disability. Distress is as often mental as physical, especially for people with delirium and dementia. Problems can be addressed using the principles of supportive and palliative care, but there is rarely a simple solution. Most problems do not have a palliative drug treatment, and the propensity to adverse effects means that drugs must be used with caution. Geriatricians use a model called comprehensive geriatric assessment, including medical, functional, mental health, social and environmental dimensions, but also use a variety of other models, such as the acute medical model, person-centred care, rehabilitation, alongside palliative care (PC). Features such as communication, family engagement and advance planning are common to them all. These approaches are often consistent with each other, but their commonalities are not always recognised. The emphasis should be on making the right decision at a given point in time, taking account of what treatment is likely to deliver benefit, treatment burden and what is wanted. Choices are often limited by what is available and feasible. PC should be integrated with all medical care for frail older people. **Abstract:** [http://bit.ly/2XiskAS](http://bit.ly/2XiskAS)

Noted in Media Watch 25 February 2019 (#603, p.13):

- **PALLIATIVE MEDICINE** | Online – 18 February 2019 – ‘What is the evidence that people with frailty have needs for palliative care at the end of life? A systematic review and narrative synthesis.’ Thirteen different measures or definitions of frailty were used. People with frailty experience pain and emotional distress at levels similar to people with cancer and also report a range of physical and psychosocial needs, including weakness and anxiety. Functional support needs were high and were highest where people with frailty were cognitively impaired. Individuals with frailty often expressed a preference for reduced intervention, but these preferences were not always observed at critical phases of care. **Abstract:** [http://bit.ly/2SaPIMz](http://bit.ly/2SaPIMz)

Back Issues of Media Watch
Hospice at Home services in England: A national survey

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 November 2019 – This national survey highlights the considerable variation in features of Hospice at Home (HAH) services in England. These services, funded largely by volunteer effort and charity donations, work alongside formal health and care provision in local areas of England to provide greater choice of palliative care at home. With such variation in services, understanding what features lead to improved patient and carer outcomes would support service provision in the future. Ongoing in-depth evaluation of 12 different HAH services that participated in this survey explore what service features and processes work best for patients and carers in different contexts, and the resource implications, in order to provide recommendations for commissioners and providers in the future. Full text: [http://bit.ly/2QlsgPt](http://bit.ly/2QlsgPt)

Psychedelics for psychological and existential distress in palliative and cancer care

*CURRENT ONCOLOGY*, 2019;26(4):225-226. In recent years, there has been renewed scientific interest in, and associated media coverage of, psychedelics. A so-called psychedelic renaissance is underway, with research programmes at major academic institutions worldwide conducting basic and clinical research into the potential therapeutic effects of psychedelic medicines for a variety of psychiatric conditions. These compounds were first studied in the 1950s, but by the mid-to-late 1960s, clinical research began to be curtailed and was almost fully terminated by the mid-1970s. Before that freeze out, however, studies into psychedelics pointed to a potential role for those agents in the setting of cancer-associated or end-of-life-associated psychological distress... Those early experiments and their contemporary counterparts invite the questions: Is there a role for psychedelics for treating patients in palliative medicine and cancer care today? And, if so, where? Full text: [http://bit.ly/2qK9gj2](http://bit.ly/2qK9gj2)


Noted in Media Watch 4 March 2019 (#604, p.13):

- *JOURNAL OF PSYCHOACTIVE DRUGS* | Online – 1 March 2019 – ‘Psychedelics and dying care: A historical look at the relationship between psychedelics and palliative care.’ As researchers in the 1950s began exploring different applications for psychoactive substances ... dying care came into clearer focus as a potential avenue for psychedelics. Before that application gained momentum in clinical or philosophical discussions, psychedelics were criminalized and those early discussions were lost. This article looks back at historical discussions about LSD’s potential for easing the anxiety associated with dying, and considers how those early conversations might offer insights into today’s more articulated discussions about psychedelics in palliative care. Abstract: [http://bit.ly/2Ta1k7V](http://bit.ly/2Ta1k7V)

Noted in Media Watch 29 January 2018 (#548, p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 January 2018 – ‘Taking psychedelics seriously.’ Even with an expanding evidence base confirming safety and benefits, political, regulatory, and industry issues impose challenges to the legitimate use of psychedelics. Given the prevalence of persistent suffering and growing acceptance of physician-hastened death as a medical response, it is time to revisit the legitimate therapeutic use of psychedelics. This paper overviews the history of this class of drugs and their therapeutic potential. Clinical cautions, adverse reactions, and important steps related to safe administration of psychedelics are presented, emphasizing careful patient screening, preparation, setting and supervision. Full text: [http://bit.ly/2tOtJBa](http://bit.ly/2tOtJBa)

Integration of an advance care planning model in home health: Favorable outcomes in end-of-life discussions, Practitioner Orders for Life-Sustaining Treatment rates, and 60-day hospital readmissions

*HOME HEALTHCARE NOW*, 2019;37(6):337-344. Only 2.3% of patients at a Midwest home healthcare (HH) agency [in the U.S.] had documented advance directives (ADs), compared with 28% nationally. Of
concern, this HH agency lacked standardized procedures for advance care planning (ACP) leading to inadequate staff knowledge regarding end-of-life, avoidable hospital readmissions, and delayed transitions into hospice care. Lack of ADs is directly correlated to higher hospital readmission rates and lower hospice length of stay. The purpose of this initiative was to develop evidence-based procedures using the Respecting Choices® ACP model to: 1) Educate staff; 2) Increase ACP conversations offered and completed among high-risk patients; 3) Increase Practitioner Orders for Life-Sustaining Treatment (POLST) rates; 4) Reduce 60-day hospital readmissions; and, 5) Support hospice care admissions. Staff received discipline-specific education on ACP/ADs. The Knowledge-Attitudinal-Experimental Survey on Advance Directives (KAESAD), assessed staff ACP/AD knowledge, confidence, and experiences. Standardized electronic medical record tools were created to track ACP conversations, POLST rates, 60-day hospital readmissions, and hospice admissions. Paired t-test and chi-square analyses compared changes pre- and post implementation. The KAESAD survey was analyzed for 75 staff (100%) and demonstrates improvement in knowledge, confidence, and experiences. Data also demonstrate increases in: ACP offered; ACP conversations completed 4% to 31%; POLST rates 26% to 43.6%; decreased 60-day hospital readmissions 40% to 20%; whereas hospice care admissions was not impacted ranging from 10% to 5.5%. Respecting Choices® serves as an effective ACP framework to improve ACP conversations, POLST rates, and hospital readmissions. Abstract: http://bit.ly/34Poguv

Related

- JOURNAL OF PALLIATIVE MEDICINE | Online – 12 November 2019 – ‘DNR, DNI, and DNO?’ The addition of a do-not-operate (DNO) section to current medical orders for life-sustaining treatment (MOLST) and physician orders for life-sustaining treatment (POLST) medical order forms would more completely document patients’ wishes for invasive interventions at the end of life. The authors propose a modification of the MOLST and POLST forms, in addition to hospital and electronic medical records, to include a DNO section, in addition to pre-existing do-not-resuscitate (DNR) and do-not-intubate (DNI) orders, with the goal of reducing suffering from non-beneficial surgical interventions in patients with severe illness at the end of life. Abstract: http://bit.ly/2QhTjIk

Noted in Media Watch 1 January 2018 (#539, p.12):

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 18 December 2017 – ‘Respecting Choices® and related models of advance care planning: A systematic review of published evidence.’ There is a low level of evidence that Respecting Choices® (RC) and derivative models increase the incidence and prevalence of advance directive and Physician Orders for Life-Sustaining Treatment completion. There is a high level of evidence RC and derivative models increase patient-surrogate congruence in Caucasian populations. The evidence is mixed, inconclusive and too poor in quality to determine whether RC and derivative models change the consistency of treatment with wishes and overall healthcare utilization in the end of life. Abstract: http://bit.ly/2Ew5GwH

Evaluation of a palliative care program for nursing homes in 7 countries: The PACE cluster-randomized clinical trial

JAMA INTERNAL MEDICINE | Online – 11 November 2019 – Is the Palliative Care for Older People (PACE) Steps to Success Program, a multi-component intervention to integrate basic non-specialist palliative care (PC) in nursing homes, effective in improving resident and staff outcomes? In a cluster-randomized clinical trial in 78 nursing homes in 7 countries evaluating data concerning 551 deceased residents at baseline and 984 post-intervention, and data concerning 2,680 staff at baseline and 2,437 post-intervention, comparing PACE Steps to Success with usual care, residents’ comfort in the last week of life did not improve. Staff knowledge of PC improved, but the difference was very small. The PACE Steps to Success Program was not effective in improving residents’ comfort in the last week of life, nor in improving staff knowledge of PC to a clinically relevant degree. Abstract: http://bit.ly/36ZLj7F

Barriers to end-of-life services for persons experiencing homelessness as perceived by health and social service providers

JOURNAL OF THE AMERICAN BOARD OF FAMILY MEDICINE, 2019;32(6):847-857. People experiencing homelessness have significantly shorter life expectancies and higher rates of morbidity and mortality than the general population. Many barriers have been identified to providing palliative care (PC) to this population. This study examines health and social service providers’ experiences providing end-of-life care (EoLC) to people experiencing homelessness, seeking recommendations to improve both patient and provider experience. Qualitative and quantitative surveys with 136 health and social service providers in Ontario’s South East Local Health Integration Network, in-depth interview with 10 key informants. Participants approached the EoLC of people experiencing homelessness from a framework of dignity and respect. Themes included barriers to EoLC internal to the healthcare system; care avoidance; the experience of stigma for this population when accessing EoLC; lack of provider information and awareness on how to provide care for marginalized groups, how to provide care in the context of substance use, and how to assist clients in accessing the formal PC system; and, the need for harm reduction approaches to EoLC for persons experiencing homelessness. Focusing on harm reduction, and using the framework of Equity-Oriented Healthcare to make systemic, cultural, and policy changes to develop a PC system for persons experiencing homelessness may improve care experience for both patients and providers. Full text: http://bit.ly/36MTzb7

Related

- JOURNAL OF THE AMERICAN BOARD OF FAMILY MEDICINE, 2019;32(6):858-867. ‘Experiences of palliative healthcare for homeless and vulnerably housed individuals.’ Study participants challenge healthcare providers to question their own paradigms, and to ensure they provide care that is: patient centered, non-stigmatizing, and non-discriminatory; that embraces principles of harm reduction, flexibility, dignity, and autonomy; provided outside of hospitals, either in institutions that feel as much as possible like a home, or on the street in an outreach setting for clients who are either not ready or not willing to be in an institution; informed by, and to some extent provided by, people with lived experience; and, equity-oriented and equity-enhancing for all. Full text: http://bit.ly/2G74/fk

N.B. Additional articles on palliative and EoLC for the homeless in Canada noted in 30 September 2019 issue of Media Watch (#633, pp.14-15).

Patients’ perceptions of the quality of palliative care and satisfaction: A cluster analysis

JOURNAL OF MULTIDISCIPLINARY HEALTHCARE | Online – 11 November 2019 – One may assume that patients’ perceptions of quality of care and satisfaction are positively associated; however, the results of this cross-sectional study shows that this relationship is more complex. The results provide multidisciplinary healthcare personnel with important knowledge about patient profiles and what characterizes them, to tailor quality work initiatives and improve person-centered care for different groups of patients in the palliative care (PC) contexts. Healthcare personnel from multiple professions should pay special attention to patients with low sense of coherence (who seem to manage their situation poorly) and who seem to not express preferences for care. Additionally, healthcare improvement initiatives should focus on implementing a person-centered approach, increasing the PC competence and training for the multi-professional staff providing PC and facilitate specialized PC services, especially in the home care context. Full text: http://bit.ly/2O189Du
The Berlin Declaration: A collaborative roadmap to advance global hospice and palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 14 November 2019 – In May 2019, the authors, as representatives of the three global palliative care (PC) organizations (i.e., International Association for Hospice & Palliative Care, International Children’s Palliative Care Network, and Worldwide Hospice Palliative Care Alliance), met in Berlin to discuss how to work more closely together to convey the same messages on major global health policy issues. In the face of changing economic times and limited funding opportunities in global PC, they also discussed future sustainability and how working together provides an opportunity to share and conserve resources. After decades of absence from the global health agenda, thanks to joint efforts from the three organizations, in collaboration with regional and national associations as well as with key partners from relevant fields, PC is now included in some important health policy documents as part of an essential spectrum of services. These documents include the United Nations’ Declaration on Prevention & Control of Non-communicable Diseases, the Political Declaration on HIV/AIDS, and the Political Declaration of the High-level Meeting on Universal Health Coverage, the World Health Organization (WHO) Report on Universal Health Coverage, the World Health Assembly (WHA) Resolution on Palliative Care, the Outcome Document of the United Nations General Assembly Special Session on the World Drug Problem, the WHA Resolution on Cancer and the WHO Global Action Plan on Demen
tia, the WHO Astana Declaration, and the Supplemental Reports by the International Narcotics Control Board on the availability of internationally controlled drugs. Notwithstanding PC’s inclusion in this high-level narrative, PC services have yet to be concretely integrated into national health strategies and included in regional and global health strategies. Access article at: http://bit.ly/2O95Xtq

Related

ISRAEL JOURNAL OF HEALTH POLICY RESEARCH | Online – 12 November 2019 – “Death is inevitable – a bad death is not.”: Report from an international workshop.’ At the workshop, both national and international figures in the field of palliative care (PC) and health policy addressed several issues, including truth telling, religious approaches to end-of-life care, PC in the community, pediatric PC, Israel’s Dying Patient Act, the Ministry of Health’s national plan for PC, and challenges in using advance directives. The author’s summarize the topics addressed, challenges highlighted, and directions for further advancement of PC in the future, emphasizing the critical role of the Ministry of Health in providing a framework for development of PC. Full text: http://bit.ly/2CjxL2f

Quality measurement of serious illness communication: Recommendations for health systems based on findings from a symposium of national experts

JOURNAL OF PALLIATIVE MEDICINE | Online – 13 November 2019 – Communication between clinicians and patients fundamentally shapes the experience of serious illness. There is increasing recognition that health systems should routinely implement structures and processes to assure high-quality serious illness communication (SIC) and measure the effectiveness of their efforts on key outcomes. The absence, underdevelopment, or limited applicability of quality measures related specifically to SIC, and their limited application only to those seen by specialist palliative and hospice care teams, hinder efforts to improve care planning, service delivery, and health outcomes for all seriously ill patients. Patients, clinicians, and health systems increasingly align around the importance of high-quality communication in serious illness. The authors offer recommendations for various stakeholder groups to advance SIC quality measurement. Enthusiasm and a sense of urgency among health systems to drive and measure communication improvements inform our proposal for a set of example measures for implementation now. Abstract: http://bit.ly/33S7o6h

Living with a hope of survival is challenged by a lack of clinical evidence: An interview study among cancer patients using cannabis-based medicine

JOURNAL OF PALLIATIVE MEDICINE | Online – 11 November 2019 – There is an increasing focus among cancer patients on the use of cannabis-based medicine (CBM) as a supplement to conventional
palliative care (PC). However, physicians are reluctant to engage in dialog with the patients as clinical evidence is lacking. As a result, the patients are often left alone to rely on their own judgment in purchasing CBM products on the illegal market. To the question addressing the main rationale for starting CBM treatment, all 20 patients responded that they carried a hope that cannabis would have a curative effect on the cancer disease. Most patients reported relief of symptoms, such as insomnia, anxiety, nausea, and pain, after initiation of CBM treatment, but this outcome was perceived as less of a focus in comparison to hope of a cure. This study contributes with knowledge from the perspective of the cancer patient in PC regarding the decision behind the use of CBM. This knowledge is essential in the dialog between the health professional and the cancer patient about the use of CBM products for treatment. Abstract: http://bit.ly/2q7Uane

Noted in Media Watch 14 October 2019 (#635, p.10):

- **JOURNAL OF PALLIATIVE MEDICINE, 2019;22(10):1173-1174.** ‘Medical cannabis in palliative care: Meaningful additions to the research evidence.’ Palliative care (PC) team members need to understand what is known and unknown about cannabis’s health effects for individuals with high physical, emotional, or existential symptom burden because cannabis use is increasing even though healthcare practitioners may feel unprepared to counsel their patients. 33 U.S. states and the District of Columbia have legalized medical cannabis use, and 11 states and the District of Columbia have legalized recreational cannabis use among adults. The October issue of *Journal of Palliative Medicine* provides a compilation articles focusing on medical cannabis use in PC. Full text: http://bit.ly/30RnR6p


**Variability in assisted living residents’ end-of-life care trajectories**

**JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE |** Online – 5 November 2019 – A growing and increasingly vulnerable population resides in assisted living (AL). States [in the U.S.] are responsible for regulating AL and vary in their requirements. Findings of this study suggest that AL residents’ dying trajectories vary significantly by state. To ensure optimal end-of-life (EoL) outcomes for assisted living residents, state policy makers should consider how their regulations influence EoL care in AL, and future research should examine factors (e.g., state regulations, market characteristics, provider characteristics) that may enable AL residents to die in place and contribute to differential access to hospice services. Abstract: http://bit.ly/2pOZv2Z

Noted in Media Watch 26 November 2018 (#591, p.10):

- **JOURNAL OF AGING, 2018;47(12):72-83.** ‘Contours of “here.”: Phenomenology of space for assisted living residents approaching end of life.’ This study, informed by theory from environmental gerontology, investigates how AL residents who are approaching end of life (EoL) navigate and experience space. Findings show that participants experience a neutral theme of shrinking space, negative themes of confinement and vulnerability, and positive themes of safety and intimacy. Findings have implications for interventions to improve place integration in AL and enhance residents’ quality of life at EoL, including developing strategies to promote small meaningful journeys within context of shrinking life space. Abstract: http://bit.ly/31mARTh

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**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
Noted in Media Watch 7 April 2014 (#352, p.10):

- *JOURNAL OF AGING STUDIES*, 2014;30(4):1-13. “*This is our last stop.*”: Negotiating end-of-life transitions in assisted living. The authors present a model for how end-of-life (EoL) care transitions are negotiated in assisted living (AL) that depicts the range of multi-level intersecting factors that shape EoL processes and events in AL. These vary across and within settings depending on multiple influences, including, notably, the dying trajectories and care arrangements of residents at EoL, the prevalence of death and dying in a facility, and the attitudes and responses of individuals and facilities toward EoL processes and events … and the impact of death and dying on the residents and staff. Abstract: [http://bit.ly/2BdR57b](http://bit.ly/2BdR57b)

**Relationships between negative exchanges and depressive symptoms in older couples: The moderating roles of care and gender**

*JOURNAL OF SOCIAL & PERSONAL RELATIONSHIPS* | Online – 23 October 2019 – This study examines the extent to which negative spousal exchanges have more impact on caregiving versus non-caregiving couples. Results indicated that there were significant differences in the magnitude of the path between negative exchanges and depressive symptoms across the subgroups. Among husbands, there was a stronger relationship between negative exchanges and depressive symptoms for care-receiving husbands than for caregiving husbands or husbands in non-caregiving relationships. Among wives, however, there was no significant difference in the path from negative exchanges with spouses to depressive symptoms across care status. The authors also found gender differences in the effect of negative exchanges on depressive symptoms among caregivers, but not among care recipients. Findings suggest that care status and gender of caregivers and care recipients have significant effects on the association between negative interactions within couples and mental health outcomes. Abstract: [http://bit.ly/33JZiZV](http://bit.ly/33JZiZV)

**Knowledge and attitudes toward end-of-life care among community healthcare providers and its influencing factors in China: A cross-sectional study**

*MEDICINE*, 2019;98(45):e17683. Community healthcare providers’ attitudes toward end-of-life (EoL) care were predicted by death attitudes, working experience, experiences of the death of relatives, and experiences of caring for the dying… This suggested that community healthcare provider’ attitudes toward EoL care were influenced by a variety of variables that were not included in this study. Public’s insufficient knowledge of EoL care, imperfect medical insurance system, imperfect policies, laws and systems of palliative care (PC), and the lack of localized EoL models also influenced community healthcare provider’ attitudes toward EoL. The development and promotion of EoL care has been a comprehensive process involving government, medical and health institutions, the public, and environment. From the government’s point of view, it was necessary to establish laws on PC to protect rights and interests of patients and medical staff. From the perspective of medical and health institutions, the state has issued the ‘Hospice Basic Standard,’ ‘Hospice Management Instrumentation,’ and ‘A Guide to End-of-Life Care.’ Medical and health institutions need to formulate regulations and rules for the administration of hospice, clarify the job responsibilities of staff, and establish a Quality Management System. Nursing school’s EoL curricula have been lacking both of didactic education and clinical experiences. A well-organized, systematic exposure to didactic and experiential components of PC education and death education is imperative. Moreover, it is necessary to explore localized hospice care mode. Only with the efforts of the whole society, the patients will be able to go through the final stage of life painlessly, comfortably, and with dignity. Full text: [http://bit.ly/36SV1sG](http://bit.ly/36SV1sG)

**N.B.** Additional articles on palliative and EoL care in China noted in 29 July 2019 issue of Media Watch (#624, p.11).

Would this article be of interest to a colleague?
Desire, duty and medical gifting: How it became possible to long for a useful death

*MORTALITY* | Online – 11 November 2019 – It is common in social science critique of medical uses of the body to portray donation of the dead body as a sacrifice. In contemporary Denmark, however, some people claim to desire post-mortem utility. The authors argue that the articulated desires for utility should not be written off as false consciousness hiding a “real” sacrifice. People use medical promises to reinvent the meaning of death; and, in turn, they make promises to medical institutions by signing up as donors. Registrations of post-mortem donations serve to uphold a sense of control; ensure post-vital dignity, and to align people with wider socially engrained ideals of productivity and agency. Abstract (w. link to references): [http://bit.ly/33DCiiQ](http://bit.ly/33DCiiQ)

Demoralization and chronic illness in rural Australia: A cross-sectional survey

*PALLIATIVE & SUPPORTIVE CARE* | Online – 11 November 2019 – Demoralization is prevalent in patients with life-limiting chronic illnesses, many of whom reside in rural areas. These patients also have an increased risk of disease-related psychosocial burden due to the unique health barriers in this population. However, the factors affecting demoralization in this cohort are currently unknown. This study aimed to examine demoralization amongst the chronically ill in Lithgow, a town in rural New South Wales, Australia, and identify any correlated demographic, physical, and psychosocial factors in this population. Prevalence of demoralization was high in this population. In line with the existing literature, demoralization was associated with the level of education, symptom burden, and psychological distress, demonstrating that demoralization is a relevant psychometric factor in rural populations. Further stratification of the unique biopsychosocial factors at play in this population would contribute to better understanding the burdens experienced by people with chronic illness in this population and the nature of demoralization. Abstract (w. list of references): [http://bit.ly/2paHI5J](http://bit.ly/2paHI5J)

N.B. Additional articles on the provision and delivery of palliative and end-of-life care in rural and remote regions of Australia noted in 23 September 2019 issue of Media Watch (#632, p.15).

Noted in Media Watch 17 June 2019 (#618, p.13):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 14 June 2019 – ‘Exploring demoralization in end-of-life cancer patients: Prevalence, latent dimensions, and associations with other psychosocial variables.’ Demoralization is an existential distress syndrome that consists of an incapacity of coping, helplessness, hopelessness, loss of meaning and purpose, and impaired self-esteem. It can affect cancer patients, and the Demoralization Scale is a valid instrument to assess it. This study aimed to investigate the prevalence of demoralization in end-of-life cancer patients and its associations with the medical and psychosocial variables. In addition, the latent dimensions of demoralization emerging in this distinctive population were explored. Abstract (inc. list of references): [http://bit.ly/2WM2Mzg](http://bit.ly/2WM2Mzg)

Defining “transition points” in the illness course as standardised times to integrate palliative care

*PROGRESS IN PALLIATIVE CARE* | Online – 14 November 2019 – Despite emerging evidence of the benefits of palliative care (PC), and the apparent match of this form of care with patient preferences in the setting of advanced disease, there remains marked variability and many gaps in access to PC. A series of barriers to accessing services include appropriate timing of introduction of PC, who requires these services and how they should be delivered. In this editorial, the authors raise the concept of evidence-based illness transitions as a solution to some of these barriers. Drawing on literature detailing integration of PC, these transitions are described as standardised points reached in an illness course, objectively identified and which herald a time of greater need – for care, for symptom relief. These transition points may be based in health service use milestones. By linking a clinician prompt to a transition point, a “flag” can be raised for the clinician to consider tasks of PC or indeed a PC referral. In this way, through identification and use of illness transitions, integration of high quality end-of-life care can become standardised across populations and benchmarks for care can be established. Abstract: [http://bit.ly/2CNLkxS](http://bit.ly/2CNLkxS)
Enhancing palliative care patient access to psychological counseling through outreach telehealth services

*PSYCHO-SOCIAL ONCOLOGY* | Online – 10 November 2019 – The authors describe the implementation of an outreach counseling program via video-conferencing or telephone to patients receiving care in an outpatient palliative care (PC) clinic and compare patients using this service to those who only received psychological counseling in our outpatient clinic. They reviewed 2,072 unique patients, who had 4,567 total counseling encounters across outreach and outpatient settings. A total of 452 (22%) patients participated in a combination of outpatient and outreach counseling services. Patients who participated in outreach services had significantly more encounters (311 had two to five sessions) compared with those who had outpatient services only (1,137 had one session only). Outreach patients also had shorter times between the initial and follow-up encounters compared with those who had outpatient services only. Outreach telehealth counseling services was found to enhance PC patient access to psychological counseling. These services represent an additional modality for providing continuous psychological care. **Abstract:** [http://bit.ly/36VM81g](http://bit.ly/36VM81g)

Noted in Media Watch 11 November 2019 (#639, p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 5 November 2019 – ‘Top ten tips palliative care clinicians should know about psychosocial and family support.’ This article brings together the perspectives of experienced social workers practicing across palliative care and hospice settings. It seeks to identify opportunities and rationale for the integration of palliative social work (PSW) in the provision of quality, person-centered, family-focused, and culturally congruent care for the seriously ill. Increasing recognition of the impact of social determinants of health highlights the critical importance of including PSW if we are to better understand and ultimately address the broad range of factors that influence people’s quality of life. **Abstract:** [http://bit.ly/36ytgW6](http://bit.ly/36ytgW6)

Emerging role of palliative care in patients with advanced liver disease

*SEMINARS IN LIVER DISEASE* | Online – Accessed 16 November 2019 – This review focuses on the current state of palliative and end-of-life care for patients with advanced liver disease, the significant associated symptom burden in this disease group, identified level of involvement and potential benefits of specialist palliative care (PC), as well as possible barriers to accessing this care. The authors demonstrate that although PC involvement varies considerably worldwide, there is much opportunity for improvement. Further research is needed to determine new interventions and models of care that may improve access for patients with liver disease, including an expansion of providers comfortable with generalist PC. **Abstract:** [http://bit.ly/377EDop](http://bit.ly/377EDop)

N.B. Additional articles on PC and liver disease noted in 23 September 2019 issue of Media Watch (#632, p.10).

The good death and the institutionalisation of dying: An interpretive analysis of the Austrian discourse

*SOCIAL SCIENCE & MEDICINE*, 2020;245. The institutionalisation of dying is recurrently assessed as adverse to a good death. However, a majority of people die in institutions such as hospitals or nursing homes and end-of-life care (EoLC) at home is more and more professionally supported. This article analyses how the discursive production of dying, the good death, and the issue of institutionalisation at the end of life are interrelated. The study empirically investigates a parliamentary enquiry on dying with dignity that took place in Austria between 2014 and 2015. In order to enable a good death, the dying person needs comprehensive support that the informal social environment is incapable to provide. Thereby, institutionalisation is associated with negative characteristics and at the same time identified as requirement for a good death considering its role in pain management and provision of care. The analysis interprets the call for institutionalisation in the context of medicalisation and the central role of physicians to alleviate pain. The article proposes a differentiated view on institutionalisation processes and practices in EoLC, also reflecting the potential of institutionalisation to obstruct fundamental societal transformation. **Abstract:** [http://bit.ly/2OjnMWT](http://bit.ly/2OjnMWT)
Dealing with death in cancer care: Should the oncologist be an amicus mortis?

SUPPORTIVE CARE IN CANCER | Online – 12 November 2019 – The way death is (not) dealt with is one of the main determinants of the current crisis of cancer care. The tendency to avoid discussions about terminal prognoses and to create unrealistic expectations of fighting death is seriously harming patients, families and healthcare professionals, and the delivery of high-quality and equitable care. The authors explore key dimensions of the taboo of death: medical, policy, cultural. They suggest that the oncologist, from a certain moment, could take on the role of amicus mortis, a classical figure in the past times, and thus accompanying patients towards the end of their life through palliation and linking them to psychosocial and ethical/existential resources. This presupposes the implementation of supportive care in cancer and the ethical idea of relational autonomy based on understanding patients’ needs considering their socio-cultural contexts. It is also key to encourage public conversations beyond the area of medicine to re-integrate death into life. **Abstract (w. list of references):** [http://bit.ly/2q1dPW9](http://bit.ly/2q1dPW9)

Related

- **SOCIAL SCIENCE & MEDICINE** | Online – 12 November 2019 – ‘Invoking death: How oncologists discuss a deadly outcome.’ This analysis reveals that when existing parameters are expanded to look at mentions of death outside of the end-of-life context, physicians do discuss death with their patients. Specifically, the most frequent way physicians invoke death is in a persuasive context during treatment recommendation discussions. When patients demonstrate active or passive resistance to a recommendation, physicians invoke the possibility of the patient’s death to push back against this resistance and lobby for treatment. Occasionally, physicians invoke death in instances where resistance is anticipated but never actualized. **Abstract:** [http://bit.ly/2CJOWko](http://bit.ly/2CJOWko)

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