Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in ***hospice*** *and* ***palliative care****, and in the quality of* ***end-of-life care*** *in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.*

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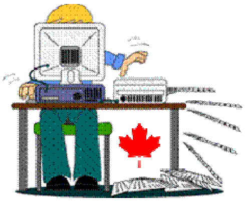

Compiled & Annotated by Barry R. Ashpole

> **There are significant disjunctions between the "blunt" tools of end-of-life care (EoLC) policy and the everyday experiences of the dying and death of an elderly patient and an urgent need to improve EoLC for our oldest generations.**
>
> 'Uncertain trajectories in old age and implications for families and for palliative and end-of-life care policy and practice' (p.8), in *Death Studies*.

Canada

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | CTV News (Montreal) – 3 October 2019 – **'Quebec isn't going to appeal the ruling that struck down a provision on assisted death.'** The Quebec government won't appeal a court ruling last month that struck down sections of the provincial law on medically assisted dying that were deemed unconstitutional. Quebec Superior Court Justice Christine Baudouin ruled in favour of two Quebecers struck by incurable degenerative diseases who had argued both the federal and provincial laws were too restrictive. Baudouin ruled invalid the Criminal Code requirement that a natural death be "reasonably foreseeable" before someone can be eligible for assisted death, as well as the provincial requirement that people "be at the end of life." The plaintiffs in the case … had argued the provisions led to their requests for an assisted death under the law being denied. Two provincial cabinet ministers told a news conference they have not decided whether the contested section of the Quebec law will be redrafted, saying the government will continue separately to study broadening access to the procedure. Justice Minister Sonia LeBel said the province could decide to rewrite the provision that has been struck down or simply drop it from the legislation. http://bit.ly/2LKFdjb

U.S.A.

Hospice legislation comes closer to House vote

HOSPICE NEWS | Online – 2 October 2019 – The number of cosponsors for the Palliative Care and Hospice Education and Training Act has reached the 290 the bill needs to come to a vote in the U.S. House of Representatives. A second bill, the Rural Access to Hospice Act, will likely be folded into a larg-

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er yet-to-be-determined piece of legislation. If enacted, PCHETA would establish fellowship programs within new palliative care (PC) and hospice education centers to provide short-term, intensive training on PC and hospice. The courses would provide supplemental training for medical school faculty as well as other educators in healthcare fields such as nursing, pharmacy, social work and chaplaincy. The centers would also develop curricula related to PC and support continuing education, retraining of faculty, practical clinical training and establish training programs for advanced practice nurses. The U.S. has 13.35 hospice and PC specialists for every 100,000 adults 65 and older, according to an April 2018 study.[1] The research estimated that by 2040 the patient population will need 10,640 to 24,000 specialists; supply is expected to range between 8,100 and 19,000. Hospice and PC providers also experience shortages in non-physician disciplines, including chaplains, nurses, and social workers. As far back as 2008, the U.S. Centers for Medicare & Medicaid Service began allowing hospice providers to use contracted nursing staff because not enough nurses were available to fill permanent positions. http://bit.ly/2ptgqHJ

Specialist Publications

'Palliative care knowledge, information sources, and beliefs: Results of a national survey of adults in the U.S.' (p.13), in *Palliative & Supportive Care*.

'District of Columbia news media coverage of the district's Death With Dignity Act' (p.14), in *Newspaper Research Journal*.

'American Nurses Association position statement: The nurse's role when a patient requests medical aid in dying' (p.15), in *Online Journal of Issues in Nursing*.

[1] 'The growing demand for hospice and palliative medicine physicians: Will the supply keep up?' *Journal of Pain & Symptom Management*, published online 2 February 2018. [Noted in 5 February 2018 issue of Media Watch (#549, p.12)] **Full text:** http://bit.ly/2CRjxwO

Noted in Media Watch 23 September 2019 (#632, p.14):

- *PROGRESS IN PALLIATIVE CARE* | Online – 16 September 2019 – **'Future-proofing the palliative care workforce: Why wait for the future?'** Careful consideration of workforce issues is not new in palliative care (PC). Indeed, calls for workforce development and future workforce planning to address shortages have been evident within the international literature for quite some time. However, there now appears to be a growing urgency. Studies conducted by the American Academy of Hospice & Palliative Medicine's Workforce Task Force have pointed towards an impending crises in the form of a "workforce valley" associated with factors such as burnout, intention to leave PC, retirement age demographics, and limitations in specialist training.[1] **First page view:** http://bit.ly/2krYIC9

  [1] 'Policy changes key to promoting sustainability and growth of the specialty palliative care workforce,' *Health Affairs*, 2019;38(6):910-918. [Noted in 10 June 2019 issue of Media Watch (#617, p.1)] **Full text:** http://bit.ly/2QMAU7N

Rural access to hospice matters for Arizonans

ARIZONA | *Arizona Daily Star* (Tucson) – 30 September 2019 – Most hospice care happens in the comfort and safety of the patient's home; but wherever patients choose to enter hospice, an entire team of caregivers is coordinated to honor the patient and help their family prepare for the end of life (EoL). The care team includes physicians and nurses, physical and occupational therapists, speech-language pathologists, hospice aides, grief counselors, social workers, chaplains, volunteers – whatever and whoever is needed to meet the patient's needs. Recognizing the numerous benefits, over 35,000 Arizonans … opt to utilize the Medicare Hospice Benefit each year, and 59% of all Medicare deaths in Arizona occur in hospice care. Patients in rural and tribal communities, however, face unnecessary barriers when it comes to choosing hospice care. Medicare beneficiaries who are eligible for hospice must select a physician or nurse practitioner to be their attending physician for hospice care. Most Americans choose their primary care doctors with whom they have built a strong, trusting relationship. But the physicians who serve at the Rural Health Centers and Federal Qualified Health Centers in the tri-community area cannot serve as attending physicians for hospice unless they volunteer their time to provide unreimbursed care. http://bit.ly/2o0m5nD

N.B. Additional articles on the provision and delivery of hospice and palliative care services in rural America noted in 28 January 2019 issue of Media Watch (#599, p.16).

International

Singaporeans more open to talking about death and care for the sick: Singapore Management University study

SINGAPORE | *Today* – 5 October 2019 – More Singaporeans are more comfortable discussing the issue of death today compared to five years ago, a study by the Singapore Management University has shown. The study also reported that more than half of the younger Singaporeans surveyed – between the ages of 21 and 50 – are now more aware and better informed of the purpose of palliative care in "relieving symptoms and improving the quality of life" of older patients. Among this age group, those who fall between the ages of 41 and 50 are the most aware – with 66% of them being better informed about end-of-life (EoL) issues. One finding is that 53% of Singaporeans said that they are more comfortable discussing EoL matters as well as their own death, a 17 percentage point increase from five years ago. http://bit.ly/2LQ3JPZ

Specialist Publications

'Attitudes and other factors influencing end-of-life discussion by physicians, nurses, and care staff: A nationwide survey in Japan' (p.5), in *American Journal of Hospice & Palliative Medicine*.

'Training in pediatric palliative care in Italy: Still much to do' (p.6), in *Annali dell'Istituto Superiore di Sanità*.

'A consensus conference report on defining the eligibility criteria for pediatric palliative care in Italy' (p.6), in *Italian Journal of Pediatrics*.

The ethics and practicalities of dealing with prisoners who are growing old and dying in custody

U.K. (England & Wales) | *The Conversation* – 4 October 2019 – In England & Wales, the number of prisoners aged over 60 is rising faster than any other age group, and government projections are that this trend will continue into the foreseeable future. HM Prison & Probation Service faces an increasing challenge to provide appropriate and safe custody for older prisoners. Research has shown high levels of frailty and vulnerability in the older prisoner population, including multiple complex health and social care needs, and challenges associated with having to take multiple medicines regularly. Many prisons are simply not suitable for old, frail people, and the equipment and resources needed to care for them are often not available. Prison staff with responsibility for older prisoners need adequate training and support, particularly when dealing with deaths in custody. Ageing and dying in prison poses important questions about ethics and justice. The United Nations General Assembly has endorsed a set of standard minimum rules for the treatment of prisoners, known as The Nelson Mandela Rules, which includes rules governing healthcare. Rule 24 states: "Prisoners should enjoy the same standards of healthcare that are available in the community, and should have access to necessary health-care services free of charge without discrimination on the grounds of their legal status." The End-of-Life Care Strategy for England & Wales also states clearly that all people approaching the end of life should be able to access high quality care, regardless of who or where they might be. So the prison service has a duty to provide adequate and equivalent care to those dying in prison. http://bit.ly/2OnGZZ3

Specialist Publications

'Improving care for the overlooked in oncology: Incarcerated patients' (p.11), in *The Lancet*.

N.B. End-of-life care in the prison system has been high- lighted on a regular basis in Media Watch. A compilation of selected articles noted in past issues of the weekly report can be downloaded/viewed on the Palliative Care Network website at: http://bit.ly/2RdegnL

New technology gives children at Tŷ Gobaith Children's Hospice a chance to explore interactive world

U.K. (Wales) | *Rhyl, Prestatyn & Abergele Journal* – 4 October 2019 – The Lifelites charity has donated a £50,000 package of technology to Tŷ Gobaith Children's Hospice in the Conwy valley. Many of the children using the hospice have complex disabilities and life-threatening conditions. The specialist technology gives youngsters the opportunity to do things they never dreamed of. With the help of playleader Diane Lloyd, Seren Williams, aged five of Kinmel Bay, got to a chance to explore an interactive world through the mobile magic carpet. The system projects an interactive moving image of everything from swimming fish to autumn leaves onto a mat which can be put on the floor, or on a bed or wheelchair. Also included in the technology donation is an Eyegaze, which enables children to operate computers using their eye movement, and a computer headset that enables children to imagine they are flying like an eagle above different cityscapes and countries. http://bit.ly/2Mfcemv

Noted in Media Watch 17 June 2019 (#618, p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 6 June 2019 – **'Virtual reality: Endless potential in pediatric palliative care.'** Pediatric palliative care (PC) deals with the physical, psychosocial, and spiritual concerns of patients and their families. And to do this, clinicians must use all the tools at their disposal, including pharmacological and non-pharmacological modalities. Virtual reality is quickly becoming a useful tool in many areas of medicine, including surgical planning, simulation training, rehabilitation, and pain prevention and treatment. Recently it has been used in the adult PC population for symptom management, and memory and legacy creation. The authors present a case report for, what they believe to be, the first time in the pediatric PC population. **Abstract:** http://bit.ly/2XbaeDz

As need rises, palliative care services remain insufficient in Uganda

AFRICA (Uganda) | *Global Press Journal* (Washington DC) – 30 September 2019 – Only about 10% of Ugandans who need palliative care (PC) receive it, according to the Ministry of Health's Annual Health Sector Performance report for 2014-2015. The Palliative Care Association of Uganda (PCAU) reports that number increased to 11% as of April 2019. But the number of people who need PC is increasing, due to a rise in diseases like diabetes and cancer. Yet government health officials say limited staffing due to restructuring national and regional referral hospitals is preventing an adequate response. "The journey for PC has been very long," says Dr. Jackson Amone, commissioner for clinical services at the Ministry of Health. "A policy on PC has been developed, but it got a snag somewhere." He adds that strengthening national PC is currently the agency's biggest challenge. But for the agency to meet care objectives outlined in its Sustainable Development Goal commitments, made in line with the United Nations targets, something needs to change. Government funding for PC and programs supporting it have been slashed. The proposed Uganda Cancer Institute budget for the current fiscal year, 2019-2020, decreased by nearly 34% over the previous year… A variety of healthcare organizations have petitioned parliament over these reductions. One of the petitioners, Mark Mwesiga, programs director at the PCAU, says as Uganda began to meet its goals of decreasing new cases of HIV/AIDS, international funding for PC is harder to find. There is a greater reliance now on government support. http://bit.ly/2mz6N9b

Noted in Media Watch 29 April 2019 (#612, p.5):

- AFRICA (Uganda) | *New Vision* (Kampala) – 23 April 2019 – **'Hospice Africa Uganda lays off staff.'** Hospice Africa Uganda (HAU) has announced a downsizing of its staff at their Mbarara and Kampala centres due to a critical cash shortfall. The Kampala-based charity, which has provided palliative care services in Uganda since 1993 was left with no choice given the fall-off in financial support from institutional and individual donors. The hospice's chair, Joan Kelly, said the decision to lay off staff was difficult. HAU founder, Dr. Anne Merriman, who was nominated for a Nobel Peace for her work in the hospice, is appealing for help. http://bit.ly/2UzSqfE

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Specialist Publications

Which ethical considerations should inform hospice decisions about caring for patients with obesity?

AMA JOURNAL OF ETHICS, 2019;21(10):E873-E878. Hospice and palliative care (PC) clinicians' fiduciary responsibility to all patients at the end of life (EoL) is a special one because it encompasses the provision of care to patients with many different types of illnesses requiring many different types of resources, often within a short time frame and within a financially constrained system. Ethical considerations of justice, resource allocation, and quality of life in such a system reveal the moral values and standards of the profession. Although hospice providers have implemented ways of allocating resources to provide quality care for patients with obesity, more research on caring for this population is needed to inform necessary policy change. Hospice and PC clinicians have an important role to play in equitably addressing the needs of patients at the EoL, whether or not they are obese. **Full text:** http://bit.ly/2ogZhAb

Insights on value and values from decision science for clinical ethics

The current issue of the *AMA Journal of Ethics* explores ethical questions about decision science – the development of methods for learning how people make decisions under conditions of uncertainty – and also considers legal, social, and cultural dimensions of applying decision science to actual decision making in ethically complex cases in healthcare settings. **Contents page:** http://bit.ly/2oYxgxR

Noted in Media Watch 13 February 2017 (#499, p.3):

- *ANNALS OF INTERNAL MEDICINE* | Online – 7 February 2017 – **'The relationship of obesity to hospice use and expenditures: A cohort study.'** In this large national sample of older American decedents, increased body mass index (BMI) was independently associated with decreased hospice enrollment, duration of hospice services, and in-home death and increased Medicare expenditures in the last 6 months of life, after adjustment for key socio-demographic, medical, functional status, and geographic factors. Increasing BMI was associated with higher expenditures for inpatient, outpatient, and physician claims, although these were partially offset by lower hospice, durable medical equipment, and skilled-nursing expenditures in this community-dwelling population. **Abstract:** http://bit.ly/2nrebnz

Attitudes and other factors influencing end-of-life discussion by physicians, nurses, and care staff: A nationwide survey in Japan

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 29 September 2019 – This study was part of a nationwide cross-sectional anonymous survey of the public attitudes toward end-of-life (EoL) medical care performed in December 2017. The participants were physicians, nurses, and care staff from randomly selected facilities, including hospitals, clinics, home-visit nursing offices, nursing homes, and long-term care facilities throughout Japan. The questionnaire was sent to 4,500 physicians, 6,000 nurses, and 2,000 care staff. The authors assessed attitudes about EoL discussion with patients near death, identification of the proxy decision maker, and sharing documented information on EoL discussion with the multidisciplinary team. They analyzed responses from 1,012 physicians, 1,824 nurses, and 749 care staff. The number of responders who considered they had adequate EoL discussion with patients near death was 281 (27.8%), 324 (17.8%), and 139 (18.6%), respectively. Participation in a nationwide education program and caring for at least one dying patient per month were factors that showed a significant association with adequate EoL discussion and identification of the proxy decision maker. **Abstract:** http://bit.ly/2n6LnjU

Training in pediatric palliative care in Italy: Still much to do

ANNALI DELL'ISTITUTO SUPERIORE DI SANITÀ, 2019;55(3):240-245. The poor attention dedicated to pediatric palliative care (PPC) and end-of-life (EoL) care training reported in Italy, according to the results of the authors' survey, was not totally unexpected, since a low level of medical professionals' training in PPC was already documented in countries other than Italy, partly due to poor dissemination of PPC service, economical and organizational issues, and lack of both formally defined classes and senior physicians with a dedicated expertise and. Moreover, very little attention is paid to ethical reflection and teamwork skills acquisition. On these bases, a mandatory PPC educational program has been proposed for all medical students, and accordingly, standardized training protocols are increasingly being offered in some countries. These programs include training in specific issues, such as communication skills and managing EoL symptoms, and are based on unconventional teaching methods (e.g., bedside training, "train-the-trainer" model, discussion-based seminar, role play). Remarkably … these approaches have been identified as those potentially most effective, and the authors therefore feel that the definition of standardized PPC training protocols based on those methods may be considered by relevant bodies. Moreover, the presence of a PPC service can improve not only the management of a child with a life-limiting illness, but also residents' training, in line with previous evidence. **Full text:** http://bit.ly/2nSD2k0

N.B. English language article. Click on pdf icon to access full text.

- *ITALIAN JOURNAL OF PEDIATRICS* | Online – 22 July 2019 – **'A consensus conference report on defining the eligibility criteria for pediatric palliative care in Italy.'** Although medical progress and technological advances have greatly reduced neonatal and pediatric mortality, they have simultaneously increased the survival of pediatric patients with serious and potentially lethal diseases. Despite the rise in pediatric life-limiting illnesses, there is little preparedness among healthcare providers on how to cope with a diagnosis of incurability requiring pediatric palliative care (PPC). This report … is intended as a practical guide for clarifying the designation of pediatric patients eligible for PPC and the consequent acceptance into care by dedicated specialist services. **Full text:** http://bit.ly/2OkqdMe

  N.B. English language article.

General practitioners' perceptions of best practice care at the end of life: A qualitative study

BJGP OPEN | Online – 3 September 2019 – The results of this study provide new insights into GPs' views about specific features of best practice palliative care (PC). Similar to other conceptualisations of PC, these findings suggest that GPs define best practice PC as being accessible, holistic, dynamic, integrated, and patient-centred. GPs perceived PC as a natural extension of primary care. The findings also indicate that there is a need for advocacy work to help educate clinicians, patients and the wider public about the role GPs can play in PC delivery. These results align with government end-of-life care strategies in Australia and worldwide, which aim to strengthen the role of GPs in PC delivery. This was an explorative study which provides some preliminary suggestions for how the identified features of care could be implemented in day-to-day practice in order to support the delivery of best practice PC. These suggestions include establishing PC pathways that involve multidisciplinary teamwork, and ensuring continuous and flexible care delivery which is tailored to the changing needs of individual patients and their families. The results may be used alongside literature detailing barriers and enablers to best practice PC provision, to develop and test strategies which could help maximise the outcomes of patients and their families. Such strategies would require further investigation in a larger sample before examining for effectiveness in clinical practice. **Full text:** http://bit.ly/2LMhfnA

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Noted in Media Watch 9 September 2019 (#630, p.6):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 3 September 2019 – **'General practitioners' engagement in end-of-life care: A semi-structured interview study.'** The authors describe the challenges general practitioners (GPs) found in providing end-of-life (EoL) care; what prompted GPs to identify and discuss approaching EoL with their patient and how their practice changed. When a life-limiting prognosis was articulated, GPs integrated EoL care into their clinical care directly. Care often included a care plan developed in consultation with the patient. Even when death was not articulated, GPs were aware of approaching EoL and changed their focus to comfort of the patient. GPs generally had an informal care plan in mind, but this developed gradually and without discussing these plans with the patient.. **Abstract:** http://bit.ly/2kfpeyJ

Barriers, enablers and initiatives for uptake of advance care planning in general practice: A systematic review and critical interpretive synthesis

BMJ OPEN | Online – 18 September 2019 – This review was set against a back drop in which uptake of advance care planning (ACP) remained consistently low, despite widespread agreement that it was beneficial, and with general agreement it was best achieved in primary care settings. The review sought to understand known barriers and enablers to ACP, and based on these, to determine what initiatives had been described to increase uptake of ACP. In seeking to understand barriers, enablers and efficacy of interventions, it was useful to understand at which level of influence across the socio-ecological perspective the interaction was occurring, and in doing so, consider how interventions had been developed to mitigate barriers and leverage enablers targeted for greatest effect. By stratifying barriers, enablers and interventions into levels of influence, the important relationship between activities operating across levels became evident. Within this complexity, it was understood that some interventions were more effective than others, and combinations of interventions were more effective again. There appeared to be a shift away from considering ACP as "a singular action" to be achieved or documented, instead to view ACP as a set of discreet steps in a complex process. Interventions targeting multiple levels of influence were said to reinforce each other, and consequently were expected to yield greater and more sustainable effects than interventions targeting only one level of influence. Findings from this review have identified a gap between historical research approaches which involved asynchronous testing of multiple mechanisms for ACP across all levels of influence, versus the potential for strategically applying the evidence across targeted levels of influence, and with an understanding of mediators and moderators to inform the design of new and effective ACP models of care. **Full text:** http://bit.ly/2nMWPBn

Noted in Media Watch 20 May 2019 (#614, p.10):

- *GP* | Online – 16 May 2019 – **'Most general practitioners have too little time to discuss end-of-life care.'** Amid rising pressure on general practice, 72% of the 370 GPs who responded to a survey by the medico-legal organisation Medical Protection said they did not have enough time to discuss end-of-life care (EoLC). The findings come after the Royal College of General Practitioners published quality improvement standards for EoLC in general practice, alongside research showing that four in five GPs felt that heavy workload left them unable to dedicate as much time as they would like to EoLC.[1] The poll found 55% of GPs felt comfortable talking to patients about dying. http://bit.ly/2HnyNms

    1. 'Palliative and End-of-Life Care Toolkit,' Royal College of General Practitioners. [Noted in 18 February 2019 issue of Media Watch (#602, p.11)] **Download/view at:** http://bit.ly/2GI2LTJ

Palliative care and moral distress: An institutional survey of critical care nurses

CRITICAL CARE NURSE, 2019;39(5):38049. This study shows that when nurses perceived more adequate use of palliative care (PC) services, they tended to have lower levels of moral distress. Although cause-and-effect relationships cannot be determined from these findings, the high importance that most respondents placed on PC, concomitant with the sources of moral distress frequently cited by the respondents, indicates that critical care nurses who perceive deficiencies in PC access may be more prone

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to moral distress – especially when these deficiencies yield perceived harm to patients, such as a painful dying process. The study respondents were not able to initiate PC referrals. Although this restriction exists elsewhere, it could have contributed to perceptions of inadequate PC involvement and affected the feelings of some nurses who reported moral distress during the study period. Physicians and advanced practice providers may not have been open to earlier indications for PC consultation, which might help explain the inconsistent use of PC services perceived by nurse respondents. **Full text:** http://bit.ly/2ojHlox

Uncertain trajectories in old age and implications for families and for palliative and end-of-life care policy and practice

DEATH STUDIES | Online – 3 October 2019 – The provision of high-quality end-of-life care (EoLC) for all is high on national (and international) agendas, but areas of unmet needs identified includes elderly people. This article draws on an autoethnographic account of the dying and death of the author's father to identify and interrogate disjunctions between EoLC policy and commonplace experiences of elderly people who die in a hospital setting. There are significant disjunctions between the "blunt" tools of EoLC policy and the everyday experiences of the dying and death of an elderly patient and an urgent need to improve EoLC for our oldest generations. **Abstract:** http://bit.ly/31LjzRl

"The future is probably now": Understanding of illness, uncertainty and end-of-life discussions in older adults with heart failure and family caregivers

HEALTH EXPECTATIONS | Online – 27 September 2019 – This study explored older adults with advanced heart failure (HF) and family caregivers' understanding of illness and their experiences of uncertainty and end-of-life (EoL) discussions. Patients and caregivers may have knowledge of HF management, and yet, there may be gaps in patients' and caregivers' understanding of the consequences of illness. Clinicians should be aware of what older adults and caregivers understand about the consequences of their illness to ensure that their care plans align with their preferences and needs, as they age and advance in their illness towards the EoL. Importantly, this study highlights that both patients and caregivers experience uncertainty in illness, which currently remains unaccounted for in the Reconceptualized Uncertainty in Illness Theory. Future studies are needed to test whether addressing the consequences of illness in HF management can improve understanding of illness and earlier integration of EoL communication for older adults and their family caregivers. **Full text:** http://bit.ly/2nAtcmT

> **N.B.** Additional articles on palliative and EoL care for patients living with heart failure noted in 19 August 2019 issue of Media Watch (#627, p.10).

Choosing, challenging, stabilizing, and fulfilling: The experiences of palliative care at home as perceived by family caregivers

HU LI ZA ZHI (Journal of Nursing), 2019;66(5):44-53. Although the Taiwan government has subsidized the provision of palliative care (PC) at home since 2000, the utilization rate of this service has been low. [In this qualitative study] four themes related to the care experiences of the participants emerged: 1) Choosing PC at home for the end-of-life journey: considering the wishes of patients and the capacities of caregivers, with hospitals providing powerful support to caregivers; 2) Facing the burdens of providing PC in a home setting: determining the caring skills while feeling fear and stress, and needing to resolve this stress and achieve a respite; 3) Pursuing stable home PC: relying on consultations with the professional PC team for information, support, and insights regarding the value of home PC; and, 4) Fulfilling the promise of a good death at home: preparing the patient to say goodbye and to experience a peaceful death and family members to express their sadness and adapt to a new life. Home PC services help provide patients and their families convenience, intimate care, and reassurance at home. However, all caregivers must be properly trained in caring skills and the skills necessary to sustain their long-term care responsibilities. **Abstract:** http://bit.ly/2mDLDqJ

> **N.B.** Chinese language article. A selection of articles noted in past issues of Media Watch on the importance of family and loved ones as members of the PC team are noted in the current issue of the newsletter of the International Association for Hospice & Palliative Care: http://bit.ly/2lJANOL

Editorial

A measured dose of optimism for the evolution of ICU-based palliative care

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 2 October 2019 – Ideally, palliative care is involved early in the course of illness, and usually in the outpatient setting. With this model of care, the treatment provided is guided by shared decision-making that includes the patient's voice and a trusted clinician's input. As the health status of the patient declines over months to years, a transition is made from treatments with curative intent toward therapies designed to optimize comfort. Throughout the entirety of the illness, the clinician also supports the patient and family, managing distress and optimizing quality of life. However, many patients spend their final days in an intensive care unit (ICU) where PC is more difficult to provide. Because of the challenges that critical illness and the ICU environment create, this setting also needs to be a focus of thoughtful palliative approaches. Critical illness is usually difficult to anticipate, acute, often multi-systemic, and may change course rapidly and unexpectedly. Critically ill patients frequently experience physical symptoms (pain, breathlessness) and psychological symptoms (anxiety, delirium) that are under-recognized and undertreated because life support machines limit patients' ability to report them. Although most of the millions of patients managed in ICUs worldwide each year want to survive, nearly 20% will die, most commonly after a decision to limit or withdraw life support. These intense, emotional end-of-life (EoL) decisions are often made by surrogates who must rely on clinicians whom they are unlikely to have known longer than hours to days in the midst of a technology-focused environment that can feel chaotic, impersonal, and overwhelming. Unsurprisingly, much research in recent years has focused on ways to improve the delivery of palliative and EoL care in the ICU setting. The report by Sprung *et al* provides a unique evolutionary insight into the provision of EoL care to critically ill patients over a 15-year period.[1] **Full text:** http://bit.ly/2pI4SAv

1. 'Changes in end-of-life practices in European intensive care units from 1999 to 2016,' *Journal of the American Medical Association*, published online 2 October 2019. **Full text:** http://bit.ly/2pz1aZI

Noted in Media Watch 30 September 2019 (#633, p.6):

- *JOURNAL OF PALLIATIVE CARE* | Online – 23 September 2019 – **'Family outcomes and perceptions of end-of-life care in the intensive care unit: A mixed-methods review.'** Five synthesized themes were identified: 1) Distressing emotions; 2) Shared decision-making; 3) Proactive communication; 4) Personalized end-of- life (EoL) care; and, 5) Valuing of nursing care. For quantitative results, study methodologies and interventions were heterogeneous and did not always improve family members' perceived quality of care and family members' psychological distress. Configuration of qualitative and quantitative data revealed ICU EoL interventions were ineffective because they were not guided by family members' reported needs and perceptions. **Abstract:** http://bit.ly/2kFg0fm

Noted in Media Watch 11 March 2019 (#605, p.9):

- *INTENSIVE CARE MEDICINE* | Online – 7 March 2019 – **'Eight things we would never do regarding end-of-life care in the ICU.'** As intensivists from three distinct regions of the world [i.e., the U.S., France, Israel] with different cultural backgrounds, the authors believe it relevant in this rapidly emerging period of healthcare to share thoughts among clinicians providing end-of-life care (EoLC) in the intensive care unit. This article presents the authors' vision of eight top-tier concepts that should be embraced to usher in the best EoLC for all patients. The authors realize that not everyone will agree with these points and anticipate that our "eight things" will stimulate healthy discussion and debate. **Abstract (w. list of references):** http://bit.ly/2XHEB1L

The fragile spirituality of parents whose children died in the pediatric intensive care unit

JOURNAL OF HEALTH CARE CHAPLAINCY | Online – 4 October 2019 – In the confrontation with the loss of their child, parents encounter special experiences of a transcending kind, which help them stay connected to their child during the end-of-life (EoL) stage – in the pediatric intensive care unit – and after

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death. The authors consider these experiences manifestations of a "fragile spirituality," which is a form of spirituality that is fragmentary, unbound, ambivalent, and referring to another dimension in this life. This spirituality is significant in the perspective it offers in the existentially disrupting reality of loss. Thus, the spiritual dimension is part of EoL care, and all caregivers should be aware of its relevance and consider offering appropriate compassionate care. **Full text:** http://bit.ly/336uky2

Noted in Media Watch 5 August 2019 (#625, p.14):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 August 2019 – **'The influence of parents' religiosity or spirituality on decision making for their critically ill child: An integrative review.'** How religion and/or spirituality may influence which treatments parents accept or decline for their child, or how they respond to significant events during their child's illness treatment, remains unclear. Analysis generated three themes: parents' religiosity or spirituality as 1) Guidance during decision making; 2) Comfort and support during the decision-making process; and, 3) A source of meaning, purpose, and connectedness in the experience of decision making. **Abstract:** http://bit.ly/2YI1TUA

Noted in Media Watch 8 October 2018 (#584, p.7):

- *ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 28 September 2018 – **'Not the whole story: Considering children's spirituality and advance care planning.'** In a society of diverse views, faiths and beliefs, what can paediatric palliative care contribute to our understanding of children's spirituality? The authors explore how developments in advance care planning are addressing these issues. Since children's spirituality is elusive and rarely explored in practice, they aim to clarify our understanding of it with a variety of examples and offer suggestions for hearing the voice of the child amid the needs of parents and professionals. **Abstract:** http://bit.ly/2Otj1fj

The feasibility and acceptability of using virtual world technology for interprofessional education in palliative care: A mixed methods study

JOURNAL OF INTERPROFESSIONAL CARE | Online – 21 August 2019 – Graduate students from five different health professions programs (medicine, nursing, nutrition, physical therapy, and social work) across two educational institutions participated in a small-group immersive educational experience focused on palliative care (PC) in the virtual world of Second Life. The authors found it was feasible to create and deliver an interprofessional educational experience in PC in a virtual world environment. The educational experience was acceptable to participants, with an improvement in attitudes toward interprofessional education and interprofessional teamwork after a single virtual world educational session, based on both quantitative and qualitative results. Students found the virtual world environment acceptable for interprofessional education focused on PC, based on qualitative results. As health professions schools develop interprofessional education curricula, the use of virtual world technology may be an important modality to consider, to effectively and conveniently bring interprofessional learners together. **Full text:** http://bit.ly/355jni3

Extract from *Journal of Interprofessional Care* article

The only other known published study combining IPE in a virtual world environment with aspects of PC is the study by Sanborn *et al* where an educational program focused on interprofessional communication competencies included a virtual patient end-of-life care discussion in Second Life.[1]

1. 'Practicing interprofessional communication competencies with health profession learners in a palliative care virtual simulation: A curricular short report,' *Journal of Interprofessional Education & Practice*, 2019;15(1):48054. **Abstract (w. list of references):** http://bit.ly/2oOg3XN

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Related

- *HEALTHCARE*, 2019;7(4):112. **'The changing nature of palliative care: Implications for allied health professionals' educational and training needs.'** A cross-sectional online survey sought to elicit allied health professionals palliative care (PC) experiences and subsequent considerations for educational and clinical practice needs. Respondents reported seeing >15 PC clients per month with 84% seen in hospital and community settings. Undergraduate education underprepared or partially prepared allied health professionals to work with these clients (96%) and 67% identified the need for further education. Access to postgraduate professional development was limited by available backfill and funding. Study findings support the importance of free, accessible, relevant educational and professional development resources to support clinical practice. **Full text:** http://bit.ly/2nZNUwl

N.B. CareSearch website: http://bit.ly/2AGTLKi

End-of-life care, palliative care consultation, and palliative care referral in the emergency department: A systematic review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 3 October 2019 – There is growing interest in providing palliative care (PC) in the emergency department (ED), but relatively little is known about the efficacy of ED-based PC interventions. A 2016 systematic review on this topic found no evidence that ED-based PC interventions affect patient outcomes or healthcare utilization, but new research has emerged since the publication of that review.[1] The authors screened 3,091 abstracts and 98 full text articles with 13 articles selected for final inclusion. Two articles reported the results of a single randomized controlled trial, while the remaining 11 studies were descriptive or quasi-experimental cohort studies. Over half of the included articles were published after the previous systematic review on this topic. Populations studied included older adults, patients with advanced malignancy, and ED patients screening positive for unmet palliative care needs. Most interventions involved referral to hospice or PC, or PC provided directly in the ED. Compared to usual care, ED-PC interventions improved quality of life, though this improvement was not observed when comparing ED-PC to inpatient-PC. ED-PC interventions expedited PC consultation; most studies reported a concomitant reduction in hospital length-of-stay and increase in hospice utilization, but some data were conflicting. Short-term mortality rates were high across all studies, but ED-PC interventions did not decrease survival time compared to usual care. Existing data support that PC in the ED is feasible, may improve quality of life, and does not appear to affect survival. **Abstract (w. link to references):** http://bit.ly/31NnxJ4

1. 'Effectiveness of emergency department based palliative care for adults with advanced disease: A systematic review,' *Journal of Palliative Medicine*, published online 9 June 2016. **Abstract:** http://bit.ly/2MbIAi5

N.B. Additional articles on palliative and end-of-life care in the ED noted in 30 September 2019 issue of Media Watch (#633, p.14).

Improving care for the overlooked in oncology: Incarcerated patients

THE LANCET, 2019;20(10):P1342-P1344. Physicians and public health practitioners often view health disparities through the eyes of birthplace, race, sex, economic class, sexuality, religion, or neighbourhood, or a combination of these. In the process, patients who are incarcerated (too often referred to as prisoners rather than patients) are overlooked as a profoundly medically vulnerable population with substantial disparities in healthcare and their health is an understudied public health crisis. Although a third of illness-related deaths in U.S. state prisons are due to cancer, and this mortality rate is double for incarcerated male patients, few recommendations exist to guide oncologists in how to address the unique challenges of providing ethically competent and high quality cancer care for incarcerated patients. **Abstract (w. list of references):** http://bit.ly/2nqCuly

N.B. End-of-life care in the prison system has been high- lighted on a regular basis in Media Watch. A compilation of selected articles noted in past issues of the weekly report can be downloaded/viewed on the Palliative Care Network website at: http://bit.ly/2RdegnL

Palliative care in the neuro-ICU: Perceptions, practice patterns, and preferences of neurointensivists

NEUROCRITICAL CARE | Online – 29 August 2019 – Severe acute brain injury presents with unique challenges, especially regarding quality of life. The growth and increased recognition of neurocritical care as a subspecialty has not been paralleled by studies regarding how best to integrate palliative care (PC) for this unique patient population. The authors surveyed members of the Neurocritical Care Society to explore current practice patterns, perceptions, and preferences regarding integration of PC in the neurological intensive care unit (Neuro-ICU). The majority (58%) of respondents were attending physicians, who worked primarily in a dedicated Neuro-ICU (67%), at university affiliated academic medical centers (65%). PC consultations are utilized infrequently by the majority of the respondents. The most common indication for a palliative consultation was to discuss goals-of-care and make treatment decisions. A large majority either agreed or strongly agreed that PC services were utilized in the management of difficult cases apart from discussions regarding withdrawal of life sustaining therapy. **Abstract (w. list of references):** http://bit.ly/2mQ0zln

Noted in Media Watch 10 December 2018 (#593, p.13):

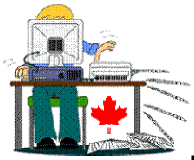
- *CONTINUUM*, 2018;24(6):1794-1799. **'End-of-life considerations and shared decision making in neurocritical care.'** Close cooperation and meaningful interaction must be achieved with family members so that the patient's "person can emerge" through discussions. This article highlights several caveats that can subvert this complex process, including the cognitive biases that affect both clinicians and surrogates. Impact, optimism, and gain-framing biases may be particularly relevant when considering patients who are receiving neurocritical care. Practitioners need to be cognizant of the distorting influences of these biases and make attempts to neutralize them. **Abstract:** http://bit.ly/2m0mUwa

Respecting the ethical principle of autonomy in end of life care decisions

NURSING STANDARD | Online – 30 September 2019 – There is a range of ethical, legal and professional issues associated with end-of-life care (EoLC) and the decisions made by healthcare professionals. The complexity of such decisions may lead healthcare professionals to question whether they have fulfilled their ethical, legal and professional duties towards the patients they care for. Respect for the ethical principle of autonomy and an understanding of the law may assist in mitigating any doubts that healthcare professionals have about fulfilling these duties. This article examines the ethical principle of autonomy and how it relates to advance decisions to refuse treatment, do not attempt cardiopulmonary resuscitation orders and the doctrine of double effect. **Abstract:** http://bit.ly/2AMVnlU

Related

- *BIOETHICS* | Online – 2 October 2019 – **'Against autonomy: How proposed solutions to the problems of living wills forgot its underlying principle.'** Significant criticisms have been raised regarding the ethical and psychological basis of living wills. Various solutions to address these criticisms have been advanced, such as the use of surrogate decision makers alone or data science-driven algorithms. These proposals share a fundamental weakness: they focus on resolving the problems of living wills, and, in the process, lose sight of the underlying ethical principle of advance care planning, autonomy. **Abstract:** http://bit.ly/2o77F5K



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

Palliative care knowledge, information sources, and beliefs: Results of a national survey of adults in the U.S.

PALLIATIVE & SUPPORTIVE CARE | Online – 1 October 2019 – Despite its established benefits, palliative care (PC) is not well known among patients and family/caregivers. A total of 3,504 respondents were identified, and approximately 29% knew about PC. Less PC knowledge was associated with: lower age, male gender, lower education, and non-internet users. A little over half (55%) of respondents accessed healthcare providers first for PC information, and 80% considered providers the most trusted source of PC information. Most of the participants strongly/somewhat agreed that the goal of PC is to help friends and family cope with a patient's illness (90.6%), offer social and emotional support (93.4%), and manage pain and other physical symptoms (95.1%). Similarly, a majority (83.3%) strongly/somewhat agreed that it is a doctor's obligation to inform all patients with cancer about the option of PC. These data provide a baseline from which PC education policies and interventions may be measured. **Abstract (w. list of references):** http://bit.ly/2ppubXV

Noted in Media Watch 6 May 2019 (#613, p.9):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 April 2019 – **'Awareness of palliative care among a nationally representative sample of U.S. adults.'** About 71% (2,097) of all survey respondents had no knowledge of palliative care (PC) and 84.5% of Hispanic respondents had no knowledge of PC. Multivariable analyses indicated the middle-aged … and elder population … have a significantly better knowledge of PC than those under age 50. Common misconceptions existed in respondents, even those who had self-reported adequate knowledge of PC. Greater efforts are needed to promote PC and reduce the misconceptions of PC in the general population. **Abstract:** http://bit.ly/2UT2Ozi

Noted in Media Watch 1 April 2019 (#608, p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 March 2019 – **'Knowledge of palliative care among American adults: 2018 Health Information National Trends Survey.'** About 71% (2,097) of all respondents had no knowledge of palliative care (PC). Multivariable analyses indicated the middle-aged and elder population have a significantly better knowledge of PC than those under age 50. Common misconceptions existed in respondents, even those who had self-reported adequate knowledge of PC. Greater efforts are needed to promote PC and reduce the misconceptions of PC in the general population. **Abstract (w. link to references):** http://bit.ly/2JCTteG

Noted in Media Watch 1 January 2018 (#544, p.19):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2018;21(S1):S30-S36. **'The impact of public health awareness campaigns on the awareness and quality of palliative care.'** A comprehensive public awareness campaign about palliative care should be based on clear and shared terminology, use well piloted materials, and the full range of mass media to suit different ages, cultures and religious/spiritual perspectives. There is evidence about key factors for success: targeting, networking, and use of specific, measurable, achievable, realistic time-bound objectives; continuous evaluation; and complementary to national and international policy. **Full text:** http://bit.ly/2VxtBlZ

Palliative care is for everyone, even for patients with life-threatening medical organ failure

UGESKRIFTET FOR LÆGER, 2019;181(40). Healthcare authorities have emphasised the need to develop palliative care (PC) for everybody suffering from life-threatening diseases, including people suffering from medical organ failure. In 2011, the Danish Health Authority requested that all medical associations developed guidelines for PC. Until now, this has been fulfilled by only four associations. The aim of this review is to summarise the status of the PC needs and PC across diagnosis for patients suffering from life-threatening medical organ failure and to draw attention to the lack of care and the importance of guidelines. **Abstract:** http://bit.ly/336IXkW

N.B. Danish language article.

What should we know about patients to give them the best possible care?

Retrospective qualitative pilot study incorporating patients' personal life aspects on admission to palliative care

WIENER KLINISCHE WOCHENSCHRIFT | Online – 1 October 2019 – This pilot study explored whether a personal question might add personal depth to the patient's medical history in addition to the list of physical symptoms and assessments of deficits and functions. The results suggest that patient responses to the question, "What should I know about you as a person to help me take the best care of you that I can?" differed in tone and content from other questions asked when taking a medical history. Besides physical symptoms, personal aspects and emotions were discussed, and in some cases revealed the person behind the illness. Answers ranged from in-depth, chronological life stories to social, intimate, and emotional life details, and in some, a reluctance to answer the question. The responses also demonstrated that relatives were motivated to respond to questions as well. This could be due to a desire to support the treatment team in learning as much as possible about the individual patient to be able to provide better care. **Full text:** http://bit.ly/2pC4l2Q

N.B. English language article.

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 3 October 2019 – **'Reciprocal dynamics of dignity in end-of-life care: A multi-perspective systematic review of qualitative and mixed methods research.'** Preserving terminally ill patients' dignity and well-being through dignified and holistic care has become the overarching goal in palliative care services. However, dignity is a multifaceted concept with a wide range of interpretations under different cultural contexts. The Dynamic Reciprocity of Dignity model highlights the importance of adopting a systemic lens to address dignity-related needs and concerns at the end of life, while providing insights on how compassionate care and self-compassion can serve as the foundation of dignified care, which in turn serve as a buffer against patients' existential suffering as well as caregivers' burnout and fatigue. **Abstract:** http://bit.ly/2oWeUNN

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 September 2019 – **'Conversations regarding personhood: Use of the Patient Dignity Question in an outpatient psycho-oncology clinic.'** The Patient Dignity Question (PDQ) asks, "What should I know about you as a person to help me take the best care of you that I can?" The PDQ enhances quality healthcare within an inpatient palliative care setting; however, no research to date has examined the PDQ in an outpatient setting, particularly a psycho-oncology setting. The themes expressed in response to the PDQ included: *Who I Am* (59.7%), which referenced individual characteristics and core personality traits; *What My Cancer Journey Has Been* (21.7%) described how patients' lives have been impacted since receiving a cancer diagnosis; and, *What I Want to Achieve* (18.4%) in which patients described what goals they wanted to achieve in their lives (both general and specific to psychotherapy). **Abstract:** http://bit.ly/2neJSR7

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *NEWSPAPER RESEARCH JOURNAL* | Online – 18 September 2019 – **'District of Columbia news media coverage of the district's Death With Dignity Act.'** In 2016, the [U.S.] District of Columbia City Council passed the Death With Dignity Act. Afterward, Congress attempted to block its implementation by first invoking Congress's power to overturn the law and then, when unsuccessful in that effort, withhold money from the District. Previous studies examining local news media coverage of aid-in-dying legislation have identified several recurrent frames. D.C. news publications invoked those frames as well as others more specific to the District. Understanding how aid in dying and related legislation is portrayed in newspaper coverage is important as more jurisdictions consider legalization of the practice. **Abstract:** http://bit.ly/2lZ8bBE

- *ONLINE JOURNAL OF ISSUES IN NURSING*, 2019;24(3). **'American Nurses Association position statement: The nurse's role when a patient requests medical aid in dying.'** This statement offers assistance with understanding nurses' ethical obligations in the context of this end-of-life option, which is legal in an increasing number of U.S. jurisdictions. This position statement recognizes that there are a plurality of views on the issue, that there is a paucity of available research on medical aid in dying. The goal of this position statement is not to frame a stance for or against medical aid in dying but rather to frame the nurse's compassionate response within the scope of practice, based on the Code of Ethics for Nurses with Interpretive Statements. This statement is intended to reflect only the opinion of the association as an organization regarding what it believes is an ideal and ethical response based on the Code of Ethics for Nurses with Interpretive Statements. Nothing in this statement is intended to advocate for the limitation of nurses' rights and protections under applicable laws and regulations or the violation of any laws or regulations that may conflict with or appear to conflict with this statement. **Full text:** http://bit.ly/2nb4xp1

Publishing Matters

Neurology editors identify the red flags of predatory publishing

NEUROLOGY TODAY | Online – 3 October 2019 – About a decade ago, researchers and physicians started receiving requests to publish in journals that were unlike the usual publishing queries. These journals offered quick turn-around, little, if any, peer-review, and the requirement that the submitter had to pay to publish. Now academic neurologists say they get 10 to 15 emails from "predatory publishers" daily, along with requests to serve on their editorial boards. *Neurology Today* asked editors at several neurology journals to discuss the proliferation of these journals, the consequences of publishing in them, and red flags that people might look for when approached with offers to publish. Everyone interviewed wanted to make it clear that there are many open access journals, like *PLOS Biology* or *Nature Communications*, that require payment to publish, but these publications have stringent acceptance guidelines, with a strong peer-review process. **Full text:** http://bit.ly/2oNXe7i

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Cont.

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

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